MULTIPLE SCLEROSIS AND PSYCHOLOGICAL WELL-BEING: THE ROLE OF PHYSICAL AND PSYCHOSOCIAL FACTORS

CHRISTINE HEALY
SWINBURNE UNIVERSITY OF TECHNOLOGY

A Research Thesis

Submitted in partial fulfilment of the requirements for the degree of Professional Doctorate of Psychology (Health Psychology)

Submitted July 2005
DECLARATION

This thesis contains no material which has been accepted for the award to the candidate of any other degree or diploma. To the best of my knowledge, this thesis contains no material previously published or written by another person except where due reference is made in the text of the thesis.

I further declare that the ethical principles specified by the Human Research Ethics Committee of Swinburne University of Technology have been adhered to in the preparation of this report.

Signed  …………………………………………………….

Christine Healy

Dated  July 2005
ACKNOWLEDGMENTS

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ABSTRACT

Multiple sclerosis, (MS), presents affected individuals with an uncertain future, and has broad physical and psychosocial implications for their daily functioning. This study aimed to investigate the psychological well-being of people with MS with an emphasis on positive psychological functioning. It also aimed to extend previous research that suggested reporting perceived benefits during adversity may be indicative of cognitive adaptation. Disease-related variables (mobility, fatigue) and psychosocial factors (optimism, coping) were examined to ascertain the effects of living with MS upon well-being. Well-being was determined using two general measures (The Profile of Mood States (POMS), Shacham, 1983; and the Ryff Psychological Well-being Scale (PWB), Ryff & Keyes, 1995), and Mohr et al.’s (1999) MS psychosocial factors (Demoralization, Deteriorated Relationships, Benefit Finding). Participants were 154 people with MS who were recruited through the MS Societies of Victoria and Tasmania. Results showed participants reported both negative and positive consequences from their MS experiences. Higher levels of Demoralization and Deteriorated Relationships were related to decreased well-being. However, no association was found between Benefit Finding and psychological well-being. Benefit Finding was also unrelated to optimism, and the disease-related variables (mobility, fatigue). Only positive reappraisal coping was predictive of reporting of benefits which lends support to the notion that it is a coping strategy. To examine the effects of mobility the sample was divided into three groups: normal gait, mild gait problems but not using aids and those who require aids for mobility. Significant differences between
the mobility groups were found on Demoralization and fatigue levels. As participants’ difficulties with mobilisation increased so too did their levels of demoralisation. However, those with mild gait problems reported fatigue levels comparable with those experiencing more complex gait difficulties. No differences were found between the groups on the general psychological measures, which may indicate some form of resilience or psychological adaptation occurring. More generally, results showed that participants who were more optimistic, less fatigued, and used less of particular coping strategies (either less avoidant coping or less blaming self or others) to deal with their MS problems reported higher well-being (less demoralisation, less psychological distress and higher positive functioning). In conclusion, the use of multi-dimensional outcomes enabled a comprehensive examination of well-being and highlighted the effects of specific illness-related factors and coping strategies. As demonstrated in this study, despite the adversity of living with MS, people are able to maintain a healthy sense of self and their relationships, and report benefits from their experiences.
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CHAPTER 1:
INTRODUCTION TO THE PRESENT STUDY

‘I am a question mark. My future is a question mark’.
Anna, 40 year old woman with MS

1.1 Overview

Multiple sclerosis or MS, as it is commonly termed, is the most common neurological disorder affecting young adults in Australia. At present, there are more than 15,000 Australians with multiple sclerosis. Typically, MS is diagnosed in adults between the ages of 20 and 40 years (Mohr & Cox, 2001). Despite the plethora of research into the aetiology of MS and treatments, there is currently no cure for the disease.

The combination of no cure for MS, and its unpredictable course of exacerbations and remissions, presents individuals who have the disease with an uncertain future and ‘lifelong stress’ (O’Brien, 1993, p. 54). Not surprisingly it has been found that many people with MS experience high levels of psychological distress (Mohr & Cox, 2001). Consequently, many studies examining the impact of MS have investigated psychological well-being in terms of such distress. However, Ryff (1989a, 1989b, 1995) contends that psychological well-being is more than the absence of psychopathology and relates as well to mastery, personal growth and positive relations with others. In line with this view, it has been found that despite the adversity of MS, there are many people
with this disease who live productive lives, experience successful relationships and can report perceived benefits from their experiences (Mohr et al., 1999; Murray, 1995).

1.2 Focus of the present study

The main focus of the present study was to investigate the psychological well-being of people with MS with an emphasis on positive psychological functioning. Most research examining psychological well-being in MS has focused on either negative psychological outcomes or quality of life domains. Indeed, there has been little research on positive aspects of psychological functioning with people with MS (Livneh & Antonak, 1997) despite the increasing focus in health psychology on taking a more salutogenic approach to coping with disease and adversity. This focus has heralded change from an emphasis on psychopathology to a broader perspective on what constitutes healthy, adaptive functioning. Some concepts that are associated with positive psychological functioning include psychological well-being, optimism and cognitive reframing (also known as positive reappraisal).

In the present study, relationships between intra-personal factors (optimism, coping); MS specific illness characteristics (fatigue, mobility status); interpersonal variables (relationships with others), and both specific psychosocial outcomes/consequences (benefit finding, demoralization, and deteriorated relationships), and general psychological well being were examined. Well-being was determined using Ryff’s Psychological Well-being Scale, a scale which emphasises important positive aspects of psychological adjustment and maturity (for example, personal growth, autonomy), in addition to more commonly used measures of negative mood (depression, anxiety and anger).
The study was a broad inquiry into how people are psychologically affected by their MS experience. Research questions included: How are people with MS affected by their condition, physically, socially and psychologically? How do they cope with the challenges imposed by MS? What effect does MS have upon their interpersonal relationships? What MS disability or illness related demographics, personality, and psychosocial factors are linked to psychological well being? Do people with MS perceive benefits from their experiences and does reporting benefits relate to being optimistic, and to increased psychological well-being? Specific aims and hypotheses are presented in Chapter 7.

1.3 Theoretical framework

The main theoretical framework for the present study was based on Lazarus and Folkman’s (1984) transactional model of stress and coping. The transactional perspective contends that stressors, coping and emotional reactions need to be considered jointly in explaining the stress-coping process because they are interdependent (Folkman, Schaefer, & Lazarus, 1979). Lazarus and Folkman (1984) view stress as a dynamic and reciprocal relationship between the person and the environment. Stressors, or environmental demands, can range from major catastrophes, or life events such as death of loved ones, to daily hassles which encompass those often small but irritating problems that people deal with on a daily basis.

According to this perspective, stress is only experienced when situations are appraised as exceeding one’s resources to cope with them. Cognitive appraisal is the ‘evaluative process’ that gives ‘meaning’ to the person-environment relationship (Cox & Ferguson, 1991, p. 8). These evaluative cognitive processes intervene between the
encounter and the reaction (Lazarus & Folkman, 1984). Figure 1.1 shows a basic model of the stress, coping and adaptation process as explained by the transactional model.

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Personality variables
- Values
- Beliefs
- Environmental variables
  - Situational demands
  - Resources (social network)
  - Ambiguity of harm
  - Imminence of harm

Coping
- Problem-focused
- Emotion-focused
- Seeking, obtaining & using social support

Physiological changes
- Somatic health
- Positive or negative feelings
- Morale (well-being)
- Social functioning

Resolutions of each stress encounter

Figure 1.1. Theoretical schematisation of the transactional model of stress, coping and adaptation. Source: Lazarus & Folkman (1984); Lazarus (1991).

The main variables of the transactional model are presented in Figure 1.1 as antecedents, mediating processes (cognitive appraisals and coping) and short and long term outcomes. Lazarus (1991) contends that each of these variables affects each other variable in the system as part of a reciprocal dynamic process. For example, personality factors influence both appraisal and coping.
As seen in Figure 1.1 there are three types of cognitive appraisals: primary, secondary, and reappraisal. In primary appraisal the encounter is assessed as being irrelevant, benign-positive, or stressful. Stressful encounters are further judged as involving harm/loss (damage already sustained), threat (anticipated damage) or challenge (potential for mastery). Primary appraisal is thus concerned with how people construe the meaning of the situation by identifying any relevant stressors while secondary appraisal refers to the selection of coping strategies (Cox & Ferguson, 1991). Reappraisal is the re-evaluation of the stressful event as it unfolds over time (Folkman & Lazarus, 1984).

How people appraise or perceive any specific problem will determine which coping strategies they use to deal with the situation. Any change in the environment will therefore result in a re-evaluation of what is to be done (Folkman & Lazarus, 1988a). Lazarus (1991, p. 112) defined coping as the ‘cognitive and behavioural efforts to manage specific external or internal demands that have been appraised as taxing or exceeding the resources of the individual’. Coping strategies are often broadly termed as being either problem-focused or emotion-focused. Problem-focused coping includes attempts of ‘managing or altering the problem’, while emotion-focused coping are those attempts to ‘regulate the emotional response to the problem’ (Lazarus & Folkman, 1984, p. 179). Problem-focused coping include problem solving activities including seeking information. Emotion-focused coping may include behaviours (seeking others’ company), and also cognitive activities such as denial of facts to distort reality or looking on the bright side of things (Payne, 1991). People often use both problem-focused and emotion-focused coping when dealing with any one problem (Folkman & Lazarus, 1985). Coping is thus a process that constantly changes according to cognitive appraisal and the given context. Therefore some types of coping in particular situations
may lead to further stresses (through their outcomes and the reappraisal process) while some other types may lead to the stressor being re-appraised as less threatening and promote less stress or fewer negative emotions being experienced.

Emotions are considered to have ‘diagnostic value’ in that they can be viewed as ‘products’ of how people appraise the person-environment relationship (Folkman & Lazarus, 1985, p. 152). Emotions are also affected by the changes that are generated by coping processes. Folkman and Lazarus (1985, p. 161) contended that individual differences in emotion can be explained by their transactional ‘theoretical formulation’ and are due in ‘large part to cognitive appraisal and coping’. Coping efforts can thus have both ‘salutary and deleterious’ effects upon mood states (Stone, Neale, & Shiffman, 1993). The transactional perspective of stress, appraisal, coping and emotions as part of a dynamic and reciprocal process thus lends itself to some degree of circularity, which Lazarus (1991) acknowledged as being inevitable. For example, emotions can be viewed as a reciprocal and circular process in the stress-coping process, affecting both appraisal of the stressful encounter, and also being an effect from the resultant coping which in turn affects future appraisals and subsequent coping strategies.

Lazarus (1991) contended that it is useful to examine adaptational outcome variables (as seen in Figure 1.1) such as somatic health, subjective well-being and social functioning as separate measures. In line with Lazarus’ view of varied outcomes as part of a transactional model and as a main focus of the present study, the decision was made to use three different outcomes to measure adaptation, rather than one global index. The three outcome measures for this study included a measure of psychological distress, of psychological well-being which encompassed social functioning, and a MS specific measure of intra-personal and interpersonal consequences.
The present study also combined concepts related to Livneh and Antonak’s (1997) model of psychosocial adaptation to a chronic illness. As seen in Figure 1.1, personality and environmental variables are considered to be important antecedents in the stress-coping model. Specific classes of variables (including disease-related, demographic and personality variables) recommended by Livneh and Antonak (1997) and others (McReynolds, Koch, & Rumrill, 1999) were chosen to enable a comprehensive and relevant examination of this MS sample.

1.4 Variables of interest

1.4.1 MS demographics

A number of disease-related variables were examined in the present study (type of MS, presence of symptoms, treatments) but the main variables of interest among the demographics were related to the duration of the illness. Two variables pertaining to duration of MS were used: age at onset of symptoms and time (in years) since diagnosis.

1.4.2 MS symptoms

There are many varied MS symptoms that can manifest as part of the disease process and which could have been used in the present study. However, fatigue and mobility were selected as two MS symptoms that warranted further investigation. Fatigue is a common MS symptom, which, although ‘invisible’ has been found to be one of the most debilitating and frustrating of MS symptoms (Ford, Trigwell, & Johnson, 1998). Fatigue affects many physical aspects of daily living, relationships, and also impacts on psychological well-being for people with MS.
Mobility status was selected as being an important variable to examine because it can be viewed as a visible marker of MS progression. Difficulties with ambulation may result in the need for walking aids and wheelchairs. Limited mobility not only has physical implications but has also been associated with psychological and social consequences.

1.4.3 Optimism

The type of optimism researched in the present study was dispositional optimism as conceptualised by Scheier and Carver (1985). Optimism has been linked with promoting positive mental health outcomes (Peterson, 2000). Dispositional optimism, as a personality factor, has been also been associated with adaptive coping strategies. More interestingly, associations have been found between optimism and individuals reporting benefit finding from adversity in some clinical samples (Affleck & Tennen 1996) which warrant further investigation.

1.4.4 Coping

There has been extensive research concerning how people cope with MS. Being diagnosed and living with MS is stressful and presents individuals with many challenges. Coping in the present study was examined by assessing eight strategies that were broadly termed as being either problem-focused or emotion-focused strategies by Folkman and Lazarus (1988b). These were planful problem solving, seeking social support, self-controlling, positive reappraisal, confrontive coping, distancing, accepting
responsibility, and escape-avoidance coping. Folkman and Lazarus’ (1988b) coping strategies were chosen for the present study because they been used in many studies examining coping and stress with people with MS, and to enable comparison of findings.

1.4.5 MS psychosocial consequences

There are many psychosocial consequences of having MS. The present study used three variables or factors identified by Mohr et al. (1999) and labelled as Demoralization, Benefit Finding and Deteriorated Relationships. These variables reflect perceived intrapersonal and interpersonal consequences of having MS. Of special interest in the present study, due to the salutogenic focus, was the Benefit Finding variable. Mohr et al. (1999) was the first study to report perceived positive experiences by people with MS. These three variables were included in the present study to enable replication of Mohr et al.’s study with another sample of people with MS.

Optimism was also chosen for the present study as a variable to extend the replication of Mohr et al.’s (1999) study since there was no measure of personality factors in their study. It was considered useful to include dispositional optimism as a variable to examine further the relationship between optimism and benefit finding.

1.4.6 Psychological distress/Negative affect

Psychological distress was studied using a measure of negative moods that included depression, anxiety and anger. While there was a focus on positive functioning in the present study, it was also considered important to examine the level of distress.
Studies with people with MS have reported that they often experience high levels of psychological distress. Negative moods or negative affect was chosen as a variable in the present study to enable a comprehensive examination of psychological functioning and secondly to enable comparison of the study’s findings with previous MS studies.

1.4.7 Psychological well-being

In line with the focus on positive psychological functioning, the present study researched a dimension of psychological well-being of people with MS using the Ryff (1989a) psychological well-being scale. This scale measures six domains considered to reflect mature mental health: autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, and self-acceptance. Although the Ryff PWB has been used with normal and clinical populations, there appears to be no published studies that have used Ryff PWB scale with a multiple sclerosis sample. Inclusion of this scale in the present study enabled a new contribution to the evaluation of psychological well-being with a sample of people with MS.

A model of all the study’s main variables is presented in Figure 1.2. While the transactional perspective acknowledges a reciprocal relationship between variables with a feedback loop influencing each other variable, for the purposes of the present study the direction of testing was one directional. The aim was to assess the role of the MS related variables and the psychosocial factors contributing to well-being. As described previously, well-being was conceptualised as encompassing three separate measures that incorporated psychosocial factors, psychological distress, and mature mental health.
Figure 1.2. The main variables of interest in the present study and the direction of hypothesis testing.

1.5 Outline of chapters

A description of multiple sclerosis as a chronic, usually progressive disorder is presented in Chapter 2. In Chapter 3, research on the emotional impact of living with multiple sclerosis is presented to highlight the complex interplay of physical, emotional and psychosocial factors for individuals with the disease. The focus of this chapter is the literature related to coping with MS. A review of the relevant literature on psychological adaptation to chronic illness is presented in Chapter 4. In this chapter, theories of psychosocial and cognitive adaptation are presented as frameworks from which to further understand the process of how people adapt to living with a chronic illness.
Research within these paradigms describes how some people report perceived benefits whilst coping with adversity.

In Chapter 5 literature and research related to dispositional optimism is reviewed to examine its association with psychological health and adaptation to adversity. Some studies which have researched the effects of optimism upon the psychological well-being of people with MS are also presented. Chapter 6 presents an overview of the measurement of psychological well-being in MS studies. Psychological well-being in MS has been predominantly measured in terms of quality of life or psychological distress. Ryff’s model of psychological well-being is presented as a measure of positive psychological functioning and to ascertain its relevance for use with people with MS.

Chapter 7 presents the specific aims and hypotheses of the present study.

Chapter 8 describes the methodological approach used to investigate the psychosocial variables associated with adaptation to living with multiple sclerosis.

Results of the present study are provided in Chapter 9. In Chapter 10 the findings of the present study are discussed in relation to the literature reviewed in Chapters 3 to 6, and the study aims and hypotheses. Limitations of the research and the clinical implications for people with multiple sclerosis and those who provide care for them and their families are discussed in the concluding chapter.
CHAPTER 2: MULTIPLE SCLEROSIS

Being diagnosed with MS is “one of the emptiest feelings which can be experienced.”
George Jelinek, diagnosed with MS at 45 years of age.
His mother also had MS. (Jelinek, 2000, p. 17)

2.1 Overview

This chapter describes the chronic disorder of multiple sclerosis. MS is the most common neurological disorder affecting young Australian adults (Jelinek, 2000).
Despite the worldwide prevalence of multiple sclerosis and the extensive medical research that has being undertaken, much of the knowledge about the cause, course and possible cure for MS remains an enigma (Jelinek, 2000). The aetiology of MS, clinical presentation, and disease process are outlined in this chapter. The unpredictable nature of MS has profound implications for those who are diagnosed. These implications will be considered in the light of the physical, cognitive, and psychological effects upon those living with multiple sclerosis.

2.2 Multiple Sclerosis

2.2.1 Chronic disorder

Multiple Sclerosis is a chronic, usually progressive disorder of the central nervous system (Jelinek, 2000). The central nervous system (CNS) includes the brain and the
spinal cord. MS is an inflammatory demyelinating condition (National Multiple Sclerosis Society, (NMSS), 1996). Myelin is the fatty material that insulates nerves, and allows transmission of its impulses or messages; it is also found in the white matter of the brain. In multiple sclerosis this loss of myelin causes the nerve transmission to be disrupted from and to the brain. The sites where the myelin is damaged are known as plaques or lesions, and appear as hardened areas or scars. The term ‘multiple sclerosis” literally refers to many scars (Multiple Sclerosis International Federation, [MSIF], 2002).

2.2.2 Demyelination

The ‘hallmark’ of MS is the process of demyelination. Demyelination refers to the destruction of the myelin sheath that surrounds or insulates the nerve cells in the central nervous system (Jelinek, 2000; Lezak, 1995). When demyelination occurs, the ability to conduct messages between axons, from the brain to the rest of the body is disrupted (Lezak, 1995). These disruptions can include delayed reaction with resultant uncoordinated responses that are evident as functional impairments. Scar tissue, identified as lesions or plaques, which replace the damaged myelin results in increasingly compromised nerve conduction.

The site and number of nerve cells affected during each acute attack is random, giving rise to the wide variety of symptoms in people with MS. Each acute attack may also involve a different group of cells from the last attack resulting in different symptoms (Lezak, 1995). There has been some evidence to show that re-myelination does occur in some people with MS (Silberberg, 2001). However, where the affected
nerve tissue has healed and re-myelination has occurred, the response time of the nerve endings tends to remain slower and compromised (Lezak, 1995). This combination of different areas of de-myelination and residual lessening of response times in areas of re-myelination generally results in the severe symptoms of an acute episode resolving, but leaving the person a little worse off each time (Lezak, 1995).

2.2.3 Aetiology

The cause of MS is largely unknown and remains a mystery (Silberberg, 2001; MSIF, 2002). It is considered that MS is caused by a combination of immunological, genetic and environmental factors (MSIF, 2002).

It is believed that MS may be caused by an autoimmune illness whereby the protective myelin sheath surrounding individual nerve cells is attacked by the body’s own defence system (McReynolds et al., 1999). However, it is not known what triggers the immune system to attack the myelin. As yet no virus has been identified, although the measles and herpes viruses have been implicated as possible triggers (MSIF, 2002).

2.2.4 Incidence

The incidence of occurrence of MS worldwide varies according to the geographic distance to the equator with more cases occurring further away from the equator, and with lower incidence of the condition in those countries closer to the equator (Jelinek, 2000). For example, in the United Kingdom the rate of occurrence is approximately 1 in 800 people while the condition only occurs at the rate of 1 in 1000 people in southern Europe. This disparity, with higher numbers affected further away from the equator, is
also evident within Australia. In North Queensland the incidence is 12 per 100,000 people while in Tasmania, the furthest Australian state from the equator, the incidence rises to 76 people per 100,000 people (Jelinek, 2000, p. 28).

Females are more likely to have MS than males with a ratio of 3 to 2 (Jelinek, 2000). Others have reported higher ratios of 3 females to 1 male (Devins & Shnek, 2000).

MS is generally not considered an inherited disease, or genetically transmitted, however, there appears to be some genetic susceptibility to the disease. There is a higher risk of MS in families where a family member if already affected. There have been reports of concordance of occurrence in monozygotic twins at rates of 29 percent to 40 percent, while fraternal twins’ rates range from 1 or 2 percent to 13 percent (Lezak, 1995). There is also a familial tendency to MS if one family member is affected (Jelinek, 2000). In Australia, between 10 and 20 percent of people with MS have a relative with the disease (NMSS, 1996).

The onset of MS usually occurs in individuals aged between 20 and 50 years (NMSS, 1996). Most people who are diagnosed with MS are in their late twenties or early thirties (Jelinek, 2000). However, there is no age barrier to contracting MS with younger and older people diagnosed with the disease (NMSS, 1996).

2.2.5 Diagnosis

According to the National Health Survey of 2001 there are more than 15,000 people diagnosed with MS (MS Society of Australia, 2003). However, despite the prevalence of MS in Australia and world-wide the diagnosis process is often protracted. MS can be difficult to diagnose, partly due to the clinical presentation and also to
diagnostic challenges (Thompson, 2002). Part of the difficulty is that there is no single
diagnostic test available (McDonald et al., 2001). MS can also be difficult to diagnose
because people with MS may present with confusing and often transient symptoms. The
early MS symptoms are vague and could be attributed to other disorders, such as stroke
or brain tumours (Rao, Huber, & Bornstein, 1992). Therefore the diagnosis process is
often one of exclusion of other possible disorders (McDonald et al., 2001).

Recent advances in magnetic resonance imaging (MRI) have improved the
efficiency of the diagnosis process (Thompson, 2002). Lesions can now be detected by
MRI and are able to provide evidence of the MS disease process (McDonald et al.,
2001). Other tests that can provide additional information about MS and aid the
diagnostic evaluation include cerebrospinal fluid (CSF) analysis, and visual provoked
potentials (VEP) (McDonald et al., 2001). While it is adults between the ages of 20 to
50 years who are usually diagnosed with MS, these more effective diagnostic
procedures have found MS lesions in children as young as 10 years of age (Jelinek,
2000).

In the past, individuals have experienced two MS attacks before they were
diagnosed as having the disease. However, the guidelines have now been changed from
the traditional reliance on the clinical presentation alone, to consider a ‘probable’
diagnosis after one attack, if there is also accompanying diagnostic radiological and
laboratory evidence of lesions (McDonald et al., 2001).

It has been noted that often people with early MS perceive that they are not treated
with sympathy by health professionals during the early stage of the diagnosis process,
partly due to the transient nature of the clinical presentation (MSIF, 2002). For example,
symptoms that are transient or invisible, such as fatigue, can be difficult to describe to
others. Even with the newer technologies the diagnosis of MS remains a ‘partly subjective and partly objective process’ (McDonald et al. 2001, p. 126).

There can be difficulty in initially determining which form of MS that a person has following a diagnosis. Although tests, such as MRI, can accurately diagnose the presence of MS lesions, there remains no way to predict the course of MS, and a differential diagnosis can sometimes only be obtained after a number of years, or after a series of exacerbations (Lubin & Reingold, 1996). This uncertainty of how MS is likely to affect one’s future and functioning can be extremely stressful (McNulty, Livneh, & Wilson, 2004).

### 2.3 Types of MS

MS is often characterised by variable sequences of relapses and remissions and it is difficult to predict the course of the disease. While there are numerous possible courses of the MS disease process (Lubin & Reingold, 1996), it has been noted that there are essentially two patterns (Mohr & Dick, 1998). These are the relapsing-remitting pattern and the other which is a gradual deterioration or progressive pattern. However, more generally there are considered to be at least four main types of MS: relapsing-remitting; benign, primary progressive and secondary progressive MS (Jelinek, 2000).

The most common type of MS is the relapsing-remitting form that affects up to 65 to 70 percent of people with MS (Devins & Shnek, 2000; Jelinek, 2000). A typical course for those with the relapsing-remitting form is having an attack followed by a period of remission in which there may be partial or total recovery. However, most
people with relapsing-remitting MS follow a course in which there is progressive degeneration and increasing disability (Lubin & Reingold, 1996).

Benign MS, which is experienced by 5 to 20 percent of those with MS, has little disease activity (Jelinek, 2000). These people may experience only one or sometimes two attacks that may resolve quickly with no evidence of lasting effects or loss of function. Benign MS can only be identified when there has been minimal disability 10 to 15 years following the onset. Some people who may have initially been diagnosed as having relapsing-remitting MS may later be identified as having the benign form. Yet this identification may be evident only years after the person has been diagnosed with MS.

Approximately 40 percent of people with MS may experience the secondary progressive form of MS (MSIF, 2002). Some people with this form initially have the relapsing-remitting form but the course of the disease changes with progressive disability (Lubin & Reingold, 1996). On the other hand, Primary Progressive MS is characterised by lack of attacks, unlike the relapsing-remitting form. Typically, Primary Progressive MS has a slow onset, with increasing worsening of symptoms. The level of disability may level out after months or years. This form of MS is experienced by approximately 15 percent of people with MS (Jelinek, 2000).

2.4 Disease Course

The course of MS is unpredictable and highly variable for individuals (Mohr & Cox, 2001). MS is notable for the erratic course in which symptoms can appear and endure even after long, stable periods of time (Lezak, 1995).
While there are four main types of MS, identifiable by their onset and course, it has been suggested there are two distinctive patterns which occur in MS: the *relapsing-remitting* course, and the *chronic-progressive* course (Lezak, 1995). Many individuals with MS, start with the relapsing-remitting pattern with episodic exacerbations and experience partial or full remissions. However, over time, most individuals, including those with the relapsing-remitting form, will develop a progressive form of MS with accumulated disability (Lubin & Reingold, 1996).

The first five years following diagnosis often give some indication of how the disease will progress (MSIF, 2002). For example, the level of disability of individuals at the 5 year and 10 year period is thought to be a reliable predictor of the disease’s future course. Research findings have indicated that the younger one is at the onset of MS usually the more favourable the prognosis. Individuals, particularly males, who develop MS at a later age (over 55 years) will probably have a more rapidly progressive MS.

As indicated, the disease process of multiple sclerosis progresses at a different rate for each person (Lezak, 1995). Devins and Shnek (2000) noted that there is some evidence that stress is implicated in the onset of an exacerbation or episode. However, the interaction between stress and MS disease activity is complex and not fully understood (Fischer et al. 1994).

A large proportion of people with MS (45 percent) are not severely affected on a daily functioning basis and live normal lives (MSIF, 2002). Nonetheless the majority of people with MS will experience increasing progressive deterioration and disability with severely impaired individuals requiring a wheelchair or being ultimately bed bound (Devins & Shnek, 2000). Despite the expected physical deterioration and subsequent disability possible with MS, most people with MS have a normal life expectancy (MSIF, 2002).
2.5 MS Symptoms

2.5.1 Overview

Individuals with MS can experience a wide array of symptoms that are dependent upon the location of the lesions in the central nervous system (Lezak, 1995). Symptoms can fluctuate quite rapidly, and vary in type and severity from one individual to another. However, despite the often seemingly random nature in which MS lesions can appear throughout the central nervous system, there are nonetheless particular symptom presentations (Lezak, 1995). For example, some newly diagnosed people with MS experience fatigue, and/or diplopia (double vision) while later, as the disease progresses the symptoms vary in severity and type (Mullins et al., 2001).

The most common symptoms reported by people with MS include fatigue, motor disturbances (including ataxia), sensations of tingling, numbness, or pain, cognitive deficits, bladder and bowel dysfunctions, visual disturbances and changes to speech (MSIF, 2002). Some of these can affect the individual’s ability to maintain a normal level of activity and impinge upon social interactions.

A table listing some of the common symptoms is presented on the next page.
Table 2.1 *List of some common symptoms experienced by people with multiple sclerosis*

<table>
<thead>
<tr>
<th>Affected System &amp; Symptoms</th>
<th>Affected System &amp; Symptoms</th>
</tr>
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<tbody>
<tr>
<td><strong>Visual disturbances</strong></td>
<td><strong>Abnormal speech</strong></td>
</tr>
<tr>
<td>Blurring of vision</td>
<td>Slowing of speech</td>
</tr>
<tr>
<td>Double vision (diplopia)</td>
<td>Slurring of words</td>
</tr>
<tr>
<td>Optic neuritis</td>
<td>Changes in rhythm of speech</td>
</tr>
<tr>
<td>Involuntary rapid eye movement</td>
<td>Difficulty in swallowing</td>
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<tr>
<td></td>
<td>Pain (e.g. trigeminal neuralgia)</td>
</tr>
<tr>
<td><strong>Balance &amp; co-ordination problems</strong></td>
<td><strong>Abnormal sensations</strong></td>
</tr>
<tr>
<td>Loss of balance</td>
<td>‘Pins and needles’</td>
</tr>
<tr>
<td>Tremor</td>
<td>Tingling</td>
</tr>
<tr>
<td>Ataxia (unstable walking)</td>
<td>Numbness</td>
</tr>
<tr>
<td>Vertigo</td>
<td>Burning sensations</td>
</tr>
<tr>
<td>Clumsiness of a limb</td>
<td>Pain eg facial (trigeminal neuralgia)</td>
</tr>
<tr>
<td>Lack of co-ordination</td>
<td>Muscle pains</td>
</tr>
<tr>
<td>Weakness (affecting legs)</td>
<td></td>
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<tr>
<td><strong>Spasticity</strong></td>
<td><strong>Cognitive disturbances</strong></td>
</tr>
<tr>
<td>Altered muscle tone/stiffness</td>
<td>Short term memory loss</td>
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<tr>
<td>Spasms</td>
<td>Loss of concentration</td>
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<td></td>
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<tr>
<td><strong>Sexuality difficulties</strong></td>
<td><strong>Bladder &amp; Bowel problems</strong></td>
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<tr>
<td>Diminished arousal</td>
<td>Frequent incomplete micturition</td>
</tr>
<tr>
<td>Loss of sensation</td>
<td>Urgency to void</td>
</tr>
<tr>
<td>Impotence</td>
<td>Constipation</td>
</tr>
<tr>
<td></td>
<td>Loss of bowel/bladder control</td>
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</tbody>
</table>

Adapted list from Multiple Sclerosis International Federation (2002)
Visual disturbances are experienced by an estimated 65 percent of people with MS at some stage, and may be transient or exist for longer periods (Lezak, 1995). These disturbances can include blurred vision, double vision or blindness in one or both eyes (Lezak, 1995). Jelinek (2000) noted that people who experience visual problems as the sole symptom of MS may be more likely to develop the benign form of MS.

Many people who have MS experience chronic pain. Pain in MS may be related to the disease process as in the case of optic neuritis, and neuralgias (Kerns, 2000). However, people with MS may also experience pain associated with stiffened or contracted muscles (Kerns, 2000).

Cognitive changes may occur as part of the MS disease process (Gold, Schultz, Monch, Schultz, & Heesen, 2003). These cognitive problems are directly related to the MS lesions and can be compounded by the effects of fatigue, stress, and medication (Foley, 2003). Cognitive dysfunction is a significant problem for many people with MS with estimates ranging from 40 to 60 percent of individuals with MS experiencing some cognitive dysfunction (Mohr & Cox, 2001; Rao et al., 1992). However, higher prevalence rates of 72 percent have been reported among more disabled people with MS (Gold et al., 2003). MS related cognitive deficits may affect language, short-term memory, information-processing, reasoning and social judgement (Devins & Shnek, 2000).

Some people with MS with cognitive impairments may deny or ignore their level of cognitive decline, while others may be overly sensitive to presumed deficits (Gold et al., 2003). A study by Gold et al. (2003) with 80 people with MS found a poor association between objective and subjective measures of cognitive functions. In their
study, some people overestimated and some underestimated the extent of their cognitive problems.

Having difficulties with concentration and communication can be very stressful for individuals and can interfere with the skills required to maintain quality interpersonal interactions (Devins & Shenk, 2000). Individuals with cognitive impairment are also less likely to participate in social activities and require more assistance with their daily activities (Fischer et al., 1994). Cognitive impairments therefore affect not only the individual affected but also their relationships with others.

Relationships can also be affected by the sexual difficulties that may be experienced as part of the MS disease process (McCabe, McKern, McDonald, & Vowels, 2003). As noted earlier MS is generally diagnosed with adults aged between 20 and 50 years, at a time when most would be sexually active, and in relationships. The impact of sexual problems at this stage of life can affect one’s quality of life (Nortvedt, et al., 2003).

It has been estimated that the prevalence of perceived sexual difficulties in those with MS is 40 to 80 percent of females and 50 to 90 percent of males (MSIF, 2002). The most commonly reported symptoms are related to impotence, and loss of libido and decreased sensations (MSIF, 2002). Nortvedt et al. (2003) also noted that MS related bladder problems impact upon the quality of sexual experiences.

2.5.2 Fatigue

Fatigue is the one of the most common MS symptoms, affecting 75 percent of people with MS (Sibley, 1996). Fatigue in MS has been defined as a subjective
experience of feeling which incorporates a ‘sense of physical tiredness and lack of energy, distinct from sadness or weakness’ (Lerdal, Celius, & Moum, 2003. p. 509). The effects of fatigue cause enormous disruptions to people’s lifestyles and have adverse effects upon the quality of life for people with MS.

Fatigue is considered one of the most difficult symptoms to treat and for others to understand because it is invisible (Sibley, 1996). As such, it is not readily apparent to other people, such as friends, family and partners and can be difficult to describe (Shuman & Schwartz, 1994).

Murray (1995) noted that MS fatigue is different from that associated with depression. The fatigue experienced by those who are depressed is often described as presenting earlier in the day and remaining a constant (Murray, 1995). However, MS fatigue is exacerbated by increased body temperature, heat and physical exertion, and the level of fatigue increases during the course of the day (Sibley, 1996; Simmons, Ponsonby, van der Mei, & Sheridan, 2004).

The fatigue experienced by people with MS is a debilitating form that is often out of proportion with the activity. For example, some people become fatigued even after a few minutes of activity. This type of fatigue has been termed fatigability by Sibley (1996). The most common form of fatigability is experienced in a person’s legs, often occurring after walking short distances. The management of fatigue is an important part of living with MS. People with this sort of fatigability are encouraged not to overdo their walking distances or instead to use aids or wheelchairs (Sibley, 1996).
2.5.3 Mobility

Changes to nerves controlling the sense of touch and an individual’s position in space are commonly part of the presenting clinical picture, particularly complaints of numbness and pins and needles in hands and feet (Mohr & Dick, 1998). Numbness and tingling often progress to more obvious symptoms such as loss of balance, tremor, and ataxia. These symptoms frequently increase in intensity, and in combination with fatigue, becomes a dominant factor in the individual’s inability to maintain pre-illness levels of interests and activities.

The visible disability of ataxia frequently results in the escalating need for aids by which level of disability is sometimes measured (by both the individual and others) by use of or reliance on walking stick, walking aid, manual wheelchair or motorised wheelchair. The emotional impact of having reliance on aids to assist mobility can be quite distressing and some people may feel stigmatised by having to use wheelchairs or aids (Nicolson & Anderson, 2001).

2.6 Psychological Distress

2.6.1 Depression

In addition to the physical sequelae there is also evidence that people with MS report higher levels of psychological distress (Jean, Paul, & Beatty, 1999; Ron, 1986). However, Devins, and Shnek (2000) contend that emotional distress might actually represent a ‘normative response’ to a highly stressful chronic illness. The most
commonly reported psychological effects include depression, anger, and anxiety (Mohr & Cox, 2001).

The incidence of depression is higher among people with MS compared to those with other chronic illnesses (Mohr & Dick, 1998; Mohr & Cox, 2001; Shnek, Foley, LaRocca, Smith, & Halper, 1995). Depression has been noted to the most common of the psychological problems associated with MS (Kerns, 2000; Shnek et al. 1995). It has been suggested that there is a lifetime prevalence of approximately 50 percent for people with MS (Lynch, Kroencke, & Denney, 2001).

Another concern is that depression is often under diagnosed and under treated within the MS population (Kerns, 2000). There is additional difficulty in detecting depression in that some of the MS symptoms are also identifiable as being depression symptoms for example, concentration difficulties, fatigue (Fischer et al., 1994; Mohr & Cox, 2001). Despite many studies, there has been no significant progress to determine whether depression in people with MS is a direct product of the disease process itself or whether it is a valid response to the illness and the stressful features associated with it (Mohr & Dick, 1998). Certain drugs, which may be used as part of the treatments of MS, such as interferon, have also been implicated as possible causes of depression as a side effect of treatment (Amato et al., 2001).

There have been suggestions that there is an inter-play between the biological changes of the MS disease and psychological distress (Rao et al., 1992). They noted that there was evidence that people with mild cognitive dysfunction reported experiencing higher levels of depression than those with MS whom had no cognitive changes.
2.6.2 Anxiety

The uncertainty of the MS disease causes much anxiety to those who are diagnosed and who are faced with an unpredictable future (Mohr & Cox, 2001). It has been estimated that there is a 19 to 34 percent prevalence rate of anxiety disorders among people with MS (Mohr & Cox, 2001). Anxiety has also been implicated in aggravating the level of depression, and being related to poorer adherence to health practices (Mohr & Cox, 2001).

It has also been suggested that certain MS-related physical symptoms influence the level of anxiety and distress experienced. For example, having unrelenting chronic pain, not surprisingly, has been associated with higher levels of anxiety (Kerns, 2000). It is generally considered that the presence of pain and level of disability may influence the level of anxiety experienced by those with MS (Kerns, 2000).

2.6.3 Anger

Although anger has been frequently noted by clinicians to be exhibited by people with MS, it has been suggested that it may be an appropriate response to a frustrating illness (Kerns, 2000; Mohr & Cox, 2001; Mohr & Dick, 1998). However, it may be problematic when the anger response intensifies or result in displacement (Mohr & Cox, 2001). Mohr and Cox (2001) recommended that the distressing mood of anger in individuals with MS requires more research.


2.7 Treatments

There is no cure for MS (NMSS, 1996; Jelinek, 2000). However, MS is considered a treatable disease in that there are both medical and alternative therapies which can retard its progress and alleviate some symptoms (Jelinek, 2000). Current medical treatments focus on symptomatic relief, for example, anti-inflammatory medications such as corticosteroids for acute episodes. During acute exacerbations steroids are used to reduce the inflammation at the site of the new demyelination and have been effective in shortening the time of relapses (Silberberg, 2001). However, steroids do not appear to have any long-term effect on the course of MS (MSIF, 2002).

Drug therapy using interferon (a naturally occurring substance that acts on the immune system) has been found to have some effect on the frequency and severity of exacerbations (MSIF, 2002; Silberberg, 2001). Interferon is also used in the treatment of some cancers (Lezak, 1995). The interferons, such as Betaferon, are used to treat those individuals with relapsing remitting MS and who are ambulatory (MSIF, 2002). However, it is not known if interferon has any effect on progressive MS (MSIF, 2002). In the future it is expected that research will develop stem cell transplant therapy which could be used to promote re-myelination (Silberberg, 2001).

There are effective symptom specific treatments available for some of the physical symptoms associated with MS (Jelinek, 2000). Effective treatments are also available for the affective disorders that may be experienced by people with MS. For example, combined antidepressants and psychotherapy is considered useful to individuals with MS for the treatment of clinical depression (Fischer et al., 1994). There are also alternative therapies being increasingly used by people with MS to manage their condition (Simmons et al., 2004). The role of non-medical elements of the treatment plan are being more widely researched and applied, with growing emphasis on coping
with the disability that results from the disease process. Alternative therapies used by people with MS include the use of vitamins and supplements, specific diets, acupuncture, yoga and meditation (Simmons et al., 2004).

Like many chronic diseases that have a range of symptoms that are present more or less for the remainder of a person’s life, exercise and diet form the basis of an ongoing treatment plan which aims is to maintain fitness and muscle tone to as high a level as possible. People with MS are encouraged to access various health professionals, for example, general practitioners, psychologists, physiotherapists, dietitians, as part of treatment regimes to optimise their health outcomes (MSIF, 2002).

2.8 Chapter Summary

MS is an inflammatory, demyelinating CNS disorder. It is the most common neurological condition that affects young Australian adults. The cause of MS is largely unknown. It has an unpredictable course with a wide array of fluctuating and confusing physical symptoms. Diagnosis is often a protracted process. There is no known cure. Some symptoms, such as fatigue, are debilitating yet are ‘invisible’ to others. On the other hand, motor weakness and subsequent ataxia are highly visible symptoms, and often a source of anxiety for those with MS. The progressive physical disabling features of MS may affect many aspects of life, for affected individuals and their families. Many people with MS also experience psychological distress, including depression, anxiety and anger.
CHAPTER 3:
PSYCHOSOCIAL ASPECTS OF MULTIPLE SCLEROSIS

“MS is linked to every aspect of life...it is a factor in all these things”
Noel, 49 year old man, diagnosed with MS five years ago.

3.1 Overview

This chapter presents literature to highlight the complex interplay of physical, emotional and psychosocial factors that are associated with living with MS. In line with the transactional stress-coping model which contends the interdependence of these factors, this chapter considers the stressors, coping and emotional impact of the MS experience. Some of the stressors faced by people with MS are presented in the first section. Disease-related factors are described to demonstrate the interdependent relationship that exists between physical and emotional functioning. Literature is also presented to further highlight the prevalence and associated effects of emotional disorders, and the impact on psychosocial factors, such as relationships. How people cope with MS has been the focus of much research that has used Lazarus and Folkman’s (1984) transactional model of stress and coping, and this research is also summarised.

Being diagnosed with MS is very stressful and individuals face challenges to their daily functioning (Murray, 1995). Indeed it has been suggested that MS with its course of unpredictable exacerbations presents people with ‘lifelong stress’ (O’Brien, 1993, p. 54). The effect of stress itself has been implicated in the disease exacerbation of MS,
although the process is not well understood (Mohr & Cox, 2001). According to Sibley (1997) clinical exacerbations of MS are more likely to be preceded by ongoing marital and job related stress, than specific major life events such as a death in the family. Ackerman et al. (2002) also reported a link between stressful life events and MS exacerbations. The one-year study by Ackerman et al. (2002) with 23 women with relapsing remitting MS found that 85 percent of the participants’ exacerbations were related to stressful life events in the preceding six weeks.

3.2 Disease related factors

3.2.1 MS diagnosis and prognosis

Having MS is deemed ‘threatening’ due to the unpredictability of the disease course and how individuals perceive this threat to their lives (Devins & Seland, 1987). This perception of MS as a ‘threat’ because of its anticipated effect has also been identified by others. Halligan and Reznikoff (1985) noted that often newly diagnosed people with MS who had no evident physical or cognitive impairment experienced high levels of distress based on perceptions of their future functioning.

Even before a diagnosis of MS is made, individuals often experience fear (Nicolson & Anderson, 2001). A study which followed 45 people with MS over a four year period found that the greatest emotional impact occurred at the time of diagnosis rather than during the disease (Hopman, Coo, Brunet, Edgar, & Singer, 2000). The ambiguity surrounding the diagnosis and prognosis of MS, combined with the unpredictable nature of the disease and the lack of a cure presents individuals with MS with an uncertain future (McNulty et al., 2004).
McReynolds et al. (1999) contend that the uncertainty related to the unpredictable course of MS is more disturbing to some people with MS than the physical presentation of the disease. However, it may be that there is a relationship between uncertainty, exacerbation and psychological distress. Uncertainty has been found to increase during times of MS exacerbations and has also been found to be associated with depression (Kroencke & Denney, 1999; Kroencke, Denney, & Lynch, 2001).

### 3.2.2 Illness intrusiveness

Studies by Ackerman et al. (2002) and Mohr, Goodkin, Nelson, Cox, and Weiner (2002) highlight the effect stress might have on MS disease activity. However, the disease itself can present debilitating and stressful demands. Many individuals may experience significant disruptions to their daily life and to activities that are valued by them. The concept of illness intrusiveness refers to the degree which an illness and or its treatments interfere with important aspects of life or valued activities (Mullins et al., 2001; Shawaryn, Schiaffino, La Rocca, & Johnston, 2002). Illness intrusiveness can be viewed as accentuating the stress experienced by people with MS, and contributing to their psychological distress (Devins et al., 1996). Mullins et al. (2001) examined relationships between illness intrusiveness, illness uncertainty and psychological distress with a sample of 78 people with MS. Illness uncertainty was conceptualised as referring to ‘perceptions of ambiguity’ regarding diagnosis, prognosis, and an unpredictable disease course. Results found that perceptions of both illness intrusiveness and illness uncertainty predicted psychological distress. The authors
concluded that non-illness factors, such as cognitive appraisal, affect adjustment to MS (Mullins et al., 2001).

3.2.3 Disease impact and functional loss

Many people with MS confront challenges directly related to their illness. Pakenham (2001) found that 78 percent of participants in his study rated their main MS related problems as being associated with physical symptoms. A study by Koch, Rumrill, Rosessler, and Fitzgerald (2001) found the more symptoms, the lower the quality of life. Noy et al. (1995) also examined illness related variables in a sample of 25 people with MS and found higher levels of anxiety and depression associated with disease activity but not with illness duration. Results found that participants’ anxiety levels were positively related with disease exacerbations (Noy et al., 1995).

It is generally considered that higher levels of disability are related to increased anxiety and depression (Janssens, van Doorn et al., 2003). Devins and Seland (1987, p. 373) noted that disease activity and functional loss ‘appear to contribute to the depression and distress in MS’. Consistent with this finding, Wineman’s (1990) study of 118 people with MS found that increased disability was associated with higher levels of depression. Similar findings were reported by Devins et al. (1996), in their study which found that participants’ increased disability was associated with increased psychological distress. A longitudinal study by Aitkens, Fischer, Namey, and Rudlick (1997) also found that psychological distress was associated with higher levels of physical and cognitive disability. Likewise, Lynch et al. (2001) examined the relationship between disability and depression in 188 people with MS and found that depression was positively correlated with disability.
However, increased disability does not always relate to increased psychological distress. Shnek et al. (1995) found no association between depression and disability or disease activity. Also, a study of 60 people with MS by DiLorenzo, Halper, and Picone (2004) found that although older participants reported more physical limitations than younger participants, there were no differences on their measures of psychological health.

### 3.2.4 Mobility status

Difficulties with mobility or ambulation have been identified as important determinants of quality of life for people with MS (Aronson, 1997). This may be due in part to mobility status being one of the more visible MS symptoms. Also there may be a fear among newly diagnosed people with MS that they will be in wheelchairs in a short space of time. Janssens, de Boer et al. (2003) investigated the perceptions of 100 newly diagnosed people with MS regarding their expectations of wheelchair dependency in two and ten years time. Results found that the majority of participants overestimated their two-year and ten-year risk of wheelchair dependency. As expected, participants with more functional limitations viewed their risks as being higher compared to those with less disability.

Some symptoms such as ataxia and spasticity are very visible to others and individuals with MS may feel self-conscious and embarrassed (Nicolson & Anderson, 2001). This may translate into a reluctance to be seen using walking sticks and wheelchairs that may in turn impinge upon social activities (Murray, 1995). A study investigating the social impact of MS, with more than 300 participants, found that
limited mobility impacted upon the level and quality of social contacts (Hakim et al., 2000). One in four participants in this study reported decreased socialising due to their poor mobility. Indeed, lack of mobility, for those people who were more disabled was considered to be one of the main contributing factors for the social isolation (Hakim et al., 2000).

Walking aids and wheelchairs may prompt very different emotional responses from people with MS, depending on their current mobility status and attitude. As noted by Janssens, de Boer et al. (2003, p. 292) people with MS with limited or poor mobility may view a wheelchair as increasing their level of mobility and decreasing fatigue while those who are fully ambulant may perceive walking aids as being a ‘major step backwards’.

### 3.2.5 Fatigue

Fatigue is not only one of the frequent symptoms experienced by people with MS but also one of the most debilitating (Ford et al., 1998; Murray, 1995). However, the aetiology of fatigue in the MS disease process is not clear (Ford et al. 1998). It has been found that fatigue is associated with increased psychological distress (Amato et al. 2001; Bakshi et al. 2000). A study with 103 people with MS by Amato et al. (2001) found that fatigue and depression were important determinants of quality of life. They noted that fatigue is as disabling as other neurological MS symptoms.

It has been contended that fatigue is not just a physical problem but that it is ‘very much a psychological issue’ (Shawaryn et al., 2002, p. 317). McCabe, McKern, and McDonald (2004) in their study of 381 adults with MS found that fatigue was a
significant predictor of psychological distress for both males and females. Results showed that women in their study experienced higher levels of fatigue compared with the men with MS (McCabe et al., 2004). In contrast, no differences between the sexes in their reporting of fatigue levels was found in Lerdal et al.’s (2003) study of 368 people with MS. However, Lerdal et al. (2003) found that participants with shorter illness duration reported higher levels of fatigue compared with participants of the same age group with longer disease duration. They concluded that over time people with MS might adapt their physical activities to a more realistic level to manage their fatigue.

Nevertheless, fatigue is a common symptom experienced by many with MS and one which affects people physically and psychologically. Ford et al. (1998) noted from their study of 68 people with MS that 85 percent of the sample reported high levels of fatigue. The authors examined the effects of fatigue upon psychological distress. Both physical and emotional fatigue were measured. Results found that emotional and physical fatigue were significantly related to increased depression and anxiety levels. They concluded that there are people with MS ‘whose debilitating fatigue could be dealt with by recognising and effectively treating their psychological problems, especially depression’ (Ford et al., 1998, p. 37).

### 3.3 Psychological distress

While clinicians often focus on physical functioning, research has found that people with MS are often more concerned with their mental health and psychosocial functioning (Hopman et al., 2000). Pakenham (2001) reported that 44 percent of participants with MS in his study nominated their main MS related problem was related to emotional problems such as depression, anger and frustration. Indeed, for some
individuals the impact of the illness may be ‘most psychologically profound’ (Mullins et al., 2001, p. 148).

Depression is considered to be the most common psychiatric disorder manifested in people with MS (Mohr & Cox, 2001; Noy et al., 1995). There have been estimates of 42 to 54 percent of lifetime occurrence of depression for people with MS (Amato et al., 2001). It is not known whether this is a result of the MS disease process or resultant from the demands and stresses which accompany the MS diagnosis. For example it has been contended that some emotional disorders may be related to altered brain functions as a result of demyelinated lesions (Rao et al., 1992). It has also been suggested that being diagnosed with MS in itself provokes an emotional upheaval which can trigger more psychological difficulties (Mohr & Cox, 2001). There has been more support for this notion of psychological distress being due to the stressful nature of having MS (Aitkens et al., 1997). However, Murray (1995) noted that one of best predictors of depression in MS is a previous experience of depression.

Anxiety is also a common emotional disorder among people with MS. Noy et al. (1995) reported a prevalence of anxiety of 90 percent in their study of 25 people with relapsing-remitting multiple sclerosis. Results from their study found a positive association between participants’ anxiety levels and the number of exacerbations. Hakim’s et al.’s (2000) larger study of 305 people with MS found that similar anxiety levels were reported by males and females but that there was a difference in anxiety levels between certain age groups. In the age group under 30 years, 37 percent of participants reported anxiety compared to only 17 percent aged 30 to 44 years. These studies highlight that anxiety may be related to disease activity, and/or duration of illness.
There may also be an interaction between the MS related disability, psychological distress, and subsequent physical pain. Janssens, van Doon et al. (2003) reported a finding of an association between level of disability and anxiety. Their study found that higher levels of disability were associated with higher levels of anxiety and depression. They also noted that those individuals with increased anxiety levels also reported higher levels of pain.

3.4 Psychosocial Factors

3.4.1 Quality of life

As discussed earlier, MS is diagnosed usually in young or middle aged adults. Therefore, MS may affect younger adults at a time when they are making decisions regarding their relationships, family planning and careers. Having MS impacts upon individuals’ plans for the future both personally and professionally (Nicolson & Anderson, 2001). As a result, an added stress for some people with MS may be work-related. They may fear that they will be prejudiced in their career opportunities because of their MS (Eklund & MacDonald, 1991).

Many people with MS face multiple losses, which may include their physical independence, social activities, and role changes that impact upon their quality of life (O’Brien, 1993). A study with 227 people with MS by Koch et al. (2001) found that role disturbance and lifestyle changes were factors that influenced estimates of quality of life. A larger, comparative study by McCabe and McKern (2002) compared 381 people with MS with 291 adults from the general population, and found that those with MS experienced lower levels of perceived quality of life. MS participants reported lower
scores on not only physical health but also on psychological health, social relationships and environment domains as compared with the other participants. MS may also impact in different ways for males and females. McCabe and McKern (2002) found that females with MS experienced lower levels of quality of life than males with MS. The women with MS reported having more psychological distress due in part to restricted social relationships as a consequence of disease-related impairments.

3.4.2 Relationships

The impact of having a chronic illness has consequences for current and subsequent social and intimate relationships. Having MS imposes adaptive challenges not only for those who are diagnosed but also for their partners and families (Livneh & Antonak, 1997; Murray, 1995). There may be role reversals required for some partnerships. For example, the healthy spouse/partner may be required to undertake paid employment and child caring responsibilities, as well as being a carer for their MS affected partner. These increased responsibilities may impose extra strain on the marital relationship (Murray, 1995).

Many individuals with MS may also experience strained relationships as a consequence of the stress related to their disease (Devins & Seland, 1987; Hakim et al. 2000). Pakenham (2001) in his study of stress reported that 22 percent of the 113 participants with MS identified relationship problems as being their main MS related problem. However, there have been mixed findings regarding the effect of MS upon relationships. Hakim et al. (2000) reported while many of 305 participants reported strained relationships, 11 percent of spouses of participants indicated that their relationship had improved since the MS diagnosis. Mohr et al. (1999) reported that 50
percent of participants in their study indicated that they felt closer to their spouse since having MS. Likewise, Eklund and MacDonald (1991) found 55 percent of 125 participants with MS in their study reported changes to their relationships with their spouse, half of the time they were perceived to have changed in positive ways. Furthermore, a study by McCabe, McDonald, Deeks, Vowels, and Cobain (1996) found a third of participants reported an increase in the quality of the relationship with their partner, while one third reported no change and the other third noted their relationship had deteriorated.

As noted in the previous chapter, sexuality can be adversely affected by MS (Devins & Shnek, 2000; Nortvedt et al., 2001). Sexual dysfunction as a consequence of MS can be problematic for both males and females and affect intimate relationships. A longitudinal study by McCabe et al. (2003) examined relationship and sexual satisfaction among people with MS. Their study compared sexual functioning and relationship satisfaction between 321 adults with MS and 239 adults from the general population. They found that compared with the other adults, individuals with MS reported lower levels of sexual activity, sexual satisfaction, and higher levels of sexual dysfunction. Nortvedt et al. (2001) in their study of 194 people with MS found a strong association between sexual difficulties and depression. They noted that the relationship between sexual dysfunctions and depression could be reciprocal in nature.

### 3.5 Coping

The unpredictable nature of the MS disease process results in individuals having many varied responses to the challenges and stresses associated with living with MS. As noted by Murray (1995, p. 205) ‘some very physically disabled people cope and manage
very well, living productive and happy lives; some others appear to decompensate when they hear the diagnosis’. The nature of MS being an ‘episodic chronic illness’ requires individuals to have flexible coping strategies to adapt to the changing conditions of disease activity (Pakenham, 1998, p. 276).

As described in the introductory chapter, the transactional model views coping as a ‘process’ rather than being ‘trait-oriented’ (Lazarus & Folkman, 1984, p. 178). According to this perspective, coping is also broadly termed as being problem-focused (directed at changing the environment) or emotion-focused (changing the meaning of the situation to regulate an emotional response). Lazarus and Folkman (1984) contend that how people appraise their situation or problems will determine their choice of coping strategy. Individuals do not automatically respond to changes or demands but rather consider options and consequences according to the context.

Studies of life stressors (Folkman & Lazarus, 1986; 1988a; O’Brien & DeLongis, 1996) have found that coping varies with the type of stressors and whether the situation is deemed to be controllable or not. For example, people are more likely to use problem-focused coping in dealing with work related problems, and use emotion-focused coping with family or health issues (O’Brien & DeLongis, 1996). It has been noted that emotion-focused coping strategies are more likely to be used in situations which are deemed outside of one’s control (such as health-related problems), and that problem-focused coping is used in situations deemed more controllable (such as work related problems). More generally, Folkman and Lazarus (1985) contend that people often use both problem-focused and emotion-focused strategies when dealing with any one problem. According to Folkman and Lazarus (1980, 1986) neither problem-focused nor emotion-focused coping is considered superior over the other. Adaptive coping is considered to be the choice of an appropriate strategy for the particular situation. The
purpose of both types of coping functions is to ease the psychological distress that accompanies the stressful experience.

The finding that people use both problem-focused and emotion focused coping was instrumental in Folkman and Lazarus (1988b) developing a questionnaire by way of factor analyses to identify coping strategies. While originally coping strategies were classed as two scales of being ‘problem-focused’ or ‘emotion-focused’, the authors (1988b, p. 9) noted that this naïve classification ‘failed to reflect the richness and complexity of human coping processes’. The Ways of Coping Questionnaire (Folkman & Lazarus, 1988b) has eight sub-scales to measure different identified coping strategies.

As seen in Figure 3.1 the eight sub-scales have been conceptualised as having either problem-focused or emotion-focused coping functions. Two coping strategies are considered to represent problem focused coping functions: Planned Problem Solving, and also Confrontive coping which has been identified as being a more aggressive approach to changing the problem. One subscale, ‘Seeking social support’ incorporates both functions of emotion and problem focused coping. This strategy may serve a problem-focused function when it is used to seek tangible or concrete information, and an emotion-focused function if the process of asking others for advice is to enables individuals to feel emotionally supported.
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Coping function</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planned problem solving</td>
<td>Problem-focused</td>
<td>Analysing the situation to arrive at solutions and then take direct action to correct the problem.</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>Problem-focused</td>
<td>Taking assertive action, often involving anger or risk taking, to change the situation.</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>Problem or emotion-focused</td>
<td>Trying to acquire information, tangible support or emotional support.</td>
</tr>
<tr>
<td>Distancing</td>
<td>Emotion-focused</td>
<td>Making cognitive efforts to detach oneself from the situation or trying to minimise the significance of the situation.</td>
</tr>
<tr>
<td>Escape-avoidance</td>
<td>Emotion-focused</td>
<td>Wishful thinking about the situation or behavioural efforts to avoid or escape the situation. Contrast with distancing coping which suggests detachment.</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>Emotion-focused</td>
<td>Attempting to modulate one’s feelings or actions in relation to the problem.</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>Emotion-focused</td>
<td>Acknowledging one’s own role in the problem while trying to put things right.</td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>Emotion-focused</td>
<td>Trying to create a positive meaning from the situation in terms of personal growth, sometimes with a spiritual dimension</td>
</tr>
</tbody>
</table>

Source: Caltabiano, Byrne, Martin, & Sarafino (2002); Folkman & Lazarus (1988b); Lazarus, (1991).
3.6 Research on coping with MS

Many studies with MS populations have used the Ways of Coping Questionnaire or modified version to examine the role of coping. The following studies are presented as being representative of the research that has used the transactional framework to examine coping with MS samples. Usually the effectiveness of coping behaviour has often been evaluated in the stress and coping research in terms of resultant emotions. Subsequently less emotional distress is often considered to be more indicative of an adaptive coping outcome.

People with MS use both problem-focused and emotion-focused strategies when dealing with a disease-related stressful event (Jean et al., 1999); although more generally it has been noted that people with MS are more likely to use emotion-focused coping strategies than problem-focused coping (Livneh & Antonak, 1997; Mohr & Cox, 2001). It has been suggested that increased use of emotion-focused coping may be the result of people with MS having few options on changing their circumstances or altering the course of their disease (Livneh & Antonak, 1997). Some studies have examined the relationship between coping and disease-related variables such as time of diagnosis (Eklund & MacDonald, 1991), illness uncertainty (Wineman, Durand, & Steiner, 1994), exacerbations (Warren, Warren, & Cockerill, 1991), and fatigue (Beatty et al., 1998).

Eklund and MacDonald (1991) conducted a mail-out survey study with 125 people with MS and found that participants with high levels of anger, fear and depression reported using the least adaptive coping strategies. In this study participants were asked retrospectively about their coping strategies at the time of diagnosis. The Ways of Coping Questionnaire was used to measure coping strategies. Emotion-focused coping
strategies were the most frequently used type of coping reported by participants. Confrontive coping, and escape-avoidance coping were found to be associated with less successful adaptation. Participants who reported having used more positive reappraisal coping strategies showed a ‘better long-term adjustment’ (Eklund & MacDonald, 1991, p. 282).

Wineman et al. (1994) studied 433 people with MS, and examined the effects of illness uncertainty upon coping choice and psychological distress, using the Ways of Coping Questionnaire and the Profile of Mood States. Results found that there was a significant difference in coping depending on participants’ level of perceived uncertainty. They found that those people who had the highest level of illness uncertainty were more likely to use emotion-focused coping strategies. However, coping strategies were not a significant predictor of emotional well-being as measured by the POMS.

Changes in MS condition, such as having an exacerbation of symptoms have been found to influence coping behaviours. Warren et al. (1991) investigated coping behaviours among 95 pairs of people with MS who were matched for age and sex. Results found that people with MS who were having an exacerbation of symptoms were more likely to use more emotion-focused coping and less problem-focused coping strategies than those people who were in remission.

Fatigue is one of the most common symptoms experienced in MS yet there has been little research to examine its relationships to coping behaviour (Beatty et al., 1998). The relationship between fatigue and coping was examined by Beatty et al. (1998) in a study with 43 people with MS. Fatigue was measured using the Fatigue Severity Scale. Results found no relationship between fatigue severity, disability severity, disease duration with coping. It was, however, found that participants who
reported higher levels of psychological distress were more like to use emotion-focused coping strategies than those with lower levels of psychological distress.

There have been consistent findings of increased use of emotion-focused coping by people with MS being associated with higher levels of psychological distress, such as depression and anxiety (Arnett, Higginson, Voss, Randolph, & Grandey, 2002; Livneh & Antonak, 1997). Some studies (Aitkens et al., 1997; Jean et al., 1999; McCabe et al., 2004; Pakenham 1999; Pakenham, Stewart, & Rogers, 1997) have examined the relationship between coping and psychological distress with people with MS. Jean et al. (1999) with a sample of 56 people with MS found that increased use of emotion-focused coping was associated with higher levels of psychological distress while participants’ use of problem-focused coping was not related to the level of psychological distress.

A longitudinal study by Aitkens et al. (1997) found that escape avoidance coping was predictive of future psychological distress. Coping was measured using the Ways of Coping questionnaire and psychological distress was measured using the Beck Depression Inventory. Results found that, at time one, escape-avoidance coping was positively correlated with depressive symptoms, while there was a negative association between depression and both positive reappraisal and planful problem solving.

An association between use of problem-focused coping and increased well-being was reported in studies by Pakenham et al. (1997) and Pakenham (1999). Pakenham et al. (1997) examined coping and adjustment with a sample of 134 people with MS. Results found that increased use of problem-focused coping was associated with better adjustment outcomes and emotion-focused coping was related to poorer adjustment. Similarly, a longitudinal study by Pakenham (1999) found use of escape avoidance coping was associated with poorer adjustment, whereas problem-focused coping was
related to better adjustment in a sample of 122 people with MS. Adjustment was measured at study entry and again at 12 months interval. Measures of adjustment included depression, global distress, social adjustment and health status scales. Overall adjustment (less distress) was predicted by less disability, less use of emotion-focused coping and increased use of problem-focused coping.

A study by McCabe et al. (2004) with 381 adults with MS (237 women and 144 men) also found that emotion-focused coping was associated with poorer psychological adjustment. More specifically, a form of avoidance emotion-focused coping, wishful thinking, was related to poorer adjustment. Adjustment was determined using the depression and tension/anxiety scales of the POMS. However, there were differences for men and women in this study. Results showed that problem-focused coping was associated with higher levels of psychological adjustment (less depression, less tension) for men but not for women. Increased psychological adjustment for women but not men was related to their use of seeking social support.

The results of the above studies indicate that the relationship between coping and psychological distress is not clear. For example, the increased use of emotion focused coping of escape-avoidance has been consistently associated with increased psychological distress, however, the link between problem-focused coping and distress is less clear. Problem-focused coping has been associated with less psychological distress in some studies (McCabe et al., 2004; Pakenham, 1999) but not others (Jean et al., 1999). Emotion-focused coping has been implicated as being maladaptive (Aitkens et al., 1997), however, there may be times when emotion-focused coping may be beneficial (Murray, 1995). For example, the use of distraction may enable an individual some respite from the reality of their illness. Despite the ongoing challenges which people with MS face, often on a daily basis, many people with MS use adaptive
strategies such as positive thinking, and humour to help them live with their condition (Murray, 1995). The use of positive reappraisal, an emotion focused coping strategy, has also been found to be related to less psychological distress for people with MS (Aitkens et al. 1997).

3.7 Chapter summary

Many people with MS face a variety of psychosocial stressors and adaptive challenges and often there is a complex interplay between physical, emotional and psychosocial factors as a consequence of the MS disease process. MS symptoms, fatigue, and limited mobility have been shown to have psychological and social consequences. The impact of MS upon relationships has also been briefly described. Much research into how people cope with MS has used the transactional model of stress and coping, which prescribes coping as a process that constantly changes according to cognitive appraisal and the given context.

Usually the effectiveness of coping behaviour has been evaluated in the stress and coping research in terms of resultant emotions. Subsequently less emotional distress is often considered to indicate an adaptive coping outcome, while higher levels of distress are indicative of maladaptive coping outcomes. Certain coping strategies, such as use of escape avoidance coping, have consistently been associated with increased psychological distress. Positive reappraisal and problem-focused coping have mixed support as being related to decreased psychological distress.

However, it may be pertinent to consider criteria other than emotions to measure the effectiveness of coping. As suggested by McCrae and Costa (1986, p. 401) whether
or not one is happy may be ‘less relevant than whether one has learned from the experience, or maintained social bonds or accomplished a significant task’.

Further examination of how people with MS try and adapt to their disease and their changed circumstances continues in the next chapter, which presents literature related to psychological adaptation to a chronic illness.
CHAPTER 4: 

PSYCHOSOCIAL ADAPTATION TO CHRONIC ILLNESS

‘I’ve learnt to accept MS but I am willing to try anything...’

Anna, 40 year old woman with MS

4.1 Overview

This chapter presents research literature related to psychosocial adaptation to explain how individuals adapt to living with a chronic illness such as multiple sclerosis. Theories of psychosocial adaptation and cognitive adaptation, have been used as frameworks to study how people live with the uncertainty and upheaval that comes with a chronic illness. Literature examining psychosocial adaptation in people with MS is presented to determine relevant illness-related and psychosocial factors associated with better health outcomes. Cognitive adaptation theory purports that people who experience chronic illness report both negative and positive experiences (Taylor & Aspinwall, 1990). According to this perspective individuals use cognitions to redefine adversity into a more positive light. Consequently, some people not only adapt to adverse situations, but are able to report perceived benefits from the experience. Most of the studies examining cognitive adaptation and reporting benefit finding have used cancer and heart disease samples. However, Mohr et al. (1999) also found that their participants reported both positive and negative consequences from their MS experience. In light of these findings of perceived benefits, Mohr et al.’s study and other
studies examining benefit finding and well-being in samples of chronically ill people are presented in the latter sections of this chapter.

4.2 Psychosocial adaptation to chronic illness

The concepts psychosocial adaptation and adjustment are often considered to be interchangeable. However, while there are overlapping features, it has been noted that both concepts have different theoretical implications and research applications (Livneh & Antonak, 1997). Adjustment refers to a particular stage, usually the final phase, of a set of responses or experiences, to a change or crisis situation. Livneh and Antonak (1997, p. 8) note that adjustment is the ‘clinically and phenomenally hypothesized final phase’. Research examining adjustment to a chronic illness often measures success in terms of self-esteem, attitudes, psychological symptoms, and efficacious behaviours (Livneh & Antonak, 1997).

On the other hand, psychosocial adaptation to a chronic illness has been defined as ‘an evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence’ (Livneh & Antonak, 1997, p. 8). Psychosocial adaptation is thus viewed as a gradual process of integration of changes that may include the ‘individual’s body, body image, ego, self concept, and person-environment interactions’ (Livneh & Antonak, 1997, p. 453).

Psychosocial adaptation has often been conceptualised in research as having both psychological and social dimensions (Antonak & Livneh, 1995). The psychological dimension constitutes the internal reaction to the chronic illness or disability: usually negative emotions such as anger, anxiety and depression. As people adapt successfully there may be evidence of personal growth including improved self-
esteem, increased self-awareness and later, acceptance. The social dimension of psychosocial adaptation comprises the external orientation of the process. Social adaptation is the process where people when faced with a disability may initially withdraw socially, and either distance themselves from others or alternatively confront others with hostility. However, as people adapt more successfully to their disability there is a movement towards an integration of their social world as evident by their increased participation. A main assumption of psychosocial adaptation as a phase model (moving through a sequence of phases) is that successful transition results in increased psychological growth (Livneh & Antonak, 1997).

In line with their view of psychosocial adaptation as a dynamic process, Livneh and Antonak (1997) developed a conceptual framework, a model of psychosocial adaptation to chronic illness and disability (CID). They contend that there are four broad classes of variables related to psychosocial adaptation that require investigation: disability related variables; sociodemographic variables; personality attributes, and variables associated with the physical and social environment. The degree and extent of psychosocial adaptation is thus determined by a complex interplay of these four classes of variables. Being a dynamic process, a major assumption of the model of psychosocial adaptation proposed by Livneh and Antonak is that adaptation changes over time, and that it is characterised by variation among individuals.

There is generally considered to be a wide variation between individuals’ reactions and their subsequent adaptation according to the type of disability or chronic illness they are experiencing. Therefore Livneh and Antonak (1997) argue that the focus of any research examining psychosocial adaptation to a specific chronic illness should be to examine within groups differences rather than those between groups.
4.3 Psychosocial adaptation to MS

4.3.1 MS related factors

Different chronic illnesses may prompt varied psychosocial reactions and subsequent process of adaptation. Compared with other chronic diseases and physical disability, Livneh and Antonak (1997, p. 321) contend that people with MS ‘express both greater variability and more intensity in their psychosocial reactions to the disease’. However, McReynolds et al. (1999) argued that MS presents individuals with a range of symptoms and challenges not faced in other chronic illnesses.

McReynolds et al. (1999) developed a Five Factor model to explain how people are affected by MS. The five components to determine the level of psychosocial adaptation to MS include: 1) range and severity of illness related symptoms, 2) uncertainty of the illness, 3) sense of loss associated with functional limitations, 4) personal resilience and 5) social supports.

The MS symptoms which McReynolds et al. (1999) note need to be considered for their disruptive features included fatigue, diminished limb strength, motor disturbances, numbness and tingling, mobility impairments, visual impairments, cognitive deficits, bowel and bladder difficulties and sexual difficulties. The authors suggest that the type of MS (benign, relapsing-remitting, chronic progressive), and the sense of functional loss which individuals experience when they compare themselves to their pre MS selves is important in people’s capacity to adapt to their condition. The fourth factor in their model, resilience, relates to psychological adjustment again based on pre-illness levels and current coping skills. The individuals’ social networks (family,
friends and rehabilitation professionals) were also considered to have an important impact upon their ability to adjust successfully to MS.

McReynolds et al. (1999) contend that these five factors need to be determined to evaluate psychosocial adjustment and to also assist with teaching people with MS appropriate coping strategies. They recommend that early interventions focusing on adaptive strategies be employed ‘immediately after diagnosis’ to increase their independence and also to prepare them for possible exacerbations. More generally, they note that ‘as a group, people with MS tend to have highly developed coping mechanisms’ and that many are able to continue with their lifestyle with modifications (McReynolds et al., 1999, p.87). The role of coping in helping individuals adapt to MS has also been noted by Livneh and Antonak (1997, p. 315) as being an important ‘area of inquiry’ into psychosocial adaptation to multiple sclerosis.

### 4.3.2 MS studies of psychosocial adaptation

Reviews by Antonak and Livneh, (1995, 1997) of studies examining psychosocial adaptation to MS suggest that adaptation is usually positively associated with remission or being symptom free, a sense of control, and social supports. However, an inverse relationship is usually found between adaptation and age, severity of functional disability, symptom exacerbation, loss of support, and perceptions of illness intrusiveness and illness uncertainty. However, these findings are not always consistent which may be due in part to the nature of MS.

A study by Larsen (1990) of 135 people with MS, found that the duration of MS did not affect psychosocial adjustment (measured by Psychosocial Adjustment to Illness Scale: PAIS). However, there were significant differences between MS status and
psychological distress; the remission participants had significantly less psychological distress than those participants who were experiencing an exacerbation of symptoms.

Walsh and Walsh (1987) examined the relationship between self esteem and adjustment stage. This study had a sample of 113 people with MS who were rated into three categories of mobility: no walking aid, some form of walking aid, and wheelchair or bedridden. Results found that participants with the lowest self-esteem were bedridden or required a wheelchair; these participants were more likely to be classified as being in the denial stage. Likewise, the highest self-esteem levels were found for participants who had less disability and who were identified in the integration stage.

While Walsh and Walsh (1987) found more disability was related to poorer adjustment, a study by Barnwell and Kavanagh (1997) found no relationship. Barnwell and Kavanagh (1997) examined relationships between mood control, social activity, self-efficacy, disability and depression in a sample of 71 people with MS. Their study found that depression, measured by the Beck Inventory, was not predicted by level of disability. They noted that this might be due in part to people being able to cope more effectively the longer they lived with their disabilities. However, as expected, disability level did impact on individuals being able to maintain certain social activities that could predispose them to social isolation. This is consistent with Larsen’s (1990) contention that the psychosocial aspects of MS may be more devastating than the physical symptoms for some individuals.

4.3.3 Psychosocial consequences of MS.

How people view the impact of the psychosocial effects of MS upon their lives, and subsequently their adaptation was examined by Mohr et al. (1999). They argued
that while there has been much research into the psychosocial impact of MS, most of the research has focused on psychological functioning by way of distress and coping. The authors contended that some aspects of psychosocial functioning might not have been identified. Psychosocial functioning was defined by Mohr et al. (1999, p. 377) as including ‘intrapersonal or interpersonal processes and excluding physical symptoms’.

Mohr et al.’s (1999) study, a two-part project, examined the psychosocial experiences of people living with MS using both qualitative and quantitative analyses. In the first stage, fifty people with MS were interviewed by telephone regarding the effects of MS upon their lives and relationships. Participants were asked demographic and disease-related information, and two open-ended questions that were constructed to identify intra-personal and interpersonal processes. These questions were: ‘How has MS changed or affected you as a person?’ and ‘How has MS changed or affected your relationships with other people?’ Responses to the questions were collated, and classified into statements reflecting psychosocial experiences.

These constructed statements were administered as a Likert scale questionnaire to a second sample of 94 people with MS. The Profile of Mood States (POMS) (McNair, Lorr, & Dropelman, 1981) and the Ways of Coping Questionnaire (Folkman & Lazarus, 1988b) were also used to measure mood and coping respectively. Factor analysis was undertaken on participants’ responses to 48 statements about psychosocial functioning that made up the Likert scale and three factors were identified: Demoralization, Deteriorated Relationships and Benefit-Finding.

Mohr et al. (1999) noted that previous research with people with MS (Mohr & Dick, 1998) has identified similar concepts to two of the factors identified in their study; Demoralization and Deteriorated Relationships. Demoralization pertained to statements concerning feelings of worthlessness, loss of self-esteem, and helplessness. An example
of a Demoralization statement is ‘I worry that I am burden to others because of MS’. The Deteriorated Relationships factor reflects a perception of a sense of inadequacy with a relationship as a consequence of MS and is characterised by statements such as ‘My spouse/significant other is often angry because of my MS’.

However, the finding of people reporting perceived benefits from their MS experience had not been previously reported in MS research (Mohr et al. 1999). Benefit-Finding items included reports of an enhanced appreciation of life, deeper relationships with others and increased spirituality. For example, ‘Since having MS I have learnt to communicate better with people’, and ‘MS has made me appreciate life more’.

Analyses showed that all three factors were not related to age, gender, time of diagnosis, or length of illness. However, participants who required aids or assistance for ambulation scored higher on the Demoralization factor than those people who did not require assistance. No other symptoms were related to any of the factors.

Certain coping strategies from the Ways of Coping Questionnaire were associated with each factor. Demoralization was significantly related to higher use of Accepting Responsibility and Escape-avoidance coping. A significant negative relationship was found between the Deteriorated Relationships factor and Self-controlling coping. Results showed that the Benefit Finding factor had a significant positive association with Positive Reappraisal and Seeking Social Support coping.

The factors were also found to have associations with the POMS subscales of depression, anxiety and anger. Demoralization was related to higher levels of depression but was not related to anger or anxiety levels. The Deteriorated Relationships factor was significantly related to higher levels of both depression, and anger, but had no relation to anxiety. Benefit Finding was found to be significantly related with increased levels of anxiety and anger, but was unrelated to depression. Thus while participants were able to
report some elements of personal growth or enhanced relationships from their experience with MS as per their responses to the Benefit Finding statements, they were also experiencing high levels of anxiety and anger.

Despite this paradoxical result of Benefit Finding being associated with increased levels of psychological distress, Mohr et al. (1999, p. 380) noted that their participants’ reporting of benefits was indicative of a ‘form of cognitive adaptation’ as described by Taylor (1983).

4.4 Benefit finding

4.4.1 Cognitive adaptation theory

Taylor (1983) proposed a theory of cognitive adaptation to explain how individuals restructure their cognitions to adapt to threatening events. Cognitive adaptation theory was developed following studies by Taylor and colleagues with women who had breast cancer. A main assumption of this theory is that individuals who experience adversity will ‘respond by cognitively adaptive efforts that may enable them to return to or exceed their previous level of psychological functioning’ (Taylor, 1983, p. 1170). When faced with adversity individuals are often motivated to evaluate the situation as being less harsh than it really may be. Thus when faced with a chronic illness, some individuals will maintain or adopt an optimistic outlook (Taylor & Brown, 1994).

Cognitive adaptation theory incorporates three themes of meaning, mastery, and self-enhancement to explain how people adjust their cognitions following adversity to perceive their situation as less threatening (Taylor, 1983). Taylor (1983) contends that
specific cognitions are related to these three themes. For example, finding meaning is associated with attributions, and with efforts to construe positive benefits from the experience. Mastery requires efforts related to beliefs of control. Self-enhancement involves social comparisons with those less fortunate and also by construing benefits from the experience. Thus perceiving benefits is considered to be related to finding meaning in adversity and also with self-enhancement: two of the themes of cognitive adaptation.

The restructured cognitions are considered to be largely due to illusions or beliefs that may not be based on reality. Taylor (1983, p. 1171) argues that these illusions are a ‘dynamic force’ which can ‘simultaneously protect and prompt constructive thought and action’. Three positive illusions which characterise beliefs identified by Taylor and colleagues (Taylor, 1983; Taylor & Armor, 1996; Taylor & Brown, 1994) are self-aggrandisement (distorted positive perceptions), overly optimistic expectations for the future, and an exaggerated sense of personal control. Rather than assuming these illusions are indicative of maladaptation, or a denial of reality Taylor (1983) contends that these illusions promote psychological adaptation. Successful adjustment to adversity is considered by Taylor (1983) to be dependent upon the ability to sustain these beliefs or positive illusions. Likewise, Mishel (1988) notes that constructing positive illusions about threatening situations may protect individuals from the negative effects of uncertainty.
4.4.2 Benefit finding

Taylor (1983) argues that benefit finding is an important component of cognitive adaptation theory whereby people evaluate their circumstances in a positive light. Taylor and Aspinall (1990) note that cognitive adaptation theory does not presume that having a chronic illness is a positive experience. Rather individuals who ‘experience a chronic illness will report both positive and negative experiences’ (Taylor & Aspinall, 1990, p. 44).

Perceiving benefits makes the experience less harsh, and in this way cognitive adaptation enables individuals to feel a sense of control over their lives, and restores a more comfortable view of their world (Taylor, 1983). Perceiving benefits or finding meaning in adversity is thus considered self-empowering. Not only does cognitive adaptation lessen the trauma of adversity at the time but it also may enable individuals to master future challenges (Taylor, 1983).

According to Affleck and Tennen (1996), Taylor’s conceptualisation of benefit finding as a cognition is more indicative of a coping strategy. In contrast, Affleck and Tennen (1996) distinguish between benefit finding and benefit reporting and argue that benefit reporting is a form of coping. They contend that benefit finding pertains to a belief system about benefits from the adverse situation. Benefit finding generally refers to a belief that adverse events or experiences have promoted positive qualities (Affleck & Tennen, 1996). These benefits may include a greater appreciation of life, enhanced interpersonal relationships or a perception of personal growth.
4.4.3 Benefit finding and well-being

There appears to be wide support in the literature for a relationship between positive outcomes and finding benefits from adversity (Affleck & Tennen, 1996; Taylor, 1983). However, past studies examining benefit finding and psychological well-being in chronic illness have reported inconsistent findings. Perceived benefits are not always associated with psychological well-being. Studies that have found a positive association between participants reporting benefits and psychological well-being include samples of women with breast cancer (Taylor 1983); HIV/AIDS caregivers, (McCausland & Pakenham, 2003); and people with cancer and with lupus (Katz, Flasher, Cacciapaglia, & Nelson, 2001). Other studies, such as Mohr et al. (1999) with a MS sample found that reporting benefits was associated with increased psychological distress. A study with women with breast cancer by Antoni et al. (2000) found no association between benefits and psychological health.

Antoni et al.’s (2001) study, with 100 women diagnosed with breast cancer, examined benefit finding using a 17 item Likert measure. The authors reported that most of the participants indicated that they had experienced positive change. The relationship between benefit finding and psychological well-being was determined using the POMS (McNair et al., 1981), and a depression scale, the CES-D (Radloff, 1977). Results found that there was no association between participants’ reporting benefits and psychological well-being.

Katz et al. (2001) examined the relationship between benefit finding and psychological distress with 56 people with cancer, and 31 people with lupus. Benefit finding was measured using the scale developed by Mohr et al. (1999), and distress (mood disturbance) was also determined by the POMS. Unlike Mohr et al. (1999),
results from this study found that there was a negative association between benefit finding and mood disturbance. Findings also showed that benefit finding was associated with positive health outcomes for both cancer and lupus groups. Participants who reported more perceived benefits also reported less pain and less fatigue. Katz et al. (2001) concluded that people with chronic conditions other than MS also reported perceived benefits from their experience, and that benefit finding was linked with physical and psychological well-being. However, the link between benefits and psychological wellbeing is not clear.

A longitudinal study by Sears, Stanton, and Danoff-Burg (2003) of 92 women with breast cancer which examined benefit finding found that 83 percent of participants reported perceived benefits from their experience with cancer. The most common reported perceived benefit was improved relationships with others. Benefit finding was determined by two measures: an open ended question and also by a measure of positive reappraisal coping. Participants were asked: ‘Have there been any benefits that have resulted from your experience with cancer’. Responses were coded into five categories. Results found that use of benefit related information as a coping strategy (positive reappraisal) was a predictor of participants’ mental and physical health at the 3 and 12 month interval in the study. However, reporting or identifying a benefit was not associated with health outcomes. The authors concluded that benefit finding and positive reappraisal coping appeared to be distinct yet related constructs.

It is uncertain how benefit finding relates to stress and coping (McCausland & Pakenham, 2003). However, generally it is considered that finding meaning or perceiving benefits enhances coping ability (Taylor, 1983; Affleck & Tennen, 1996). But it may be that benefit finding is a coping strategy or at least is related closely to positive reappraisal coping as identified by Sears et al. (2003).
Another variable which is considered to mediate benefit finding and psychological well-being is optimism. Affleck and Tennen (1996) found that optimistic people were more likely to report benefits from adverse experiences and also report more positive mood states. They concluded that investigations into benefit finding need to consider the role of personality traits such as dispositional optimism.

A review of studies concerned with optimism by Affleck, Tennen, and Apter (2001, p. 147) argues that dispositional optimism is the new ‘focal point of theory and research on adaptation.’ Affleck et al.’s (2001) assertion, and the association between optimism and benefit finding found by Affleck and Tennen (1996) warrants the inclusion of optimism in the present study. Literature and research concerning dispositional optimism is presented in the next chapter.

4.5 Chapter summary

This chapter presented literature and research related to theories of psychosocial adaptation and cognitive adaptation. Livneh and Antonak’s (1997) conceptual framework of psychosocial adaptation to a chronic illness, and the Five Factor model proposed by McReynolds et al. (1999) recommends examination of characteristics related to the condition, the individual and the social environment. In line with their recommendations, psychosocial adaptation research involves considering relevant disease-related variables, and examining the impact upon both psychological and social dimensions. Thus, MS specific related variables, such as fatigue and mobility, are considered to be important determinants of adaptation.
The study by Mohr et al. (1999) investigating the psychosocial consequences of living with MS showed that people report both negative and positive effects from their experiences. Of particular interest is the notion of benefit finding identified in this study. Mohr et al. (1999) were the first study to report that people with MS perceived such benefits. However, unlike other studies, Mohr et al. (1999) found that perceived benefits was associated with increased psychological distress. The reporting of benefit finding by Mohr et al. (1999) warrants replication and extension of their study.

Benefit finding is a component that appears to be related to Taylor’s (1983) cognitive adaptation theory that purports that people when faced with adversity modify their cognitions to lessen their threatening situation. Research by Mohr et al. (1999) and others demonstrates that people perceive both positive and negative consequences from their experiences of chronic illness. Lastly, individuals’ personality characteristics may influence their ability to adapt to MS, and also to report perceived benefits from adversity. Dispositional optimism has been mooted by Affleck et al. (2001) as a recent focus of psychological adaptation, and is the topic of the next chapter.
CHAPTER 5: OPTIMISM

‘Having a positive attitude and faith have been my mainstay with my fight against MS’

Joyce, 55 year old woman with MS.

5.1 Overview

Research concerning optimism has found it linked to a wide range of apparently positive outcomes including academic and occupational success, positive moods, high morale, popularity with others, and good health (Peterson, 2000). Optimism has been broadly defined as ‘a mood or attitude associated with an expectation about the social and material future – one which the evaluator regards as socially desirable, to his (or her) advantage or his (or her) pleasure’ (Tiger, 1979, p. 18). More simply optimism is defined as reflecting an expectation that good things will happen (Chang, 2001).

Optimism has been conceptualised in many ways (Peterson, 2000). Literature concerning optimism or optimistic beliefs shows that the most common concepts of optimism are based on theories related to self-efficacy theory (Bandura, 1986), attributional/explanatory styles (Peterson & Seligman, 1987), positive illusions (Taylor, 1989) or positive expectations (Scheier & Carver, 1985). While this variation has enriched research into optimism, Chang (2001) noted that it has also been problematic because it has made comparison of research findings more difficult. However, dispositional optimism based on Scheier and Carver’s (1985) positive expectations
model has been one of the most popular ways to conceptualise optimism in the research
literature (Chang, 2001). According to Scheier, Carver, and Bridges (1994) there is
growing evidence that dispositional optimism is beneficial to physical and
psychological well-being.

This chapter presents literature and research related to dispositional optimism,
its role in adaptation to adversity, and its promotion of psychological health. Research
concerning dispositional optimism and its effects upon psychological well-being,
coping patterns, and the reporting of perceived benefits in adversity are presented. Some
studies that have examined the relationship between optimism and well-being in people
with MS are also reviewed.

5.2 Dispositional Optimism

5.2.1 Definition

Dispositional optimism has been defined by Scheier and Carver (1985) as the
tendency to believe that one will generally expect good outcomes in life. This
description of optimism incorporating positive expectations is based on their
behavioural self-regulation theory (Scheier & Carver, 1985). According to this
perspective, people continue to engage in efforts to overcome adversity and attain their
goal if they expect to be successful. However, if they think they will be unsuccessful,
they are more likely to give up their goals. Optimists tend to hold positive expectations
for their future, while pessimists tend to hold negative expectations for their future.
Accordingly, those who are optimistic and have more positive expectations for the
future are more likely to make the effort to achieve their goals. Scheier and Carver’s
(1985) model views optimism as being quite a ‘stable generalized expectation that good
outcomes will occur across important life domains’ (Wrosch & Scheier, 2003, p. 64). As the name implies, dispositional optimism is conceptualised and often measured as being a personality variable.

5.2.2 Measuring dispositional optimism

Scheier and Carver (1985) developed a measure of dispositional optimism, the Life Orientation Test (LOT). The LOT is one of the most popular measures in researching optimism (Chang, 2001; Peterson, 2000). This may be because the LOT is considered to be ‘very close to the dictionary definitions of optimism and pessimism’ (Peterson, 2000, p. 48).

The LOT scale has twelve items (including four filler items) presented as statements representing examples of both optimistic and pessimistic expected outcomes. A revised scale was developed (Scheier et al., 1994) following some conceptual concerns about the original measure. For example, the LOT was found to be closely associated with neuroticism and anxiety in a study by Smith, Pope, Rhodewalt, and Poulton (1989). The revised Life Orientation Test (LOT-R) has ten items, of which four are filler items (Scheier et al. 1994). Two of the original items that appeared to be indicative of a coping style were removed. Three items in the LOT-R are positively worded and three items are negatively worded. An example of one of the statements from the LOT-R measuring positive expectations is ‘In uncertain times, I usually expect the best.’

reported that when used either as a two dimensional or unidimensional measure it
appears that the LOT-R is measuring optimism (and pessimism) as a trait. However,
generally, the revised scale, LOT-R is considered to be a unidimensional measure of
dispositional optimism (Chang, 2001).

5.2.3 Research examining dispositional optimism

The LOT and the LOT-R have been used to investigate relationships between
optimism and health, happiness, and coping with adversity (Carver et al., 1993; Scheier
et al., 1989; Scheier, Carver, & Bridges, 2001). Both measures have been used in many
cross sectional and prospective studies with normal and clinical populations.

Reviews by Scheier and Carver and colleagues (1989, 1992, 2001) concluded
that studies found optimists have more positive moods, better health habits, and more
adaptive patterns of coping than pessimists. The authors even argued that optimism was
associated with better physical health. They noted that ‘compared with pessimists,
optimists manage difficult and stressful events with less distress and less adverse impact
on their physical well-being’ (Scheier & Carver, 1992, p. 224).

Andersson (1996) also undertook a meta-analysis of over fifty studies that had
used the LOT examining the effects of optimism on coping, physical symptoms and
negative affect. Findings from this review concluded that although studies had
demonstrated optimism has significant associations with symptom reporting, coping and
negative affect, the most reliable association was the negative association between
optimism and negative affect.

As noted previously, there has been much research investigating the link
between dispositional optimism and outcomes of psychological well being in normal
populations of younger and older adults. For example, the LOT and the LOT-R have been used in samples of undergraduates (Scheier, Weintraub, & Carver, 1986; Chang, 1998); and in adults who were carers (Robinson-Whelan et al., 1997).

The studies that used student populations to examine the benefits of optimism upon well-being, often used examination time as a stressor. However, it is important to consider how optimism may be beneficial to others who experience longer term adverse conditions such as chronic illness. People who are experiencing medical conditions such as surgery or chronic illness face difficult unique challenges in their endeavours to adapt to their situation. It has been noted that health stressors or health related problems offer particular opportunities for researchers to evaluate whether and how optimism incurs benefits for emotional and physical well-being (Scheier & Carver, 1985). Affleck and Tennen (1996, p. 907) in reviewing research on optimism with clinical samples suggested optimists exhibit ‘superior adaptation’ when faced with medical stressors.

5.2.4 Optimism, coping and well-being

Empirical research on optimism, with clinical populations, demonstrate that optimism may be able to explain adaptation to some health problems (Scheier & Carver, 1992). Past research with clinical samples examining dispositional optimism has included people with breast cancer (Carver et al., 1993; Epping-Jordan et al., 1999), rheumatoid arthritis (Affleck et al. 2001), and recovery from cardiac surgery (Scheier et al., 1989). All these studies reported that higher levels of optimism were associated with increased psychological well-being. In particular, the studies of women with breast cancer by Carver et al. (1993) and Epping-Jordan et al. (1999) highlight that optimism appears to have both direct and indirect effect upon well-being.
Carver et al. (1993) examined optimism and psychological well-being in a sample of 59 women with a diagnosis of breast cancer. Well-being was measured using the POMS to ascertain the level of psychological distress. Participants’ coping styles were determined using Carver et al.’s (1989) COPE scale. Results found that higher levels of optimism predicted less psychological distress at each time of assessment, including 12 months post diagnosis. Pre and post surgery, optimism was associated with specific coping patterns such as acceptance or use of humour. 

Similar findings were reported by Epping-Jordan et al. (1999). Their longitudinal study of 80 women with breast cancer, investigated participants’ psychological well-being at diagnosis, at intervals of three and six months post diagnosis. Well-being was measured using levels of anxiety and depression. Results showed that lower optimism scores for participants predicted higher anxiety and depression levels at diagnosis and also at six months post-diagnosis. Those participants who were more optimistic (higher LOT-R) reported less psychological distress.

Research has shown that the differences in outcomes for optimists and pessimists are due in part to differences in the way they cope with adversity (Scheier et al. 1994). For example, dispositional optimism has been linked to more use of active and effective coping.

Scheier et al. (1986) examined relationships between optimism and coping in studies with undergraduates. Coping was measured using the Ways of Coping Questionnaire and participants were asked to recall the most stressful event which had happened in the last month. Results found a positive association between optimism and use of problem focused coping strategies when the stressful situation was controllable. Optimism was also related to the use of positive reappraisal, and when the situation was
uncontrollable, with accepting the situation. A negative association was found between optimism and use of avoidant type coping such as denial and distancing.

As highlighted in the Scheier et al. (1986) study, different situations prompt different responses from optimists depending on the controllability of the problem. Likewise, studies of clinical samples have also found that optimism is associated with specific types of coping. Scheier et al. (1989) examined coping in a sample of men undergoing cardiac surgery. They reported that the optimists in their study used more problem-focused coping strategies. Results also showed that optimists had quicker rates of recovery following surgery and post-discharge. Even six months after surgery those participants who were classified as optimists were experiencing better physical health.

Wrosch and Scheier (2003) reviewed past research examining relationships between optimism and coping upon quality of life. They noted that findings from this field of research suggest that optimists are more likely to use problem-focused coping strategies than pessimists. However, when ‘problem focused coping is not a possibility’ then optimists will use adaptive emotion focused coping strategies, such as positive reframing, acceptance and use of humour (Wrosch & Scheier, 2003). They concluded that dispositional optimism affects subjective well-being directly and is also indirectly mediated by coping.

5.2.5 Optimism and benefit finding

According to Affleck and Tennen (1996) it is more probable that optimists rather than pessimistic people are able to construe perceived benefits even when faced with adverse situations. This supposition proposes that while optimists have a
generalised expectation for positive outcomes in the future, they may also interpret the present time in a more hopeful or positive light than pessimists.

A study by Tennen, Affleck, Urrows, Higgins, and Mendola (1992) examined the relationships between dispositional optimism, reporting benefits and positive moods in a sample of 75 people with rheumatoid arthritis. They found that there was a significant association between participants’ LOT scores and the reporting of perceived benefits. The optimists also reported higher levels of daily positive moods. Re-examination of their 1992 findings with the LOT-R also found a significant association between optimism and benefits (Affleck & Tennen, 1996).

Despite the findings of Affleck and colleagues (1992, 1996) the relationship between optimism and benefit finding does not appear to be clear-cut. It may be that coping mediates the relationship between optimism and benefit finding. Relevant to the issue of a possible links between coping, optimism and benefit finding is the study by Sears et al. (2003) discussed in the previous chapter. Their longitudinal study of 92 women with breast cancer over 12 months reported a link between participants’ higher LOT-R scores and the reporting of perceived benefits. Participants’ level of optimism at study entry was found to be a significant predictor of reporting benefits. As noted previously, results from Sears et al. (2003) showed that reporting benefits was related to higher use of positive reappraisal coping. They concluded that both concepts, optimism and benefit finding, may reflect stable positive outcome expectancies.

In summary, optimism has been found to be related to higher levels of self-reported psychological well-being, perceived adaptive coping patterns (such as problem solving coping, positive reappraisal), and the reporting of perceived benefits from adversity. The studies in the preceding sections demonstrate that the role of optimism needs to be considered when examining adaptation to stressful life events such as health
problems. Indeed, as noted by Fournier, de Ridder, and Bensing, (2002a) growing numbers of studies have found that optimism plays an important role in adapting to a chronic illness. Yet how optimism influences adaptation remains a matter of debate (Fournier et al., 2002a).

5.3 MS research and optimism

MS offers distinctive life challenges with its unpredictable course. It has been suggested that being optimistic may be of special benefit to people with MS (de Ridder, Schreurs & Bensing, 2000). There have been few studies that have examined the effects or benefits of optimism with MS samples. Most of these studies have used comparative groups to study optimism. Studies include, for example, comparison of individuals with MS and their partners (Gold-Spink, Sher, & Theodos, 2000); MS and Parkinson’s disease samples (de Ridder et al., 2000); MS, Parkinson’s disease, diabetes and rheumatoid arthritis samples (Fournier et al., 2002a, 2002b).

A study with 75 participants with MS was undertaken by Fournier, de Ridder, and Bensing (1999) to examine the effect of optimism (dispositional optimism, measured by the LOT; self-efficacy; and unrealistic thinking) upon adaptation. Adaptation was measured using the Positive and Negative Affect, Coping Inventory, Beck Depression Inventory, and the mobility range scale of the Sickness Impact Profile. A main aim of their study was to investigate the effects of the different dimensions of optimism upon adaptation. Results showed that dispositional optimism was related, both directly and indirectly, to lower depression levels in this MS sample. They reported that optimism was negatively associated with depression and that the relationship between optimism and depression was mediated by the use of emotion focused coping. No
relation was found between physical health or impaired mobility and dispositional optimism.

A study by Gold-Spink et al. (2000) examined the relationships between optimism, illness uncertainty and depression with a small sample of 18 individuals with MS and their partners. Optimism was measured using the LOT. Results showed there was a strong negative association between optimism and depression for participants who had MS. There was also a negative association found between their levels of optimism and illness uncertainty. The authors concluded that this might have been due to the tendency of optimists to expect favourable outcomes.

There is an assumption in the research examining the role of optimism in chronic illness that ‘optimism is good’, and that greater optimism is even better (de Ridder et al., 2000, p. 143). However, de Ridder et al. (2000) argue that differing levels of optimism may promote different outcomes dependent upon the illness and that higher levels may not be beneficial for all illnesses.

De Ridder et al. (2000) examined the relationship between dispositional optimism and adjustment to illness, in a sample of 96 people with MS and 70 people with Parkinson’s disease (PD). Parkinson’s disease is considered to be more predictive and controllable than MS in that there is medication that is effective in managing symptoms. Adjustment was measured using the Sickness Impact Profile, and the Beck Depression Inventory. Participants’ coping style was measured using the Coping Inventory for Stressful Situations. Results found that MS participants and PD participants reported similar levels of optimism. However, there were differences in the effects of optimism upon the other variables. For the MS participants, higher levels of optimism were related to higher levels of adjustment and less depression. For the PD
participants, higher levels of optimism were related to higher levels of adjustment and increased use of emotion-focused avoidant type strategies.

Other studies by Fournier et al. (2002a, 2002b) examined the role of optimism and well-being among people with MS, diabetes or rheumatoid arthritis. They reported that the only difference between the three groups was that diabetic participants used more problem-focused coping compared with MS and rheumatoid participants. Results showed a significant negative association between LOT-R scores with anxiety, depression and avoidant coping for MS participants (Fournier et al., 2002a).

A longitudinal study by Fournier et al. (2002b) examined the level of optimism on adaptation at 6 and 12-month intervals amongst the three medical conditions and found that participants’ LOT-R scores remained stable over the 12 months. In particular, results showed dispositional optimism was related to decreases in anxiety, and depression after 12 months by way of increased use of problem-focused coping and less emotion-focused coping.

More recently, comparisons of these previous samples, with a healthy control group of sixty people showed similar levels of optimism (Fournier et al., 2003). The researchers concluded that healthy people and those with chronic illnesses, such as MS and diabetes, hold similar positive views regarding their future and their ability to deal with adversity.

The MS studies and their findings presented in this section are consistent with those studies related to other health outcomes. In general, these studies with normal and clinical populations, including those with MS samples, demonstrate that optimism has been linked with increased psychological well-being. As described, inverse relationships have been found with dispositional optimism and various measures of psychological distress among both physically healthy and clinical samples.
However, a major limitation of the studies reviewed in the present chapter has been the omission of measures of perceived positive outcomes to evaluate the effects of optimism upon psychological adaptation. All the studies only used measures of psychological distress to assess well-being or adaptation. Although increased optimism has been consistently linked with less psychological distress, there appears to be a gap in the literature to explain the role of optimism and its relation to positive psychological functioning. As such, the role of optimism in psychological adaptation requires examination in terms of broader, long-term outcomes, rather than limited short-term, subjective outcomes of psychological distress. In line with the focus of this study, the next chapter will review psychological well-being, including measures of positive functioning.

5.4 Chapter summary

Research examining dispositional optimism has shown that it has been linked to increased psychological health outcomes among normal and clinical populations. Optimism has found to have both direct and indirect effects (by way of coping) upon psychological well-being. In particular, studies have found a relationship between optimism and specific coping strategies during times of adversity. It would appear that being optimistic promotes more use of perceived adaptive coping such as problem-focused coping strategies, and less use of avoidant type coping. The link between optimism and benefit finding as reported by Affleck and colleagues, (1992, 1996), and Mohr et al. (1999) of perceived benefits from the MS experience warrants further investigation of this relationship among people with MS. As noted, there are some studies (Fournier et al., 1999, 2002a, 2002b), examining the effects of optimism as part
of adaptation among people with MS. These studies have focused on between group comparisons with other chronic illness groups. What is needed is within group examination of MS samples to determine the effects of optimism upon different outcomes; psychological distress, interpersonal relationships and measures of positive psychological functioning. The inclusion of optimism enables the present study to have a broader view of examining adaptation in a group of people with MS.
CHAPTER 6: PSYCHOLOGICAL WELLBEING

6.1 Overview

The present study aimed to investigate psychological well-being using general and MS specific measures. The first two sections of this chapter present examples of studies with MS samples which have examined quality of life or psychological distress to ascertain psychological well being. Within the psychological literature there has been a general criticism that there has been an emphasis on psychological dysfunction rather than positive psychological functioning (Lucas, Diener, & Suh, 1996; Ryff & Singer, 1996, 1998). Livneh and Antonak (1997) recommended that research with people living with a chronic illness or a disability needs to focus on positive outcomes, and positive aspects of psychological adaptation. In line with this view, the third section of the chapter presents literature related to the development and use of Ryff Psychological Well-being (PWB) Scale. The Ryff PWB scale has not been used in MS studies. Therefore some studies that have used this scale with normal and clinical samples are reviewed to determine its appropriateness for use with a sample of people with MS. These include studies using adults or middle aged populations (similar to the age groups of the present study) and studies that have used clinical populations (affective disorders, and physical illnesses such as neurological conditions or cancer).
6.2 Psychosocial domains

There has been much research undertaken to examine the quality of life experienced by people with MS (Rothwell, 1998). However, despite many studies, Rothwell (1998, p. 433) noted that there is ‘no satisfactory definition’ of health related quality of life. Similarly, Nicolson and Anderson (2001) noted that the measurement of quality of life as a concept remains complex. Due to the complexities regarding conceptualising quality of life, and also in view that there has been much research already in this field with people with MS, health related quality of life will be not examined per se in the present study. However, some important considerations that have arisen from previous research on quality of life issues and people with MS will be presented briefly.

The most common domains investigated when measuring health related quality of life with MS samples include general well-being (encompassing physical health and level of disability), social and psychological functioning. Studies by Murphy et al. (1998) and Rothwell, McDowell, Wong, and Dorman (1997) highlight the perceived effects of MS upon well-being.

Murphy et al. (1998) examined the effects of MS upon social, physical and psychological domains of well-being in participants from Germany, France, and the United Kingdom. Their study of 360 people included 90 people with MS and 30 people without MS from each of the three countries. Participants with MS were allocated to one of three groups dependent upon the severity of their disease as measured by the Expanded Disability Severity Scale (EDSS). Results showed that there were no significant differences in psychological function across the three groups of disease severity of MS in all three countries. They also reported that the level of physical
disability experienced by people with MS impacted on their social role functions, but not upon their psychological functioning.

It would appear from this study and also from Mohr et al. (1999), described previously which had identified psychosocial factors (Demoralization, Deteriorated Relationships and Benefit Finding), that any examination of the well-being of people with MS needs to include some measure of their perception of their social relationships.

Which domains of functioning are considered to have the most influence on well-being may be perceived differently by the person with MS and their health clinician. A study by Rothwell et al. (1997) examined perceived influences on the quality of life of people with MS. Participants for this study included 45 people with MS and 25 clinicians (including neurologists and neurosurgeons) who were asked to nominate which domains of health related quality of life they considered to be the most important for people with MS. The domains investigated were mental health, physical function, physical role limitations, emotional role limitations, general health, social function, vitality, and pain. The authors found that there were significant differences on the perceived importance of several of the domains. Clinicians were significantly more likely than the MS participants to rate physical functioning and associated limitations as being important determinants of quality of life. The MS participants, on the other hand, rated the domains of mental health and vitality as being perceived to be more important determinants of their quality of life. The results demonstrate that any research examining well-being needs to consider the effects of vitality or lack of it as experienced in fatigue, as well as psychological distress.
6.3 Psychological distress

Many MS studies have used self-report ratings of psychological distress (depression, anxiety, stress, etc) as measures of psychological functioning.

As noted in preceding chapters the incidence of depression is higher among people with MS as compared to the general population. Depression is also considered to be more prevalent in MS populations than those who have some other chronic illnesses (Mohr & Cox, 2001). There have been estimates of a lifetime prevalence of clinical depression of approximately 50 percent for people with MS (Kroencke et al., 2001). People with MS may also experience high levels of other negative emotions, such as anxiety and anger, in response to the general stress of living with MS and may be especially vulnerable during MS exacerbations (Aitkens et al., 1997; Hakim et al., 2000).

Many of the studies examining the impact of MS upon psychological well-being have used the presence or absence of anxiety and depressive symptoms as their defining measure of well-being. For example, the Beck Depression Inventory was used in studies by Aitkens, et al. (1997), Barnwell and Kavanagh (1997), de Ridder et al. (2000), and Pakenham (1999), while the Self Rating Depression Scale was used in the Kroencke et al. (2001) study. Other measures of psychological distress with MS samples have included the Hospital Anxiety and Depression Scale (HADS) used by Hakim et al. (2000), the Symptom Checklist –90 used in the Jean et al. (1999) study, and the Anger-Fear-Depression (AFD) Personality questionnaire used by Eklund and MacDonald (1991).

Mood states, specifically negative moods, have also been used as measures of psychological distress. One such measure of mood states is the Profile of Mood States
(POMS; McNair et al., 1971). The POMS has scales measuring levels of self-reported anger, depression, anxiety, fatigue, and confusion. This scale uses a list of adjectives describing the various emotions. The POMS, or alternative shortened versions, have been in MS studies to measure psychological well-being including studies by Mohr et al. (1999), and Wineman et al. (1994). It has also been used with Australian MS samples (McCabe et al., 2004).

There are some difficulties noted with measuring psychological distress in MS samples. One problem is differentiating between MS disease symptoms and psychological distress, which can be difficult because some symptoms such as fatigue may also overlap or be indicative of depressive symptoms (Eklund & MacDonald, 1991; Jean et al., 1999). For this reason, the present study measured the level of fatigue (POMS subscale) separately and not as part of the total POMS score as a measure of psychological distress. A further criticism of the methodology often employed to ascertain psychological functioning has been that most of the MS studies use a single measure to describe psychological adjustment or functioning (Aitkens et al., 1997). To counter this criticism the current study employs three measures of psychological functioning to ascertain well-being.

Despite concerns regarding measurement, continued study of the psychological distress of people with MS is warranted on several grounds. Firstly, as noted by Hakim et al. (2000) there has been a paucity of studies examining relationships between MS and psychological well-being. Secondly, the relationship between life satisfaction and affect is considered to be interdependent in that current mood can influence their perception of well-being (Lucas et al., 1996). So current mood is considered to be an important factor to consider when determining the level of well-being. Measures such as the POMS tap these transient emotions. Thirdly, to ensure part replication of past MS
studies and enable comparisons requires the continued use of measures of psychological
distress, although the use of alternative measures of well-being are also warranted.

People with MS are generally adults who are trying to live normal lives managing
their health issues, relationships and often, careers. While the rates of psychological
distress might be higher than those experienced in the general population, nonetheless,
many continue to maintain close relationships with others and are being successful in
other domains. It would seem both relevant and important to consider examining
evidence of positive psychological functioning as well as measuring levels of
psychological distress. Lower levels of psychological distress alone cannot be
considered be an adequate measure of psychological well-being. As noted by Ryff and
Singer (1998, p. 76) ‘avoiding depression, anxiety or other forms of symptomatology
following adversity is not equivalent to demonstrating growth, purpose, positive
relations, and mastery in the wake of difficult life experiences’.

6.4 Psychological well being

6.4.1 Perspectives on psychological well-being

A main aim of the present study was to measure well-being not only in terms of
levels of psychological distress (with less distress equated to higher levels of well-
being), but also to explore the notion of psychological well-being in terms of positive
psychology functioning. The field of positive psychology emphasises a change of focus
from solely on psychopathology to a focus on what constitutes healthy, adaptive
functioning (Seligman & Csikszentmihalyi, 2000). Concepts related to positive
psychological functioning may include well-being, satisfaction, hope and happiness.
There are generally considered to be two general perspectives on well-being; hedonic and eudaimonic approaches (Ryan & Deci, 2001). The hedonic approach focuses on happiness and usually defines well-being in terms of attaining pleasure or satisfaction or avoiding pain. Often research into this aspect of subjective well-being might use measures such as life satisfaction, negative and positive affect (Ruini et al., 2003). On the other hand, the eudaimonic perspective defines well-being as being quite distinct from happiness, and in terms of meaning and self-realisation (Ryff, 1989a, 1989b). Ryff has contended that happiness is not everything and is not an adequate assessment of well-being (Ryff, 1989b; Ryff & Keyes, 1995). Thus well-being, according to this approach, is measured in degrees of psychological growth or positive functioning. Literature and research by Ryff and colleagues is an example of the eudaimonic approach to well-being (Ryan & Deci, 2001).

A major criticism by Ryff has been that well-being or wellness has often been conceptualised as feeling happy, and the eudaimonic approach is defining in a different way something that is popularly understood (Schmutte & Ryff, 1997). Ryff argues that there has been a tendency in the past for psychology literature to define well-being ‘almost exclusively in terms of affect’ (Schmutte & Ryff, 1997, p. 551). This has resulted in psychological well-being measures often tapping three basic concepts of positive and negative affect and life satisfaction. According to Schmutte and Ryff (1997, p. 551) well-being measures have often been conceptualised as being indistinct from ‘either personality or affect’, and has resulted in a ‘limited view’ of psychological health. Ryff asserts that well-being needs to be considered in more diverse aspects than being happy or in terms of life satisfaction.
6.4.2 Ryff’s model of psychological well-being

The literature concerning higher psychological functioning was examined and integrated by Ryff (1989b) into basic components of what were perceived to be common tenets of psychological well-being. The theoretical perspectives on mature adult functioning considered by Ryff (1989b) included Maslowe’s (1968) self-actualization, Allport’s (1961) concept of maturity, Jung’s (1933) view of individuation, and Roger’s (1961) notion of a fully functioning adult (Ryff, 1989a). The life span development theorists of Erikson (1959), Buhler and Massarik (1968), Neugarten (1973), and Jahoda’s (1958) critique of positive mental health were also examined for descriptions of what constitutes ‘good psychological health’ (Ryff, 1989b, p. 1070). Integrating these perspectives, Ryff elicited some common themes exemplifying positive mental health or wellness. These themes included positive evaluations of one’s self and others, the belief that life was meaningful, having healthy relationships with others, the capacity to manage ones’ life, self-determination, and an awareness of continued personal growth and development.

Ryff (1989b) developed a psychological well-being (PWB) scale that incorporated the integration of several theoretical paradigms of psychological positive functioning. The multi-dimensional PWB model has been described as representing psychological dimensions of ‘challenged thriving’ (Keyes, Shmotkin, & Ryff, 2001, p. 1008).
6.4.3 Ryff’s Psychological Well-Being (PWB) Scale

Ryff (1989b) identified six main dimensions or domains indicative of psychological health for adults which were deemed as measurable. The six dimensions were autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, and self-acceptance.

The autonomy dimension refers to the qualities of self-determination, independence and ability to regulate behaviour. Ryff (1989b) cites this concept as being partly based on the examples of self-actualizers who function autonomously.

The environmental mastery dimension is related to mature healthy individuals being able to choose or create environments appropriate to their psychological condition. This factor was selected by Ryff (1989b) as being relevant to life span theories that promote the notion of the ability of mature individuals being able to control their environment. In short, it is having the capacity and understanding to manage life effectively.

The purpose in life domain was formed from the notion that psychologically mature individuals have a sense of purpose, make appropriate goals, and are able to change direction when required (Ryff, 1989b).

The domain of positive relations with others was selected by Ryff (1989b) on the basis that most of the theories of positive or mature functioning emphasise the value of having warm and trusting relationships. For example, self-actualizers have been noted for having strong empathy for others (Maslowe, 1968). Also, Erikson’s (1959) theory emphasises maturity of adult development as being based in part on the type of relations that one has with others.
The personal growth dimension is based on the notion that healthy mature individuals not only exist but also continue to develop their potential and grow intrapsychically as persons (Ryff 1989b).

The self-acceptance dimension was selected because it is a ‘central component of mental health’ (Ryff, 1989b, p. 1071). Self-acceptance is considered an attribute of self-actualized persons and indicative of maturity. Having a positive view of one’s self is viewed as exemplifying positive psychological functioning.

Ryff (1989b) developed the Psychological Well-being Scale (PWB) scale by initially constructing definitions or descriptions for each of the six dimensions based on bipolar characteristics (high and low scorers) (see Table 6.1). Statements were then generated based on these definitions and developed into six scales, representing autonomy, environmental mastery, positive relations with others, personal growth, self-acceptance and purpose in life, to constitute the scale.

The statements representing the well-being scale were initially presented as a trial to a sample of 320 adults (Ryff, 1989b). Other instruments used in this study as a comparison with the PWB scales included measures of affect, morale, life satisfaction, depression, and self-esteem. Results from this study found that some of the PWB scales (self-acceptance, environmental mastery) were associated with measures of life satisfaction, affect, self-esteem and morale. However, others scales (autonomy, purpose in life, personal growth, positive relations with others) were not associated with any of the measures. Ryff (1989b) suggested that this finding supported the notion that these dimensions of psychological functioning were not represented in prior indices of mental health.
Table 6.1 Definitions of Ryff’s characterisations of the six dimensions of psychological well-being.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Characteristics of a high scorer</th>
<th>Characteristics of a low scorer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>Is self-determining and independent; able to resist social pressures to think and act in certain ways; regulates behaviour from within; evaluates self from personal standards</td>
<td>Is concerned about the expectations and evaluations of others; relies on judgements of others to make important decisions; conforms to social pressures to think and act in certain ways.</td>
</tr>
<tr>
<td>Environmental mastery</td>
<td>Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values.</td>
<td>Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.</td>
</tr>
<tr>
<td>Purpose in life</td>
<td>Has goals in life and sense of directedness; feels there is meaning to present and past life; holds beliefs that life gives purpose; has aims and objectives for living.</td>
<td>Lacks a sense of meaning in life; has few goals or aims; lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.</td>
</tr>
<tr>
<td>Positive relations with other people</td>
<td>Has warm, satisfying, trusting relations with others; is concerned about others’ welfare; capable of empathy, affection and intimacy; understands give and take of human relationships</td>
<td>Has few, close trusting relationships; finds it difficult to be warm, open, and concerned about others; is isolated and frustrated in interpersonal relationships; nor willing to make compromises with others.</td>
</tr>
<tr>
<td>Personal growth</td>
<td>Has feeling of continued development; see self as growing; is open to new experiences; sense of realising one’s potential; sees improvement of self over time; is changing ways that reflect more self-knowledge and effectiveness.</td>
<td>Has a sense of personal stagnation; lacks sense of improvement over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviours.</td>
</tr>
<tr>
<td>Self-acceptance</td>
<td>Possesses a positive attitude to self; acknowledges and accepts multiple aspects of self, including good and bad aspects; feels positive about past life</td>
<td>Feels dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities; wishes to be different than what one is.</td>
</tr>
</tbody>
</table>

There are a number of versions of the Ryff PWB scales. These include the original parent scale with 20 items for each scale; a long form which has 84 statements with 14 items representing each scale; and a short form which has 18 statements with 3 items representing each scale. The short form was developed specifically for use in telephone surveys (Ryff & Keyes, 1995). Usually all six scales are administered and each scale is scored separately. There is no hierarchical status, ranking or preference for particular domains over others. Research by Ryff and colleagues have used the six domains as separate factors of psychological well-being. However, others (Lindfors, 2002; Holland & Holahan, 2003) have used composite indices of the six scales to measure psychological well-being.

### 6.4.4 Research with normal populations

Most of the research using the Ryff PWB scale has been undertaken with normal populations, more specifically with middle-aged or older adults. Studies by Ryff and colleagues (1989a, 1989b, 1995, 1996) have reported that the scores on environmental mastery usually increases with age, while scores on purpose in life and personal growth declines with age. Also Ryff and Singer (1996) note that women of all ages consistently rate themselves higher on positive relations with others than men, and often have higher scores on the personal growth domain than men. However, on the other four domains there have been no consistent findings of significant gender differences.

A longitudinal study by Kling, Seltzer, and Ryff (1997) with 449 women (mean age 70 years) studied the effects of two life challenges (relocating to a new community, and looking after an adult child with mental retardation) upon coping and psychological
well-being. These two life circumstances were chosen as stressors, because they were considered to offer distinctive challenges to adults. Psychological well-being was measured using the Ryff PWB scale and a measure of depression. As expected, the women who were relocating reported higher levels of psychological well-being than those women who were carers. Well-being was measured again at 18 months intervals. At Time 2 those women who had experienced relocation reported increased levels of psychological well-being, (environmental mastery, personal growth domains) and lower levels of depression compared with the carers. Results showed that those carers who used more emotion-focused coping reported lower levels of psychological well-being (environmental mastery, self acceptance), and higher levels of depression.

A large study with 450 Italian adults examined relationships between the Ryff PWB scales with personality and psychological distress (anxiety, depression) measures (Ruini et al., 2003). Results showed significant negative correlations between the PWB scales and all the distress measures, but with only one personality measure (TPQ Harm Avoidance). The TPQ Harm Avoidance scale is considered to be conceptually similar to Neuroticism (Ruini et al., 2003). Schmutte and Ryff (1997) also reported significant negative associations between self-acceptance, environmental mastery, and Neuroticism (NEO inventory), with weaker associations for the purpose in life and autonomy scales.

Lindfors (2002) examined the relationship between Ryff scales, negative affect, physical symptoms and the General Health Questionnaire, with a sample of 91 Swedish workers. They reported low internal consistency for the six Ryff PWB sub-scales, and so computed a composite index of the scales. Results found that the Ryff PWB index had negative correlations with the other measures. This finding was consistent with the proposition that the Ryff scales tap positive psychological functioning, and supported the possibility of using the total score as an overall index of well-being.
6.4.5 Research with clinical populations

The Ryff PWB scale has been used to measure psychological well-being with clinical populations. These studies include people who have experienced strokes (Hoen, Thelander, & Worsley, 1997); breast cancer (Holland & Holahan, 2003) and affective disorders (Rafanelli, Park, Ottolini, Cazzaro, & Fava, 2000). However, these clinical studies used relatively small samples.

A study by Hoen et al. (1997) examined the well-being of 35 people who had experienced aphasia following a stroke using the Ryff PWB scale to ascertain the effectiveness of a community based program. The PWB was administered twice, six months apart; prior and post participation in the program. The authors reported that there was an improvement for participants across all six domains at the post program measure. This improvement was perceived as being attributable in part to successful participation in the community program.

Rafanelli et al. (2000) examined measures of distress and psychological well-being using 20 participants who were remitted patients with affective disorders and 20 control participants. The clinical sample was assessed on the measures before treatment (cognitive behaviour therapy) and one-month post treatment. Results found negative correlations between the PWB scales and psychological distress. As expected, the remitted participants had significantly lower scores on the PWB scales than the controls, both before and after treatment. However, there was a significant improvement in some of the PWB scales for the remitted participants following treatment. The authors concluded from this study, albeit with a small sample, that the PWB scales appeared to be more sensitive to measuring psychological changes following treatment than the exclusive use of the distress measures.
The Ryff PWB scales have been used as a measure of adaptation following a diagnosis of breast cancer. A cross sectional study by Holland and Holahan (2003), with a sample of 56 women used the PWB scale to investigate ‘positive adaptation’. Positive adaptation was defined as higher levels of psychological well-being (Ryff PWB) and positive health behaviours (for example, not smoking). The Ryff PWB scale was chosen as the major outcome variable by the authors because it was considered indicative of a positive, adaptive approach and was deemed a theoretically derived measure of well-being. Similar to Lindfors (2002), this study also used a composite index of the scales rather than the separate scales. Holland and Holahan (2003) investigated the effects of social support, and coping strategies upon adaptation measured with the composite index of five PWB scales. One scale, positive relations with others, was omitted from the study because it overlapped with the social support measure. Coping strategies were measured using the Ways of Coping Questionnaire (WCQ). In this study the eight coping strategies of the WCQ were identified as being examples of either approach or avoidant types of coping, rather than the usual classification of problem focused or emotion focused coping. The coping strategies classed as being approach types were positive reappraisal, problem solving, confrontive coping, and seeking social support. The coping strategies of distancing, self-control, escape avoidance, and accepting responsibility were identified as being indicative of avoidant types of coping. Results found that the approach type coping strategies and social support were related to higher levels of total psychological well-being, while the avoidant type coping strategies were related to lower levels of total psychological well-being.

As noted, Holland and Holahan (2003) used a composite PWB total score as a measure of adaptation for participants in their study. However, the authors did not report reliability coefficients for any of the scales or for the total score. Descriptive data
about the composite total score would have been useful information for other researchers wishing to use the PWB as a measure of psychological well-being.

While most of the research using the Ryff PWB has been with normal populations, its use with the clinical samples may also be valuable. Although the three clinical studies presented here had small samples, nonetheless they were able to measure positive changes among their participants.

6.5 Chapter summary

Many MS studies examining psychological well-being have used measures of psychological distress. Given the higher levels of psychological distress that have been noted by researchers and clinicians in MS samples, it is remains pertinent to include measures of depression, anxiety and anger in the present study. However, measures of psychological functioning of adults need to include both intrapersonal and interpersonal processes, as evident by Mohr et al.’s (1999) study which found that individuals with MS perceive both positive and negative consequences from their illness experience upon their psychosocial domains.

A focus on positive functioning would be useful in studies with people with MS. The Ryff psychological well-being scale was developed from the literature pertaining to optimal psychological functioning of mature adults. This scale would seem to have applications for use with a sample of adults with MS. Its inclusion in the present study enables a broader examination of participants’ psychological functioning. As noted by Ryff and Singer, (1996) optimal human functioning is seen in those individuals who lead lives that are purposeful, and who have meaningful relationships with others. These are characteristics that apply to adults with chronic illnesses as well as to physically healthy adults. Therefore the researcher chose to investigate psychological well-being in
the present study by examining outcomes incorporating psychosocial factors, psychological distress and dimensions of positive psychological functioning.
CHAPTER 7: AIMS AND HYPOTHESES

7.1 Aims of the present study

The overall aim of the present study was to examine psychological well-being in a sample of people with MS. Psychological well-being was measured using two general measures, the Ryff Psychological Well-being Scale and the POMS (a measure of psychological distress). A scale developed by Mohr et al. (1999) was also used to ascertain well-being as it related more specifically to MS. This scale assessed the psychosocial consequences of living with MS using three subscales (Demoralization, Deteriorated Relationships, and Benefit Finding).

The first specific aim of the present study was to replicate and extend the findings of the Mohr et al. (1999) study. The study aimed to re-examine the relationships between the MS psychosocial factors, Demoralization, Deteriorated Relationships, Benefit Finding, as identified by Mohr et al. (1999), with psychological distress, measured by the POMS, and coping strategies, measured with the Ways of Coping Questionnaire. In particular, the present study aimed to explore further the MS psychosocial factor, Benefit Finding. Mohr et al. (1999) had been the first study to report findings of perceived benefits from people’s experiences with multiple sclerosis. In line with the study’s focus on positive functioning and past studies (Affleck &
The second specific study aim was to investigate the physical and psychosocial factors identified as being associated with psychological adaptation to MS as shown in the model presented in Figure 1.2. The variables in the study represented disease-related factors (Mobility, Fatigue) and psychosocial factors (Optimism, coping strategies) to enable a comprehensive examination of adaptation or well-being. The outcome variables were psychological distress (Negative Affect: depression, anxiety, anger), psychological well-being (Ryff’s measure), and the three specific MS psychosocial factors, Demoralization, Benefit Finding and Deteriorated Relationships.

7.2 Hypotheses

7.2.1 Replication and extension of Mohr et al. (1999).

The first set of hypotheses, formed the part replication of Mohr et al.’s (1999) study. These hypotheses were related to the three MS psychosocial factors, Demoralization, Deteriorated Relationships, and Benefit Finding.

Hypothesis 1: It was expected that higher scores on the two MS psychosocial factors of Demoralization and Deteriorated Relationships would be associated with higher levels of Negative Affect (psychological distress).

Hypothesis 2: It was hypothesised that there would be a negative relationship between the psychosocial factor, Benefit Finding and Negative Affect (psychological distress). This prediction was in line with findings by Katz et al. (2001).
The next two hypotheses which related to the Benefit Finding factor were based on psychological adaptation literature which suggests that it is related to being optimistic or using positive reappraisal coping.

Hypothesis 3: It was hypothesised that there would be a positive relationship between Benefit Finding and Optimism. This prediction was in line with findings by Affleck and Tennen (1996).

Hypothesis 4: It was expected that Benefit Finding scores would be positively related to the coping strategies of Positive Reappraisal and Seeking Social Support. This prediction was based on findings by Mohr et al. (1999).

7.2.2 Well-being: Testing the model

The next set of hypotheses related to testing the model as depicted in Figure 1.2. It was expected that the MS related variables and psychosocial factors would correlate with and predict (in regression analyses) the three groups of well-being measures (Ryff, POMS, and Mohr et al.’s MS psychosocial factors). These hypotheses were based on findings from studies as reviewed in the introductory chapters. Studies included those examining optimism using normal and clinical samples (Affleck et al., 2001; Scheier et al., 2001) and MS populations (Fournier et al., 1999; de Ridder et al., 2000). Other MS studies (Aitkens et al., 1997; Jean et al., 1999; Pakenham, 1999; McCabe et al., 2004) examining coping, MS related variables of fatigue and/or disability and psychological distress also informed the following hypotheses.

Hypothesis 5: It was predicted that higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping,
and lower escape avoidance coping would be related to better well-being (lower scores on Demoralization and Deteriorated Relationships, and higher Benefit Finding scores).

Hypothesis 6: It was predicted that higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping, and lower escape avoidance coping would be related to better well-being (less psychological distress as measured by lower POMS scores).

Hypothesis 7: It was predicted that higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping, and lower escape avoidance coping would be related to better well-being as measured by higher Ryff scale scores.

7.3 Exploratory analyses

The relationships between the disease-related variables (age of onset, duration of illness), other coping strategies (Confrontive Coping, Seeking Social Support, Self-controlling, Distancing) and the specific well-being measures were also examined in the above analyses, but no specific hypotheses were generated from the literature regarding these relationships. This was an exploratory aspect of the study.

Additionally, exploratory regression analyses were conducted to examine whether the disease related and psychosocial factors (Mobility, Fatigue, Optimism, coping) differentially predicted the six sub-scales of Ryff’s Psychological Well-being Scale (autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, self-acceptance). The aim of these analyses was to shed further light on what types of well-being were best predicted by these factors.
CHAPTER 8: METHOD

8.1 Pilot study

8.1.1 Preliminary Interviews

Interviews, lasting approximately one hour, were conducted with two Victorian women with MS to ascertain the impact of the condition upon them and their families. These interviews were undertaken for the researcher to further her understanding of MS and inform the questionnaire study to follow. These women were recruited through informal contacts of the researcher. They gave their written consent to be interviewed, and were told that they were free to withdraw from the study at any time without explanation. A copy of the information sheet and consent form is seen in Appendix A.

The format of the interviews was semi-structured and included questions regarding MS disease demographics and two questions that were selected because they had been used in previous studies with MS samples (Mohr et al., 1999). These questions were:

- How has MS changed or affected you as a person?
- How has MS changed or affected your relationship with other people?

The first woman, Anna, 40 years of age, had been diagnosed 19 years ago, and was quite severely disabled. Anna was confined to a wheelchair and required full time carers to assist her in her daily activities. She was married with a small child. Anna was interviewed in her home with a carer present.
The second woman, Susan, was 26 years old and had been diagnosed with MS less than one year. Susan was married and employed on a part-time basis. She was symptom free at the time of interview. Susan was interviewed at Swinburne University at her request.

These two women were also invited to provide feedback on the initial questionnaire for its suitability for use by people with MS sample. They, and a third woman involved in the pilot study, were the only participants who were recruited outside the MS Societies for the present study. The three women, however, are on the MS Society of Victoria (MSSV) database and regularly contact the Society for information and support.

The full transcripts of these interviews are not presented as part of this thesis. However, some of the comments made by the interviewees appear in some sections of the thesis for the purpose of illustration of particular issues.

8.1.2 Piloting of the questionnaire

The questionnaire was tested in a pilot study using a small sample of six adults, three whom had multiple sclerosis, and three who did not. Two of the adults with MS were also interviewed as noted above. The third person with MS provided feedback about the questionnaire but choose not to participate in the interview. All adults were recruited through informal contacts of the researcher. The adults, five females, and one male, were aged between 25 and 70 years.

The six adults were given copies of the questionnaire package comprising five standardised scales and three pages seeking demographic information. The amount of time required to complete the questionnaire was noted by these people, and they were
given a feedback sheet (Appendix B) to record any difficulties encountered in completing the questionnaire.

Feedback from the piloting of the questionnaire resulted in the font size being enlarged for certain sections, and shading of alternate items in the longer scales. These changes were implemented to aid those participants who may have some visual deficits.

There was also some refinement to the demographic information section with an ambiguous item regarding religious/spiritual beliefs omitted from the final draft of the questionnaire. Otherwise the content of the questionnaire used in the study was unchanged.

8.2 Participants and recruitment procedure

8.2.1 Ethics Approval

Permission was obtained from Swinburne University of Technology Research Ethics committee to conduct the research with a sample of people who had MS. Approval was also given to the researcher by the Ethics committee to approach the MS Societies of Victoria and Tasmania to recruit participants for the study.

Criteria for participation in the study were that participants were adults (aged between 18 and 80) with multiple sclerosis. The information sheet outlining the study also informed prospective participants that they were free to withdraw at anytime from the study. A copy of the information sheet can be seen in Appendix C. Prospective participants were informed that return of a completed questionnaire implied consent.
8.2.2 Recruitment

Prospective participants for the survey of the present study were recruited through the MS Societies of Tasmania and Victoria. These organisations are part of the Australian MS societies whose aims are to promote the care and well being of people with MS or affected by MS. Each state of Australia has an MS Society that provides a range of services to people with MS and their families. Services provided by the societies include; resource centres, self help groups, specialist assistance and assessment, education and information, research, and accommodation and respite services. These societies maintain a database of clients with multiple sclerosis who have registered in their respective state.

8.2.3 Tasmanian Sample

The Multiple Sclerosis Society of Tasmania was contacted, and after discussions with the Client Services Manager, permission was obtained to mail questionnaires to the society for distribution to 60 people with MS who were clients. The identity of the Tasmanian clients was not made known to the researcher so as to ensure confidentiality and anonymity of participants.

It was agreed that only clients of the MS Society of Tasmania who resided in the North and North West regions of Tasmania would be recruited for the study. This decision was undertaken since clients from the other parts of Tasmania had recently been recruited for a large study.

The questionnaires and information sheets regarding the study were mailed to the Client Services Manager in Tasmania who then managed their distribution. A letter of support from the MS Society of Tasmania (Appendix D) was included in the mail out to 60 prospective participants. Questionnaires were completed by respondents and
returned to the university in reply paid envelopes. There was a sixty-percent return rated on distributed questionnaires with 36 completed questionnaires received.

8.2.4 Victorian Sample

The MS Society of Victoria (MSSV) was contacted and two meetings with the Chief Executive Officer took place to discuss the feasibility of the study.

Permission was granted from the MSSV for the researcher to undertake recruitment through a mail out of questionnaires to prospective participants. The mail out was conducted by the MSSV. The researcher did not contact prospective participants directly and the identity of MSSV clients was not revealed to the researcher to maintain confidentiality and anonymity of participants. Questionnaires were mailed to 300 randomly selected clients who were listed on the MSSV client database (approximately 3,000 clients). It was agreed that the mail out would be to 200 people who resided in rural areas of Victoria and 100 people who resided in the metropolitan area of Melbourne.

The MSSV’s decision to recruit higher numbers of rural clients than metropolitan clients was to give clients in rural Victoria an opportunity to participate in research. According to MSSV, in Victoria in recent years, there had been more research participation opportunities for people with MS who resided in the metropolitan area than for clients who resided in regional areas. No other criteria were used in selecting prospective participants. It was agreed in line with the MS society’s research conditions that participants of this study be offered the opportunity to individually receive a copy of the study findings. The MS Society of Victoria also requested regular updates on the research project and its findings.
The mail out to 300 randomly selected MSSV clients was undertaken at the end of July 2002, facilitated by MSSV volunteers. The questionnaire pack included the questionnaire, information sheet about the study, a letter of support from the MS Society of Victoria (Appendix E), and a reply paid envelope addressed to the university.

Participants’ completed questionnaires were returned to the university in reply paid envelopes. One hundred and twenty five questionnaires were returned resulting in a 41.6 percent return rate.

Five questionnaires mailed to the university were not completed. Two returned questionnaires had letters from carers attached signifying that the addressee was unable to participate. One respondent, aged 16 years, was younger than the age criterion for the study and her questionnaire was not included in analyses.

A number of questionnaires (8) were returned unopened to the university deemed undeliverable to the addressees due to change of address or unknown at present address. MSSV was notified of the names and addresses of undelivered mail so that their database could be updated.

The mail out of 300 questionnaires resulted in 118 eligible questionnaires being returned complete and able to be used for analyses. There was no follow-up mail or contact with those people who had not responded or returned questionnaires.

8.2.5 Sample demographics

The total number of participants in the study was 154 adults with MS who were clients of the MS Societies of Victoria or Tasmania.

There were 36 participants from Tasmania, with a mean age of 46.5 years (SD = 11.67, range = 23 – 64). The sample comprised 24 (67 percent) females and 12 (33
percent) males. Most of the Tasmanian participants (81 percent) were married or living with a partner. Three quarters (75 percent) of the Tasmanian sample had the relapsing-remitting form of MS.

The sample also comprised 118 Victorians with MS. The mean age of the Victorian participants was 47.9 years (SD = 11.77, range = 25-79). There were 87 (74 percent) females and 31 (26 percent) males. Three quarters of the Victorian participants were married or living with a partner. Eighty-four participants (71 percent) in the Victorian sample had the relapsing-remitting form of MS. No information was obtained from participants regarding their place of residence (metropolitan or rural).

Employment demographics for the combined sample of 154 participants (Tasmanian and Victorian) showed that nearly half of the sample (45 percent), or 70 participants were in employment, 31 were not working (20 percent), 24 were retired (16 percent), and 29 participants (19 percent) described their occupation as home duties. Fifty-nine people (38 percent) were receiving disability benefits at the time of the survey. Overall there were 43 males (28 percent), and 111 females (72 percent) and 72 percent of the sample had relapsing-remitting MS.

8.3 Questionnaire Pack

A survey was used in the present study. The questionnaire pack comprised five standard measures, and questions enabling self-report of demographic and disease characteristics. A page with instructions on how to complete the measures was attached to front of the questionnaire. A reply paid university addressed envelope was supplied. A copy of the questionnaire can been seen in Appendix F. The order of the measures
was the same for all participants. Measures are discussed in the order they were presented in the questionnaire pack. Shortened versions of some measures were used in the present study (where available) to minimise participants’ fatigue and time commitment. These are identified in the following sections.

8.4 MS History and disease-related characteristics.

8.4.1 Duration of illness.

Duration of illness was assessed by two questions inquiring about the length of time since diagnosis, and age at onset of MS symptoms.

There is often difficulty in asking people with MS for the length of time since diagnosis, as the diagnostic process may have been protracted (Devins & Seland, 1987; Thompson, 2002). The symptoms that often accompany the onset of MS can be vague so that initially some people may be given a probable diagnosis rather than a definite diagnosis (McDonald et al., 2001). For these reasons, in the present study, participants were asked to record both their age at the ‘onset’ of MS symptoms, and the length of time (in years/months) since diagnosis. No medical evidence of diagnosis was obtained for the participants.

8.4.2 Type of MS

Participants were offered three options to identify the type of MS; relapsing-remitting; progressive, or other. These options were chosen in line with Lezak’s (1995) contention that there are usually only two distinctive patterns of MS identifiable as the
relapsing-remitting form and the progressive form. The ‘other’ option was for those participants who might have been unsure of MS status.

8.4.3 MS Symptoms

Participants were asked to record whether or not they were experiencing MS related symptoms at the time of the survey. Twelve common MS related symptoms were presented to participants: fatigue, vertigo, numbness, tremors, spasms, visual impairment, pain, paralysis, problems related to each of bladder and bowel functioning, concentration, and communication. Experience of symptoms was gauged using a tick the box if present at time of survey.

Participants were given the opportunity to add to this section and record other symptoms not listed that they may have been experiencing at the time of the survey.

8.4.4 Fatigue

Fatigue is considered to be one of the most common symptoms affecting those with MS. Participants were asked if they were experiencing fatigue at the time of the survey (as in 8.4.3).

In addition, the level of fatigue experienced by participants was measured in this study using the Fatigue-Inertia subscale of the shortened version of the Profile of Mood States (POMS) (Shacham, 1983). The POMS scale (McNair et al., 1971) has been used in other MS studies to measure the level of fatigue (Mohr et al., 1999).

The Fatigue-Inertia subscale is a checklist comprised of five adjectives which describe feelings of fatigue. Examples of some of the items include ‘worn out’, ‘weary’, and ‘exhausted’. Respondents are asked to rate how often over the past week, they have
been experiencing these feelings using a 5 point Likert scale from 0 ‘not at all’ to 4 ‘extremely’. Higher scores on the POMS Fatigue subscale indicate higher levels of fatigue. Shacham (1983) reported a reliability coefficient of .87 for the Fatigue-Inertia subscale.

### 8.4.5 Mobility

Participants were offered six categories of differing mobility ability to rate their motor function. The categories were selected by the researcher to represent the wide range of mobility ability that may be experienced by people with MS. The categories presented included: normal gait with no difficulties; mild gait problems but able to walk without aids; unable to walk without aids; combination of aids and wheelchair; wheelchair at all times, and no mobility.

For later analyses in the study, the six categories were re-organised into three categories to equate with three levels of mobility status. The latter mobility categories were:  
- Group 1 - normal gait  
- Group 2 - mild gait problems, but not using aids  
- Group 3 – walking aids or wheelchairs required for mobility.

### 8.4.6 Treatments

Many people with MS use a variety of treatments for symptom management. In the present study there was an open-ended section entitled ‘Current treatments’ where participants could record any treatments. Responses to this section were allocated to either ‘yes, having treatment’ or ‘no treatment’. Participants’ responses were
categorised to specific forms of treatments: Betaferon; drug therapy, and alternative therapies.

8.5 Psychological measures

8.5.1 Optimism

Optimism was measured using the revised Life Orientation Test (LOT-R, Scheier et al., 1994). The LOT-R is a reliable measure that has been widely used in much research with normal and clinical populations (Affleck & Tennen, 1996).

The LOT-R is a 10 item self-report scale with 3 positively worded items, 3 negatively worded items and 4 fillers. Examples of target items include ‘In uncertain times I usually expect the best’ (positive), and ‘Things never turn out the way I want them to’ (negative). Respondents are asked to indicate the extent of their agreement with statements using a Likert type scale: 0 ‘strongly disagree’, 1 ‘disagree’, 2 ‘neutral’, 3 ‘agree’, and 4 ‘strongly agree’. Only the six target items are added to obtain a total score, with the negative items being reversed scored (items 3, 7, and 9). Possible scores range from 0 to 24. Higher total scores indicate higher levels of optimism.

Internal consistency of $\alpha = .78$, and item-scale correlations ranging from .43 to .63 were reported in validation studies (Scheier et al., 1994). A study by Fournier et al. (2002) using an MS sample reported alpha reliability coefficients of between .66 and .87 over a twelve-month period. While Fournier et al., (2003) reported a LOT-R mean of 16.7 from their MS study.
8.5.2 Ryff Psychological Well-Being Scale

Psychological well-being was assessed using the Psychological Well-Being Scale (PWB) (Ryff & Keyes, 1995). The PWB scale comprises six dimensions or sub-scales that are considered to be areas of psychological wellbeing: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self–acceptance.

The present study used the short form of the Ryff Psychological Well-Being Scale that has 18 items, with three items representing the six dimensions of psychological well-being. The shortened version has been noted to have lower internal consistency than the larger 84-item version. Internal consistency (alpha) coefficients for the shortened version sub scales have ranged from .33 (purpose in life) to .56 (positive relations with others) (Ryff & Keyes, 1995). Keyes et al. (2002) also reported alpha coefficients for the 3 item PWB scales from .37 (purpose in life) to .59 (self–acceptance). However, Ryff and Keyes (1995, p. 721) contend that the modest alphas obtained reflected the small number of items per scale and that items had been selected to represent ‘conceptual breadth’ rather than maximise internal consistency. Despite its low internal consistency, the brevity of the short form renders it more appropriate for this MS sample than its larger counterpart.

The PWB scale includes positively and negatively worded statements to which respondents use a 6-point Likert scale of ‘strongly agree’, ‘moderately agree’, ‘slightly agree’, ‘slightly disagree’, ‘moderately agree’, and ‘strongly disagree’.

Responses to negatively scored items are reversed in the final scoring process. Higher scores on all the sub scales indicate higher levels of psychological well being. A total score for well-being was obtained by summing the six subscales.
8.5.3 MS Psychosocial factors

The MS psychosocial factors were assessed using the measure developed by Mohr et al. (1999). Mohr et al. (1999) initially examined the experiences of the psychosocial consequences of living with MS by asking participants with MS, two open-ended questions posed to specifically identify both intrapersonal and interpersonal processes. These questions were: ‘How has MS changed or affected you as a person?’ and ‘How has MS changed or affected your relationships with other people?’. Initially 67 statements were elicited from the participants’ responses to these questions. However, some items, which were considered to reflect neurological functioning rather than psychosocial functioning were discarded by Mohr et al.

A questionnaire of 48 statements was developed from the remaining responses. Factor analysis of the 48 items identified three factors with items loading at above .40. The factors were labelled Demoralization, Benefit-Finding, and Deteriorated Relationships.

Demoralization pertained to statements concerning feelings of self worth, for example, ‘I feel more worthless since having MS’ and ‘I’ve lost my confidence in being a man/woman’.

Deteriorated Relationships items included statements that were related to relationship difficulties, such as ‘My spouse/significant other often is angry because of my MS’ and ‘I feel MS has caused my relationship/marriage to deteriorate’

Benefit-Finding items included reports of an enhanced appreciation of life, deeper relationships with others and increased spirituality. Examples include ‘Since having MS I have learnt to communicate better with people’, ‘MS has made me appreciate life more’.
Internal consistency for scales derived from the three MS psychosocial factors, (Demoralization, Deteriorated Relationships, and Benefit Finding), as measured by Cronbach’s alpha, ranged from .84 to .90 (Mohr et al., 1999).

While the Mohr et al. (1999) scale was developed specifically for use with people who had MS, the scale was used in a study by Katz et al. (2001) with a sample of people who had cancer or lupus. Katz et al. (2001) reported a factor structure of the three factors similar to Mohr et al. (1999).

The present study used the 48 statements of the Mohr et al. (1999) scale to measure perceived psychosocial consequences of having MS. The 48-item questionnaire was administered with a five-point Likert scale assessing agreement to each statement of 1 ‘strongly disagree’, 2 ‘disagree’, 3 ‘neutral’, 4 ‘agree’, and 5 ‘strongly agree’. Ratings were summed and divided by the number of items in the subscales to obtain mean scores for each of the three factors.

In line with Mohr et al. (1999) participants’ responses were also calculated as percentages of endorsing (either agree or strongly agree) individual items to enable comparison with these studies.

8.5.4 Profile of Mood States

A shortened version of the Profile of Mood States (POMS) (Shortened Version), (Shacham, 1983) was used to assess mood states. Shacham’s (1983) shortened version of POMS was derived from the original POMS (McNair et al., 1971), yet retains psychometric validity (Shacham, 1983). High correlations of over .95 for the scales of the original and the briefer form of the POMS were reported by Shacham (1983).
Internal consistency for the scales of this shortened version were found to range from .80 to .91 (Shacham, 1983).

The shortened POMS (Shacham, 1983) comprises a checklist of 37 adjectives. Respondents are asked to rate the adjectives that describe feelings that may have occurred over the last week using a 5 point Likert scale. Possible responses to occurrence of feelings include 0 ‘not at all’, 1 ‘a little’, 2 ‘moderately’, 3 ‘quite a bit’ and 4 ‘extremely’. Six sub scales can be derived from the POMS. These scales are Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment.

For the present study, three of the six sub scales the POMS were used to measure psychological distress (depression, anxiety, anger) while a fourth scale, as noted earlier, was used to measure fatigue. Scores for the Vigor-Activity and Confusion-Bewilderment subscales were not calculated or used in the present study.

The depression subscale, Depression-Dejection, has eight items, which include adjectives such as ‘unhappy’, ‘blue’, and ‘sad’. Anxiety was measured using the Tension-Anxiety subscale that has six items. Examples of items include ‘on edge’, ‘tense’ and ‘uneasy’. Anger was measured using the seven items of the Anger-Hostility sub scale. Examples of the anger items include ‘angry’, ‘annoyed’ and ‘peeved’. Scores for the sub-scales were obtained by summing the responses to the specific items related to each of the subscale. Higher scores on the depression, anxiety, and anger sub-scales indicated more negative mood states.

A variable, measuring psychological distress (Negative Affect), was formed by summing scores of the depression, anxiety, and anger sub-scales. This scale had an alpha reliability coefficient of .94.
8.5.5 The Ways of Coping Questionnaire

Coping was measured using a modified version of the Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988b). The WCQ or variations of the scale, has been used in previous research with MS populations (Mohr et al., 1999).

The Ways of Coping Questionnaire consists of statements about cognitive and behavioural efforts used to manage a specific stressful event. Respondents are asked to think of a recent specific stressful event and respond using a 4 point Likert scale of 0 ‘does not apply’, 1 ‘used somewhat’, 2 ‘used quite a bit’, 3 ‘used a great deal’ to each of the statements.

Eight scales can be derived from the scoring the items. These scales include examples of problem-focused and emotion-focused coping strategies. The problem-focused scales are Planful Problem Solving (six items) and Confrontive coping (six items). The emotion-focused scales include Self-controlling (seven items), Positive Reappraisal (seven items), Distancing (six items), Accepting Responsibility (four items), and Escape-Avoidance (eight items). One scale, Seeking Social Support incorporates both problem-focused and emotion-focused functions. Internal consistency coefficients of the eight scales have been reported as ranging from .61 to .79 (Folkman & Lazarus, 1988).

In the present study the WCQ was modified to include only the 50 items that form part of the eight coping subscales. The 16 filler items of the WCQ were omitted so that an abbreviated form could be used to minimise participants’ fatigue while completing the survey. Other studies with clinical samples have also used modified or shortened versions of the WCQ.
Participants in the present study were instructed to respond to this questionnaire while recalling an MS-related problem that they had experienced recently. Ratings of the items were summed and used to calculate scores for each of the eight scales.

8.5.6 Stressor Descriptions

As described above, as part of the Ways of Coping Questionnaire, participants were asked to provide descriptions of the most stressful MS related event that they had experienced in the last week. Their stressor descriptions were used as data in their own right. They were organised into categories, based on groupings described by Pakenham (2001) in a study of 113 Australians with MS. The categories were physical problems (including MS related symptoms), emotional difficulties, instrumental problems (difficulties with daily living activities, employment, access) and relationship problems (difficulties with family members, partners, and friends).

8.6 Analyses

There were three sets of analyses conducted. The first set involved data screening and checking the scales for statistical qualities. The second set involved inter-variable and group comparisons. The third set included correlations and regression analyses for hypothesis and model testing.

Data were checked for errors and missing items. Preliminary analyses were conducted on the data from the Tasmanian and Victorian samples to ensure that the samples were similar in composition before combining the data as a total sample. A series of chi-square and t-test analyses were performed on the demographic characteristics of the two samples to ensure homogeneity of variance. Content analyses
and frequency counts were conducted on the open-ended questions related to symptoms, treatments, and MS related problems. Reliability coefficients were calculated to determine the internal consistencies of the scales and sub-scales used in the present study.

The next set of analyses included descriptive statistics for both categorical data (frequencies) and continuous variables. Differences between sub-groups (gender, mobility) were calculated by series of ANOVAS and MANOVAS.

Finally, the third set of analyses involved correlations to check for multicollinearity, and also for hypothesis testing between the main variables. Multiple regression analyses were conducted to explore the relationships between the variables and to ascertain the ability of particular variables to predict each of the well-being domains. Exploratory analyses using the Ryff six sub-scales were undertaken to further examine psychological well-being.
CHAPTER 9: RESULTS

9.1 Data analysis procedure

Statistical analyses of the quantitative data were conducted using Statistical Package for the Social Sciences (SPSS for Windows, Version 11.0), (2001). Content analyses were performed on data derived from responses to open-ended questions regarding MS related problems.

9.2 Data Screening

The data were screened using the Explore option of the SPSS program to check for errors and missing values, and to identify any outliers. The data from one participant who was aged 16 years were discarded from further analyses. A criterion for participation in this study had been that participants would be adults, aged from 18 onwards. Nine other questionnaires where the majority of the scales had not been completed were also excluded. Some of these incomplete forms had attached notes from carers that indicated that the person to whom the questionnaire had been addressed had a cognitive disability and was not able to participate in the study. Where there were only one or two incomplete items within specific scales (continuous variables) the missing data were replaced with the item mean. Tabachnick and Fidell (1989) note that replacing missing data with the mean is a conservative solution that may reduce the variation of the variable, and its correlations with other variables. However, in those questionnaires where an entire scale was incomplete the data was treated as ‘missing’.
9.3 Preliminary analyses

9.3.1 Demographic characteristics

The demographic and MS–related illness characteristics of the Tasmanian, Victorian samples, and combined sample are presented in Table 9.1

Table 9.1 Demographic and MS illness characteristics of participants according to breakdown of state samples and also as combined total sample (N=154)

<table>
<thead>
<tr>
<th></th>
<th>Tasmanian (N = 36)</th>
<th>Victorian (N = 118)</th>
<th>Total sample (N = 154)</th>
<th>Statistical Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>24 (67%)</td>
<td>87 (74%)</td>
<td>111 (72%)</td>
<td>$\chi^2 = .38$, NS</td>
</tr>
<tr>
<td>Male</td>
<td>12 (33%)</td>
<td>31 (26%)</td>
<td>43 (28%)</td>
<td></td>
</tr>
<tr>
<td>Age (range)</td>
<td>23 – 64 yrs</td>
<td>25 – 79 yrs</td>
<td>23 – 79 yrs</td>
<td></td>
</tr>
<tr>
<td>Age (mean)</td>
<td>46.5 yrs</td>
<td>47.9 yrs</td>
<td>47.6 yrs</td>
<td>$t = .61$, NS</td>
</tr>
<tr>
<td>Age at diagnosis (mean)</td>
<td>34.4 yrs</td>
<td>34.8 yrs</td>
<td>34.7 yrs</td>
<td>$t = .17$, NS</td>
</tr>
<tr>
<td>Time since diagnosis (mean)</td>
<td>7.4 yrs</td>
<td>9.8 yrs</td>
<td>9.2 yrs</td>
<td>$t = 1.57$, NS</td>
</tr>
<tr>
<td>Type of MS</td>
<td></td>
<td></td>
<td></td>
<td>$\chi^2 = .47$, NS</td>
</tr>
<tr>
<td>Relapsing-remitting</td>
<td>27 (75%)</td>
<td>84 (71%)</td>
<td>111 (72%)</td>
<td></td>
</tr>
<tr>
<td>Progressive</td>
<td>7 (19%)</td>
<td>29 (25%)</td>
<td>36 (23%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (6%)</td>
<td>5 (4%)</td>
<td>7 (5%)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td>$\chi^2 (df1)=.38$ #</td>
</tr>
<tr>
<td>Married/ partner</td>
<td>29 (81%)</td>
<td>89 (75%)</td>
<td>118 (77%)</td>
<td>$\chi^2 (df1)=.38$ #</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>4 (11%)</td>
<td>15 (13%)</td>
<td>19 (12%)</td>
<td>$\chi^2 (df1)=.38$ #</td>
</tr>
<tr>
<td>Single</td>
<td>3 (8%)</td>
<td>11 (9 %)</td>
<td>14 (9%)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>3 (3%)</td>
<td>3 (2%)</td>
<td></td>
</tr>
</tbody>
</table>

NS = not significant, # Married/partner versus not married

Table 9.1 shows that the samples from Tasmania and Victoria were quite similar in composition with regard to demographic and MS related illness characteristics. A series of chi squares and t-tests were conducted and no significant differences were found between the demographics of the two samples. Data from the two samples were therefore combined and analysed as one group (N = 154) in subsequent analyses. The
characteristics of the present sample depicted the usual demographics of many MS samples with more females than males, and more participants being affected by the relapsing-remitting type of MS.

### 9.3.2 Symptoms

As indicated in Section 8.4.3, participants in the study were presented with a list of common MS related symptoms and asked to report which of these were being experienced at the current time of survey participation. Results are presented in Table 9.2.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Reported by</th>
<th>Symptom</th>
<th>Reported by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>131 (85%)</td>
<td>Bowel problems</td>
<td>55 (36%)</td>
</tr>
<tr>
<td>Numbness/Tingling</td>
<td>107 (70%)</td>
<td>Tremors</td>
<td>47 (31%)</td>
</tr>
<tr>
<td>Bladder problems</td>
<td>72 (47%)</td>
<td>Spasticity</td>
<td>47 (31%)</td>
</tr>
<tr>
<td>Pain</td>
<td>72 (47%)</td>
<td>Vertigo</td>
<td>38 (25%)</td>
</tr>
<tr>
<td>Concentration difficulties</td>
<td>67 (44%)</td>
<td>Speech difficulties</td>
<td>23 (15%)</td>
</tr>
<tr>
<td>Visual Problems</td>
<td>64 (42%)</td>
<td>Paralysis</td>
<td>11 (7%)</td>
</tr>
</tbody>
</table>

As shown in Table 9.2 fatigue was the most reported symptom being experienced by 85 percent of the participants. The symptom, numbness or tingling was the second most reported symptom being experienced by 70 percent of the participants at the time of the survey. This category included a range of symptoms from numbness in specific areas such as fingers being numb to more painful sensations. For example, one participant reported that she was ‘...feeling electric shocks every time I put my foot on the ground when walking’.
Pain of either muscle or neural origin was reported by nearly half of the participants. Some participants gave detailed accounts of pain that included facial pain, such as trigeminal neuralgia. Bladder and bowel problems were also reported respectively by about half to about a third of participants.

Further MS related symptoms listed by participants included short term memory loss, coordination difficulties affecting balance or resulting in clumsiness, muscle wasting and spasms, breathing and swallowing difficulties, hot and cold sweats, and sexual dysfunction, for example, impotence.

Also, some participants reported that they were affected by symptoms that may or may not have been MS related. These included the presence of depression, seizures, feeling easily irritated and insomnia.

9.3.3 Mobility

There were 49 participants who reported normal gait; 59 participants who reported mild gait problems; 15 participants who required aids, 17 participants who reported they used aids and wheelchair, and 14 participants who used a wheelchair for mobility. No participant ticked the last category ‘no mobility’. For correlation and regression analyses, mobility status was treated as a continuous variable, and given a score of 1 to 5 dependent upon the participants’ grouping of limitations. For example those with normal gait were rated as 1, with those who required wheelchairs were rated as 5. From these five categories, participants were later divided into three groups (normal gait = 49; mild gait problems (no aids) = 59; aids required = 46) for analyses examining between group differences.
9.3.4 Treatments

Ninety-nine of the 154 participants responded to the open-ended section requesting information about their current treatments. Forty-two participants were being treated with Betaferon at the time of the survey. Other participants, not receiving interferon treatment, listed prescribed medications that included Prednisolone, Baclofen, Rebif, Avonex, and Copaxone.

Participants also listed other alternatives including use of specific diets such as low fat, low diary, or high fish consumption and vitamin supplements. Therapies listed by some of the participants as part of their treatment regime included physiotherapy, hydrotherapy, massage for symptom management, and alternative therapies, such as naturopathy, Bowen technique, and yoga. One older participant who has had MS for nearly 20 years indicated that he found cannabis, which he took daily, was effective in reducing muscle spasms.

9.3.5 MS related problems

Eighty-five participants provided written descriptions of recent stressful MS related problems. These descriptions were classified into broad categories similar to those reported by Pakenham (2001). The main categories included physical symptoms, relationship difficulties, instrumental difficulties (related to daily activities, employment or access), emotional problems and those related to treatment. Some respondents reported multiple stressors across more than one category, for example, being frustrated in their daily activities by their level of fatigue, poor mobility or poor vision.
Results for the five main categories were as follows. Physical symptoms were reported by 44 percent of participants (fatigue, mobility, visual disturbances, sensory, and bladder symptoms) as being the most stressful MS related problem. Thirty three percent reported emotional problems (depression, anxiety and frustration), 24 percent reported relationship difficulties (partners, family members, colleagues), 16 percent of participants cited instrumental problems (work related, accessing benefits from Centrelink), and 10 percent reported treatment issues (lack of choice, disagreements with health professionals, discomfort).

9.4 MS psychosocial factors

9.4.1 Impact of MS

One of the aims of this study was to examine the impact of the psychosocial consequences of living with MS upon participants’ lives and their interpersonal relationships using Mohr et al.’s (1999) scale. The items representing three MS psychosocial factors, Demoralization, Benefit Finding, and Deteriorated Relationships, and percentages of participants positively endorsing each item are shown in Table 9.3. Frequencies are reported to enable comparison between the present sample and the Mohr et al (1999) sample.

Table 9.3 shows that the highest agreement was for Items, 3, 20 and 48. Since having MS, more than seventy eight percent of the sample felt their family and friends worried more. There was high agreement for individuals to acknowledge that having MS made their own future more uncertain (73.4 percent), and made them realise the importance of being independent (75.4 percent).
Table 9.3. Comparison of Percentage of Participants in the Present Study endorsing the ‘Agree’ or ‘Strongly agree’ option to statements of the MS Psychosocial Factors with Mohr et al.’s (1999) study.

<table>
<thead>
<tr>
<th>Statements</th>
<th>Present study N = 154</th>
<th>Mohr et al 1999 N = 96</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1. Demoralization</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. MS has made me more dependent on others</td>
<td>59.7</td>
<td>65.3</td>
</tr>
<tr>
<td>6. MS has made me more cynical</td>
<td>31.8</td>
<td>23.2</td>
</tr>
<tr>
<td>8. I’ve become much more defensive since I’ve had MS</td>
<td>40.2</td>
<td>27.7</td>
</tr>
<tr>
<td>9. I worry that I bring people down because of my MS</td>
<td>32.4</td>
<td>27.4</td>
</tr>
<tr>
<td>10. I feel like my family is just waiting for me to die or go away.</td>
<td>5.8</td>
<td>1.1</td>
</tr>
<tr>
<td>12. I am more embarrassed about my being seen by friends because of my MS.</td>
<td>13.6</td>
<td>23.2</td>
</tr>
<tr>
<td>22. Since having MS I think less of myself.</td>
<td>24.0</td>
<td>16.8</td>
</tr>
<tr>
<td>24. I am less happy since I have had MS.</td>
<td>41.5</td>
<td>38.3</td>
</tr>
<tr>
<td>26. I feel worthless since having MS.</td>
<td>14.9</td>
<td>8.4</td>
</tr>
<tr>
<td>27. MS has made me learn to rely more on people.</td>
<td>53.3</td>
<td>69.5</td>
</tr>
<tr>
<td>28. I’ve lost my confidence in being a man/woman</td>
<td>22.0</td>
<td>25.2</td>
</tr>
<tr>
<td>29. I am more anxious since having MS.</td>
<td>53.9</td>
<td>52.6</td>
</tr>
<tr>
<td>30. I have become more depressed since having MS.</td>
<td>53.9</td>
<td>43.6</td>
</tr>
<tr>
<td>31. MS has made me much more irritable with others.</td>
<td>35.0</td>
<td>36.8</td>
</tr>
<tr>
<td>35. I worry I am not a good friend because of my MS.</td>
<td>20.1</td>
<td>18.1</td>
</tr>
<tr>
<td>37. I worry I have become a burden on others.</td>
<td>42.9</td>
<td>47.4</td>
</tr>
<tr>
<td>38. I am embarrassed to be seen in public because of my MS.</td>
<td>16.2</td>
<td>11.6</td>
</tr>
<tr>
<td>39. Since having MS I have become moodier.</td>
<td>49.3</td>
<td>52.1</td>
</tr>
<tr>
<td>42. MS has made relationships with friends more distant.</td>
<td>26.6</td>
<td>20.0</td>
</tr>
<tr>
<td>43. I feel nobody cares about me since I’ve had MS.</td>
<td>5.2</td>
<td>5.2</td>
</tr>
<tr>
<td>45. I feel more useless since having MS.</td>
<td>49.3</td>
<td>38.9</td>
</tr>
<tr>
<td>48. MS has made me more uncertain about the future.</td>
<td>73.4</td>
<td>80.0</td>
</tr>
<tr>
<td><strong>Factor 2. Benefit Finding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Since having MS I have learned to communicate better with people.</td>
<td>30.5</td>
<td>48.4</td>
</tr>
<tr>
<td>3. I feel my family or friends worry about me since I have had MS.</td>
<td>78.0</td>
<td>89.5</td>
</tr>
<tr>
<td>4. I keep in better touch with my family since having MS.</td>
<td>25.9</td>
<td>44.7</td>
</tr>
<tr>
<td>7. MS has helped me be closer to my family.</td>
<td>31.8</td>
<td>70.5</td>
</tr>
<tr>
<td>13. MS has made me appreciate life more.</td>
<td>66.9</td>
<td>73.7</td>
</tr>
<tr>
<td>15. I express my feelings more since I have had MS.</td>
<td>47.4</td>
<td>54.7</td>
</tr>
<tr>
<td>17. MS has made me more independent in many ways.</td>
<td>36.4</td>
<td>37.9</td>
</tr>
<tr>
<td>18. Having MS has helped me become more compassionate towards others.</td>
<td>59.8</td>
<td>67.4</td>
</tr>
<tr>
<td>19. Having MS has helped me be closer to my spouse/significant other.</td>
<td>42.2</td>
<td>50.6</td>
</tr>
<tr>
<td>20. MS has made me realize the importance of being independent.</td>
<td>75.8</td>
<td>83.0</td>
</tr>
<tr>
<td>23. My friends and family have become more helpful since I’ve had MS.</td>
<td>58.5</td>
<td>76.6</td>
</tr>
<tr>
<td>25. MS has helped me be a better friend.</td>
<td>30.5</td>
<td>47.9</td>
</tr>
<tr>
<td>33. MS has made me more conscientious and self-disciplined.</td>
<td>46.1</td>
<td>60.0</td>
</tr>
<tr>
<td>34. I have become more introspective.</td>
<td>37.7</td>
<td>71.6</td>
</tr>
<tr>
<td>36. I am less inhibited now as compared to before I had MS.</td>
<td>24.6</td>
<td>32.6</td>
</tr>
<tr>
<td>40. I have become more spiritual.</td>
<td>22.7</td>
<td>44.7</td>
</tr>
<tr>
<td>41. I have become more respectful of others.</td>
<td>44.8</td>
<td>58.5</td>
</tr>
<tr>
<td>44. I am more compassionate towards others since having MS.</td>
<td>54.5</td>
<td>64.9</td>
</tr>
<tr>
<td>47. I am more motivated to succeed since having MS.</td>
<td>47.4</td>
<td>47.9</td>
</tr>
<tr>
<td><strong>Factor 3. Deterioration in Relationships</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. My spouse/significant other has been much more irritated with me since I’ve had MS.</td>
<td>20.1</td>
<td>14.4</td>
</tr>
<tr>
<td>11. My spouse/significant other belettes me because of my MS.</td>
<td>5.1</td>
<td>2.4</td>
</tr>
<tr>
<td>14. I feel MS caused my relationship/marriage to deteriorate.</td>
<td>21.4</td>
<td>13.8</td>
</tr>
<tr>
<td>16. My spouse/significant other is often angry at me because of my MS.</td>
<td>12.3</td>
<td>4.8</td>
</tr>
<tr>
<td>21. I feel my spouse/significant other babies me more since having MS.</td>
<td>18.1</td>
<td>44.2</td>
</tr>
<tr>
<td>32. I feel my spouse/significant other is in denial about my disease.</td>
<td>17.5</td>
<td>18.3</td>
</tr>
<tr>
<td>46. I worry I am not a good partner because of my MS.</td>
<td>37.7</td>
<td>44.8</td>
</tr>
<tr>
<td><strong>Total Scale</strong></td>
<td><strong>α = .91</strong></td>
<td><strong>α = .87</strong></td>
</tr>
</tbody>
</table>
Similarly, these three items also had the highest agreement from Mohr et al.’s (1999) sample. The least agreement from both samples were for Item 10 (‘I feel like my family is waiting for me to die’), Item 43 (‘I feel no one cares about me since I have had MS’) and Item 11 (‘My spouse/significant other belittles me because of my MS’).

As noted, the statement from the Demoralization sub-scale with the highest agreement from participants (73%) was Item 48 ‘MS has made me more uncertain about the future’. Other items with over 50 percent agreement in this section pertained to statements suggesting that since having MS, participants had had become more dependent upon others, more depressed and more anxious. The least agreed items in this section, Item 10 and Item 43 were statements related to feelings that others were not interested or worse, waiting for them to die.

The statement from the Deteriorated Relationships section with the highest agreement from participants was Item 46 endorsed by just over one-third respondents: ‘I worry that I am not a good partner because of my MS’. The least agreement was for Item 11 that pertained to a partner belittling them because of their MS.

Several Benefit Finding statements showed strong agreement. The highest agreement was for Item 3 (helpful family/friends), followed by Item 20 (appreciation of independence). Both these items were endorsed by about three-quarters of the sample. About two-thirds of the sample agreed that MS had made them appreciate life more, while approximately half agreed that they had become more compassionate since having MS. The least agreed statement in this section was item 40, with less than a quarter of participants agreeing with it. This was ‘I have become more spiritual’.
9.4.2 Comparisons with Mohr et al.’s (1999) sample

The sample in the present study was similar in composition to the demographic characteristics reported by Mohr et al. (1999). Mohr et al.’s participants were aged from 18 to 66 years with a mean age of 42.6 years; mean time since diagnosis was 8.1 years. There was a gender composition of 70 (74.5 percent) females and 24 (25.5 percent) males. Most of Mohr et al.’s sample were married (62 percent).

Despite similarities in demographic characteristics regarding age and time since diagnosis, there were differences in the mobility status of participants between the two samples (present and Mohr et al. 1999). In the present study there were 14 people who described themselves as being wheelchair dependent, while in the Mohr et al. (1999, p. 378) there was only one participant who was reported to be ‘confined to a wheelchair’. In both studies the participants using wheelchairs for mobility were categorised into a broader group of needing aids to assist mobilisation that also included participants who required walking aids to assist ambulation.

As noted earlier in this section, the reliability coefficients obtained for the three MS psychosocial factors, and for the total scale, in the present study were similar to those reported by Mohr et al (1999). Table 9.3 shows similar agreement between the two samples on a number of items, for example: Demoralization Item 43, and Item 48 (uncertainty about the future); Benefit Finding Item 13 (appreciate life more); and Deteriorated Relationships Item 32 (partner’s denial about disease).

However, there were also a number of differences between participants’ responses in the two samples. For example, in the Demoralization section, the present sample reported higher agreement to being more defensive Item 8 (40% compared with 27%), and depressed (53.9% compared with 43.6%). The present sample reported less
agreement with some Benefit Finding items, for example Item 7 ‘MS has helped me be closer to my family’ (31.8% compared with Mohr et al’s 70.5% agreement). There was also less agreement by the present sample with Item 34 ‘I have become more introspective’ (37.7% compared with 71.3%) and also to the Item 40 ‘I have become more spiritual’ (22.7% compared with 44.7%). The main difference between the samples in the Deteriorated Relationships was for Item 21 ‘I feel my spouse often babies me because of my MS’ (18% in the present sample compared with 44% in Mohr et al. Study). Differences in responses to this statement may have been related to the ambiguous content of the item; the term ‘babies’ may have different connotations in American and Australian culture.

9.5  Reliabilities and descriptive data

To examine the internal consistency of the scales and sub-scales used in the present study, Cronbach’s alphas were calculated. More detailed information about the reliability of the scales and sub-scales, including the item total correlations, are presented in Appendix G. The reliability coefficients and other descriptive statistics of the scales and sub-scales including the means, standard deviations, are presented in Table 9.4, and reported below.

9.5.1  Optimism

Table 9.4 on the following page shows that the Cronbach’s alpha obtained in the present study for the LOT-R scale was .83, which is higher than the alpha coefficient of .78 reported by Scheier et al. (1994). However, the present study’s alpha (.83) is
Table 9.4 Descriptive Data (Means, Standard Deviations and Reliability Coefficients) for Participants’ Scores on the Main Variables of the Study.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Optimism (LOT-R)</strong></td>
<td>14.75</td>
<td>4.41</td>
<td>.83</td>
</tr>
<tr>
<td>Range 0-24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fatigue (POMS)</strong></td>
<td>2.29</td>
<td>1.11</td>
<td>.91</td>
</tr>
<tr>
<td>Range 0 – 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Coping Scales</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 0-3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.77</td>
<td>.57</td>
<td>.62</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>1.25</td>
<td>.65</td>
<td>.68</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>.76</td>
<td>.69</td>
<td>.82</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>.90</td>
<td>.72</td>
<td>.81</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.65</td>
<td>.63</td>
<td>.61</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>1.15</td>
<td>.76</td>
<td>.78</td>
</tr>
<tr>
<td>Self Controlling</td>
<td>1.16</td>
<td>.56</td>
<td>.61</td>
</tr>
<tr>
<td>Distancing</td>
<td>1.02</td>
<td>.63</td>
<td>.68</td>
</tr>
<tr>
<td><strong>OUTCOME VARIABLES</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MS Psychosocial Factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 1-5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demoralization</td>
<td>2.70</td>
<td>.77</td>
<td>.93</td>
</tr>
<tr>
<td>Benefit Finding</td>
<td>3.25</td>
<td>.56</td>
<td>.85</td>
</tr>
<tr>
<td>Deteriorated relationships</td>
<td>2.22</td>
<td>.88</td>
<td>.84</td>
</tr>
<tr>
<td><strong>Psychological distress (POMS)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>.87</td>
<td>.91</td>
<td>.91</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.15</td>
<td>.90</td>
<td>.85</td>
</tr>
<tr>
<td>Anger</td>
<td>.91</td>
<td>.93</td>
<td>.91</td>
</tr>
<tr>
<td>Negative affect # (0-12)</td>
<td>2.94</td>
<td>2.50</td>
<td>.95</td>
</tr>
<tr>
<td><strong>Well being Scale (Ryff) Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 18–108</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>13.90</td>
<td>2.55</td>
<td>.51</td>
</tr>
<tr>
<td>Environmental Mastery</td>
<td>12.94</td>
<td>2.94</td>
<td>.59</td>
</tr>
<tr>
<td>Personal Growth</td>
<td>14.02</td>
<td>2.61</td>
<td>.47</td>
</tr>
<tr>
<td>Positive Relations</td>
<td>11.64</td>
<td>2.06</td>
<td>.57</td>
</tr>
<tr>
<td>Purpose in Life</td>
<td>12.67</td>
<td>3.13</td>
<td>.36</td>
</tr>
<tr>
<td>Self Acceptance</td>
<td>12.75</td>
<td>3.23</td>
<td>.52</td>
</tr>
</tbody>
</table>

# Negative Affect (Anxiety + Depression + Anger POMS scores) (0-12)
comparable with alphas (.83, .87) reported by the Fournier et al. (2002a) using the LOT-R scale with a MS sample. The mean for Optimism (14.75) was lower than that reported by Fournier et al. (2002a)’s MS study, but approximately equal to norms reported by Scheier et al. (1994) for normal samples (14.28 to 14.33) and slightly lower than means reported for clinical sample of bypass patients (14.92 to 15.24). Therefore, the present sample was not diminished in optimism in relation to a non-clinical sample.

9.5.2 Profile of Mood States

The reliability coefficients calculated from the sub-scales, Anger, Anxiety, Depression, Fatigue of the shortened POMS scale in the present study ranged from .85 to .91 which were consistent with those reported by Shacham (1983). However, the Anger, Anxiety and Depression sub-scales showed correlations above .7 (see Appendix H) and to avoid multicollinearity in later multiple regressions the scores from these three sub-scales were combined to form one scale, Negative Affect. Internal consistency of the Negative Affect scale, measured by Cronbach’s alpha, resulted in an alpha of .94.

The means in the present study obtained for the POMS scales of Depression, Anxiety were lower than those reported by Shacham (1983) of 1.19, 1.44 respectively with a clinical sample of cancer patients. However, the means for Anger (.91) and Fatigue (2.29) for the present sample were higher than those reported by Shacham of .65 and 1.73 respectively. The present sample reported higher levels of anger and fatigue in relation to Shacham’s clinical sample of people with cancer.
9.5.3 MS Psychosocial factors

Table 9.4, on the previous page, shows that the internal consistency of the three MS psychosocial factors, Demoralization, Benefit Finding, and Deteriorated Relationships ranged from .84 to .93. These coefficients were similar to alphas (.84 to .90) reported by Mohr et al. (1999). For comparison of current sample responses with Mohr et al. (1999) see Table 9.3 and annotated discussion.

9.5.4 Coping

The reliability coefficients obtained for the Ways of Coping sub-scales ranged from .62 to .81 in the present study which were consistent with those reported by Folkman and Lazarus (1988b). Higher means indicated higher use of coping strategies. Problem Solving was the most used strategy, followed by use of Seeking Social Support, and Self-Controlling strategies. Accepting Responsibility was the least used coping strategy. Coping means for the current sample cannot be meaningfully compared with normative samples as participants had responded to the scales in relation to their own individual problem.

9.5.5 Psychological Well-being

The coefficients obtained for the six sub-scales (each of 3 items) of the Ryff Well-being scale were quite low with Cronbach’s alphas ranging from .36 to .59. However, these were similar to those reported by Ryff and Keyes, (1995, p. 721) (.33 to .56), and Lindfors (2002) (.26 to .59). The reliability coefficient calculated on the total scores of Ryff Well-being Scale in the present study was .80 which was higher than
Cronbach of .74 reported by Lindfors (2002). The mean total score of 80.10 for the current sample was slightly lower than the total composite score of 82.62 obtained by Lindfors (2002). Means for the sub-scales in the present study ranged from 11.46 to 14.02, which were lower than those obtained (14.6 to 15.7) by Ryff and Keyes (1995). In the current study, both the total scores for the Well-being Scale (summing of six scales) and the six sub-scale scores were used in analyses.

9.6 Sub-samples differences

9.6.1 Overview

To examine the sample in more detail, some analyses were conducted to consider the differences between sub-samples. A series of analyses were conducted to examine differences between participants based on their gender and on their mobility status according to use or not of aids. The method of data collection with subsequent anonymity of participants, meant that no data were collected that could identify participants as being from the urban and rural areas and differences between these two groups could not be examined.

9.6.2 Gender differences

A series of one-way between groups multivariate analyses were conducted to investigate gender differences on variables related to physical factors, coping and psychological well-being. The first MANOVA examined physical factors that included the variables of fatigue and mobility. The second examined coping variables, that is, the eight coping strategies of the WCQ. The last MANOVA examined well-being including the variables of Optimism, MS factors, Negative Affect and Ryff Well-being total scores. Results are reported in Table 9.5.
Table 9.5. MAVOVA results for gender groups for physical, coping and well-being measures.

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Males Mean</th>
<th>Females Mean</th>
<th>Gender F</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 43</td>
<td></td>
<td>N = 110</td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue (0-4)</td>
<td>2.19</td>
<td>2.33</td>
<td>.54</td>
</tr>
<tr>
<td>Mobility (1-5)</td>
<td>2.42</td>
<td>2.22</td>
<td>.78</td>
</tr>
<tr>
<td>Coping (0-3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem solving</td>
<td>1.21</td>
<td>1.27</td>
<td>.20</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.76</td>
<td>.78</td>
<td>.10</td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>.61</td>
<td>.81</td>
<td>2.19</td>
</tr>
<tr>
<td>Escape-avoidance</td>
<td>.86</td>
<td>.92</td>
<td>.19</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>.83</td>
<td>.78</td>
<td>9.67**</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>1.10</td>
<td>.54</td>
<td>.45</td>
</tr>
<tr>
<td>Distancing</td>
<td>.99</td>
<td>.63</td>
<td>.08</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>.68</td>
<td>.64</td>
<td>.015</td>
</tr>
<tr>
<td>Optimism</td>
<td>13.88</td>
<td>15.08</td>
<td>2.29</td>
</tr>
<tr>
<td>MS Demoralization</td>
<td>2.78</td>
<td>2.67</td>
<td>.58</td>
</tr>
<tr>
<td>MS Deteriorated relationships</td>
<td>2.50</td>
<td>2.12</td>
<td>5.94*</td>
</tr>
<tr>
<td>MS Benefit Finding</td>
<td>3.30</td>
<td>3.24</td>
<td>.36</td>
</tr>
<tr>
<td>Negative affect</td>
<td>2.94</td>
<td>2.95</td>
<td>.00</td>
</tr>
<tr>
<td>Ryff Well-being</td>
<td>78.28</td>
<td>80.81</td>
<td>1.34</td>
</tr>
</tbody>
</table>

Note *p = <0.05, **p = <0.01

The results from the MANOVAS showed that overall there were few differences between the genders on the main study variables. There were no significant differences between the groups on the physical factors as measured by their level of fatigue and their mobility status.

As indicated in Table 9.5, a significant difference was found between males and females in their choice of coping. The women in this sample were more likely than men to use seeking social support to deal with their MS related problems. There was also a gender difference on the MS psychosocial factors, Deteriorated Relationships. Men
were more likely than women to report that having MS had a detrimental effect on their relationships.

In view of few gender differences found in this sample, the rest of the analyses were conducted using group data.

9.6.3 Mobility status group differences

A series of one-way between-groups analysis of variance were conducted to explore the impact of mobility on the measures of psychological distress and wellbeing. As indicated previously, participants were divided into three groups according to their self-reported level of mobility.

Table 9.6. Differences in Mobility subgroups with Mean scores on the POMS, LOT-R, Ryff Well-being Scale, MS Psychosocial Factors Scales and univariate ANOVAs

<table>
<thead>
<tr>
<th>Mean scores</th>
<th>Group 1 (N=49)</th>
<th>Group 2 (N=59)</th>
<th>Group 3 (N=46)</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism</td>
<td>14.96</td>
<td>14.81</td>
<td>14.46</td>
<td>.16</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>1.96*</td>
<td>2.45</td>
<td>2.46</td>
<td>3.32*</td>
</tr>
<tr>
<td>MS Psychosocial Factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demoralization</td>
<td>2.50</td>
<td>2.69</td>
<td>2.92#</td>
<td>3.64*</td>
</tr>
<tr>
<td>Deteriorated Relationships</td>
<td>2.07</td>
<td>2.20</td>
<td>2.42</td>
<td>1.99</td>
</tr>
<tr>
<td>Benefit Finding</td>
<td>3.16</td>
<td>3.29</td>
<td>3.36</td>
<td>1.44</td>
</tr>
<tr>
<td>Negative Affect (POMS)</td>
<td>2.69</td>
<td>3.18</td>
<td>2.89</td>
<td>.54</td>
</tr>
<tr>
<td>Well being (Ryff)</td>
<td>81.55</td>
<td>81.17</td>
<td>77.11</td>
<td>1.96</td>
</tr>
</tbody>
</table>

*p < 0.05
Group 1 = Normal Gait, Group 2 = Mild gait problems – No aids, Group 3 = Needs Aids
* < other two groups
# > group 1

Results presented in Table 9.6 show the mean scores obtained for each of the mobility groups for the main study variables. When ANOVAs were conducted the only significant differences between the groups were related to Fatigue scores and the MS
factor, Demoralization. Post hoc analyses were conducted on the significant results to ascertain differences between the three groups.

A significant difference was found between levels of Demoralization for the three groups. Group 3 (those who required aids for mobility) reported higher levels of Demoralization than participants with normal gait, or mild gait problems. The effect size, calculated using eta squared, was 0.05. Post hoc comparisons using the LSD test indicated the mean score for Group 1 was significantly different from Group 3 while Group 2 did not differ significantly from either Group 1 or 3.

As indicated in Table 9.6, a statistically significant result between the fatigue scores for the three groups was found \[ F(2, 151) = 3.3, p < 0.05 \]. Group 1 participants reported lower levels of fatigue than Group 2 and Group 3. The effect size, calculated using eta squared, was .04. Post-hoc comparisons using the LSD test indicated that there was no significant difference in fatigue levels between Group 2 (those people who had mild gait problems and did not use aids) and Group 3 (those people who needed aids for their mobility).

### 9.7 Correlation Analyses

#### 9.7.1 Overview

Pearson’s product correlation coefficients were conducted to explore relationships among the main variables of the study, including the demographic variables. These coefficients including correlations between the sub-scales of the main scales in the present study are presented in Appendix H.

A significant positive relationships between participants’ age and mobility status \( r = .49, \ p < 0.01 \) was found. Older participants had increased mobility disability.
Likewise, there was a significant positive association between time since diagnosis and mobility status \((r = .38, p < 0.01)\). A longer time since diagnosis was associated with increased motor disability.

The age of onset of MS was also found to have a significant positive association with mobility \((r = .21, p < 0.05)\). There was a significant negative association between participants’ age of onset and the MS psychosocial factor, Deteriorated Relationships \((r = -.25, p < 0.01)\) and Negative Affect \((r = -.17, p < 0.05)\). Participants who were older at the onset of their MS reported higher levels of mobility disability, but were less distressed. They had lower levels of Negative Affect and lower scores on Deteriorated Relationships than those participants who were younger at the time of onset.

Duration of illness was found to have a significant association with decreased mobility \((r = .39, p < 0.01)\). Participants who had MS for longer times had higher levels of mobility disability. However, duration of illness was not associated with any of the dependent variables.

### 9.7.2 MS psychosocial factors

Correlations between the three MS factors (Demoralization, Benefit Finding, and Deteriorated Relationships), psychosocial and physical variables (Optimism, Fatigue, Mobility, Coping) and well-being measures (Negative Affect and Ryff Well-being) are presented in Table 9.7.

Significant positive relationships were found between Demoralization and Deteriorated Relationships with the each of the three POMS scales (Depression, Anxiety, and Anger). Therefore, depressed, anxious and angry participants were also more likely to be more demoralised and have more likely to have deteriorated
relationships. However, Benefit Finding was not associated with any of the POMS sub-scales.

As predicted there was a highly significant relationship between Negative Affect and both Demoralization and Deteriorated Relationships factors supporting the first hypothesis. Higher scores on these two MS factors were associated with higher levels of psychological distress. However, there was no association found between Benefit Finding and Negative Affect. Therefore the second hypothesis, predicting a negative relationship, was not supported.

Table 9.7. Correlations of MS Psychosocial Factors with main study variables

<table>
<thead>
<tr>
<th></th>
<th>Demoralization</th>
<th>Deteriorated Relationships</th>
<th>Benefit Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part A (part replication)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (POMS)</td>
<td>.67**</td>
<td>.46**</td>
<td>-.04</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.62**</td>
<td>.46**</td>
<td>0</td>
</tr>
<tr>
<td>Anger</td>
<td>.52**</td>
<td>.37**</td>
<td>.09</td>
</tr>
<tr>
<td>Negative Affect# (POMS)</td>
<td>.66**</td>
<td>.46**</td>
<td>.02</td>
</tr>
<tr>
<td>Coping:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-.07</td>
<td>.01</td>
<td>.35**</td>
</tr>
<tr>
<td>Planful problem Solving</td>
<td>-.17*</td>
<td>-.05</td>
<td>.09</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>.40**</td>
<td>.27**</td>
<td>.05</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.31**</td>
<td>.32**</td>
<td>.12</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>-.03</td>
<td>-.04</td>
<td>.21*</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>.20*</td>
<td>.13</td>
<td>.05</td>
</tr>
<tr>
<td>Distancing</td>
<td>.22*</td>
<td>.20*</td>
<td>.09</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.01</td>
<td>.02</td>
<td>.09</td>
</tr>
<tr>
<td>Part B – (extended study)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism (LOT-R)</td>
<td>-.49**</td>
<td>-.25**</td>
<td>.09</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>.38**</td>
<td>.24**</td>
<td>.13</td>
</tr>
<tr>
<td>Mobility</td>
<td>.23**</td>
<td>.20**</td>
<td>.08</td>
</tr>
<tr>
<td>Ryff Well-being</td>
<td>-.65**</td>
<td>-.47**</td>
<td>-.01</td>
</tr>
</tbody>
</table>

*p < 0.05, ** p < 0.001  # Negative Affect (depression + anxiety + anger)
Both the Demoralization and Deteriorated Relationships factors were found to have significant positive associations with Fatigue and Mobility. There were also significant negative associations found for Demoralization and Deteriorated Relationships factors with Optimism. Less optimism, higher levels of fatigue, and disability (less mobility) were associated with higher scores on these two MS factors.

In contrast there were no associations between Benefit Finding with Optimism, Fatigue or Mobility. Therefore the third hypothesis predicting a positive association between Benefit Finding and Optimism was not supported.

Correlations between Demoralization and the coping scales showed significant positive associations. Demoralization was positively associated with four emotion-focused coping strategies (Escape–Avoidance, Accepting Responsibility, Self-Controlling and Distancing coping). A significant, but weak, negative association was found between Demoralization and Problem Solving coping. Demoralised participants were more likely to use less problem-focused coping and more emotion-focused coping to deal with their MS problems.

There were significant, weak correlations found between Deteriorated Relationships and three emotion-focused coping strategies (Escape-Avoidance, Accepting Responsibility, and Distancing). Participants who used more emotion-focused coping strategies were more likely to report deteriorated relationships.

Correlations between Benefit Finding and the coping scales indicated significant though relatively weak relationships between Benefit Finding and both Positive Reappraisal and Seeking Social Support, which supported the fourth hypothesis. Benefit Finding was not associated with any of the other coping strategies. Therefore, people who were more likely to report benefits from their MS experience also used the coping strategies of positive reappraisal and seeking social support.
There were highly significant, negative relationships between Demoralization and Deteriorated Relationships with Ryff Well-being scores. Higher well-being was associated with low demoralisation and less deteriorated relationships. However, no association was found between Benefit Finding and Ryff Well-being scores.

9.7.3 Negative Affect

The correlation coefficients between Optimism, Mobility, Fatigue, coping strategies, Negative Affect, and Well-being are presented in Table 9.8. There was a significant negative association between Optimism and Negative Affect. Higher optimism scores were associated with lower POMS scores. A significant positive association was found between Fatigue and Negative Affect. Higher levels of fatigue were associated with reported higher levels of psychological distress.

Table 9.8. Correlations of outcome variables of Negative Affect and Well-being with Optimism, Fatigue, Mobility and Coping variables.

<table>
<thead>
<tr>
<th></th>
<th>Negative Affect (POMS)</th>
<th>Well being (Ryff PWB)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism (LOT-R)</td>
<td>-.43**</td>
<td>5.1**</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>.52**</td>
<td>-.32**</td>
</tr>
<tr>
<td>Mobility</td>
<td>.01</td>
<td>-.18*</td>
</tr>
<tr>
<td>Coping (WCQ)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>.01</td>
<td>.14</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>-.14</td>
<td>.23**</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>.55**</td>
<td>-.41***</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.29**</td>
<td>-.24**</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>.04</td>
<td>.10</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>.36**</td>
<td>-.19**</td>
</tr>
<tr>
<td>Distancing</td>
<td>.25**</td>
<td>-.23***</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.27**</td>
<td>-.02</td>
</tr>
<tr>
<td>Ryff Well-being (total)</td>
<td>-.54**</td>
<td>1</td>
</tr>
</tbody>
</table>

* p< 0.05, ** p < 0.01
As indicated in Table 9.8 there were significant positive associations between five coping strategies and Negative Affect. Increased use of emotion-focused coping (Escape-Avoidance, Accepting Responsibility, Self-controlling, Distancing) and the problem-focused Confrontive coping was associated with increased psychological distress.

Correlations showed a highly significant negative relationship between Ryff Well-being scores and Negative Affect. Higher scores on the Ryff Well-being scales were associated with lower levels of psychological distress (POMS scores).

### 9.7.4 Ryff Well-being

Table 9.8 shows that Optimism was found to have a high significant positive relationship with Ryff PWB scores. There were significant negative associations between Fatigue and Mobility with Ryff scores. Higher optimism, lower levels of fatigue, and less disability (mobility) were associated with higher levels of well-being (Ryff scores).

Other findings included significant relationships found between Well-being (Ryff) scores and five coping strategies. A significant positive association was found between Well-being with Problem Solving. Significant negative associations were found between Well-being (Ryff) scores and four emotion-focused strategies (Escape-Avoidance, Accepting Responsibility, Self-controlling and Distancing coping). Higher Well-being was associated with increased use of problem-focused coping and decreased use of emotion-focused coping.
9.8 Regression analyses

9.8.1 Predictors of MS psychosocial factors

One of the aims of the present study was to examine further the psychosocial consequences of MS as conceptualised by the three factors (Demoralization, Deteriorated Relationships and Benefit Finding). Standard multiple regressions were conducted to determine which of the independent variables, (Optimism, Fatigue, Mobility, and the eight Coping strategies) predicted Demoralization, Benefit Finding and Deteriorated Relationships, and to test the fifth hypothesis. The results of the standard regression equations are reported in Table 9.9.

The combined variables (Optimism, Fatigue, Mobility, and the eight coping strategies) accounted for 45 percent of the variance of Demoralization scores. Scores on the Optimism, Fatigue, Mobility and Accepting Responsibility coping scales were the significant independent predictors of Demoralization. Optimism made the largest unique contribution to the equation. The coping scale, Accepting Responsibility, describes coping efforts that acknowledge one’s own role in a stressful encounter that may also include blaming oneself for the situation. This coping strategy made the largest positive contribution to predicting Demoralization. More demoralized people with MS were less optimistic, more fatigued, had lower levels of mobility and tended to take responsibility (or blame themselves) for their problems.
Table 9.9 Results of 3 Standard Multiple Regression Indicating the Relationship between the three MS Factors Demoralization, Benefit Finding, Deteriorated Relationships and the main variables

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>Demoralization</th>
<th>Deteriorated Relationships</th>
<th>Benefit Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism (LOT-R)</td>
<td>-.30***</td>
<td>-.09</td>
<td>.05</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>.20**</td>
<td>.14</td>
<td>.17</td>
</tr>
<tr>
<td>Mobility</td>
<td>.19**</td>
<td>.16</td>
<td>.06</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>- .05</td>
<td>.01</td>
<td>.39***</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>-.13</td>
<td>-.09</td>
<td>-.11</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>.16</td>
<td>.13</td>
<td>-.10</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>.21**</td>
<td>.32***</td>
<td>.17</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>.00</td>
<td>-.04</td>
<td>.15</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>.07</td>
<td>-.10</td>
<td>-.21</td>
</tr>
<tr>
<td>Distancing</td>
<td>.04</td>
<td>.09</td>
<td>.09</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>-.06</td>
<td>-.02</td>
<td>.00</td>
</tr>
<tr>
<td>R Square</td>
<td>.45</td>
<td>.23</td>
<td>.20</td>
</tr>
<tr>
<td>F</td>
<td>9.13***</td>
<td>3.46***</td>
<td>2.84***</td>
</tr>
<tr>
<td>Df</td>
<td>(11,125)</td>
<td>(11,125)</td>
<td>(11,125)</td>
</tr>
</tbody>
</table>

*p < 0.05, **p < 0.01, ***p < 0.001

The second equation showed that the combined variables (Optimism, Fatigue, Mobility and the eight coping strategies) accounted for 23 percent of the variance of Deteriorated Relationships. The only significant independent predictor of Deteriorated Relationships scores was the coping strategy, Accepting Responsibility, which made a positive contribution to deteriorated relationships.

When Benefit Finding was the dependent variable in the regression equation, the combined variables (Optimism, Fatigue, Mobility and the eight coping strategies) accounted for 20 percent of the variance in Benefit Finding scores. However, Positive Reappraisal coping was the only significant independent predictor of Benefit Finding scores. Positive Reappraisal coping describes efforts that aim to create a positive
experience that focus on the personal growth that is gained from the stressful or challenging experience, and it predicted higher levels of benefit finding.

Results from these equations showed only partial support for the fifth hypothesis. Higher optimism scores, higher mobility (less disability) and lower fatigue predicted lower Demoralization scores but did not predict Deteriorated Relationships (although these variables were correlated weakly with Deteriorated Relationships). Contrary to the hypothesis, there were few correlates and only one predictor (Positive Reappraisal coping) of Benefit Finding.

9.8.2 Predictors of Negative Affect

To examine the relationships between the outcome variables of psychological distress (Negative Affect) and Well-being with the main variables (Optimism, Fatigue, Mobility, Coping), and to test the sixth and seventh hypotheses, multiple regressions were conducted. Results are shown in Table 9.10.

The first regression equation with Negative Affect as the dependent variable was to determine which of the variables, Optimism, Fatigue, Mobility and Coping, predicted psychological distress. The combined variables accounted for 54 percent of the variance of Negative Affect scores. The four significant predictors of Negative Affect were Optimism, Fatigue and the coping strategies of Escape Avoidance and Confrontive coping. There was only partial support for the sixth hypothesis. As predicted higher optimism, lower fatigue, and less use of escape-avoidance coping predicted lower psychological distress (POMS scores). However, mobility status, and use of problem solving and positive reappraisal did not predict Negative Affect scores (nor were they correlated, as indicated in Table 9.8).
Table 9.10. Results of Standard Multiple Regressions Indicating the Predictors of Psychological outcomes of distress (Negative Affect) and Well-being (Ryff PWB total)

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>Negative Affect</th>
<th>Well-being (Ryff –total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism</td>
<td>-.20***</td>
<td>.32***</td>
</tr>
<tr>
<td>Fatigue</td>
<td>.28***</td>
<td>-.13</td>
</tr>
<tr>
<td>Mobility</td>
<td>.02</td>
<td>-.15*</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-.09</td>
<td>.11</td>
</tr>
<tr>
<td>Problem solving</td>
<td>-.14</td>
<td>.14</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>.23*</td>
<td>-.21*</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.10</td>
<td>-.13</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>-.04</td>
<td>.08</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>.13</td>
<td>-.08</td>
</tr>
<tr>
<td>Distancing</td>
<td>.03</td>
<td>-.09</td>
</tr>
<tr>
<td>Confrontive</td>
<td>.18*</td>
<td>.03</td>
</tr>
<tr>
<td>R Square</td>
<td>.54</td>
<td>.43</td>
</tr>
<tr>
<td>F</td>
<td>13.23***</td>
<td>8.64***</td>
</tr>
<tr>
<td>DF</td>
<td>(11, 125)</td>
<td>(11, 124)</td>
</tr>
</tbody>
</table>

*p <0.05, **p <0.01, ***p <0.001

9.8.3 Predictors of Well-being (total)

In the second regression, results shown in Table 9.10, Optimism, Fatigue, Mobility and the eight coping strategies were entered as independent variables, with Well-being (Ryff PWB total) as the dependent variable. The combined variables accounted for 43 percent of the variance in Well-being. The significant predictors of Well-being scores were Optimism, Mobility, and Escape-Avoidance coping. Those participants with the strongest level of well-being were more optimistic, had less disability and were less likely to try and avoid their problems. The results from this equation showed partial support for the seventh hypothesis. As predicted, higher optimism, higher mobility (less disability), and less use of escape-avoidance coping predicted better well-being as measured by the higher Ryff scores. However, fatigue, and use of problem solving and positive reappraisal did not predict Ryff scores.
Nevertheless both fatigue and problem solving were correlated with Ryff well-being (Table 9.8), supporting hypothesis seven further but reflecting overlapping variance between these two variables (fatigue, problem solving) and the significant predictors.

9.9 Summary of model testing

In summary, the five equations (sections 9.7 and 9.8) examining the model (Figure 1.2) showed that few of the variables related to the hypotheses were able to predict multiple outcome variables.

The two MS related variables, Mobility and Fatigue, predicted Demoralization, and one general measure. Lower mobility (higher disability) predicted higher Demoralization, and lower Ryff Well-being (total) scores, and was also a correlate of higher Deteriorated Relationships scores. On the other hand, increased Fatigue predicted higher Demoralization and Negative Affect scores. Fatigue was also correlated with these two variables and Ryff Well-being and Deteriorated Relationships. However, neither Fatigue nor Mobility correlated with or predicted Benefit Finding.

Optimism was correlated with all outcome variables except Benefit Finding and predicted three outcome variables (Negative Affect, Ryff PWB, Demoralization). Higher optimism predicted lower levels of Demoralization, less psychological distress (Negative Affect scores) and higher levels of psychological well-being (Ryff scores).

Different coping strategies correlated with and predicted specific outcome measures. Escape-avoidance coping was correlated with all outcome variables except Benefit Finding and was a significant predictor of both general outcome measures. Increased use of escape-avoidance coping predicted higher psychological distress (Negative Affect) and lower psychological well-being (Ryff scores).
Problem solving coping was correlated with Ryff Well-being and Demoralization but did not predict any of the outcome variables. Positive Reappraisal was a correlate and predictor of Benefit Finding. Increased use of Positive Reappraisal predicted only higher Benefit Finding scores and was not related to other outcomes.

Accepting Responsibility was correlated with four of the five outcome variables (not Benefit Finding), but only predicted two MS psychosocial factors. Higher use of Accepting Responsibility (self-blame) predicted higher Demoralization and Deteriorated Relationships scores.

Confrontive coping was correlated with and predicted Negative Affect. Higher use of this problem-focused coping predicted higher levels of psychological distress.

9.10 Exploratory analyses with Ryff sub-scales

One aim of the study was to examine relationships between physical, psychosocial variables and well-being using Ryff total and sub-scale scores as multiple measures of this concept. The following analyses using the six sub-scales of the Ryff well-being measure need to be viewed with caution due to the low reliabilities of these measures. Nevertheless they have been conducted as an attempt to further understand the pattern of well-being outcomes, and their associates, for people with MS. Correlations between six sub-scales and the study’s main variables are presented in Appendix I.

A series of regression analyses was performed to examine associations between the physical, psychosocial factors and coping factors and each of the six Ryff Well-being scales and are presented in Table 9.11 and 9.12.
Table 9.11 Results of 3 Standard Multiple Regressions predicting Autonomy, Environmental Mastery and Personal Growth from physical, psychosocial factors and coping.

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Autonomy</th>
<th>Environmental Mastery</th>
<th>Personal Growth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism (LOT-R)</td>
<td>.04</td>
<td>.22**</td>
<td>.33***</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>.08</td>
<td>-.32***</td>
<td>.03</td>
</tr>
<tr>
<td>Mobility</td>
<td>.07</td>
<td>-.06</td>
<td>-.23**</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>-.02</td>
<td>-.01</td>
<td>.11</td>
</tr>
<tr>
<td>Problem solving</td>
<td>-.01</td>
<td>.25**</td>
<td>-.09</td>
</tr>
<tr>
<td>Escape-avoidance</td>
<td>-.10</td>
<td>-.26**</td>
<td>-.24</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>-.17</td>
<td>-.22**</td>
<td>.13</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>-.08</td>
<td>.03</td>
<td>.10</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>-.13</td>
<td>.10</td>
<td>-.15</td>
</tr>
<tr>
<td>Distancing</td>
<td>-.01</td>
<td>.04</td>
<td>-.04</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.25*</td>
<td>.14</td>
<td>.07</td>
</tr>
<tr>
<td>R Square</td>
<td>.10</td>
<td>.50</td>
<td>.28</td>
</tr>
<tr>
<td>F</td>
<td>1.31</td>
<td>11.16***</td>
<td>4.46***</td>
</tr>
<tr>
<td>Df</td>
<td>(11, 124)</td>
<td>(11,124)</td>
<td>(11,124)</td>
</tr>
</tbody>
</table>

*p < 0.05, ** p < 0.01, ***p < 0.001

The combined variables (Optimism, Fatigue, Mobility and the eight coping strategies) accounted for only 10 percent of the variance of the Autonomy sub-scale of the Ryff PWB scale, with Confrontive coping being the only significant predictor of Autonomy scores.

However, these same combined variables accounted for a high 50 percent of the variance of the Environmental Mastery sub-scale. The significant predictors were Optimism, Fatigue, and the coping strategies, Problem solving, Escape-Avoidance, and Accepting Responsibility. Thus, being more optimistic, having less fatigue, and using as coping strategies more problem solving and less escape-avoidance and less self blame (Accepting responsibility) predicted higher scores on the Environmental Mastery scale.
Environmental mastery encompasses having a sense of mastery and perceiving oneself as being able to manage one’s environment in terms of personal needs and values.

When Personal Growth was the dependent variable in the regression equation, the combined variables accounted for 28 percent of the variance. Optimism and Mobility were the significant predictors of Personal Growth scores. People who were more optimistic and had less disability reported higher levels of a sense of seeing themselves as being open to new experiences and personal growth.

The regression equations where the Ryff sub-scales, Positive Relations, Purpose in Life, and Self-acceptance, were the dependent variables are presented in Table 9.12.

Table 9.12 Results of 3 Standard Multiple Regressions predicting Positive Relations, Purpose in Life, Self-acceptance from physical, psychosocial factors and coping.

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Positive Relations</th>
<th>Purpose in Life</th>
<th>Self acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism (LOT-R)</td>
<td>-.02</td>
<td>.21**</td>
<td>.21**</td>
</tr>
<tr>
<td>Fatigue (POMS)</td>
<td>-.04</td>
<td>-.13</td>
<td>-.10</td>
</tr>
<tr>
<td>Mobility</td>
<td>-.08</td>
<td>-.24**</td>
<td>-.13</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive reappraisal</td>
<td>-.10</td>
<td>.14</td>
<td>.14</td>
</tr>
<tr>
<td>Problem solving</td>
<td>-.09</td>
<td>.04</td>
<td>.21*</td>
</tr>
<tr>
<td>Escape-avoidance</td>
<td>-.21</td>
<td>-.06</td>
<td>-.12</td>
</tr>
<tr>
<td>Accepting responsibility</td>
<td>-.18</td>
<td>.10</td>
<td>-.25*</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>.14</td>
<td>.10</td>
<td>-.01</td>
</tr>
<tr>
<td>Self-controlling</td>
<td>.13</td>
<td>-.14</td>
<td>-.05</td>
</tr>
<tr>
<td>Distancing</td>
<td>.04</td>
<td>-.30**</td>
<td>.06</td>
</tr>
<tr>
<td>Confrontive coping</td>
<td>.02</td>
<td>-.10</td>
<td>-.09</td>
</tr>
<tr>
<td>R Square</td>
<td>.10</td>
<td>.36</td>
<td>.29</td>
</tr>
<tr>
<td>F</td>
<td>1.18</td>
<td>6.25***</td>
<td>4.64***</td>
</tr>
<tr>
<td>Df</td>
<td>(11,124)</td>
<td>(11,124)</td>
<td>(11,124)</td>
</tr>
</tbody>
</table>

*p < 0.05, ** p < 0.01, *** p < 0.001
The combined variables (Optimism, Fatigue, Mobility and the eight coping strategies) accounted for only 10 percent of Positive Relations scores. There were no significant independent predictors of Positive Relations with Others scores.

When Purpose in Life was the dependent variable in the regression equation, the combined variables accounted for 36 percent of the variance. Optimism, Mobility and Distancing coping were the significant predictors of Purpose in Life scores. People who were more optimistic, had less ambulatory disability and who were less likely to use the emotion-focused coping strategy of distancing (detachment or minimising problems) reported higher levels of having goals and a sense of purpose or meaning to their lives.

The last dependent variable in this series of regressions (Table 9.12) was Self-acceptance. The combined variables accounted for 29 percent of the variance with the significant predictors being Optimism, and the coping strategies, Problem Solving and Accepting Responsibility. Accepting Responsibility coping which describes self criticism or acknowledging blame for one’s problems made the largest negative contribution to predicting Self-acceptance. People with higher Self-acceptance scores were likely to be more optimistic, use more problem-solving strategies and not blame themselves for their problems.

In summary, the regression equation examining the relationships between the physical, psychosocial factors and coping with the total Ryff PWB scores (Table 9.8) indicated three significant predictors, Optimism, Mobility and Escape-Avoidance coping. Participants who were more optimistic, had higher mobility (less disability) and used less escape-avoidance coping had higher levels of psychological well-being. The results from the regressions with the individual sub-scales as dependent variables showed that Optimism was a significant predictor of Environmental Mastery, Personal Growth, Purpose in Life, and Self-acceptance scores. Higher levels of optimism
predicted higher scores on these scales. The two MS related physical variables, mobility and fatigue, were found to predict several sub-scale scores. Mobility was a significant predictor for Personal Growth and Purpose in Life scores with less disability predicting higher scores on these scales. Fatigue was a significant predictor of Environmental Mastery scores with lower levels of fatigue predicting higher scores.

Different coping strategies were able to predict specific sub-scale scores. Less use of Escape-Avoidance coping was a significant predictor of higher Ryff (total scores) and also higher Environmental Mastery scores. Increased use of problem solving and less use of Accepting Responsibility (self-blame) predicted higher Environmental Mastery and Self-acceptance scores. Lower use of Distancing coping predicted higher Purpose in Life scores.

Overall, the aspects of well-being which were most strongly predicted by the set of disease-related (mobility, fatigue) and psychosocial (coping, optimism) variables were related to the Environmental Mastery (R-square = .50) and Purpose in Life (R-square = .36) scales. On the other hand, there was least support for the variable set to be able to predict Autonomy and Positive Relations scores.
CHAPTER 10: DISCUSSION

10.1 The study

This study aimed to examine the psychological well-being of a sample of adults who have multiple sclerosis. Disease-related variables (fatigue, mobility) and psychosocial factors (optimism, coping) were examined to ascertain the impact of living with MS and effects upon well-being. Well-being was determined with a multidimensional assessment using two general measures (Negative Affect and the Ryff PWB scale for positive psychological functioning), and Mohr et al.’s (1999) MS psychosocial factors. One aim of the study was to replicate and extend the findings of Mohr et al.’s (1999) study whose participants had reported perceived benefits from living with multiple sclerosis. An additional aim of the study was to compare how the physical and psychosocial factors related differentially to the different well-being measures.

10.2 Summary of findings

10.2.1 General findings

The most commonly reported symptom was fatigue experienced by 85 percent of the sample. Additionally, about one-third had normal gait and one-third described themselves as having mild gait problems but not using walking aids. The remaining
third required the use of aids, and/or wheelchairs for mobility. Older participants were found to have increased mobility disability. Nevertheless, those who were older at the onset of MS reported significantly lower levels of psychological distress.

There were few gender differences in key variables. There were no differences between men and women on their level of optimism, psychological distress or well-being. On the other hand, women were more likely to use the coping strategy, seeking social support, rather than men. This result was consistent with findings of McCabe et al. (2004) that women from both MS and normal populations were more likely to use seeking social support (and positive reframing) than men. No differences were found for the use of the other coping strategies.

In general, MS research has shown support for the notion that people with MS often experience strained relationships (Hakim et al., 2000). Results from the present study showed a significant gender difference for perceived interpersonal effects as a consequence of MS. Men in this study were more likely than women to report that having MS had a detrimental effect upon their relationships. Mohr et al. (1999) using the same measure with a MS sample of similar gender composition did not find any gender differences for the Deteriorated Relationships factor. Also inconsistent with the findings of Mohr et al. (1999), results of the current study showed participants who had a later onset of MS reported significantly lower scores on the Deteriorated Relationship measure.

Analyses examining group differences based on mobility disability showed significant differences related to levels of demoralization and fatigue. As participants’ motor disability increased they reported feeling more demoralized. Those who required aids and/or wheelchairs reported the highest levels of demoralization. This result was consistent with findings reported by Mohr et al. (1999) that those who required aids for
ambulation scored higher on the Demoralization factor than those with normal gait. The Demoralization factor reflects feelings of alienation, distress and loss of self-esteem. Participants who required aids to assist their mobility reported more negative consequences, particularly those related to their self view. This finding is also consistent with findings reported by Walsh and Walsh (1987) who found that people requiring wheelchairs had lower self-esteem levels than those who did not use aids.

An interesting finding from this study was the link found between mobility and fatigue. There was a significant difference on fatigue levels between the normal gait group and the other two mobility groups. Participants with mild gait problems who did not use aids to assist their mobility reported fatigue levels comparable with those experiencing more complex gait difficulties. These results show while those with mild gait problems may be able to ambulate without aids nevertheless they are experiencing increased levels of fatigue. Janseen et al. (2003) noted that some ambulant people view walking aids as a highly visible step back rather than a tool to increase mobility and alleviate fatigue. However, studies by Ford et al. (1988), Sharawyn et al. (2002) and McCabe et al. (2004) demonstrate the effects of fatigue extend beyond the physical domain and are related to increased psychological distress. In light of these studies, people with mild gait problems who may require but not use aids to assist their ambulation, appear to be at risk for the physical and emotional consequences of elevated fatigue.

10.2.2. MS psychosocial factors

One aim of the present study was the part replication and extension of Mohr et al.’s (1999) study which had developed measures of psychosocial factors identified as Demoralization, Deteriorated Relationships and Benefit Finding. The use of Mohr et
al.’s (1999) scale enabled participants in the present study to respond to specific MS measures of their well-being and to report both negative and positive consequences from their experiences (see Table 9.3 and section 9.4.2 for previous discussion).

The first hypothesis predicting positive associations between Negative Affect and the MS psychosocial factors, Demoralization and Deteriorated Relationships was supported. Higher levels of these two MS factors were associated with increased levels of distress. This finding was similar to that reported by Mohr et al. (1999) and Katz et al. (2001) who had also used the POMS to measure psychological distress by way of separate indices of Depression, Anxiety and Anger. As noted previously, Mohr et al. (1999) found a positive association between Demoralization and the Depression sub-scale; and positive associations between Deteriorated Relationships and the Depression and Anxiety POMS scales.

Results of the current study also showed a significant negative association between the Ryff PWB and both Demoralization and Deteriorated Relationships. Lower scores on these two measures were associated with higher scores on psychological well-being.

Similar to Mohr et al. (1999), participants in the present study reported perceived benefits from their MS experience including perceptions of enhanced relationships, personal growth and increased compassion. This finding was also consistent with studies using cancer samples (Katz et al., 2001; Taylor, 1983) which found that even during adversity some people are able to perceive benefits from their illness experience. Although the present study found that the participants were able to report perceived benefits from their experience with MS, the extent to which positive outcomes were reported was lower than in previous studies.
The second hypothesis predicting a negative association between Benefit Finding and psychological distress (Negative Affect) was not supported. Results showing no association between Benefit Finding and psychological distress were inconsistent with findings reported by Mohr et al. (1999) and Katz et al. (2001). Mohr et al. (1999) had found a significant positive association between Benefit Finding and distress with their MS sample. Katz et al. (2001) found a negative association between the two variables using a cancer/lupus sample. More specifically, Mohr et al. (1999) reported positive associations between Benefit Finding with both the Depression and Anger POMS scales. However, the present study found no associations between Benefit Finding with any of the total and separate indices of psychological distress and psychological well-being (Table 9.7).

These findings are also inconsistent with studies by Affleck and Tennen (1996) who found that those who reported more benefits, as a consequence of their illness, were less psychologically distressed. Although participants in the present study reported perceived benefits from their experience with MS, there was no association with their subsequent reporting of psychological distress, nor with their scores on the Ryff PWB. The finding that reporting benefits did not relate to either increased or decreased psychological distress for participants in the present study was however, consistent with studies with cancer patients by Antoni et al. (2001) and Sears et al. (2003).

The inconsistency between findings in the Mohr et al. (1999) and Katz et al. (2001) studies and the present study may be due in part to the Benefit Finding scale itself. As noted earlier (section 9.4.2), Item 3 (I feel my family and friends worry about me more since having MS) had the highest agreement in both the present and Mohr et al. (1999) study. Likewise, Katz et al. (2001) found high agreement for this statement with their combined sample of people with cancer or lupus. However, Katz et al. (2001)
found, after factor analysis, that this item loaded onto the Deteriorated Relationships factor and so it was not included in their Benefit Finding scale. It would seem that inclusion of this item in the Benefit Finding scale may be problematic and requires review. Mohr et al. (1999) had used statistically rigorous criteria for their factor analysis for items for their scales, nevertheless, it would seem that Item 3 represents a statement which would not be generally perceived by mature adults as being necessarily a beneficial consequence. Having others worry more about one’s self would probably not be considered a favourable outcome or perceived benefit for many adults, regardless of whether or not they had MS. These doubts about the content validity of the Benefit Finding scale are further increased when there was no association found between the scale and the other general psychological measure, the Ryff PWB which purports to encompass positive functioning.

Relationships between Benefit Finding and both optimism and coping were of particular interest in this study to further understand this phenomenon of reporting benefits. The third hypothesis predicting a positive association between Optimism and Benefit Finding was not supported after results showed no association. Higher levels of optimism were not associated with increased reporting of benefits. This finding was inconsistent with Affleck and Tennen’s (1996) finding of a positive association between optimism and increased benefit reporting. This may be related to the conceptual problems in the Benefit Finding scale itself that may capture items not perceived as being benefits or positive outcomes by participants.

The fourth hypothesis was supported when positive associations were found between Benefit Finding and the coping strategies, positive reappraisal and seeking social support. Participants’ higher scores on the Benefit Finding factor were associated with increased use of positive reappraisal coping and seeking social support for their
MS related problems. This finding was consistent with findings reported in Mohr et al.’s MS study (1999). Similarly, Sears et al. (2003) with a cancer sample had found that reporting benefits was associated with higher use of positive reappraisal coping. Such findings lend support to Affleck and Tennen’s (1996) contention that reporting benefits may at times be viewed as a particular form of coping.

10.3 Testing the model: Dimensions of well-being

10.3.1 MS psychosocial factors

A series of correlations and standard regression analyses were conducted to examine the relationship of optimism, MS related fatigue, mobility, and coping strategies to each of the three MS psychosocial factors, Demoralization, Deteriorated Relationships and Benefit Finding as outlined in Figure 1.2 (Section 1.4).

The fifth hypothesis predicted higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping and lower use of escape-avoidance coping would be related to better well-being (lower Demoralization and Deteriorated Relationships and higher Benefit Finding scores). There was only partial support for this hypothesis.

Results showed lower disability, lower fatigue, and higher optimism were correlated with lower Demoralization and Deteriorated Relationships. The association between increased disease/physical dysfunction and increased reporting of perceived negative consequences of having MS was expected. Indeed, the Mohr et al. (1999) scales were developed to ascertain specific intrapersonal and interpersonal consequences. However, regressions showed these variables predicted Demoralization scores only, with optimism being the most significant predictor. The link found between higher optimism and lower Demoralization is consistent with literature showing that
generally optimistic people expect and report more positive outcomes (Wrosch & Scheier, 2003). These findings also lend support to Gold-Spink et al. (2000)’s conclusions that people with MS who are more optimistic expect more favourable outcomes than those who are not.

Accepting Responsibility, the least used coping strategy, was a significant predictor for both Demoralization and Deteriorated Relationships scores. This coping strategy is described by Folkman and Lazarus (1988b) as incorporating themes which acknowledges one’s own role in the problem with a view to put things right. However, examination of the four items which make up this scale reveal themes of self-blame and regret. For example, ‘Realized that I had brought the problem upon myself’; ‘Criticized or lectured myself’. For the current study, participants were asked to describe their coping behaviour in relation to a MS-related problem. In view of increased use of this coping strategy being identified as a significant predictor of two MS psychosocial factors, both of which could be viewed as negative outcomes, this type of coping is not indicative of being an adaptive or helpful coping strategy for people with MS. Increased use of Accepting Responsibility coping, or taking the blame for their MS-related problem, was related to loss of self-esteem (Demoralization) and detrimental effects upon relationships (Deteriorated Relationships).

The only significant predictor of Benefit Finding, in the present study, was the coping strategy, Positive Reappraisal. Unlike the other two MS psychosocial factors, the disease-related variables, mobility and fatigue, and optimism, which would be expected to impact upon participants’ perceptions of quality of life were found to be unrelated to reporting of perceived benefits. However, increased use of positive reappraisal coping predicted higher Benefit Finding scores. Positive Reappraisal coping includes efforts aimed to create a positive experience or focuses on personal growth from the
experience. This finding is consistent with cognitive adaptation theory (Taylor, 1983) which purports that people who are facing adversity may use cognitive reframing to perceive benefits from their experience. It also lends support to Sears et al. (2001) who identified a link between benefit finding and positive reappraisal coping and concluded that these variables appear to be separate but related constructs. Furthermore, Affleck and Tennen’s (1996) claim that benefit finding at times may best be described as a coping strategy is supported by these findings, particularly in light of positive reappraisal being the only predictor of Benefit Finding.

10.3.2 Negative Affect

Many MS studies have used the POMS as a measure of psychological distress. In the current study, a composite of three of the POMS scales (Depression, Anxiety, Anger) was used as a measure of Negative Affect, after the POMS scales were found to be highly correlated with each other (Appendix H).

The sixth hypothesis predicted higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping and lower use of escape-avoidance coping would be related to less psychological distress (lower Negative Affect, POMS scores). There was only partial support for the sixth hypothesis. Results showed less disability, less fatigue, higher optimism, and less use of escape-avoidance coping were correlated with lower levels of psychological distress. However, less fatigue, higher optimism, and less Escape-Avoidance coping were the only significant predictors of lower Negative Affect. Increased use of Confrontive coping was also found to be a predictor of increased psychological distress.

There was mixed support for the part of the sixth hypothesis concerning disease-related factors of fatigue and mobility status. Increased disability (less mobility) and
fatigue were correlated with higher psychological distress. The finding of a positive association between mobility disability and psychological distress is consistent with findings of Aitkens et al. (1997). However, regressions showed that fatigue and not mobility predicted Negative Affect. Indeed, fatigue predicted the most variance in Negative Affect of all the variables. This finding was consistent with previous MS research including findings by Amato et al. (2001), Ford et al. (1998) and McCabe et al. (2004).

As expected more optimistic people reported less psychological distress. The negative association between optimism and psychological distress is consistent with findings from previous MS studies (Fournier et al., 1999; Gold-Spink et al., 2000; de Ridder et al., 2000).

There was no support for the prediction that increased use of planful problem solving and positive reappraisal coping would be related to lower levels of psychological distress. Participants’ use of these coping strategies was not significantly associated with psychological distress. This finding differed from other MS studies by Aitkens et al. (1997), Pakenham et al. (1997) and Pakenham (1999), who found that increased use of problem-focused coping was associated with less psychological distress. Unlike the present study, Aitkens et al. (1997), using the Ways of Coping Questionnaire with a MS sample reported a negative association between depression and both positive reappraisal and planful problem solving.

A positive association was found between escape-avoidance coping and psychological distress. This finding lends support to other MS studies including those by Jean et al. (1999), McCabe et al. (2004) and Pakenham et al. (1997) that have reported a link between the use of avoidant coping and increased levels of psychological distress. As expected increased use of Escape-Avoidance was also found to be
predictive of increased psychological distress. However, unexpectedly, Confrontive coping was also found to predict psychological distress. Escape-avoidance is an emotion-focused coping that has been described as avoidant strategies including wishful thinking. On the other hand, Confrontive coping is problem-focused coping which pertains to efforts to take aggressive action to change a problem. An example of a statement representing Confrontive coping strategy is ‘I expressed anger to the person who had caused the problem’. The finding that increased use of both these coping strategies were related to increased distress is consistent with results reported by Eklund and McDonald (1991) who found that Escape-Avoidance and Confrontive coping were related to poorer emotional adjustment. In the present study, participants’ increased use of wishful thinking (or avoiding) or aggressive responses when dealing with MS related problems predicted increased levels of psychological distress.

10.3.3 Ryff well-being

The use of the Ryff PWB as a measure of psychological well-being for people with MS was exploratory in the present study. Most studies that have used the Ryff PWB scale with normal and clinical samples have described their findings in terms of the six scales. However, in the present study, preliminary analyses showed low internal reliability coefficients for the subscales. A total scale score calculated by summing the six scales was used. A similar approach, of using a composite score, was adopted by Holland and Holahan (2003), with a sample of women with breast cancer.

The seventh hypothesis predicted higher mobility (less disability), lower fatigue, higher optimism, higher use of problem solving and positive reappraisal coping and lower use of escape-avoidance coping would be related to better well-being as measured
by higher Ryff PWB scores. Results from correlation and regression analyses showed
only partial support for this hypothesis.

There was mixed support for the disease-related variables. Less fatigue was
associated with, but did not predict, increased well-being. Nevertheless, this finding
lends further support to Shawaryn et al.’s (2002) notion that fatigue experienced by
people with MS is more than a physical problem and impacts upon their psychological
well-being. On the other hand, less disability was associated with and predicted
increased well-being (higher Ryff scores). Further analyses using the six scales showed
specific differences with these variables. Lower fatigue may not have predicted total
Ryff scores but it did predict higher Environmental Mastery scores. Indeed fatigue was
the most significant predictor for this sub-scale. Environmental mastery describes the
ability to manage ‘everyday affairs’ with a sense of control, and this finding may reflect
the pervasive effects of physical and emotional fatigue upon daily activities. On the
other hand, less disability (mobility) was a predictor of higher Personal Growth and
Purpose in Life scores. Participants who were more mobile had higher scores on these
two Ryff scales. Personal Growth describes a sense of continued growth as an
individual while Purpose in Life pertains to the belief that one’s life has direction and
that it is purposeful and meaningful. Both these scales appear to tap into beliefs about
one’s goals and likely future directions. Generally, it would be expected that people
who are currently experiencing more ambulatory difficulties and subsequent limitations
would view their futures with more trepidation than those who are less disabled. Lower
scores on these two scales may be reflecting a form of anticipated demoralisation.

Increased optimism was associated with and predicted higher levels of well-
being (Ryff PWB) supporting this part of the hypothesis. Optimism was the most
significant predictor of psychological well-being. There appears to be no study which
has employed both the LOT-R and the Ryff PWB scale with either normal or clinical populations, however, these results are consistent with the research literature (Peterson, 2000) which has linked increased optimism with positive outcomes. This finding is also consistent with findings of clinical studies (Affleck et al., 2001; Carver et al., 1993; Epping-Jordan et al., 1999) which have shown that increased optimism was associated with increased psychological well-being; albeit as measures of decreased psychological distress.

There was limited and mixed support for the relation of coping to increased well-being. As expected there was a positive association between Planful problem solving and well-being, however, this form of coping did not predict well-being. Negative associations were found between well-being (Ryff) and four coping strategies (Escape-Avoidance, Accepting Responsibility, Self-controlling, and Distancing) including Escape-Avoidance as was predicted. However, the only coping scale to predict well-being in the regression was Escape-Avoidance coping. Decreased use of Escape-Avoidant coping predicted increased well-being. This result was consistent with findings of Holland and Holahan (2003) who, like the present study, used the Ways of Coping Questionnaire and the Ryff PWB scales and found that increased use of avoidant strategies were related to lower levels of psychological well-being.

10.3.4 Overview

Findings from the present study enabled a broad examination of the psychological well-being of participants by way of general and MS specific measures and showed different variables were predictors of particular outcomes.
The disease related variables of mobility and fatigue predicted Demoralization, which measured the negative intrapersonal consequences of having MS. Fatigue predicted Negative Affect but not Ryff total well-being scores. On the other hand, mobility status predicted psychological well-being (Ryff) but not Negative Affect. Negative Affect (POMS) measures transient mood states while in part the Ryff appears to be reflecting both current and future assessments of how one is dealing with life. This is most clearly indicated by the finding that mobility predicted Personal Growth and Purpose in Life scores. Participants with increased disability reported lower scores on these scales which appear to reflect future or anticipated demoralisation. Therefore participants’ mobility status did not predict their current psychological distress (POMS) but it did predict their current demoralisation (Mohr et al. scale) and anticipated demoralisation (Personal Growth and Purpose in Life, Ryff scales).

Optimism was a significant predictor of Demoralization, Negative Affect and Ryff well-being. The versatility of optimism to predict both general and a MS specific outcome gives credence to its place as a measure for any study of adaptation for people with MS. However, unexpectedly it did not relate to or predict participants’ reporting of perceived benefits.

Participants’ increased use of Escape-Avoidance coping to deal with their MS related problems predicted their increased psychological distress (Negative Affect) and decreased psychological well-being (Ryff PWB). As discussed previously, this finding has been consistently found in other studies. Escape-Avoidance coping was also associated with but did not predict the two negative MS factors. However, the coping strategy Accepting Responsibility (self-blame) predicted Demoralization and Deteriorated Relationships. Increased use of the problem-focused coping strategy, Confrontive coping, was found to predict increased psychological distress but was not
associated with any other outcome variable. It seems that the best outcomes are among those who accept their situation of their disease (low escape avoidance coping), but do not blame themselves (low accepting responsibility) or others (low confrontive coping) for it.

Positive Reappraisal coping was the only significant predictor of Benefit Finding, and was not associated with psychological distress or well-being. Therefore, while some people with MS may reframe what is happening to deal with their stress, and report some perceived benefits from their experiences, there do not seem to be any benefit or effects upon their well-being levels.

A diagram, summarising these findings and showing the significant predictors of well-being, can been seen in Appendix J.

10.4 Limitations of the study

A weakness in the present study was the sole reliance on the use of self-report measures. The inclusion of objective measures could have included, for example, a medical examination to ascertain current symptomatology and disability level. An important area of the study was the investigation of participants’ perceptions of the effects of MS upon their relationships. It would have been useful to survey their partners’ view. Participants’ partners and families may have a different (more or less favourable) view of the impact of MS upon the quality of the relationships. A major omission from the study was any information regarding participants’ sexual functioning that would have also been useful to assess the effects of MS and their perceptions of themselves and their intimate relations. A further limitation was that there was no screening for cognitive dysfunction, which may have affected participants’ perceptions
and responses. In addition, a more comprehensive measure of physical functioning may have been desirable.

The cross-sectional design is another weakness in the present study since there can be no causality determined between the variables based on the study’s findings. Rather the present study was based on a one-off survey of participants. Nevertheless, it should be noted a number of aims of the present study were related to replication and extension of Mohr et al.’s (1999) study which was also cross-sectional. However, a longitudinal study with more sophisticated analyses may enable causal connections to be established.

In addition there may have been some conceptualisation problems with the methodology used in the present study. As previously discussed, the Benefit Finding factor scale (Mohr et al., 1999) appears to have items which may represent more closely concepts related to the other factors despite the robust factor analysis method by Mohr et al. (1999) with their sample. In particular, Item 3, previously identified as a benefit, was found by Katz et al. (2001) to load onto the Deteriorated Relationships factor. Use of another benefit scale, which had been validated by use in more studies, may have elicited a more detailed examination of the phenomenon of reporting perceived benefits from adversity.

Finally, the sample comprised people with MS who were recruited through the MS Societies of Victoria and Tasmania. This sample may have been biased toward people who were adapting successfully because of their access to resources and supports available through these organisations. The survey of only participants who are registered with MS societies may not have provided a broad or accurate range of the difficulties of living with MS. While no measure was taken in the present study to determine perceived support from these organisations it could be expected that these
participants would have access to services and support available through the MS societies. Participants in contact with the societies would probably be more proactive in educating themselves about their illness and lifestyle possibilities. It has been noted that ‘informal communications between service providers and recipients can exert a powerful influence on illness-related self representations’ (Devins & Shnek, 2000, p. 170). Indeed the aim of the societies to provide such psychosocial and educational support which empowers individuals with MS and enhances their quality of life. Also, participants in the present sample were volunteers and there may have been a sample bias in that those who chose to participate may have been people who were already coping well.

Strengths of the present study included the use of more than one measure of psychological well-being. The concurrent use of a measure of psychological distress (POMS) and also a measure to determine positive psychological functioning (Ryff PWB) ensured a broader interpretation of well-being than has been undertaken in many previous studies with MS samples. In addition, the inclusion of positive concepts, such as benefit finding and optimism, was another strength of the present study. Livneh and Antonak (1997) recommend that research into psychosocial adaptation needs to consider positive outcomes rather than focus solely on the negative consequences of living with a chronic illness. A specific focus on the effects of living with MS was attained in this study by use of Mohr et al.’s (1999) psychosocial factors that examined both perceived negative and positive consequences from participants’ experience with MS.
10.5 Implications of the research

10.5.1 Theoretical implications

The present study used a transactional stress-coping framework to examine psychosocial adaptation to MS. Livneh and Antonak (1997, p.315) noted the selection of coping strategies has been a popular way to examine psychosocial adaptation to chronic illness. Yet there have been mixed findings from the MS research regarding what is adaptive coping. More generally, like the present study, it has been found that increased use of avoidant coping is related to decreased well-being. However, there have been inconsistent findings regarding problem-focused coping and psychological distress. In the present study, Planful Problem Solving was correlated with but did not predict well-being (Ryff PWB). On the other hand, increased use of Confrontive coping, another problem-focused coping, predicted increased psychological distress. It seems that problem-focused coping, at least how it is defined by the Ways of Coping Questionnaire, is not necessarily always adaptive in dealing with MS-related problems. There may be times when due to the unpredictable (and uncontrollable) nature of MS that individuals are more able to deal with their stress by way of managing emotional responses using wishful thinking, distraction or positive reappraisal rather than being able to change their circumstances.

A major premise of the transactional perspective is that coping is a dynamic reciprocal process. However, the present study used a cross-sectional one-off survey to examine variables in a unidirectional way and there can be no causality from the study’s findings. Therefore it is not possible, for example, to determine if increased use of Accepting Responsibility (self-blame) coping causes people with MS to feel more demoralised or if it is that demoralised people are more likely to use this type of coping.
While the transactional framework may be useful to ascertain information about people’s specific coping in particular circumstances, it is pertinent to acknowledge an inevitable degree of circularity in explaining coping behaviour by way of this perspective.

The finding that people with MS report perceived benefits from their experience is consistent with literature regarding cognitive adaptation theory (Taylor, 1983). Although, this support needs to be tempered with the findings that there were no associated beneficial outcomes or increased well-being associated with benefit finding. Unexpectedly, there were no links found between optimism, conceptualised as expecting positive outcomes, and reporting benefits. However, participants’ reporting of perceived benefits finding was predicted by their use of Positive Reappraisal coping. Together these findings lend further support to Affleck and Tennen’s contention that reporting benefits is more indicative of a coping strategy than a belief system.

Participants’ well-being was measured using a mood state measure (POMS) and the Ryff PWB, a measure of positive functioning. Results showed that the Ryff well-being scale had a negative association with the POMS composite scores. This finding is consistent with other studies (Ryff, 1989b) reporting associations between mood measures and Ryff subscales. However, Schmutte and Ryff (1997, p. 552) cautioned that the Ryff PWB ‘is not a mood measure’. Findings from the present study showed common predictors for both outcomes were optimism, and use of Escape-Avoidance coping. Increased optimism and decreased avoidant coping have been found consistently in other studies to be associated with increased well-being by way of a variety of measures (less psychological distress). On the other hand, there was a difference between the disease-related variables. Mobility and fatigue were correlated
with both outcomes, but only fatigue predicted psychological distress, while mobility predicted Ryff PWB total scores.

The use of the Ryff PWB scale in the present study enabled a more salutogenic approach to measuring the well-being of people with MS. The six sub-scales that comprise the Ryff PWB scale are considered to be separate measures of domains of equal importance to adult psychological health. However, individuals with a chronic disability or impairment may score lower on some of the items related to environmental mastery because of the constraints of their disability, yet may maintain social contact and healthy interpersonal relationships. To this end, the use of the total score of the Ryff PWB, rather than as separate domains, enables an index of the participants’ overall psychological health, and maybe a more valid global assessment.

10.5.2 Clinical implications

Researchers of psychosocial adaptation (Livneh & Antonak, 1997; McReynolds et al., 1999) recommend the examination of disease-related variables to enable a comprehensive assessment of associated effects upon well-being. In the present study, use of the variables (mobility, fatigue) ensured that these two common MS symptoms could be considered in terms of general and specific consequences.

Mobility status was an important and pertinent variable to examine between group differences in terms of participants’ physical and psychological well-being. Participants who had higher levels of disability reported more negative consequences (or higher levels of Demoralization). Results showed that participants who were older at the onset of MS reported higher levels of mobility disability, and they also reported lower levels of psychological distress and fewer negative consequences upon their relationships. However, there were no significant differences between the three mobility groups on the
general measures of psychological well-being (POMS and Ryff PWB) which could indicate some form of resilience. It may be that as people become more physically disabled most are able to adapt psychologically to their changed circumstances. Alternatively, those people who are older at onset of MS may have already established intimate relationships and learnt life skills so as to be able to deal more successfully with the impact of MS.

An important finding was the link shown between mobility and fatigue. In the present study participants with mild gait problems who did not use walking aids reported fatigue levels comparable with those who had more complex gait difficulties. Sibley (1996) noted that some people with MS experience fatigability in their legs even after walking short distances. It may be that people with mild gait problems, are more at risk of experiencing such fatigue. According to Sibley (1996), people with this sort of fatigability are encouraged not to over do their walking distances or instead to use aids or wheelchairs. Since energy for people with MS is often compromised by their condition, it may be that, those with mild gait problems who do not use walking aids, consider judicial and appropriate use of aids. Walking aids used even for short periods may conserve energy for individuals for other valued activities.

Findings examining the impact of mobility and fatigue upon well-being, show that particular groups (for example, early onset, increased disability) may be more at risk from specific forms of distress (demoralization, relationship difficulties). However, results also demonstrate that more visible disability does not always equate with more psychological distress. In particular, the link found between mobility and fatigue has clinical and practical implications. Health professionals need to consider that people with mild gait problems may be at risk of experiencing high levels of fatigue and
psychological difficulties as a result of trying to maintain their independence and walking unassisted.

10.6 Conclusions

The present study’s use of three measures of well-being outcomes enabled a broad examination of the impact of living with MS and showed the effects of specific coping strategies upon each of these outcomes. Most of the research with MS samples has focused on psychological distress as an outcome. However, broadening the scope of outcome measures to include both intra-personal and interpersonal variables elicits a more comprehensive view of the well-being of people with MS. Findings from the present study show that people with MS report both negative and positive consequences from their experiences with MS. Findings also indicate that coping strategies and fatigue are important determinants of psychological well-being. These variables, unlike their mobility disability status, are able be controlled, to a certain extent, by individuals. Education re choice of appropriate coping strategies to deal with their MS related problems, and effective management of fatigue may increase the psychological well-being of people with MS.

In conclusion, the present study examined the well-being of 154 people with MS by way of measures of psychological distress, psychological well-being or positive functioning, and specific MS psychosocial factors which had been identified by Mohr et al. (1999). The study also partly replicated and extended Mohr et al.’s (1999) MS study, which demonstrated that participants reported perceived benefits from their experiences with MS. Results showed some consistencies with Mohr et al.’s findings with positive associations found between the negative psychosocial factors, Demoralization and
Deteriorated Relationships and psychological distress. However, the expected association between Benefit Finding and psychological distress was not supported in the present study. Benefit Finding was also not related to optimism as had been hypothesised. Analyses showed that the only significant predictor of Benefit Finding was participants’ increased use of positive reappraisal coping. The findings of the study regarding benefit finding lends support to the notion that it is a coping strategy or at the least a separate but related construct to positive reappraisal.
REFERENCES


