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THE EFFECT OF EXERCISE AND AUTOGENIC TRAINING ON THE PSYCHOLOGICAL WELL-BEING AND HEALTH-RELATED QUALITY OF LIFE OF PEOPLE WITH MULTIPLE SCLEROSIS

BY GEORGINA SUTHERLAND

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ABSTRACT

This thesis was an investigation of physical activity and the effects of exercise and autogenic training (AT) on the health-related quality of life (HRQOL) and psychological well-being of people with multiple sclerosis (MS). The terms HRQOL and psychological well-being in this thesis were operationally defined by the instruments used. The Multiple Sclerosis Quality of Life Instrument (MSQOL; Vickrey, Hays, Harooni, Myers, & Ellison, 1995) that includes constructs of physical, psychological, and social health measured HRQOL. Although psychological well-being is considered a component of HRQOL, measures of psychological well-being were extended by using the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), the Daily Hassles Scale (DHS; De Longis, Folkman, & Lazarus, 1988), and the Profile of Mood States-Short Form (POMS-SF; Shacham, 1983).

The first study in this thesis concerned the physical activity and exercise patterns of a sample of people with MS. This study also examined the relationship between duration, frequency, and type of physical activity, and aspects of psychological well-being and HRQOL of individuals with MS. The participants were 105 people with confirmed diagnoses of MS who completed a battery of questionnaires designed to measure some of the most frequently cited psychosocial problems associated with living with MS (i.e., HRQOL, mood, hassles and uplifts, depressed affect, social support). Participants also completed a leisure activity recall scale. Bivariate correlations indicated that those people who reported higher levels of physical activity exhibited more positive psychological health profiles in comparison to relatively sedentary individuals. In addition, many of the psychosocial variables, such as energy, role functioning, emotional well-being, and depressed affect were more highly correlated with recreational physical activities than those activities undertaken for work. Although this retrospective, descriptive study merely suggested possible connections between physical activity and HRQOL, the results laid the foundation for investigating whether exercise may actually lead to enhanced psychological health for people with MS.

The second study concerned the effect of an exercise program on the HRQOL and psychological well-being of a group of mild to moderately disabled people with MS (Expanded Disability Status Score; EDSS < 5.0). Individuals participated in either a no special activity control group ($\underline{n} = 11$) or a treatment group ($\underline{n} = 11$) that involved water aerobics three times per week for 10 weeks. Measures taken pre- and post-intervention included scales for HRQOL, mood, hassles and uplifts, depressed affect, and social support. Participants in the treatment group also performed a cycle ergometer submaximal exercise test prior to, and following the exercise program. Results indicated that individuals involved in the exercise program improved physical fitness over the course of the 10-week training period (Cohen's d = .47). ANCOVAs using social support and the appropriate pretest scores as covariates revealed that, at the post-test, the exercise group had much more energy and vigor (extremely large effect sizes) than the control group. Other very large effects were found in that the exercise group had better social and sexual functioning, and less bodily pain and fatigue. Moderate to large improvements for the exercise group were also found for health perceptions, physical health, emotional well-being, anger, and depressed affect. Exercise, however, may not always be a viable option for people with MS.

The third study examined the effect of an autogenic training program (AT; a relaxation intervention) on the HRQOL and psychological well-being of a group mild to

moderately disabled people with MS (EDSS ≤ 5.0). Participants either met weekly for sessions in AT for 10 weeks (<u>n</u> = 11) or were assigned to the control group (<u>n</u> = 11). The AT group was also asked to practice the technique daily at home. Scales designed to measure HRQOL, mood, hassles and uplifts, depressed affect, and social support were taken pre- and post-intervention. ANCOVAs using the same covariates as described in the previous study, revealed that, at the post-test, the AT group had more energy and vigor than the control group, and were less limited in their roles due to physical and emotional problems (very large effects). Moderate improvements for the AT group were also found for pain, fatigue, and daily hassles.

Finally, the efficacy of the exercise and AT programs for enhancing HRQOL and psychological well-being for people with MS were compared by examining the treatment groups and the magnitude of changes in the psychosocial variables measured. Results showed a number of similar effects for those involved in the interventions, including improved energy and vigor, and reduced fatigue. The exercise and AT interventions also had some unique contributions to improving the HRQOL and well-being for the participants. Overall, results indicated that the exercise and AT programs were beneficial adjunct therapies for improving psychological health for people with MS. Because participants involved in the studies, however, were mild to moderately disabled, the positive results may not be applicable to individuals with more severe physical and cognitive disabilities. The comparative results showed that it may be appropriate to consider the two interventions, not only as complementary therapies in their own right, but as complementary to each other.

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CHAPTER 1

INTRODUCTION

Multiple sclerosis (MS) is a chronic, unpredictable, and potentially debilitating neurological disease. The disorder has been extensively studied since the first descriptions were reported in the early 19th century, yet MS remains poorly understood by medical and health professionals, as well as by the general community (Miller, 1997). Moreover, individuals diagnosed with MS are confronted with an illness in which there are many unexplained factors. The cause is unknown; there is no known cure; neurological symptoms can appear, remit, and relapse without warning, and no reliable indicators exist to predict future functional deficits or verify the course of the disease. In many cases, individuals have already spent a considerable amount of time dealing with strange and intermittent abnormalities in motor, sensory, and visual function before a diagnosis of MS is confirmed. With the varying age of onset of MS between 20 and 50 years, the disease may have a dramatic effect on an individual's career, family, and social commitments. Thus, it is not surprising that people with MS have a high prevalence of psychosocial problems (Murray, 1995).

Until recently, research in MS has mainly focused on pathological and physiological manifestations of the disease. Over the last decade, however, there has been an increasing interest in studying the psychological, social, and emotional adjustments of people with MS. The impetus for much of the research may be that many people with MS have close to normal life expectancies (Olek, 1999), yet are often faced with increasing disability, as well as serious social and emotional sequalae. Thus, attention is shifting from traditional medical treatments to symptom management and health-related quality of life (HRQOL) issues.

HRQOL assessment in chronically ill individuals allows a broad measure of disease burden (Cella et al., 1997). Researchers have suggested that HRQOL deserves attention in its own right as a health concern for those with chronic disease and it is increasingly recognized as an important benchmark for clinical effectiveness research (e.g., Aronson, 1997).

One class of behaviours, physical activity, has been repeatedly shown to be related to improved HRQOL. The term physical activity defines movements of the muscles that produce expediture in energy (Dubbert, 1992), and the general health benefits of participation in regular physical activity is well-documented (e.g., Blair et al., 1989). Research has demonstrated that physical activity may also be associated with positive psychological consequences (Singer, 1992). Exercise is frequently used interchangeably with the term physical activity. Exercise, however, is considered a subcategory of physical activity that is planned and structured (U.S Department of Health and Human Services, 1996). Although exercise is recognised, in some disabled populations, as a complementary therapy (Hammond, 1998), people with MS have long been advised to avoid physical activities. Current opinion is changing, however, and in the past few years there has been some encouraging evidence that physical activity for people with MS may have physiological and psychological benefits (Petajan et al., 1996). Yet, for some people, MSrelated disabilities such as muscle weakness, compounded by spasticity, and impaired coordination may not render physical activity a viable option. A number of cognitivebehavioural interventions, including relaxation techniques, have demonstrated positive effects on psychological well-being in chronically ill individuals (Baum, Herberman, & Cohen, 1995). Although the effects of relaxation on psychosocial function in MS has not been extensively studied, research has shown that some techniques may provide people

with MS another means for enhancing psychological health (Crawford & McIvor, 1987; Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987).

The main aim of this research was to investigate the effect of an exercise and autogenic training (a relaxation intervention) program on the psychological well-being and HRQOL of people with MS. The first study in this thesis concerned the physical activity and exercise patterns of a sample of people with MS. This study also outlined the relationship between duration, frequency, and type of physical activity, and aspects of psychological well-being and HRQOL of individuals with MS. The second study examined the effect of exercise on psychological health status in MS. Specifically, the study examined the effect of a 10-week aerobic exercise training program on psychological well-being and HRQOL for a group of ambulatory people with MS compared with a matched control group. The third study used autogenic training as a cognitive-behavioural technique and examined changes in psychological well-being and HRQOL for a group of people with MS involved in a 10-week program, in comparison to a matched control group. Finally, this thesis examined the efficacy of exercise and autogenic training for improving psychological health status and HRQOL for individuals with MS by comparing the autogenic and exercise groups on the magnitude of changes in the psychosocial variables measured.

CHAPTER 2

LITERATURE REVIEW

Introduction

In this chapter, the pathology and symptomatology of MS are described, as well as issues of diagnosis and treatment. Psychological well-being and HRQOL in MS are also explored. Responses of people with MS to exercise training are considered, including physiological and psychological adaptations. Current views are also noted regarding symptom stability in relation to thermal stress experienced during exercise, together with exercise prescription guidelines for people with MS. Next, the psychological benefits of relaxation strategies, as a cognitive-behavioural intervention, are reviewed, along with the relationship between relaxation training and psychological aspects of health for people with MS. Autogenic training is then considered as a therapeutic relaxation technique for people with MS. This chapter concludes with a statement of the purpose of this thesis.

Multiple Sclerosis

MS is a chronic and unpredictable disease for which there is no known cure. It is the most common cause of neurological disability among young adults, primarily affecting individuals between the ages of 20 and 50 years (Sadovnick & Ebers, 1993). Although the cause of MS has not been determined, it is thought to be a disease of autoimmune aetiology in genetically susceptible individuals (Lechtenberg, 1995). The neurological symptoms typical in MS result from damage to myelinated axons in the central nervous system (CNS). Although there are some predictable features of the disease, in general, no two cases of MS are alike, and the pattern in which symptoms combine can result in remarkable clinical variation. For many people, the early stages of MS are characterised by the appearance,

remission, and relapse of symptoms, which usually results in progressive accumulation of disability. Not all people diagnosed with MS, however, conform to this pattern, and no reliable indicators exist to predict the clinical course of the disease. Although there are some drug treatments associated with reduced severity and duration of symptom exacerbations in MS, currently, no pharmacological therapies clearly arrest the progression of primary neurologic deficits in the long-term.

Clinical Course

Variability in the way symptoms manifest in MS has led to the establishment of clinical categories designed to describe the pattern and course of the disease. Individuals can demonstrate neurological and functional decline ranging from very slow progression to rapid deterioration. Standardisation of disease category terminology has recently been established (Lublin & Reingold, 1996). At onset, the majority of people with MS develop a relapsing-remitting course, characterised by exacerbations in which symptoms appear or increase in severity, and then remit leaving no neurological impairment, or partially remit with some residual deficit. A large percentage of individuals initially experiencing a relapsing course will eventually exhibit slow deterioration with few remissions and be classified as <u>secondary progressive</u>. Individuals experiencing continuing deterioration at onset are classified as having a <u>primary progressive</u> disease type. The <u>acute</u>, malignant disease course is the least common clinical type, characterised by rapid progression to severe disability or death in a relatively short period of time after onset. The relapsing course, in which individuals remain fully functional at least 15 years after diagnosis is categorised as <u>benign</u> MS.

The Expanded Disability Status Scale (EDSS; Kurtzke, 1983) also provides a taxonomy for classifying people with MS. An individual's score on the 10-point scale, measured in half points, is derived from a neurologist's examination, with assignment of a numerical value based on neurological and physical impairment. An overall disability rating on the EDSS is based on the level of physical impairment observed by an examining neurologist, combined with a score on the Functional Systems Scale (FSS; Kurtzke, 1961). The FSS is indicative of the degree of impairment in eight discrete categories of the CNS (pyramidal, bowel and bladder, cerebellar, visual, brainstem, cerebral, sensory, and other). The EDSS ranges from 0, which indicates normal functioning, to a score of 10, which indicates death due to MS. An EDSS rating of 1.0 to 4.5 describes a person with MS who is fully ambulatory with moderate to severe deficits in one or more of the FS categories. As ratings on the EDSS increase from 5.0 through to 9.5 the scores are mostly indicative of ambulatory impairment, with higher scores inversely related to the ability to ambulate independently. The process by which a score on the EDSS is derived has been criticised for the predominant focus on the effects of the disease on ambulatory ability. There have also been some criticisms of the scale's subjectivity and insensitivity, and thus, inability to monitor the effects of interventions (Willoughby & Paty, 1988). In the absence of other classification systems, the EDSS is widely used in research. The EDSS in this thesis was not used to monitor the effects of the interventions, but was only used as a component of participant selection criteria.

Symptomatology

MS commonly affects several different functions within the CNS manifesting in a variety of clinical symptoms (Posner, 1993). Motor and sensory dysfunction are the most

common complaints among people with MS, affecting approximately 90% of individuals at some time during the course of the disease (Paty & Ebers, 1998). Weakness and spasticity are the most common motor abnormalities reported by people with MS. In general, weakness in the lower extremities occurs more frequently and is more severe than in the upper extremities (Olek, 1999). Sensory dysfunction often presents as tingling paresthesias in the face, hands, or feet, or as a constrictive sensation around the thoracic region (Collins, 1997). Lhermitte's sign, described as an "electrical current" sensation down the spine is commonly reported among people with MS, and usually manifests after forward flexion of the neck (Paty & Ebers, 1998). Non-specific chronic pain is also a common sensory symptom, despite much of the literature underestimating the frequency of pain associated with the disease (Archibald, McGrath, Ritvo, Fisk, & Murray, 1994). Visual dysfunction is also a common symptom in MS. Most individuals will experience some problems with vision during their clinical course, and visual irregularities are often present in the first attack (Collins, 1997). The most common visual problem is optic neuritis, which is characterised by acute or subacute loss of vision in one eye. Optic neuritis is usually associated with the active stage of the disease, and impairment generally resolves over a period of time. More severe visual problems can also occur, including permanent vision loss (Anderson & Cox, 1998).

There are numerous other symptoms associated with MS, including brain stem signs that may include loss of taste, facial palsy, deafness, vertigo, and dysarthria or speech disturbance. Cognitive deficits, including impairments in memory, attention, verbal fluency, conceptual reasoning, and dementia, may also affect people with MS. Autonomic disturbances, such as bowel and bladder problems may also be present. Sexual dysfunction is a major symptom of MS, and usually involves decreased libido, sensation, and frequency of orgasm, and erectile dysfunction in males (Szasz, Paty, & Maurice, 1984). Although the cause of sexual dysfunction in MS is unresolved, authors of a review concluded that problems may result from a combination of both neurological and psychological components (Dupont, 1995). Likewise, the high prevalence of depressive symptoms in MS is also presumed to be caused by an interaction of neurological and psychosocial factors (Minden & Schiffer, 1991). Some researchers, however, have reported more robust correlations between depression and perceived levels of psychological distress than between brain involvement and depression in MS (e.g., Ron & Logsdall, 1989).

One of the most common and perhaps pervasive symptoms reported by people with MS is fatigue. It is generally evident in all stages of the disease, and in some cases it is the only disabling feature (Krupp, 1997). There is little understanding about the physiological cause of MS-related fatigue, and it has only recently been recognised as a valid criterion of disability (Schwartz, Coulthard-Morris, & Zeng, 1996). The fatigue seen in MS is considered to be distinct from other types of fatigue associated with physical exertion and depression (Krupp, Alverez, LaRocca, & Scheinberg, 1988). Krupp et al. (1988) described fatigue in MS as a sense of tiredness regardless of the amount of energy expended or disability level. Perception of fatigue varies widely among individuals and may affect other MS-related symptoms, such as mobility, depression, and cognitive functioning (Schwartz et al., 1996). It is probable that a combination of neurological, psychological, and social factors affect fatigue in MS.

Epidemiology

MS is primarily a disease of young adults, and is the most common cause of nontraumatic neurological disability in this population. Although the disease most commonly presents in individuals between 20 and 50 years, it can affect children and the elderly. For many years, the epidemiology of MS has been closely scrutinised, because it is thought that patterns relating to sex, familial risks, geography, and racial distribution may help uncover the underlying cause of the disease. Susceptibility according to sex in MS follows a similar pattern to that seen with other autoimmune disorders, and suggests possible genetic and hormonal factors. The prevalence of MS in females in comparison to males is approximately a 2:1 ratio (Compston & Robertson, 1998). Children of parents with MS are at risk for developing the disease, with the highest at-risk individual being a female child of a parent with MS, regardless of the sex of the parent (Multiple Sclerosis Genetics Group, 1998). The geographic distribution of MS is regularly cited as a clue to the influence of environmental determinants. The prevalence of MS varies according to distance from the equator in either a northern or southern direction. The incidence, prevalence, and mortality rates increase with increasing latitude. Moreover, results from epidemiological studies have confirmed that migrating to low risk areas prior to puberty may decrease the risk of developing MS (Kurtzke, Beebe, & Norman, 1985). It seems, however, that the prevalence of MS is not adequately explained simply by its relationship to latitude, because rates can be variable among populations living on the same latitude. It appears that racial background may also play a role in susceptibility to MS (Weinshenker & Rodriguez, 1994). There are a number of racial groups in which MS has never been reported, such as Eskimos and Australian Aborigines, with those most at-risk tending to have Scandinavian and European

ancestry (Olek, 1999). Despite these distinct, if complex, landmarks in terms of genetic, hormonal, and environmental determinants, the cause of MS remains elusive. Pathophysiology

MS is an inflammatory and demyelinating disease of the central nervous system (CNS). The disorder is characterised by recurrent and chronic inflammatory lesions disseminated in time and in separate parts of the myelinated white matter of the brain and spinal cord (ffrench-Constant, 1994). Myelin is a metabolically active membrane that wraps spirally around axons to form a segmented sheath (Scolding, 1999). The sheath is interrupted uniformly along the axons by unmyelinated constrictions called nodes of Ranvier. Apart from its protective function, the myelin sheath insulates axons and facilitates the transmission of action potentials. If the myelin sheath were continuous, action potentials could not be produced. In myelinated axons, action potentials occur only at the nodes of Ranvier. Action potentials induced by depolarisation generate electrical currents at one node of Ranvier, which in turn triggers depolarisation, not along the myelinated path, but at the next node of Ranvier. This process is called saltatory conduction (Van De Graaff & Fox, 1988). Because the spread of depolarisation between the nodes is extremely fast and fewer action potentials are required, saltatory conduction facilitates a faster rate of conduction than would be possible in an unmyelinated fibre. In demyelinating diseases, such as MS, saltatory conduction is disrupted. Action potentials are forced to propagate along the entire length of the axon, resulting in reduced amplitude and velocity of impulse transmission (Smith, 1996). The neurological symptoms in MS probably reflect abnormalities in demyelinated central axonal pathways.

Although several researchers have proposed that the neurological symptoms in MS result from demyelination in the CNS (e.g., Scolding, 1999), there is considerable speculation concerning the exact pathological process, and why MS is commonly characterised by symptom remission and relapse and eventual progression to permanent neurological disability. In a review of the pathogenesis of MS, ffrench-Constant (1994) concluded that the characteristic relapse and remission of neurological symptoms in MS may occur because mechanisms exist to repair the myelin sheath during the early stages of inflammation and demyelination. This newly formed myelin thus restores normal axonal conduction and resolves impairment. Despite evidence of myelin destruction in MS, it is unclear whether the primary target of attack is the myelin or the oligodendrocytes in the glial cell responsible for synthesis and maintenance of myelin. When oligodendrocytes involved in myelin regeneration are attacked, they are replaced by gliotic scar tissue (Moore, 1998). The destruction of glial cells responsible for myelin synthesis, may thus be responsible for permanent neurological damage. The destruction of oligodendrocytes, however, does not appear to follow a uniform path in all people with MS. Researchers investigating oligodendrocyte loss in lesions of comparable age and stage in different people with MS have found marked variation. Raine (1997) found that early or acute lesions in some individuals was characterised by rapid loss of oligodendrocytes, whereas a similar stage lesion in another person showed almost complete preservation of oligodendrocytes. In addition, researchers have recognised that the inability of the system to remyelinate, due to oligodendrocyte death, does not provide a complete explanation of the progressive nature of clinical features in MS (Scolding, 1999).

Researchers have suggested that both demyelination and inflammatory lesions cause conduction block in MS (McDonald, 1996). Thus, remission of symptoms may simply reflect resolution of acute inflammatory lesions, rather than remyelination. Yet, demyelination as the active component of the lesion may persist, and thus provides an explanation of the characteristically persistent decline in specific symptoms, despite some remission. Researchers have also demonstrated that demyelinated axons can re-attain the capacity for functional conduction by adjusting sodium and potassium channels previously concentrated in the nodal areas (Smith, 1996; Waxman, 1997). Functional demyelinated fibres may explain the fluctuations in symptom severity that many people with MS experience with increased temperature, because demyelinated axons are sensitive to changes in core body or environmental temperature (Guthrie & Nelson, 1995).

Why then is MS generally characterised by gradually accumulating and chronic disability as the disease progresses, if damaged axons can remain functional? Researchers have proposed that repeated episodes of acute inflammatory lesions at the same site or chronic lesions may lead to the destruction of the axons themselves (Trapp, Ransohoff, & Rudick, 1999). It is possible that persistent axonal loss, increasing with disease progression, provides the physiological explanation why many people with MS eventually experience permanent loss of neurological function. The case for axonal loss, however, is yet to be proven, and a definite explanation for the idiosyncratic nature of symptoms and disease progression remains poorly understood.

Speculation regarding disease pathology is fuelled by the heterogeneity in pathophysiological processes among individual MS cases. Although there are some key pathological features that charaterise the disease, there are demonstrable differences in patterns of demyelination, lesion formation, and axonal loss from one person to the next, and in some cases from one lesion to another (Raine, 1997). Such differences have even led researchers to question whether MS is a single disease (van Noort, 1996). Despite substantial progress in recent years, interpretation of the pathophysiology of MS remains open to conjecture and controversy. It is probable that a number of factors in the pathological process, including demyelination, inflammation, gliosis, and axonal loss, all play a role in the expression of clinical symptoms in MS.

Immunology

Over the years, a vast array of hypotheses have been proposed to explain the cause of MS. It is clear that the process by which damage in the CNS occurs in MS is immunemediated. Thus, the most accepted theory to date, although not consensual, supports the notion that MS is an autoimmune disorder. This theory is supported by similarities in immune dysfunction between MS and other known autoimmune disorders. as well as the studies of the animal model of MS (experimental allergic encephalomyclitis; EAE). The target, however, against which the dysfunctional immune response in MS is directed remains unidentified, and thus, much of the research continues to examine peripheral immune parameters in the blood and cerebrospinal fluid (CSF) of people with MS. It is yet to be determined whether immune function in the periphery influences the pathogenesis of disease activity in the CNS.

One of the most consistently studied peripheral immune markers associated with MS has been T-cell function. Fluctuations in both T-cell type and function during the course of MS has provided evidence that MS is a disorder of immunity. The most recent reviews have proposed that subpopulations of autoreactive T cells are instrumental for initiating the disease process in MS (Cuzner & Smith, 1995; Martino & Hartung, 1999; Scolding, 1999). Under normal conditions, the blood-brain barrier (BBB) protects the CNS from much of the cellular activity in the periphery (Coles & Scolding, 1999). In MS, it appears that changes or defects in autoreactive helper (CD4⁺) T cells allow the BBB to be penetrated by increased numbers of activated lymphocytes, which then leads to inflammation. This inflammatory process then creates the conditions necessary for myelin, oligodendrocyte, and axonal damage (Martino & Hartung, 1999).

Much less is known about the role of suppressor (CD8⁺) T cells in the inflammatory process in MS. Yet, one of the most frequently reported immune abnormalities associated with MS has been a reduction in the number of CD8⁺ T cells in the peripheral blood of persons in the active phase of the disease, in comparison to those in the stable phase, as well as in comparison to healthy controls (Antel, Freedman, Brodovsky, Francis, & Duquette, 1989; Thompson et al., 1986; Reinherz, et. al., 1987; Zaffaroni, Caputi, Ghezzi, Marforio, & Cazzullo, 1988). This abnormality in circulating suppressor cells is also expressed as an increase in the helper (CD4⁺)/suppressor (CD8⁺) T-cell ratio. CD8⁺ T cells mediate suppression in the immune system, (Nicholson, Windhagen, Das, Hafler, & Kuchroo, 1997), and studies have shown that abnormalities in T-cell mediated suppression correlate with disease activity in MS (Balashov, Khoury, Hafler, Weiner, 1996). Researchers have suggested that exacerbations in MS may be associated with defective Tcell suppressor activity, and thus defective immune system reactions, which under normal circumstances act to "turn off" activated autoreactive T cells (Zhang, 1995). The role of CD8⁺ T cells in the pathogenesis of MS, however, remains controversial.

Neuroimmunology

Although for many years the immune system was considered an autonomous, selfregulating unit, the interrelationship between the neuroendocrine and immune system is increasingly recognized (Chelmicka-Schorr & Arnason, 1994; Dunn, 1995; Kemeny, Solomon, Morley, & Herbert, 1992). Furthermore, advances in understanding the role of CD4⁺ T cells has illustrated that neuroendocrine activity may affect immune function in MS. Research on EAE has demonstrated that the development of an autoimmune disorder may be described by a preferential skewing towards the Th1 CD4⁺ helper T-cell subpopulation in response to an antigen (Coyle, 1996; Liblau & Fontaine, 1998; Ransohoff & Bö, 1996). Th1 cells are associated with pro-inflammatory cytokines such as interleukin-2 (IL-2) and interferon-gamma (IFN- γ), and these cells upregulate the inflammatory response (O'Garra & Hosken, 1997). Alternatively, Th2 cells down-regulate the inflammatory response because of their association with anti-inflammatory or regulatory cytokines such as interferon alpha (IFN- α) and interferon-beta (IFN- β) (Coyle, 1996). Although much less is known about MS than the experimental animal model (EAE), it is increasingly recognised that cytokines may play some part in the manifestation of disease activity in MS (Ackerman, Martino, Heyman, Moyna, & Rabin, 1998; Constantinescu & Cohen, 1994). Researchers have demonstrated that recruitment of inflammatory cells to the CNS may occur during active stages of MS, and may be associated with breakdown of the BBB (McDonald, 1994). There is also evidence of elevated levels of pro-inflammatory cytokine expressing cells in the blood and CSF of people with MS (Link, et al., 1994; Moynihan & Ader, 1996). Perhaps the role of cytokines in MS is best illustrated by the contrasting effects of IFN- γ and IFN- β on MS-related symptomatology. Administration of

IFN- β for people with MS is associated with beneficial effects. By contrast, a clinical trial designed to test the effects of IFN- γ was terminated when almost 40% of the participants experienced an exacerbation after treatment for only one month (Panitch, Hirsch, Schindler, & Johnson, 1987).

Bidirectional communication between the immune and neuroendocrine system is well documented (Maier, Watkins, & Fleshner, 1994). Moreover, researchers have suggested that neuroendocrine activity may be a potential mediator in determining the balance between pro-inflammatory and anti-inflammatory cells during immune reactions (Ackerman, Martino, Heyman, Moyna, & Rabin, 1998; Coyle, 1996; Moynihan & Ader, 1996). It is likely that Th1 and Th2 cytokine cells execute counter-regulatory processes in response to an antigen, and thus, any imbalance may result in immune dysfunction. Studies have indicated that Th1 and Th2 cell activation, and thus cytokine production, may be affected by adrenal hormones associated with neuroendocrine activity, namely glucocorticoid hormones (Dayne & Araneo, 1989). Glucocorticoids inhibit, or oppose, a number of mediators of inflammation, including cytokine production (Barnes & Adcock, 1993). In MS, researchers have proposed that defective inhibitory products, such as glucocorticoids, may account for the aberrant pathological response, which under normal circumstances would be suppressed (Cuzner & Smith, 1995). A number of studies have confirmed that MS may be associated with alterations in the mechanisms designed to oppose or mediate inflammation (Michelson et al., 1994; Zoukos, Leonard, Thomaides, Thompson, & Cuzner, 1992).

Researchers have suggested that physical and emotional stress may influence immune function (Cohen & Herbert, 1996; Dunn, 1995; Kemeny, Solomon, Morley, &

Herbert, 1992; Maier, Watkins, & Fleshner, 1994). Results of a recent study showed that acute stress produced immediate and prolonged increases in pro-inflammatory cytokine production in a group of people with MS (Ackerman, Martino, Heyman, Moyna, & Rabin, 1998). Although differences were not detected in immunological responses between the MS group and healthy controls, the authors concluded that the shift towards Th1 activity may be deleterious to those with autoimmune disorders, such as MS. The mechanism for stressrelated cytokine activation remains unclear, but may be associated with neuroendocrine activity. Stressful stimuli activate a central stress response, mainly activation of the hypothalmic-pituitary-adrenal (HPA) axis (Nisipeanu & Korczyn, 1993). Dunn (1995) has suggested that HPA activation acts as a negative feedback mechanism provided by the immunosuppressive activity of the glucocorticoids. In EAE, there is evidence that stressful experiences, correlated with glucocorticoid release, can inhibit clinical symptoms and decrease disease severity. It is an unresolved paradox, however, that in the human condition, MS, the opposite may occur. There is a wealth of anecdotal evidence suggesting a relationship between psychological stress and MS symptomatology. Nevertheless, results from controlled studies have been equivocal. Several studies have found increased risk for MS exacerbation associated with, or following the experience of stressful life events (Franklin, Nelson, Heaton, Burks, & Thompson, 1988; Grant et al., 1989; Schwartz, et al., 1999). Other studies have demonstrated no significant increase in exacerbations associated with stress and anxiety (Nisipeanu & Korczyn, 1993). To date, however, only two published studies have investigated the association between psychosocial stress and potential markers of immune regulation in MS. Foley et al. (1988) found that anxiety and depression in a sample of people with MS was associated with alterations in T-cell subset

populations. Specifically, psychologically distressed individuals displayed a relatively higher percentage of CD4⁺ T cells and a relatively lower percentage of CD8⁺ T cells, resulting in an increase in the CD4⁺/CD8⁺ T cell ratio. The researchers recognised that the findings mirrored changes in these cells noted during MS exacerbations. In a later study, Foley et al. (1992) also examined psychological distress and immune function in MS. Their findings were consistent with the results from the previously cited investigation. They also noted depletion in circulating CD8⁺ T cells associated with times of high depression in people with MS. These studies, however, have been criticised for the simplistic approach to measuring and comparing psychological and immunological status (Waksman, 1994). Nevertheless, the research provides some evidence that a dysfunction in immune suppression, evident in MS, may be mediated by the influence of psychological status on the neuroendocrine system.

<u>Diagnosis</u>

A diagnosis of MS is usually confirmed via three main methods (viz., cerebrospinal fluid [CSF] analysis, examination of evoked potentials [EP], and magnetic resonance imaging [MRI]). In most cases, the tests are used to eliminate the presence of other diseases, before a diagnosis of MS is confimed. Analysis of CSF is performed during an exacerbation, and diagnosis is based on evidence of elevated levels of immunoglobulin G (IgG; Collins, 1997). Elevated levels of IgG are indicative of an infectious or immune activated condition, but do not always rule out other illnesses that present with similar symptoms to MS. Examination of EP is used to test the rate of action potential conduction at the brain cortex, with a slow rate usually reflecting lesion formation in the brain. Visual EP response is commonly tested because of the frequency of optic neuritis in MS. Once again, however, other types of lesions, such as those found in stroke, may also slow conduction (Paty, Noseworthy, & Ebers, 1998). The most accurate diagnostic tool for MS, at present, is MRI. Demyelination can be detected on MRI scans as multiple plaques around the ventricles of the brain, the brain stem, and spinal cord. Researchers have demonstrated that brain MRI scans are abnormal in 95% of people with clinically definite MS (Francis, Evans, & Arnold, 1995). The introduction of MRI as a diagnostic tool in MS has not only increased accuracy of diagnosis, but has also increased understanding of disease pathology, and is now widely used for disease tracking in clinical trials because the scans can detect plague activity in the CNS.

Treatment

Treatment in MS can be divided into three main areas: (a) treatment to ameliorate symptoms, (b) treatment to arrest disease progression, and (c) treatment for long-term maintenance of general health. Treatment and care of individuals with MS has long centred on intermittent acute or chronic care of primary symptoms, such as spasticity, bladder dysfunction, and fatigue. There are a number of pharmacological agents designed to alleviate symptoms in MS, yet many are associated with adverse side effects. For example, amantadine can reduce MS-related fatigue, but clinical trials have shown limited success, demonstrating a number of possible side effects that potentially affect well-being to the same extent as the fatigue itself (Cohen & Fisher, 1989). Corticosteroids are the most common form of acute treatment for major MS exacerbations. Their therapeutic effect is thought to reduce edema or inflammation, and thus, shorten the duration of an attack. The drugs, however, probably do not affect long-term damage caused in the CNS by

inflammation (Lechtenberg, 1995). Corticosteroids are also associated with a number of adverse short- and long-term side effects, including depression and osteoporosis.

The production of genetically altered IFN- β in the 1980s has resulted in two main treatments aimed specifically at altering disease progression in MS. IFN- β is produced naturally by the body, and exerts influence on the immune system by down-regulating the inflammatory response. The drug treatments, IFN-\beta-1b (Betaferon®; Betaseron®) and IFN- β -1a (Avonex®), are designed for people with relapsing-remitting MS, and are associated with reduced frequency, severity, and duration of exacerbations (Panitch & Beaver, 1993). Neither of these treatments, however, has succeeded in halting neurologic decline over the long term. In addition, side effects are common, and may include flu-like symptoms, injection site reactions, pain, weakness, and fatigue (Neilley, Goodkin, Goodkin, Mohr, & Hauser, 1996). Researchers have also found that many people with MS have unrealistic pretreatment expectations of IFN- β therapy and that disappointing results may contribute to an increase in depressive symptomatology and discontinued treatment (Mohr et al., 1996). It appears that none of the drugs being considered at present are likely to cure the disease, and there is little hope that disability can be reversed. It is becoming increasingly clear that pharmacological therapies alone do not represent optimal care for people with MS (Johnson, 1996).

Treatment aimed at maintaining and improving long-term health for people with MS has been considered a supplementary treatment to drug therapies. Increasingly, however, more attention is being directed towards rehabilitative efforts designed for effective symptom management over the long illness trajectory. Despite the large number of publications outlining what rehabilitation in MS should include, there are relatively few

studies examining the effect of rehabilitation as treatment in MS. LaRocca and Kalb (1992) reviewed the literature between 1981 and 1991 on medical rehabilitation in MS. The studies reviewed describe inpatient and outpatient rehabilitation as a comprehensive, multidisciplinary package of care that includes physical, occupational, and psychotherapeutic, as well as medical, nursing, and social services. The authors noted that generally, rehabilitation does not significantly affect neurological or disability status. They did establish, however, that for people with MS, rehabilitation can positively affect functional abilities, such as mobility, self-care, and independence. The authors, however, highlighted the difficulties in drawing conclusions about the efficacy of rehabilitation in MS because of the persistent methodological limitations, including lack of comparison groups evident in all the reviewed literature.

Two more recent controlled investigations have found that rehabilitation positively affects functional ability for people with MS. Freeman, Langdon, Hobart, and Thompson (1997) measured the effect of a short-term (25 days) inpatient rehabilitation program on impairment, functional ability, and handicap for people with progressive MS. Results indicated that, although impairment for the treatment group, as measured by the EDSS, remained the same, functional ability and handicap significantly improved. In another study, Di Fabio, Soderberg, Choi, Hansen, and Schapiro (1998) examined outpatient rehabilitation services for people with MS over an extended period (one year). The results indicated that, in comparison to the control group, participants in the treatment group showed a reduced rate of functional decline and symptom frequency over the one-year period. The authors noted that considering the participants were diagnosed as having progressive MS, a lower rate of decline in physical abilities was a positive outcome. Although it seems that comprehensive medical rehabilitation in MS is efficacious, it is clear that improved research methodologies are required, including more inclusive outcomes, such as measures of psychological health, and their interactions with physical disability. In addition, one of the primary concerns in assessing rehabilitation programs as multidisciplinary packages is that one cannot conclude which of the many interventions influenced the outcome measures employed. Di Fabio et al. (1998) attributed the therapeutic benefits of rehabilitation to social and emotional support, whereas Freeman et al. (1997) concluded that educational aspects of the rehabilitation and regular attention by research staff may have influenced the results. It is clear that additional research is necessary to assess the influence of specific types of rehabilitation on self-perceived problems in MS.

Psychological Health

Several factors make MS a disease with numerous psychological and social implications. The unpredictable and episodic nature of MS-related disabilities, compounded by the lack of reliable indicators to predict the course of the disease may give rise to psychological sequelae for affected individuals. There have been numerous studies evaluating psychosocial function, and results have indicated that a wide range of responses occur among people with MS, with psychological stress and depression identified as the most common (Devins & Seland, 1987). A meta-analysis of six publications concluded that depression appears to be more prevalent in MS than in both the general population, and among patients with other medical and neurological disorders (Schubert & Foliart, 1993). Researchers have also indicated that, although depression in MS may be associated with severity of physical impairment, other psychosocial aspects of living with a chronic illness

may play an important role in the manifestation of depressed affect in MS (Aikens, Fischer, Namey, & Rudick, 1997; Shnek, Foley, LaRocca, Smith, & Halper, 1995).

Shnek et al. (1995) involved a sample of 80 individuals (mean EDSS 5.0) to examine predictors of depression among people with MS. They found that helplessness, as measured by the helplessness subscale of the MS Attitudes Index (MSAI), was the best predictor of depression in MS, in comparison to physical disability, cognitive function, and self-efficacy. Helplessness is a psychological state in which an individual expects efforts to control certain situations to be ineffective. The authors of the study concluded that the unpredictable course of the disease may contribute to an increased sense of helplessness in MS. Similarly, Aikens et al. (1997) found that depression in a sample of 27 people with MS was associated with psychosocial stressors other than level of physical impairment. Results indicated that life stress, and, in particular, negative life events were associated with depression in MS. The participants, however, had a mean EDSS of 2.2, indicating only mild MS-related disability. In addition, results from the prospective data demonstrated that, along with negative life events, physical disability was a predictor of future depressive symptoms. They stated, however, that level of disability may magnify the intensity of certain life events, and thus, the combination of impaired ability and stressful life circumstances may adversely affect depression in MS.

Smith and Young (2000) reversed the traditional notion that disability may influence depressed affect in MS, and investigated how depression affects perception of disability. Individuals with MS (N = 88) completed two depression inventories, as well as a scale identifying disability level (also completed by an attending physician). Results indicated that over 30% of the sample were categorised as clinically depressed, and another 30% as

borderline depressed. The study found that those individuals categorized as depressed were three times more likely than non-depressed individuals to perceive their disability as being greater than the physicians' perceptions. This finding, however, does not indicate whether the perception of disability was perceived as a significant stressor for the affected individual. Researchers have demonstrated that people with MS tend to be less concerned than their physicians about physical disabilities related to their illness (Rothwell, McDowell, Wong, & Dorman, 1997). Nevertheless, the Smith and Young (2000) study raises some questions about how mental well-being may influence general health perceptions for people with MS.

Researchers have found that people with MS tend to have psychological health problems to a greater extent than individuals of a similar age in the general population. In a study of psychosocial and neurological predictors of mental health, Ritvo, Fisk, Archibald, Murray, and Field (1996) described a sample of 130 individuals with MS (EDSS ratings 0 to 9.0). The Mental Health Inventory (MHI; Veit & Ware, 1983) was used to measure general psychological health, and results indicated that the mean MHI score for people with MS corresponded with the 25th percentile in a comparative group of healthy individuals. As many as half the MS sample fell into the lowest category of mental health status recorded in the comparative group. Similar to previous research, the Ritvo et al. study also showed that mental health status may not necessarily be a function of neurological or physical impairment. The study employed a multiple regression analysis to determine predictors of mental health in MS. The authors found four factors; namely, fatigue, social support, duration, and response to stressful life events accounted for nearly half the variance in total MHI scores, with fatigue being the single best predictor. Although the authors noted that the large percentage of women in the research may have limited its generalisability to the whole MS population, the study is unique because of the large range of impairment included in the research. Participants' disability status, as measured by the EDSS, ranged from no neurological or physical impairment (EDSS = 0) to those fully wheelchair bound, with several cognitive deficits (EDSS = 9). The authors concluded that identifying determinants of psychological health for the MS population may help to guide appropriate and effective intervention strategies.

Health-Related Quality of Life (HRQOL)

Much of the current literature in MS is divided into research that addresses the physiological aspects of the disease and research that addresses social and emotional factors. Cella et al. (1996) proposed that there is a need to capture the multidimensional effect of MS on physical, mental, and social well-being. Increasingly, quality of life (QOL) and health-related quality of life (HRQOL) measures are being used to assess the effects of diseases such as MS, because these measures encompass the multidimensional concepts of physical and psychological health. QOL has been defined as a person's subjective sense of well-being and satisfaction with life (Pfenning, Cohen, & Van der Ploeg, 1997). HRQOL has been described in more broad terms as a multidimensional construct that includes the effects of illness and treatment on physical, mental, and social health (Wilson & Clearly, 1995). HRQOL is based on health domains that can be measured and quantified, and has been conceptualised as a three-part model. The model includes clinical status, disease-specific and treatment-specific symptoms, and general health perceptions assessed regardless of an individual's age or health state (Patrick & Erickson, 1993).

Research on QOL and HRQOL issues in MS is recent, and has shown that people with MS report reduced levels of QOL, in comparison to the general population, and in comparison to those with other chronic illnesses. Rudick, Miller, Clough, Gragg, and Farmer (1992) compared QOL among people with inflammatory bowel disease (IBD), rheumatoid arthritis (RA), and MS using the generic Farmer QOL Index. Overall, QOL scores were consistently lower for the MS group, in comparison to people with IBD and RA. The researchers suggested that the multiplicity of symptoms in MS may have contributed to the decrement in QOL scores for this population. Results from previous research has demonstrated that people with co-morbid conditions generally exhibit reduced functioning and well-being in comparison to patients with only one condition (Stewart et al., 1989). This finding illustrates the various psychosocial implications of a disease, such as MS, which presents with a variety of medical and psychological problems.

A number of studies have not only compared HRQOL in MS to the general population, but also examined the relationship between HRQOL and disability status. Brunet, Hopman, Singer, Edgar, and MacKenzie (1996) described and compared a sample of 97 people with MS (EDSS ratings 0 to 8.5) to a sample of non-institutionalised healthy individuals. Using the Rand 36-item Health Survey 1.0 (SF-36; Hays, Sherbourne, & Mazel, 1993), which is a generic HRQOL scale, the researchers found the only significant difference between the two populations was on the physical functioning subscale. This finding is in contrast to other investigations that have found differences between MS and normative samples on physical, mental, and social health (Aronson, 1997; Canadian Burden of Illness Study Group, 1998; Nortvedt, Riise, Myhr, & Nyland, 1999). Brunet et al. indicated that the range of responses among the MS sample, as indicated by large standard deviations for mean scores on each of the HRQOL subscales, may have influenced the results. A large range of EDSS scores among a relatively small sample may have also affected the results. Of note, however, in this study, and in two subsequent investigations using the SF-36 (Pfenning et al., 1999; Rothwell, McDowell, & Wong, 1997), is that disability as quantified by the EDSS was significantly correlated only with the physical function subscale on the HRQOL index. Considering the EDSS predominantly measures ambulatory ability, the association between this scale and self-perceived rating of physical function is expected. Nevertheless, such results indicate that HRQOL may provide information about the effects of the disease for people with MS beyond that provided by the EDSS.

Categorising disease severity based on measurements such as the EDSS does not seem to be associated with how an individual perceives problems associated with living with MS. A study using the SF-36 to measure HRQOL among 198 people with MS concluded that the disease substantially affects HRQOL and that the effects were notable even among those with low EDSS scores or when impairment of ambulation was not yet a major symptom (Canadian Burden of Illness Study Group, 1998). Nortvedt et al. (1999) supported this finding in their study, reporting reduced HRQOL compared with the general population, even among people with MS with few neurological and physical impairments (EDSS \leq 2.5). Furthermore, Aronson (1997) demonstrated that the psychological effect of MS cannot be predicted solely on the basis of disease severity. The study assessed a number of demographic items and the relationship with HRQOL. Results indicated that interference by MS with social activities was most strongly related to decreased perceptions of HRQOL across all domains. The researchers concluded that determining those factors that appear to play an important role in the health and well-being of people with MS is essential for planning interventions, treatment, and services.

The SF-36 is probably one of the most common generic psychometric scales used to measure HRQOL in a wide range of illnesses, including MS. Recently, however, the relevance of this scale for the MS population has been questioned (Freeman, Langdon, Hobart, & Thompson, 1996). In a study of HRQOL for people with MS in rehabilitation, a number of subscales were described as irrelevant for a population in which functional skills may be highly impaired (Freeman et al., 1996). The authors referred to the appropriateness of a HRQOL scale specific to MS developed in an earlier study (Vickrey, Hays, Harooni, Myers, & Ellison, 1995). Vickrey and colleagues developed the Multiple Sclerosis Quality of Life (MSQOL) instrument, which includes the SF-36, as its generic core, with supplemented items that target aspects of HRQOL that are particularly relevant to individuals with MS. The development of the scale involved a review of the literature and consultation with a number of MS medical specialists. Additional items were included on the social function, pain, energy, and overall quality of life subscales of the SF-36. In addition, four new dimensions were added by including items relating to health distress, sexual function, satisfaction with sexual function, and cognitive function. The authors considered these new areas were not only specific to a neurological disease such as MS, but were also potential factors affecting overall psychological health. Although this scale has not been widely used in MS research to date, it appears to be a valuable tool, not only because of its specificity to MS, but also because the original SF-36 items can be used for comparison to previous research in MS, as well as research in general and disabled populations.

In the past, much of the research in MS has quantified outcome measures in relation to scores on the EDSS and MS-related symptoms, and largely ignored concepts such as psychological health and well-being. More recently, HRQOL has been recognised as a central measure in health care research (LaRocca et al., 1996), and it is increasingly used when investigating the effects of various intervention strategies in MS, because it can measure and assess the physical, mental, and social implications. HRQOL assessment in chronically ill individuals allows a broader measure of disease burden than traditional measures of impairment and disability. A number of researchers have proposed that outcomes in health research that only focus on the severity of the biological processes in disease may obfuscate important behavioural outcomes (Kaplan, 1990; Nortvedt, Riise, Myhr, & Nyland, 1999; Rothwell, McDowell, Wong, & Dorman, 1997). Behavioral health outcomes, such as HRQOL, provide meaningful measures relating to how physical dysfunction interferes with regular daily activities. As Kaplan (1990) has argued so convincingly, behaviour should be the focus of the final outcome in health research.

Exercise and Multiple Sclerosis

For many years individuals diagnosed with MS have limited their physical activity levels. This restriction has often been on the advice of physicians in an effort to help minimise the risk of exacerbations and symptoms of fatigue. In addition, one of the most common responses to mobility problems, typical in MS, is to cease many recreational activities (Stuifbergen & Roberts, 1997). The health risks associated with physical inactivity have been well documented in healthy individuals (Pate, Pratt, & Blair, 1995). Together with the risk of developing chronic conditions, such as cardiovascular disease and osteoporosis, physical inactivity is also associated with muscle weakness and atrophy, fatigue, depression, and sleep disturbances (Stewart & King, 1991). In MS, these problems have often been attributed to the disease itself, rather than resulting from leading sedentary lives.

As an individual limits physical activity, the capacity to perform physical acts becomes diminished. For people with MS, who may be already experiencing problems with physical abilities, the effect of inactivity may be even more significant. The general health consequences and increasing physical limitations of inactivity, compounded by unpredictable disease progression may also contribute to less social interaction, depressed mood, and diminished general well-being (Stuifbergen, 1997). Numerous studies have demonstrated that clear correlations exist between regular physical activity and positive psychological health (reviewed in Morgan, 1997). Researchers investigating other conditions have shown that exercise increases physical function and psychological wellbeing, as well as reducing anxiety and depression (Hickey, Wolf, Robins, & Wagner, 1995; La Perriere et al., 1994). These findings have provided a foundation for investigating the suitability of exercise as a complementary therapy for people with MS, not only for counteracting the physical limitations imposed by the disease, but also for enhancing physical fitness and psychological well-being.

Exercise and Psychological Health

The relationship between exercise and psychosocial health has been widely researched, and results suggest that exercise has psychological benefits. Reviews of the literature have indicated that exercise and physical activity are associated with several key markers of psychological well-being and HRQOL, such as mood, anxiety, depression, selfperceptions, and subjective well-being (Byrne & Byrne, 1993; Fox, 2000; McAuley, 1994; Morgan, 1997; Paluska & Schwenk, 2000; Weyerer & Kupfer, 1994). In an overview of the literature investigating the links between physical activity and psychological health, Byrne and Byrne (1993) reported that the majority of studies provided support for physical activity reducing depression and anxiety, and enhancing positive mood states. They did, however, caution that results are often based on indirect evidence. In another review of the literature, McAuley (1994) concluded that 69% of the studies demonstrated that physical activity was positively associated with subjective well-being. Weyerer and Kupfer (1994) examined intervention and observational studies on physical activity and mental health, and noted that physical activity appeared to be an efficacious method for treating mental health problems, as well as an effective preventive treatment. Paluska and Schwenk (2000) focused their review on studies investigating the influence of physical activity on depression and anxiety in clinical and non-clinical populations. They found that regular physical activity may play an important therapeutic role in alleviating depression and anxiety across a number of age and population groups. In a comprehensive summary of the research on psychological responses to physical activity, Morgan (1997) concluded that both acute (single episode) and chronic (acute episodes repeated several times per week for months or years) physical activity are associated with positive psychological outcomes. More recently, Fox (2000), in a review of the physical activity and mental health literature, concluded that there is overwhelming evidence that exercise can affect psychological health via its influence on anxiety, depression, mood, self-esteem, and stress responsitivity. Nevertheless, both Morgan and Fox cautioned that much of the exercise and psychological health research is plagued by methodological limitations, including inadequate comparison groups, insufficient descriptions of exercise modalities and intensities, and small sample sizes.

Despite numerous limitations in the research, it appears that exercise is an effective means of enhancing psychological health and well-being. How exercise acts to attenuate negative affect and influence positive psychological health status has been explained in a variety of neurophysiological, biochemical, and psychological models.

Neurophysiological models. Elevating core body temperature, through a variety of methods, has been used for centuries for therapeutic benefits, and research has shown that saunas and warm showers can reduce muscle tension (Kuusinen & Heinonen, 1972) and self-reported levels of state anxiety (Raglin & Morgan, 1987). Based on research into passive heating, deVries (1987) proposed that the benefits of exercise may be related to elevations in body temperature. Originally developed by von Euler and Soderberg (1957), and based on research with animals, de Vries proposed the thermogenic model. He hypothesised that elevation in core body temperature, mediated by the hypothalamus' influence on the thalamus, promoted EEG alpha activity and reduced gamma motor neuron activity, which may lead to "relaxing" changes in peripheral musculature and CNS activity associated with relaxation. Although during exercise the physical demand on the muscles would seem to negate the reduction in afference, the main period of research focus has been on post-exercise when temperature remains elevated for some time after the termination of physical activity.

Although a number of studies have demonstrated an association between exerciseinduced elevated core temperature and decreases in state anxiety levels (e,g., Petruzzello, Landers, & Salazar, 1993), there appears to be limited evidence supporting this hypothesis. Research has demonstrated decreases in anxiety following exercise at an intensity, or under environmental conditions, that do not elicit body temperature rises (Reeves, Levison, Justesen, & Lubin, 1985). Furthermore, methodological and measurement considerations that need to be addressed before the thermogenic hypothesis can be used to explain the relationship between exercise and psychological health. For example, esophageal or rectal temperature measures may not reflect physiological changes mediated by the hypothalamus. Future research adopting new technology examining tympanic temperatures may be able to measure brain warming more accurately.

In contrast to the thermogenic hypothesis, the opponent-process model attempts to explain psychological benefits in terms of acute and habitual physical activity. The model's theoretical basis assumes a rebound effect of the CNS to a given stressor (Solomon & Corbit, 1973). That is, arousal of the sympathetic nervous system (SNS) during engagement in a stressful activity, such as exercise, is followed by an opposing process and affective state (e.g., relaxation, feelings of pleasantness, enhanced mood states) upon cessation of exercise. A central feature of this hypothesis is that with habitual physical activity, the arousal level of the SNS does not change but remains the same, whereas the opposing process and perception of general well-being become enhanced. In a meta-analysis, Petruzzello et al. (1991) supported the model, in that post-exercise anxiety was significantly reduced in most of the studies examined. The researchers did note, however, the difficulty in adequately assessing the model in terms of acute exercise only. Boutcher and Landers (1988) also supported the model in their research using acute exercise with trained and untrained runners. The results indicated that the runners who were more fit had significantly greater opponent processes after ceasing exercise than did the untrained runners.

Finally, in terms of neurophysiological models, some evidence supports the role of neuroendocrine responses as possible mediators of positive changes in mental health

observed following physical activity. The model relates to changes in monoamine activity in response to exercise, which are thought to reflect sympathoadrenal activity (Crews & Landers, 1987; Dishman, 1997; Mazzeo, 1991; Sothmann, 1991). The sympathoadrenal system has been the focus of many studies because of its ability to mediate a host of physiological adjustments to physical, environmental, and psychological stressors. Attempts to test the model have involved the measurement of peripheral monoamines, which are principally secreted from the SNS and adrenal gland (Sothmann, Hart, & Horn, 1991). The amines are some of the most common CNS and SNS neurotransmitter substances and thus, any change in activity could have an influence on central brain processes (Simono, 1991). Although few studies in the physical activity literature have focused specifically on brain monoamine activity and psychological health, there is evidence that exercise-induced changes in neurotransmitters and hormones, such as norepinephrine, may act as neuromodulators of negative affect, such as anxiety and depression. A number of studies have shown aerobic exercise reduces levels of plasma norepinephrine in response to endurance training for a given submaximal workload (Galbo, Kjaer, Richter, Sonne, & Mikines, 1986). The relationship between exercise, aminergic activity, and psychological health is complex, and although the neurotransmitter model for exercise-induced improvements in psychological health remains questionable, it may provide an important component, in conjunction with other psychophysiological adaptations to exercise, that can help explain positive affective change.

<u>Biochemical models.</u> Perhaps the most prominent and controversial biochemical model of exercise-induced changes in psychological health is the endorphin hypothesis. A number of studies have demonstrated enhanced sensation of well-being and feelings of

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pleasantness, together with an increase in peripheral plasma beta-endorphin levels in the post-exercise period (Goldfarb, Hatfield, Armstrong, & Potts, 1990, 1991; Wildman, Kruger, Schmole, Niemann, & Matthaei, 1986). Endorphins are the body's natural, endogenously produced, opioid peptides and tend to remain "silent" unless a challenging stressor, such as vigorous exercise, appears or is initiated (Hatfield, 1991; Hoffman, 1997). The issue, however, has been debated because increases in peripheral plasma betaendorphins do not necessarily reflect changes in CNS opioid activity. Actually, the influence of peripheral endorphins on the brain is questionable considering the blood brain barrier to peptides (Dishman, 1994). Although experimental data indicate activation of endorphins by exercise, their role in enhancing psychological health status is questionable. Research has suggested that endorphins may act to promote positive psychological affect by simply reducing discomfort during exercise (Morgan, 1985). Although it seems that endorphins may explain some of the positive changes in psychosocial health associated with exercise, other physiological and psychological adaptations to physical activity are involved.

<u>Psychosocial models.</u> Although the previous models have suggested that enhanced well-being via participation in physical activity is primarily physiological in nature, Bahrke and Morgan's (1978) distraction hypothesis proposes a psychological mechanism. The authors proposed that cognitive diversion may be the agent responsible for the positive changes in mental states seen with exercise. Exercise may act as a temporary distraction from immediate emotional concerns or as a time-out from stressful stimuli. The premise of the hypothesis, however, leads to the possibility that exercise may not be the critical variable in alleviating negative affect. In formulating the distraction hypothesis, Bahrke and

Morgan contrasted an equal amount of treadmill running, at 70% V0₂ max, with meditation and reading. They found that physical activity was as effective in reducing anxiety as the other cognitively based distraction therapies. Other researchers, however, have revealed that exercise-induced changes in well-being lasts significantly longer than other cognitive interventions when outcome measures are assessed over prolonged periods (Raglin & Morgan, 1987). Based on the research, it appears that exercise as a time-out from emotional concerns positively affects psychological health, but it may only represent one possible factor. Morgan and O'Connor (1989) concluded that the distraction theory complements, rather than contradicts, other psychological and physiological mechanisms.

Several other cognitively based mechanisms have also been proposed to explain how the psychological benefits of exercise are mediated. Researchers have suggested that exercise may influence some variables that may be related to changes in psychological health status (Sime, 1996). In particular, exercise-induced reductions in negative affect appear to be associated with increases in self-efficacy. Bandura (1991) has proposed that the positive psychological influence of physical activity may be an outcome of increases in, or the restoration of, self-efficacy. Broadly defined, self-efficacy concerns the convictions that one has the capabilities to engage successfully in a course of action required to satisfy situational demands. Bandura (1977, 1986) emphasised that self-efficacy is not directly concerned with ability, but with perception or belief in those abilities. Efficacy cognitions influence not only behaviour, but also thought patterns and affective reactions to anticipated and actual stressors.

Research investigating self-efficacy and physical activity has consistently demonstrated that both chronic and acute exercise produces increases in physical self-

efficacy (McAuley & Courneya, 1992; McAuley, Courneya, & Lettunich, 1991; Rudolph & McAuley, 1995). Research, however, has also shown that exercise itself may not be as important as mastery experiences that occur as an outcome of physical activity (Norris, Carroll, & Cochrane, 1992). For example, Dzewaltowski, Acevedo, and Pettay (1992) found that exercise participants who did not achieve their fitness goals had lower selfefficacy than that of those who did achieve their goals. Self-efficacy theory also contains the premise that the psychological strengthening effects of mastery experiences gained through habitual physical activity, can lead to increased efficacy cognitions and reduced physiological stress reactions (Bandura, 1991). This concept complements Dienstbier's (1989, 1991) model of active toughening in the form of regular exercise, which postulates that mastery experiences affect physiological and psychological health. Some evidence supports the relationship between exercise and efficacy cognitions in the regulation of psychobiological functioning. A number of studies have demonstrated increases in selfefficacy may be related to the regulation of endocrine, catecholamine, and endogenous opioid systems (Bandura, Cioffi, Taylor, & Brouillard, 1988; Weidenfeld et al., 1990). As noted above, such neurophysiological systems are thought to be integrally linked to exercise-induced sensations of well-being and positive mood.

It is important to note the suggestion that the effectiveness of exercise to reduce negative affect may be a result of a placebo effect (Sime, 1996). Exercise is a prominent feature in psychological health-related information, and partaking in exercise may carry with it an expectancy of psychological benefits. Studies focusing specifically on the placebo effect have concluded that exercise does indeed carry an expectancy for affective change (McCann & Holmes, 1984). Although participation in an exercise program may give rise to an expectancy effect, particularly for clinical populations, the placebo effect does not appear to be as influential as the other psychological and physiological mechanisms discussed.

From the preponderance of literature available, there seems little doubt that both acute and chronic exercise represent effective means of enhancing psychological health. Understanding the mechanisms of exercise-induced changes will, more than likely, contribute to the development of more efficacious treatments. Although much of the research has attempted to isolate and explore single mechanisms, it is far more likely that different mechanisms work in concert with one another, possibly in an interactive, or even additive manner. It is possible that some of the physiological models are interrelated. For example, elevated body temperature may influence the release and function of monoamines (Morgan, 1985). In addition, evidence supports the interrelationship between endocrine function and monoamine and endorphin release (Smith & Curzner, 1994). It is also likely that cognitive mechanisms are intimately associated, and that both physiological and psychological factors mediate the changes in psychosocial health observed with physical activity (Dienstbier, 1991). It is also possible that any one mechanism, or the interactive or additive effect of mechanisms may work differently for different people (Martinsen & Morgan, 1997). Although the exact process by which exercise promotes changes in affect is uncertain, the value of exercise for enhancing psychological health status is clear.

Exercise, Psychological Health, and MS

The demands of chronic illness and associated disability in MS result in a high prevalence of life-altering problems that may detract from general well-being. As previously discussed in this chapter, people with MS often report reduced levels of psychosocial functioning in comparison to the general population, as well as other illness populations. There is an increasing recognition that aerobic exercise can positively influence psychological well-being and health for disabled people (Shepard, 1991). Yet, researchers have shown that physical activity tends to be reduced for people with MS, in comparison to the general population, as well as those with other chronic conditions (Ng & Kent-Braun, 1997; Stuifbergen, 1997). Results from studies have also indicated that lower activity rates for people with MS may not necessarily be a function of ambulatory impairment or disease severity.

Ng and Kent-Braun (1997) examined physical activity levels in MS (EDSS ratings 1.5 to 6.0) compared to a sedentary, age, and gender matched control group. The study used two instruments to measure activity level: a seven-day recall questionnaire (7-d RQ) and an accelerometer activity monitor. The participants wore the activity monitor around the waist. The monitor recorded motion in terms of acceleration of the body, at one-minute intervals for seven days. Results from the 7-d RQ indicated no differences in activity between the groups. This result may have been expected considering the control group was described as sedentary. The accelerometer, however, showed that the MS participants were significantly less active than the sedentary control group. The discrepancy between the two measures may mean that, although people with MS reported participating in daily activities, their actual physical movement was reduced in comparison to a healthy, non-disabled population. Neither measure of activity, in this study, correlated with disability as measured by the EDSS, or measures of muscular strength recorded prior to the commencement of the study. This result seems to indicate that reduced activity levels, for persons with MS, are not necessarily a direct result of deficient muscular, ambulatory, or neurological function.

The authors suggested that for people with MS, simply having the disease may be sufficient to limit physical activities. This explanation does not seem to provide an adequate reason why individuals with MS are less active than a healthy comparison group. The long-held belief that exercise may affect symptom severity and fatigue in MS cannot be underestimated as a potential reason for limiting activity.

Despite the well-established relationship between physical activity and positive psychological health, there is scant literature describing the health status of those individuals with MS who do participate in physical activity. Stuifbergen and Roberts (1997) described the health-promoting behaviours of a large sample (N = 629) of women with MS, and the relationship to impairment and QOL. The study found that exercise was described as an important feature of health-promoting behaviour, yet results showed that only a small proportion of the sample exercised as part of their daily activities. In relation to other behaviours, women with MS rated exercise as the least participated in activity. The author referred to a previous investigation that found many people with MS feel they lack the appropriate knowledge and skills to exercise safely as possible reasons why this sample did not participate regularly in physical activity (Stuifbergen, 1995). The study, however, did find a strong relationship between involvement in health-promoting behaviours and QOL, regardless of severity of impairment.

In another study, Stuifbergen (1997) described the level of physical activity in a group of people with MS, as well as the relationship to HRQOL. Participants completed a measure of daily activity, the Human Activity Profile (HAP; Fix & Daughton, 1988) and a HRQOL measure, the short form SF-36 (Ware & Sherbourne, 1992). The HAP contains two subscales; a maximum activity score (MAS), which refers to the highest level of energy

expenditure, and an adjusted activity score (AAS), which is interpreted as the average level of energy expenditure. Results revealed that, in comparison to a sample of healthy adults from a previous investigation, as well as those scores reported for people with other chronic conditions, the MS group reported the lowest level of physical activity. The MS group also exhibited the largest difference between MAS and AAS scores, indicating average level of energy-demanding activities was much less than the maximum amount of energy they were capable of expending. In addition, physical activity, whether maximal or adjusted, was positively associated with aspects of general health, vitality, and physical and social functioning. The authors indicated that the positive influence of physical activity did not seem to pertain exclusively to formal or structured exercise programs, but also to other forms of physical activity, such as gardening and housework.

Physiological Responses to Exercise in MS

Although it seems participation in regular physical activity may influence psychological health for people with MS, the appropriateness of an exercise intervention largely depends on physiological tolerance and responses to exercise. Much of the research has established that people with MS can benefit from participation in exercise programs in the same way as people without MS (Petajan et al., 1996; Peterson & Bell, 1995; Svensson, Gerdie, & Elert, 1994). For people with MS, as with healthy individuals, the physiological response to exercise depends on type, duration, and intensity of training, as well as initial fitness levels. Tolerance to exercise in MS, however, may also be influenced by a number of factors relating to the disease, including duration of illness, level of impairment, and limitations imposed by exacerbation of symptoms. Ponichtera-Mulcare (1993) reviewed the literature between 1951 and 1993 on MS and physiological responses to acute and chronic exercise. The review investigated four main areas: autonomic function, cardiorespiratory fitness, skeletal muscle function, and the effects of exercise-induced temperature increases on MS-related symptoms. The reviewer noted that some physiological deficits are evident in people with MS during acute exercise, and may influence responses to exercise training. The review also established that for many people with MS, exercise can positively affect fitness levels without causing symptom instability. The author stated, however, that research findings appeared to be partially influenced by the level of neurological impairment of the experimental sample. Less impaired individuals tended to demonstrate training effects congruent with healthy individuals of a similar age. Research on more severely impaired participants showed less dramatic improvements in physical fitness. Ponichtera-Mulcare concluded that research needs to include a broad spectrum of impairment levels so that exercise protocols can be established for the MS population.

In MS there is evidence of dysfunction of the autonomic nervous system (ANS) with documented abnormalities in sexual and bladder function (Bakke, Myhr, Gronning, & Nyland, 1996). During physical stress, such as exercise, cardiovascular adjustments such as regulation of heart rate (HR) and blood pressure (BP) are almost entirely mediated by the ANS (Rowell, 1986). Researchers have demonstrated moderate abnormalities in HR and BP in MS populations at rest (Anema et al., 1992; Senaratne, Carroll, Warren, & Kappagoda, 1984; Sterman, Coyle, Panasci, & Grimson, 1985). This condition has implications for the safety and efficacy of exercise training for people with MS. Pepin, Hicks, Spencer, Tran, and Jackson (1996) examined the pressor and HR responses of 104 people with MS (mean EDSS of 4.0) during isometric handgrip exercise. The participants performed the handgrip exercise at 30% of their maximal voluntary contraction. Results from previous research have established that a sustained handgrip contraction is a reliable method for detecting HR and pressor responses to isometric exercise for people with MS (Pepin, Spencer, Hicks, Jackson, & Tran, 1998). Systolic blood pressure (SBP), diastolic blood pressure (DBP), maximal arterial pressure, and HR were recorded at rest, and at five intervals during the exercise. Twenty-five healthy people evaluated for normative pressor responses served as controls for the study, and pre-test HR and BP measures showed no difference between the groups. Results during the isometric exercise, however, revealed that, although HR increased normally with exercise duration, over half the MS sample exhibited attenuated pressor responses. This finding may mean that some people with MS cannot exercise at sufficient intensity or duration to yield the benefits of training. Inadequate pressor response may also compromise the safety of participating in exercise training. A number of studies, however, have not supported such abnormalities in autonomic cardiovascular function (ACF; Ponichtera-Mulcare, Glaser, Mathews, & Camaione, 1993; Ponichtera-Mulcare, Mathews, Glaser, & Ezenwa, 1992).

As the mechanisms governing ACF responses to isometric exercise are not identical to those operative during dynamic exercise, Ponichtera-Mulcare et al. (1992) measured ACF responses of 18 people with MS at rest, during sustained isometric exercise, and during dynamic exercise. Measures of HR at rest and DBP during sustained isometric handgrip showed no abnormal ACF responses. Following these tests, measures of HR and SBP were recorded while participants performed submaximal, incremental exercise on a recumbent leg ergometer. Results indicated responses to dynamic exercise to be normal and adequate to meet the exercise demand, even at maximal effort.

In another study, Ponichtera-Mulcare et al. (1993) examined HR responses of nine people with MS (EDSS ratings 1.0 to 4.0) and nine non-disabled individuals who comprised a control group. Both groups participated in a discontinuous dynamic exercise test with a final bout of continuous cycling on land and in water. They found normal HR responses in both exercise environments during the discontinuous and continuous exercise stages. In addition, only two individuals, one from each of the control and experimental groups exhibited abnormal pressor response to a sustained isometric contraction. It appears that, although some people with MS may experience abnormal ACF responses, data obtained during dynamic exercise has not been conclusive, and abnormalities may be related to disease progression. Among studies observing abnormalities, the samples have tended to include more highly impaired individuals (i.e., high EDSS ratings). Abnormal HR and BP responses to exercise represent probable evidence of lesions located on or near the neurons involved in ACF (Kosich, Molk, Feeney, & Petajan, 1987). Like other clinical manifestations of MS, autonomic dysfunction may alter in severity as duration of illness increases. Such findings indicate that a relationship may exist between duration of illness, level of impairment, and tolerance to exercise.

Researchers have also found that tolerance to exercise may be compromised for people with MS due to deficits in cardiorespiratory fitness. Much of the literature has focused on the comparison of MS groups with healthy individuals during acute exercise. Together with HR measures, Ponichtera-Mulcare et al. (1993) examined aerobic capacity in nine minimally-impaired people with MS (EDSS rating 1.0 to 4.0), matched with non-MS controls. The non-disabled group were matched to the MS participants in terms of gender, age, height, weight, and previous exercise participation levels. All participants completed four discontinuous five-minute stages, as well as a final stage of continuous exercise to maximal effort on land and in water. The VO2 outcome measures in this study were referred to as "peak," rather than "maximal" because it was representative of the highest VO2 attained by each participant. They found that VO_{2 peak} was similar for both groups until the final stage of continuous exercise, when a significantly lower $VO_{2 peak}$ was observed in the MS group in both environments. One of the strengths of this study is the comprehensive matching of the MS people to non-MS controls, particularly in terms of participation in exercise. As physical fitness was assumed to be similar for both groups, it appears that differences observed in cardiorespiratory measures may be due to involvement of the disease. Ponichtera-Mulcare et al. indicated that it is possible that motor weakness in the legs may have influenced output during the final stage of exercise. Weakness, spasticity, and localised fatigue are common motor symptoms in MS, that tend to occur to a greater extent in the lower extremities (Lenman, Tulley, Vrbova, Dimitrijevic, & Towle, 1989; Olek, 1999). A deficit in the exercising musculature would almost certainly contribute to the reduced ability of people with MS to perform dynamic exercise to the same extent as individuals without disability.

In another study, designed to diminish the influence of specific muscle fatigue, Ponichtera-Mulcare, Mathews, Glaser, and Gupta (1995) used three modes of exercise to compare the aerobic capacity of ten minimally-impaired people with MS (EDSS ratings 1.0 to 4.5) to healthy, non-disabled controls. The non-disabled group were chosen to reflect the MS participants as closely as possible in terms of gender, age, height, weight, previous exercise participation level, and "lifestyle." All participants performed a discontinuous, progressive intensity, submaximal exercise test on leg, arm, and combined leg and arm ergometry. Similar to the previous study, VO_{2 peak} was used to reflect maximal aerobic power. The results showed that $VO_{2 peak}$ was significantly lower for the MS group in comparison to the control group during all three exercise modes. The disparity, however, between the two groups was lower during exercise that combined the lower and upper extremities. Furthermore, the MS group achieved the highest VO_{2 peak} during the test using combined arm and leg ergometry. By matching the treatment and control groups on aspects of "lifestyle" and physical activity level, a similarity in terms of physical fitness was assumed. This assumption meant that factors relating to MS may have accounted for the differences observed. Ponichtera-Mulcare et al. indicated that aerobic capacity may have been limited in MS because of peripheral factors, such as muscle weakness and fatigue. Limitations due to localised symptomatology would also explain the inverse relationship observed between VO_{2 peak} and EDSS ratings, in that higher EDSS ratings are generally indicative of increased disability in the lower extremities. Studies of patients with upper motoneuron dysfunction have suggested that pathological changes in the CNS may alter the recruitment of certain muscle fibres (Miller, Green, & Moussavi, 1990), and therefore, compromise the ability of the muscles to exercise at an intensity necessary to elicit physiological benefits. Effective exercise programs designed to improve cardiorespiratory fitness for people with MS may need to eliminate the potential for localised fatigue.

Ponichtera-Mulcare, Mathews, Glaser, and Gupta (1994) compared maximal aerobic capacity in ambulatory (EDSS ratings 1.0 to 5.5) and semi-ambulatory (EDSS ratings 6.0 to 7.5) individuals with MS and non-MS controls. Results revealed that there was no

significant difference in VO_{2 max} between the ambulatory MS group ($\underline{n} = 20$) and the non-MS group ($\underline{n} = 10$). The semi-ambulatory MS group ($\underline{n} = 8$), however, demonstrated significantly lower VO_{2 max} than the other two groups. These results are problematic in that the absence of a significant difference may be due to low power as a result of the small numbers of participants in each subgroup. Unfortunately, power and effect size analyses were not reported. In addition, although the authors indicated that the severity of physical impairment may have contributed to the differences observed in cardiorespiratory fitness, they did not control for or mention the influence of initial fitness levels. Fully ambulatory individuals are more likely to have higher initial fitness levels than people requiring assistance to walk as little as 20 metres. Of more interest in this study is the similarity in maximal exercise test outcomes for the minimally-impaired MS group in comparison to the non-disabled control group.

Researchers have shown that cardiorespiratory adjustments during exercise may be related to respiratory muscle (RM) function in healthy individuals (Bye, Farkas, & Roussos, 1983). Deficits in RM function have been cited as possible explanations for documented reductions in aerobic capacity for people with MS. Foglio et al. (1994) demonstrated that exercise capacity appears to be reduced in people with MS, in conjunction with reduced RM function. Their investigation examined RM strength, endurance, and aerobic capacity in 24 people with MS (mean EDSS of 5.3). A continuous, progressive intensity arm ergometer was used to evaluate aerobic capacity by measuring VO_{2 max} and HR max. Foglio et al. found that VO_{2 max} and HR max were reduced in comparison to predicted normative values. Correlational analysis found that the reduction in aerobic capacity was associated with RM dysfunction. Furthermore, results revealed that RM function was significantly

inversely related to duration of illness. The altered RM function observed, however, may not necessarily represent physiological involvement of the disease, but may reflect the result of physical inactivity as the duration of the illness increases. RM dysfunction can, at least, be partially reversed with adequate physical training.

The available research appears to show that for people with MS, exercise capacity is reduced in a single bout of continuous exercise to maximal effort, in comparison to healthy controls. Of note, however, is the finding that minimally impaired people with MS often exhibit similar cardiorespiratory responses in comparison to healthy individuals during discontinuous exercise. The disparity in results between different exercise intensities may mean that dysfunction in the exercising musculature plays a major part in the ability to exercise for people with MS. This idea is reinforced by the findings that aerobic capacity tends to decline as physical impairment increases. The observed deficits for those with higher impairment levels may, in large part, reflect deconditioning due to inactivity as levels of physical impairment increases. Furthermore, these findings do not necessarily mean that people with MS cannot improve fitness in response to exercise training.

Schapiro, Petajan, Kosich, Molk, and Feeney (1988) found that less impaired people with MS (EDSS \leq 3.5) were able to exercise longer and achieve higher maximal intensities during a single bout of cycling than individuals having a higher EDSS rating (> 3.5). As noted in Ponichtera-Mulcare's (1992) review, because cessation of the exercise test was based on participant's rating of perceived exertion, other factors, such as MS-related muscle fatigue, may have contributed to the differences observed. Nevertheless, the study did find that improvements in cardiorespiratory fitness were evident for the whole sample after 16 weeks of home-based exercise training, although less impaired persons experienced greater improvements in fitness than those who were more severely disabled.

Gappmaier et al. (1994) established a more definitive relationship between the magnitude of intensity and duration necessary to elicit physical fitness improvements in a sample of people with MS. Twenty-six people with MS were recruited and assigned to either the treatment or control group. The participants were representative of mild to moderate impairment (EDSS ratings 1.0 to 6.0). The exercise group (n = 13) participated in three supervised sessions per week of combined leg and arm cycling for 15 weeks. Training consisted of 40 minutes of cycling per session at an intensity of approximately 60% VO2 max determined by maximal exercise testing prior to training. Results revealed the exercise group significantly improved VO_{2 max} by over 21% from baseline. The training effect was similar to that observed in people without MS. This finding indicated that physiological adaptations to training were close to normal for individuals with MS with impairment up to a moderate level. The study, however, does not provide more detailed individual impairment characteristics beyond a fairly wide range of EDSS scores. If, for example, the majority of participants were mostly minimally impaired (EDSS < 3.5), then the results are comparable with other studies on acute and chronic exercise (Ponichtera-Mulcare et al., 1992; Ponichtera-Mulcare et al., 1994; Shapiro et al., 1988).

White et al. (1994), in relation to the 15-week exercise program in the previous study (Gappmaier et al., 1994), provided information regarding exercise training and functional performance. Participants were tested for aspects of functional ability that included testing for gait abnormalities, balance, dexterity, and grip strength prior to, and following 35 minutes of aerobic exercise at 60% VO_{2 max}. The participants with MS

performed this single bout of exercise prior to, and following 15 weeks of exercise training. The results showed that there was no significant difference in functional performance after acute exercise in comparison to initial levels, regardless of the training effect produced by the exercise program. The study provided some evidence that aspects of functional performance for people with MS are not diminished from initial levels after the physical effort of a single bout of exercise. Although assessment of the 15-week training program was not the central focus of the investigation, the research indicated that 15 weeks of physical training did not affect the functional performance of gait, balance, dexterity, and grip strength. The reporting of no significant difference between groups in terms of functional performance, however, must be viewed with caution because of issues relating to low statistical power and possible Type II errors with such a small sample size (N = 26).

Petajan et al. (1996) evaluated the cardiorespiratory responses of people with mild to moderate MS (EDSS ratings 1.0 to 6.0) involved in three training sessions per week for 15 weeks (exercise group $\underline{n} = 21$, control group $\underline{n} = 25$). The training sessions were designed to improve aerobic fitness with individual workloads of 60% VO_{2 max} determined by a graded exercise test prior to training. By week 5 of the 15-week program, the exercise group had already significantly increased VO_{2 max} and physical work capacity (PWC) from baseline levels. After 15 weeks of training the exercise group exhibited a mean increase in VO_{2 max} of 22% and PWC of 48%. Even when the authors divided the exercise sample according to level of impairment (EDSS \leq 3.5, n = 14 and EDSS > 3.5, $\underline{n} = 7$), results indicated changes in VO_{2 max} from pre- to post-training were not related to level of impairment. Yet, this result is highly suspect because with such small subsamples the differences would have to be very large in order to approach statistical significance. The finding of no significant difference between the observed fitness gains and level of impairment, however, is consistent with results from the Gappmaier et al. (1994) study, but in contrast to the earlier study by Schapiro and colleagues (1988). The major difference between the studies is that the participants Schapiro et al. evaluated were involved in a home-based exercise program. It is possible that during unsupervised exercise people with higher levels of disability work at lower intensities, diminishing the magnitude of training adaptations. Lack of adequate training intensity may occur because more highly involved people with MS may be more concerned about "over-doing it." One can only speculate on the influence of attending physicians who regularly reinforce the notion that minimising physical activity can help preserve energy and reduce chronic fatigue. When differences in training method are accounted for, however, the results represent encouraging evidence that people with MS, up to moderate levels of disease severity, can show fitness improvements comparable to the healthy population.

In the most recent investigation, Ponichtera-Mulcare, Mathews, Barrett, and Gupta (1997) examined the effect of six months of training on 23 individuals with MS. The participants were divided into three groups representing ambulatory (EDSS ratings 1.0 to 4.5, $\underline{n} = 11$) and semi-ambulatory (EDSS ratings 5.0 to 6.5, $\underline{n} = 8$) individuals and a control group (EDSS ratings 1.0 to 6.0, $\underline{n} = 4$). The ambulatory and semi-ambulatory groups participated in three, 30-minute training sessions per week for six months at an intensity of 55-60% VO_{2 max}. Pre-training exercise testing revealed a higher VO_{2 max} for the ambulatory group in comparison to the semi-ambulatory group. Thus, as expected, initial fitness levels

were lower for the MS group experiencing greater disability. After six months of training the entire sample showed a mean increase in VO_{2 max} of 15%. The ambulatory group continued to show a higher mean VO_{2 max} while also exhibiting a mean increase in VO_{2 max} of 19% in comparison to a 7% mean increase for the semi-ambulatory group. The modest improvement in aerobic capacity for the more highly impaired individuals suggests that the efficacy of exercise training may have been compromised as the level of physical impairment increased.

At the conclusion of the 6-month training period, however, a number of the semiambulatory participants had experienced subtle declines in neurological functioning that did not register as exacerbations by neurological standards employed in the study. The decline for some of the participants may have affected the results for this group. When data for these participants were removed from the analysis, the mean increase in VO_{2 max} for the semi-ambulatory group increased to 16%, which is comparable to the ambulatory group. Perhaps the increased instability of clinical features in the more severely impaired individuals compromised physical training benefits. In the absence of disease progression, it appears that even people with MS with impairment levels that may restrict ambulation can achieve fitness benefits in response to long-term exercise programs. In addition, the observed deficits in aerobic capacity during acute exercise to maximal effort does not appear to compromise participation in moderate intensity exercise programs for mild to moderately impaired people with MS.

Researchers measuring muscular strength, endurance, power, and fatigue have shown that people with MS may exhibit deficits in skeletal muscle function (Armstrong et al., 1983; Chen, Pierson, & Burnett, 1987; Ponichtera-Mulcare, Rodgers, & Glaser, 1992). It seems that these deficits may play a role in the attenuated response to maximal exercise testing, and may affect the ability of people with MS to benefit from physical training. Although case studies provide limited data, a number of reports have indicated that exercise training can positively influence aspects of skeletal muscle performance for people with MS. Woods (1992) described two case studies involving long-term aquatic exercise designed to develop muscular strength. One of the participants sustained an exacerbation during the aquatic program, and physical abilities were severely diminished. The other participant, however, improved muscle strength and endurance demonstrated by increased independence in activities of daily living and increased exercise activities during the aquatic sessions.

Svensson, Gerdie, and Elert (1994) involved five individuals with MS (EDSS ratings 2.0 to 7.0) in four to six weeks of muscular endurance training for the lower extremities. Each participant was evaluated pre- and post-training by 50 repeated maximum knee flexions. After training, three of the five individuals indicated some improvement in muscular endurance. In addition, perception of fatigue, as indicated on a visual analogue scale, decreased along with improvements in well-being for four of the five participants. The study also used electromyographic (EMG) recordings on the exercising muscles to indicate whether fatigue experienced during the endurance test was of peripheral or central origin. The results demonstrated that peripheral fatigue reported in the muscles was not accompanied by a shift in the EMG signal, which suggested that the fatigue experienced during the endurance test was of mainly central origin. The authors suggested that central origin fatigue in MS may be an indication of upper motoneuron dysfunction that influence the ability of people with MS to strengthen specific muscle groups.

Investigating the effects of a 10-week exercise program, Gehlson, Grigsby, and Winant (1984) found that people with MS can positively improve muscle performance through training in much the same way as healthy populations. The training consisted of three one-hour sessions of freestyle swimming and callisthenics per week. Pre-, mid-, and post-exercise measures for isokinetic peak torque, power, work, and fatigue were taken for ten people with MS (EDSS not reported). Significant improvements from pre- to post-test were evident in the lower extremities for work and fatigue. Although there were improvements from pre- to mid-test for peak torque, there was a decrease in the second five-week training period. In the upper extremities, significant increases occurred in force, power, and work. Measures of fatigue, however, showed a 14% increase. An increase in fatigue in the muscles most heavily involved in the training modality (i.e., freestyle swimming) was an interesting finding that the authors did not explore. It is possible that the isokinetic exercise tests did not adequately duplicate the movement and effort required during the training, in that isokinetic exercise necessitates maximal effort over the full range of motion. The study also contained a number of other methodological problems limiting its generalisability. The small sample size ($\underline{N} = 10$) without a control group made quantifying the observed changes difficult, as did discrepancies in testing protocols for different muscle groups. In addition, characterising the participants as "ambulatory" makes the study difficult to compare with other studies using EDSS ratings.

Petajan et al. (1996) reported improvements in maximum isometric strength for people with MS (EDSS ratings 1.0 to 6.0) after 15 weeks of aerobic training. Although the muscular strength of the exercise group was initially weaker than the control group, upper and lower extremity strength of the exercise group demonstrated improvements after 15 weeks of training. Measures of upper extremity strength showed significant improvements, and although results showed improved strength in the lower extremities, most of the changes were not significant. Differences between training adaptations for the upper and lower extremities could not be explained by the training methods because the exercises consisted of combined leg and arm ergometry. This mode of ergometry, however, can unevenly disperse the magnitude of effort between the arms and legs. The relative percentage of power output for the arms for the particular type of ergometer used in this study was not reported. Nevertheless, the exercise program was not specifically strength oriented, yet improvements were observed with no detrimental effects to motor or other MS-related symptoms.

It seems clear that some people with MS may experience aberrant physiological responses to exercise. Exercise training seems to be tolerated for mild to moderately impaired people with MS, despite some observed deficits in autonomic, respiratory, and motor function during acute exercise. As level of impairment increases, however, the ability to exercise, and the associated risks, may limit participation in physical activity. Unfortunately, there is a lack of scientific data regarding the exercise responses of people with MS over a broad range of impairment levels. Most of the studies to date have not included participants fully dependent on ambulation aids, such as wheelchairs, or those people with high levels of neurological impairment. Although conducting exercise studies on such severely impaired individuals is obviously problematic, there is a need to understand how level of impairment and duration of illness in MS affect tolerance to physical training. In addition, research to date has not determined if some of the deficient physiological responses to exercise are related to disease pathology or to secondary disease

factors, such as mobility problems leading to deconditioning. With sufficient precautions, however, it appears that the majority of people with MS experiencing mild to moderate disability can benefit physiologically from exercise.

Exercise, Temperature, and Symptom Instability in MS

Exercise prescription guidelines for people with MS often advise individuals to avoid increases in body temperature because symptoms may appear or increase in severity for a short period of time (Peterson & Bell, 1995; Poser & Ronthal, 1991; Rosenthal & Scheinberg, 1990). Research investigating the effects of increased endogenous temperature on MS symptomatology has had a long and controversial history (Guthrie & Nelson, 1995). Studies, dating back to the early 1950s, have used a range of techniques, from hot water immersion to ingesting hot soup, to increase core body temperature in people with MS (Accorneo, DeVito, Rotunno, Perugino, & Manfredi, 1989; Namerow, 1971; Nelson & McDowell, 1959). Studies have reported a variety of symptom exacerbations, most being ophthalmological, and in some cases, permanent neurological deficits have been reported (Berger & Sheremata, 1983). Despite the obvious ethical problems of some of the research, they have provided evidence that temperature increases of as little as 0.1°C can result in the appearance of transient neurological symptomatology. Although consensus on the mechanism responsible for reaction to heat has not been reached, research has established a relationship between temperature, demyelination, and nerve conduction (Guthrie & Nelson, 1995). Specifically, temperature elevation may lead to a reversible block in the conduction of action potentials in demyelinated neurons. The temperature at which such a conduction block occurs is thought to be related to the degree of demyelination, with more damaged axons susceptible to blockage with smaller temperature increases (Schauf & Davis, 1974).

Considering that activity involving large muscle groups is associated with increases in endogenous temperature, suprisingly few studies have examined the effects of exerciseinduced hyperthermia on MS symptom stability. In a case study, Namerow (1968) used measures of visual acuity (VA) to document symptom instability from temperature increases in response to exercise on a bicycle ergometer (no EDSS score reported). The study reported no VA deficits during the exercise until oral temperature increased 0.3° C from baseline, when VA deteriorated dramatically. This finding, however, must be viewed with caution because an increase in temperature as measured via an oral method is not necessarily indicative of core temperature increases.

Without directly measuring temperature, van Dieman, van Dogen, Dammers, and Polman (1992) also reported visual function deficits in two case reports after 15 minutes of low intensity exercise (no EDSS score reported). The participants involved in the research reported experiencing visual problems that deteriorated with increases in endogenous and ambient temperature. The study provided some evidence that temperature increases during exercise affect MS symptoms, with results indicating that VA and contrast sensitivity decreased after the exercise session. Further testing revealed less pronounced visual deficits when two different methods of body cooling were used during similar intensity exercise. Although it seems obvious that people who report symptoms in response to environmental or body temperature increases will experience similar symptom exacerbation in response to exercise, it is an important consideration when advising people with MS about safe and effective modes of exercise. This study reinforces the idea that the idiosyncratic nature of symptoms in MS may require individual assessment for exercise prescription. Ponichtera-Mulcare et al. (1993) measured core temperature rectally in nine people with MS (EDSS ratings 1.0 to 4.0) during exercise on land and in water. Participants engaged in four discontinuous submaximal exercise stages, and a final stage of continuous cycling until maximum effort in both environments. The mean change in core temperature over the test period was 0.1°C on land and -0.1°C in water. Although direct measures of symptom instability were not recorded, anecdotally, participants reported experiencing no symptoms during or after the exercise testing besides general fatigue. In addition, the benefit of the heat dissipation properties of water did not affect exercise performance in terms of intensity or endurance. The participants did, however, report that the perception of physical stress during exercise in water was diminished. Although it appears that the mean temperature change in both environments was not enough to affect effort during exercise, the results provide useful information for the development of exercise perscription for people with MS. If water is perceived as a less stressful environment in which to exercise, it is likely that individuals with MS will be more motivated to exercise, have increased adherence, and will perform at intensities sufficient to elicit health benefits.

Much of the exercise and MS research has not measured temperature increases during either acute or chronic exercise, yet most studies have noted that people with MS can exercise without exacerbating MS-related symptoms (Petajan et al., 1996; Ponichtera-Mulcare et al., 1997; Ponichtera-Mulcare et al., 1995; Woods, 1992). In most instances, general fatigue is the only symptom reported by people with MS, and general fatigue is also reported by healthy people following exercise. It is unfortunate, however, that much of the existing research has not enhanced our understanding of heat sensitivity and symptom instability by measuring changes in body temperature during exercise. Although more clinical investigations are required in order to provide adequate exercise guidelines for people with MS concerned about symptom instability, there are numerous ethical difficulties. Specifically, any research on exercise and MS that intentionally raises core body temperature may be ethically suspect because of the potential for neurological damage.

Psychological Responses to Exercise in MS

Researchers investigating exercise responses of people with MS have primarily conducted investigations using neurological or physiological variables. Such narrowly defined outcome measures are common to exercise and MS research. This research has recently been criticised for not incorporating psychological outcome measures, such as general well-being and HRQOL (Brunet, Hopman, Singer, Edgar, & MacKenzie, 1996; Nortvedt, Riise, Myhr, & Nyland, 1999). HRQOL has been identified as an important measure when evaluating interventions for chronically disabled people (Devinsky, 1995). In addition, there is an increasing recognition of the importance of the individual's point of view in assessing the experience and outcomes of medical care (Freeman, Langdon, Hobart, & Thompson, 1997). Interpretations of neurological and physiological changes do not indicate whether individuals with MS, after an intervention such as exercise, function better in the physical, mental, and social aspects of life. The idea that an individual's perception is an important part of monitoring and evaluating heath care strategies is the essence of HRQOL measures.

Research investigating the effect of physical activity on psychological health in MS is limited. Assessment of rehabilitation programs that include physical therapy constitutes the bulk of the literature. Two studies to date have assessed rehabilitation in MS using

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measures of psychological health. Di Fabio, Choi, Soderberg, and Hansen (1997) evaluated the influence of a rehabilitation program on the HRQOL of people with MS. Participants (n = 12) diagnosed with chronic progressive MS (EDSS ratings 5.0 to 8.0), who received weekly comprehensive outpatient rehabilitation, were compared with a similar control group (n = 19). The rehabilitation program was similar to previously described programs, and included physical, occupational, cognitive, and psychotherapeutic, as well as spiritual and social work services. The authors used Cohen's (1988) conventions for effect size to demonstrate the magnitude of change in HRQOL. The results showed that although both groups experienced a decline in physical function over the course of the year, the functional status of the control group declined more than the status for those involved in the rehabilitation program (treatment group $\underline{d} = -.33$ vs. control group $\underline{d} = -.52$). In addition, there were small to medium positive effects, that were not noted for the control group, for aspects of physical health, fatigue, cognitive ability, role limitations due to physical and emotional health, and social function for the treatment group. There was also a considerable change in overall health perception from the previous year for the participants involved in the rehabilitation program. The positive change in overall health perception did not appear to be related to disease progression, considering physical function declined over the course of the program. This finding suggests that the influence of rehabilitation on a person's perception of health and well-being cannot be predicted by traditional measures that only assess physical impairment and disability.

In another study, Freeman, Langdon, Hobart, and Thompson (1999) measured the long-term effectiveness of a brief inpatient rehabilitation program on functional abilities, disability status, and psychological health for people diagnosed with progressive MS. Moderately to severely disabled people with MS (N = 44; EDSS ratings 6.0 to 9.0) were admitted for an average of 23 days for comprehensive rehabilitation as previously described and assessed at pre- and post-treatment, as well as at three-month intervals for one year. Results indicated that despite deterioration in neurological and disability status, participants improved, and for the most part, maintained aspects of physical and mental health over the study period. The design of the research, however, was flawed somewhat by the lack a comparison group. In addition, the results from this study must be considered a function of the multidisciplinary nature of the programs. Comprehensive rehabilitation programs in MS reveal little about the effect of exercise alone on psychological health in MS. To date, there is only one study that specifically assessed the effect of physical rehabilitation on HRQOL in MS.

Solari et al. (1999) evaluated the influence of an inpatient physical rehabilitation program on physical disability and HRQOL for people with MS. Mild to moderately disabled people with MS ($\underline{n} = 27$; EDSS ratings 3.0 to 6.5) received three weeks of supervised physical training, as well as instructions for home-based training at the conclusion of the three-week period. A similarly matched group of people with MS ($\underline{n} =$ 23), who received only home-based exercise training instructions, acted as the control group. Measures were taken at baseline, week 3, 9, and 15, and results indicated no change in physical impairment, as measured by the EDSS, for either the treatment or control group at any of the measurement intervals. The results showed moderate to large effects for functional abilities, such as mobility, self-care, and locomotion, for the treatment group. The effect sizes for some measures, however, varied considerably at each measurement interval. For example, mobility showed a very large effect ($\underline{d} = .9$) at week 3, but only a small effect (d = .3) at week 9 for those in the treatment group. Although this result may be indicative of the variability in the way physical symptoms manifest in MS, the authors did not explore this finding. The treatment group also showed improvements that were not noted for the control group in aspects of general and mental health (at week 3, 9, and 15). vitality (at week 3 and 15), emotional well-being, and social functioning (at week 9). Composite scores were also calculated for physical and mental health. Significant differences between the treatment and control groups were only evident on the mental health composite score week 3 and 9. Unfortunately, effect sizes were not reported for the HRQOL data. In terms of demonstrating the efficacy of physical training in MS, it may seem inappropriate that both the treatment and control group were instructed in physical training. The results, however, indicated that those who were initially involved in the inpatient, supervised exercise program elicited greater improvements in physical and mental health than those who only exercised at home. The study did not report the extent to which participants from either of the groups adhered to the home-based exercise program. Perhaps being involved in a supervised program, even for a relatively short period of time, increased motivation and adherence to exercise for those in the treatment group. It is an encouraging finding that the positive change in mental health scores for the treatment group was sustained for a period after inpatient training ceased. The results provided some evidence that physical rehabilitation in MS is efficacious, and highlight the importance of supporting initiation of behaviour change to increase participation in physical activities.

Despite the finding that physical therapy may enhance HRQOL and general wellbeing in MS, few studies have investigated the effect of exercise training outside the rehabilitation setting. Stuifbergen (1997) reported on four case studies involving a six-week swimming program. Selected subscales of the SF-36 (Hays, Sherbourne, & Mazel, 1993) were reported for each of the female participants pre- and post-training, and at 6 months. Results revealed that all participants involved in the exercise program positively improved vitality post-exercise. Improvements were also noted for some of the participants on physical functioning, and mental and emotional well-being. Results indicated a decrease in social functioning for two of the four participants. The authors proposed that the people in this study may have experienced difficulties integrating a structured exercise program into their daily lives. Although it is unclear whether any of the participants continued to be involved in regular physical activity after the six-week training period, results revealed that most scores returned to baseline six months after the exercise program. This result once again highlights the importance of supporting, not only exercise adoption for people with MS, but also the maintenance of activity change over time. Nevertheless, the results of this study must be interpreted with caution due to the small sample size and limitation in research design.

Researchers have found that alternative modes of physical activity may also positively influence psychosocial health in MS. Husted, Pham, Hekking, and Neiderman (1999) examined the influence of tai chi on physical functioning and HRQOL for people with MS. Participants with MS (N = 19) were involved in an eight-week tai chi program specifically adapted for those experiencing mobility problems. Measures of physical health included walking speed over 25 feet and hamstring flexibility, and HRQOL was measured using the SF-36 (Hays, Sherbourne, & Mazel, 1993). Results demonstrated that participants increased walking speed by 21% and improved hamstring flexibility by 28%. In addition, there were notable improvements in vitality, social functioning, mental health, and reductions in role limitations due to physical and emotional problems. Many of the participants, anecdotally, attributed benefits to the supportive environment engendered by participating in a group. Although the positive results provided the impetus for the implementation of tai chi classes for people with MS, the study had several limitations. Apart from the problems associated with conducting non-randomised and non-controlled research, the authors also did not adequately describe the characteristics of the sample. Without knowledge of physical and neurological impairment or symptomatology of the participants, it is difficult to describe who may benefit from such as intervention.

To date only one published study has investigated the effect of aerobic exercise on HRQOL in MS, in comparison to a sedentary control group. Petajan et al. (1996), mentioned earlier in this chapter, examined aspects of psychological health in 21 ambulatory persons with MS. Measures included the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1981), Sickness Impact Profile (SIP; Gibson, Bergner, & Bobbit, 1979), and the Fatigue Severity Scale (FSS; Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). Measures were taken at baseline and at each five-week interval of the 15week program. Results indicated that the exercise program significantly improved a number of components of mental health status.

Specifically, participants in the treatment group significantly reduced scores for depression, anger, and fatigue as measured by the POMS. The most improved scores relating to affect and mood occurred at week 10, with a partial reversal of some psychological variables at week 15. There were no significant changes for any of the items on the FSS. This result is in contrast to the finding that the treatment group decreased fatigue as measured by the POMS. Although the authors suggested that the FSS may not have been sensitive to marginal changes in perception of fatigue, the small sample size may have also contributed to the non-significant results.

A number of researchers have argued that "non-significant" results do not necessarily mean that there was no "real difference," and that reporting effect size. particularly in studies with small sample sizes, may provide a more meaningful way to determine the effects of an intervention (Andersen & Stoové, 1998; Cohen, 1990; Speed & Andersen, 2000). Petajan et al., however, did not provide data so that effect size could be calculated, and thus the results must be viewed with caution. Change scores for the SIP mirrored the pattern of scores for the POMS, in that the most improved scores, relating to ambulation, body care, movement, social interaction, and emotional behaviour were evident at week 10, but not at week 15. The researchers concluded that anticipation of the end of the program, and thus, the removal of the social interaction inherent in group exercise, may have contributed to the reversal of many improvements at week 10. The authors also indicated that social interaction promoted by programs whereby participants exercise in groups may nebulise the effects of exercise alone. Nevertheless, such positive findings have provided a foundation for investigating exercise as a complementary therapy for people with MS for enhancing physical and psychological health.

Exercise has only recently been recognized as a viable therapy for people with MS. It is an intervention that is non-invasive and avoids the potentially negative effects of many of the pharmacological therapies designed to alleviate MS symptoms. Despite significant progress made in terms of new pharmacological treatments, it is increasingly clear that such therapies may not be adequate for a population needing a high level of health care service over the long term (Johnson, 1996). The limited research available provides evidence that exercise as therapy for people with MS moves beyond health care services that deal almost exclusively with symptoms and complications. It appears that exercise training can enhance general well-being for people with MS, while offsetting some of the typical psychological difficulties, including fatigue, stress, and depression.

Exercise Guidelines for MS

There are few resources available on exercise prescription for the MS population, primarily due to the inherent variability of the disease and the historical prescription to avoid exercise. In most cases, the literature emphasises that exercise training guidelines should be tailored to met individual circumstances in terms of medications, exacerbations, and recovery stages (Petajan & White, 1999; Rosenthal & Scheinberg, 1990). In addition, guidelines are usually only relevant for those with mild to moderate physical impairment. Aquatic activities are generally considered the most appropriate mode of exercise (Peterson & Bell, 1995; Poser & Ronthal, 1991). Water offers several unique properties that appear to be advantageous for the MS population. Given the prevalence of gait and balance problems in MS, water can provide buoyant support allowing movement that may be difficult to achieve on land. An aerobic workout for the upper and lower extremities is also possible with the resistant properties of water allowing for flexibility in training effort. Furthermore, because sustained activity may result in increased core body temperature, which may worsen symptoms in some people with MS, water provides an exercise environment with optimal heat dissipation. Other guidelines closely resemble those available for healthy populations, and are therefore not appropriate or relevant for people with MS who have more severe impairment.

To date, guidelines for severely impaired persons with MS are mostly drawn from activities suited to other chronic conditions, such as stroke or spinal cord injury. Rosenthal and Scheinberg (1990) recommended that exercises designed to maximise independence, such as strengthening muscles used for activities of daily living, were the most appropriate for individuals with severe physical impairments. Recently, Petajan and White (1999) published recommendations for exercise in MS and highlighted the need to increase activity levels for functional performance before initiating more active recreational or structured exercise programs. The physical rehabilitation program evaluated in the study by Solari et al. (1999) provide an example of the type of exercises appropriate for individuals with MS across a range of impairment levels. The program included passive and active interventions (depending on the severity of disability), as well as physical therapy for balance, coordination, gait, and range of motion for those using mobility aids and orthoses. Much of the exercise and MS research has noted that exercise for people MS is highly recommended and the advantages of being physically active far outweigh any side effects, such as increased susceptibility to fatigue.

Cognitive-Behavioural Interventions and Multiple Sclerosis

The possibility that negative psychological health status alters the course of MS has been debated since the time Charcot (1879) first commented that grief, worry, and adverse social circumstances may influence disease onset and exacerbations. Although researchers have not demonstrated a distinct relationship between disease activity and emotional states in clinical studies (Goodin et al., 1999), it is clear that MS is associated with profound social and psychological consequences (Murray, 1995). Chronic illnesses, such as MS, are disruptive, and may interfere with employment, social networks, sexual and family relationships, future plans and expectations, and general activities of daily living (Lechtenberg, 1995). A substantial component of distress for people with MS may also be due, in part, to anxiety about the unpredictable occurrence or re-occurrence of symptoms and disabilities (Miller, 1997).

Not suprisingly, high levels of psychological distress associated with anxiety, depression, and reduced general well-being have been reported in MS populations (Rudick, Miller, Clough, Gragg, & Farmer, 1992). Given the challenges posed by the disease. efficacious cognitive-behavioural interventions designed to facilitate the coping process and enhance HRQOL may play an important role in the comprehensive treatment of MS. Numerous studies have shown that a variety of cognitive-behavioural techniques may reduce distress and improve HRQOL for people with chronic, episodic, and life-threatening illnesses (Achterberg, McGraw, & Lawlis, 1981; Eller, 1999; Elsesser, van Berkel, Sartory, Biermann-Goeke, & Ohl, 1994; Kaplan, Goldenberg, & Galvin-Nadeau, 1993; Lundgren & Stenstrom, 1999). Some interventions have also shown beneficial effects in modulating immune function for various chronic illnesses, such as some cancers and acquired immunodeficiency syndrome (AIDS; Golden & Gersh, 1990; McCain, Zeller, Cella, Urbanski, & Novak 1996). A primary intervention for anxiety and worry is relaxation, and its use in the management of MS is growing (Lechtenberg, 1995).

Relaxation Interventions

Cognitive-behavioural interventions have been widely used in research to determine their effects on physical and psychological health in clinical and non-clinical populations. These interventions have generally been implemented as multicomponent "packages," comprising relaxation skills training, cognitive restructuring techniques, assertiveness and social skills training, and instruction in self-monitoring of environmental stressors (Lichstein, 1988). Although relaxation techniques have frequently been used as components of cognitive-behavioural therapy, relaxation training is by far the most comprehensively studied and widely applied cognitive-behavioural technique (Poppen, 1998). A variety of relaxation strategies have been used in clinical research, and despite their apparent diversity, techniques such as meditation, progressive muscular relaxation, guided imagery, and autogenic training all share a common underlying set of physiological changes that constitute the relaxation response (Benson, 1989). Relaxation training techniques are designed to attenuate physiological responses to acute and chronic stress, and have been associated with improvements in psychological health status among ill populations (Baum, Herberman, & Cohen, 1995).

A number of studies have examined relaxation training for people with inflammatory rheumatic diseases, such as rheumatoid arthritis (RA). RA. like MS, is considered an autoimmune disorder, and is generally characterised by unpredictable disease progression, which results in erosion of cartilage and joint-cavity destruction (Young, 1992). In addition, exacerbation of disease activity in RA has been associated with psychological distress (Achterberg, 1982). Although much of the literature has examined the effect of relaxation training on disease progression and functionality in RA (Young, 1992), some studies have also evaluated the effect of relaxation on psychological wellbeing and HRQOL.

Lundgren and Stenstrom (1999) evaluated the influence of progressive muscular relaxation (PMR) training on the HRQOL, muscle function, and disease activity of individuals with RA. The authors noted that 10 weeks of PMR appeared to have physical and psychological benefits for people with an unpredictable and debilitating disease, such as RA. Such results were consistent with previous research using relaxation training as therapy for people with RA (Acterberg, McGraw, & Lawlis, 1981; Kraaimaat, Brona, Geenen, & Bijlsma, 1995). In another study, Stenstrom, Arge, and Sundbom (1996) compared the effect of exercise and relaxation training on HRQOL and physical function for people with rheumatic diseases. The exercise and relaxation programs involved homebased training for three months. Results indicated that the relaxation training significantly improved joint tenderness and muscle function, as well as a number of aspects of HRQOL (e.g., energy). The authors noted that relaxation training may actually be superior to dynamic training for people with high levels of physical disability.

Enhanced psychological health status has been recognised as an important benefit of relaxation training via studies involving people with life-threatening illnesses. Researchers have provided evidence from prospective, randomised, and controlled studies that relaxation training can enhance HRQOL and general well-being for people diagnosed with some cancers (Baider, Uziely, & Kaplan-De-Nour, 1994; Elsesser et al., 1994; Larsson & Starrin, 1992). Researchers have also shown that relaxation training has benefits as an adjunct therapy to reduce physical and psychological side effects associated with some forms of cancer treatment, such as chemotherapy (Decker, Cline-Elsen, & Gallagher, 1992; Vasterling, Jenkins, Tope, & Burish, 1993). Relaxation training has also been shown to modulate immune system functioning in a way that may be relevant to the progression of diseases associated with immune dysfunction, such as HIV/AIDS (Baum, Herberman, & Cohen, 1995; Zakowski, Hall, & Baum, 1992).

In general, studies in the HIV/AIDS population have shown that relaxation training, combined with other cognitive-behavioural techniques, is associated with improvements in several markers of immune functioning, as well as positive changes in a number of psychological variables, including mood, anxiety, self-esteem, and HRQOL (Antoni et al., 1991; Eller, 1995, 1999; McCain, Zeller, Cella, Urbanski, & Novak, 1996; Taylor, 1995). Although many of the studies have employed a variety of cognitive-behavioural interventions, combined with relaxation training, Antoni et al. (1991) found that frequency of relaxation practice was correlated with positive changes in some psychological variables, such as depression. The authors concluded that the relaxation component of the program may have been an important determinant in the positive changes noted in psychological health status.

Psychological Responses to Relaxation in MS

Although researchers have provided some evidence that relaxation techniques may positively affect physical and psychological health for people with a variety of chronic medical conditions, research investigating relaxation training in MS is limited. The use of cognitive-behavioural interventions in MS dates back to the 1950s, but the literature primarily comprises group studies of psychodynamic therapy (Day, Day, & Hermann, 1953; Larcombe & Wilson, 1984), psychodrama therapy (Langenmayr & Schöttes, 2000), psychoeducational programs (Barnes, Busse, & Dinkin, 1954), and programs designed to enhance coping strategies (Mohr et al., 2000). To date, there are few studies that have investigated the effect of relaxation training on psychological health status of people with MS.

Crawford and McIvor (1987) investigated the influence of relaxation training, combined with other cognitive and behavioural strategies, on psychological adjustment in MS. Moderate to severely disabled people with MS ($\underline{n} = 34$), who participated in a weekly program for 10 weeks, were compared with a similarly categorised control group ($\underline{n} = 21$). Participants were encouraged to practice the relaxation techniques between formal sessions. Three follow-up sessions were also conducted six weeks after the conclusion of the study. Four subscales (depression, anxiety, vigor, and fatigue) of the POMS (McNair et al., 1981) were used to assess psychological adjustment. The results indicated that the reduction in depression and anxiety, and increase in vigor were statistically significant, with moderate effects for those individuals participating in the relaxation therapy. The fatigue subscale, however, showed a small, non-significant effect ($\underline{d} = .16$). The authors concluded that the positive changes in mood indicated that interventions designed to reduce stress may be viable treatment options for psychological distress in MS. There are, however, a number of limitations of the study. First, it is unclear why the authors omitted the confusion and anger subscales from the POMS. Second, it appears that measures were not taken at the conclusion of the follow-up sessions conducted after a six-week respite. Such information may have provided a valuable insight into the sustainability of the positive effects of the relaxation strategy over time. Finally, as the authors noted, structuring the program so that individuals participated in a group setting may have contributed to the positive results evident in the research. Providing an environment whereby persons with MS can share experiences more than likely affects perception of social support, encourages social interaction and may, therefore, affect mood states, such as tension and depression.

In contrast to the previous study using a group-oriented relaxation program, Foley, Bedell, LaRocca, Scheinberg, and Reznikoff (1987) examined the effect of individualised stress inoculation training (SIT) on a number of aspects of psychological health status for people with MS. All participants in the study (N = 41) were part of an outpatient program, and thus, received continued care involving psychotherapeutic and medical interventions. A subset of the sample ($\underline{n} = 24$; EDSS ratings 1.0 to 8.0) formed the treatment group. These participants also received six sessions of SIT over a five-week period. The training involved cognitive-behavioural procedures designed to prevent maladaptive psychological responses to stress and enhance coping strategies, as well as individually adapted progressive muscular relaxation (PMR) training. Results revealed that the treatment group showed positive changes that were not noted for the control group, in depression, state anxiety, coping with daily stressors, and problem-focused coping efforts. Although the authors stated that there was no significant difference between groups on personality factors of locus of control and trait anxiety, there was actually a moderate effect for trait anxiety $(\underline{d} = .43)$. For no apparent reason, baseline and post-test data were not available for locus of control. The SIT did not appear to change neurological or functional disability level, and the authors concluded that because improvements for the treatment group could not be attributed to naturally occurring remission of symptoms, the positive changes were more than likely a function of the SIT. The results are also distinctive because the control group received a variety of psychological interventions and support during the study period. The authors concluded that specialised relaxation and stress management programs appear to be superior to non-specific psychological interventions for helping people with MS cope with psychosocial problems associated with chronic illness. In addition, six-month follow-up

data on a subgroup of participants in the treatment group ($\underline{n} = 10$) demonstrated that improvements were mostly maintained from post-test measures. Although caution is warranted because only 10 participants completed follow-up data, the results indicate that a relatively brief intervention may be effective for addressing psychosocial problems in MS over the long term.

In a more recent investigation, Maguire (1996) examined the effect of relaxation and imagery on mood and attitudes for people with MS. The treatment group (n = 15) were involved in six, one-hour sessions that included PMR and imagery. Audio tapes of the relaxation and imagery program were provided, and participants were asked to practice daily throughout the duration of the study. Measures were taken prior to, and at the conclusion of the study, and included mood (POMS; McNair et al., 1981), state and trait anxiety (State-Trait Anxiety Inventory; STAI; Spielberger, 1983), beliefs about causes and cures of illness (Health Attributions Test; HAT; Achterberg & Lawlis, 1990), and an MS symptom checklist. Results indicated that state anxiety, as measured by the STAI, was the only variable that showed a significant difference between groups. The participants in the imagery program were significantly less anxious than those people in the control group at the conclusion of the study. Similar to the previous investigation using PMR (Foley et al., 1987), trait anxiety remained relatively stable for both groups during the study period. The treatment group also remained relatively stable on the "internal control of health" subscale of the HAT, whereas scores for the control group indicated a shift to less internal locus of control. The authors noted that assignment of participants to the control group may have negatively influenced perception of internal control of health.

The results revealed no significant change for the treatment group in symptomatology or any of the mood variables. Although previous research has indicated that relaxation training for people with MS may positively affect mood (Crawford & McIvor, 1987), the different relaxation techniques employed make comparison between studies problematic. In addition, results showed that mood scores for the treatment group prior to the commencement of the study were similar to mean values from a comparative, healthy sample. Perhaps changes were not evident because the mood states of participants with MS in the study sample were relatively positive prior to the intervention.

The non-significant results for each of the mood subscales, however, does not necessarily mean that there was no meaningful change for those in the treatment group. Low statistical power in this study may have increased the risk of making a Type II error, and thus, the non-significant result may have been due to the small sample size (N = 33). Although effect size is increasingly being recognized as a more meaningful way to evaluate the outcomes of an intervention (Andersen & Stoové, 1998; Cohen, 1990; Speed & Andersen, 2000), data was not provided to calculate effect size in this research. The authors also indicated that the brevity of the imagery program may have influenced the results, particularly aspects of locus of control and trait anxiety, and that future research should assess extended relaxation programs for people with MS.

The limited research available provides evidence that relaxation training in MS can offset some of the psychological problems associated with the disease, such as depression, stress, and anxiety. Unfortunately, to date, there are no published studies evaluating the influence of relaxation on HRQOL in MS. The need for such studies is critical for several reasons. MS typically affects physical, mental, and social functioning, and thus, outcome measures in relaxation intervention research in MS should focus on clearly establishing the scope of the therapeutic effects. Researchers evaluating the effect of relaxation training on HRQOL in other chronic disease populations have found results that may be clinically relevant to MS. For example, Stenstrom, Arge, and Sundbom (1996) found improved physical function, along with increases in energy level in RA patients after relaxation training. Considering physical disability and fatigue are common problems in MS that potentially affect other aspects of psychosocial health in this population, it is clear why evaluation of relaxation training needs to measure disease burden more broadly.

Autogenic training (AT) has been previously described as the therapeutic relaxation intervention of choice in Europe (Pikoff, 1984), yet the technique is not well known or practiced in Australia. Nevertheless, there is a strong research base supporting AT as viable form of relaxation for improving general health and well-being in a variety of clinical populations (summarised in Linden, 1990). These positive findings have provided the basis for investigating AT as a relaxation therapy for improving psychological health for people with MS.

Autogenic Training (AT)

The word autogenic means self-regulation or self-generation, and AT is based on self-suggestion. It is a psychophysiological relaxation technique that individuals carry out themselves by the use of passive concentration (Benor, 1996). The technique originated in the early part of the 20th century in Germany. Johannes Schultz, based on reports from hypnotised clients, formulated a technique by which individuals could self-generate physical sensations associated with relaxation, which often occur spontaneously during hypnosis, by the silent repetition of physiologically-oriented phrases. The AT technique published by Schultz and Luthe (1969) comprises standard verbal exercises emphasising heaviness in the limbs, peripheral warmth, cardiac and respiratory regulation, warmth in the abdominal region, and coolness of the forehead. The formulas are presented in a prescribed sequence, so that the bodily sensations of warmth and heaviness relax the body, and then the use of imagery extends this relaxed state (Greenberg, 1993). Schultz and Luthe speculated that, during the practice of AT, the warm sensations were a function of dilation of the blood vessels, and that the perception of heaviness was caused by the muscles relaxing. Because both vasodilation and muscular relaxation are physiologic components of the relaxation response (Benson, 1975), AT has been used as a relaxation technique in a variety of clinical populations. Unlike some other forms of relaxation training, such as PMR, AT does not require a conscious, active effort to relax the muscles. One of the cornerstones of the therapy is passive concentration, which means that the person concentrates on specific bodily sensations without directly trying to bring about change (Lehrer, 1994). Trying to elicit the specified sensations in AT may actually be detrimental to the overall response. A passive attitude is helpful in AT for achieving relaxation via selfsuggestions.

Theoretical Models

The effectiveness of AT for treating numerous disorders has been reported since its introduction in clinical research in the 1950s. The empirical evidence has prompted investigation into how AT may act to attenuate physiological and psychological symptomatology. Although a clearly articulated AT mechanism remains elusive, there are some tentative explanatory hypotheses. Schultz and Luthe (1959) speculated on the AT mechanism based on evidence of documented changes in heart rate, respiration, muscle

tension, and cortisol arousal during the practice of AT (summarised in Luthe, 1970). They proposed that the above noted autonomic and central effects were indicative of downregulation of sympathetic nervous system (SNS) activity. In general, negative psychological affect, such as stress and anxiety, leads to SNS activation or arousal, and increased cortisol release (Whitacre, Cummings, & Griffin, 1994). Schultz and Luthe proposed that autogenic exercises may counter-regulate this stress response by modulating afferent stimulation from peripheral muscles. A number of studies have demonstrated an association between AT and reduced SNS activity evidenced via positive changes in blood pressure, heart rate, breathing frequency, and skin conductance level (Blumenstein, Breslav, Bar-Eli, & Tenenbaum, 1995; Fredrikson, 1990; Houghton, 1996). Decreased SNS activation has also been associated with reduced pain perception (Max & Gilron, 1999), and the model of arousal reduction may provide an explanation as to why AT has been associated with decreased perception of pain for individuals with chronic illnesses (Dinges et al., 1997).

Together with the theory of arousal reduction, Schultz and Luthe (1959) also proposed that AT may act to mediate physical and emotional problems by helping the nervous system respond more functionally to physically or emotionally stressful stimuli. They suggested that the practice of autogenics may result in a overall "normalising" influence in the nervous system, in that SNS hyperactivity may return to more homeostatic levels, and thus, decrease the perception of stressors. Researchers examining other relaxation techniques that elicit similar physiologic changes to AT, have also supported the homeostatic or protective model, in that relaxation may act by "dampening" or balancing sympathetic and parasympathetic activity (Benson, 1975; Jacobson, 1938). Researchers have also proposed that the homeostatic mechanism in AT appears to be bi-directional

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(Linden, 1993), whereby the technique may be effective in regulating abnormal autonomic functions in either direction (e.g., raising or lowering dysfunctional blood pressure).

Finally, researchers have proposed that the AT mechanism may incorporate a cognitive perspective (Pikoff, 1984). Schultz and Luthe recognised that the technique may produce positive changes in physical and psychological health without direct evidence of physiological adaptations. Because AT was designed to eliminate the need for technical devices (e.g., biofeedback) or therapists (e.g., hypnotherapist), and because it is a readily learnable skill, the concepts of confidence, mastery, and control of symptomatic episodes or stressful events have been proposed to explain the benefits of AT (Luthe, 1962). In addition, because AT and other relaxation methods lead to similar relaxation responses, albeit, by different means, mechanisms proposed to explain the changes elicited via relaxation techniques, such as meditation, may also be valid in AT. The premise of the altered state of consciousness theory proposes that when a person is in a relaxed state there is a shift in cognitive processes towards decreased sensory input or desensitisation (Gelderloos, Hermans, Ahlscröm, & Jacoby, 1990). This shift has been associated with indicators of mental "calmness," such as an increased production of alpha brain waves (Benson, 1989). Researchers have found increased alpha wave activity during the practice of AT (Montgomery, Robb, Dwyer, & Gontkovsky, 1998). It seems that the focusing of attention on physiologically-oriented phrases in AT may have positive psychophysiological benefits because the person is, at least temporarily, distracted from immediate emotional concerns and stressful stimuli.

Understanding the mechanisms of AT-induced psychophysiological changes will, more than likely, contribute to the development of efficacious treatment strategies using the technique. There has been little research attention, however, directed toward understanding the theoretical basis for AT. Although there are a few speculative models, it is likely that different mechanisms operate in an interactive manner. For example, arousal reduction may influence, or be influenced by, the change in cognitive processes associated with AT. Pikoff (1984) proposed that analysing separate components of the autogenic exercises may shed some light on how the benefits of AT are derived. Although the exact process by which AT promotes psychophysiological adaptation is uncertain, the benefit of AT for enhancing physical and psychological health has strong empirical foundations.

Psychophysiological Responses to AT

Much of the literature investigating the effectiveness of AT has focused on outcomes relating to physiological target indices. Several researchers have investigated whether the self-suggestive formulas in AT produce physiological changes, and have demonstrated that AT is associated with reduced respiratory and heart rate, oxygen consumption, blood pressure, and muscle tension, and increased blood flow, skin temperature, and hemispheric alpha wave activity (summarised in Linden, 1990). Researchers have also investigated the clinical outcomes of AT. Pikoff (1984) reviewed 30 published English language studies, and found positive outcomes from AT in a variety of clinical populations. He found several controlled investigations supporting the effectiveness of AT for reducing psychophysiological symptomatology for people with insomnia, migraine, and Raynaud's disease, and that AT was superior to other forms of relaxation therapy (e.g., PMR) in the treatment of migraine. Pikoff also reported the positive effects of AT, from case reports, for various psychosomatic and thought disorders (e.g., obsessional disorder). Pikoff concluded, however, that because only two of the 30 studies reviewed actually used the six standard exercises described by Schultz and Luthe (most only used the heaviness and warmth formulas), it was difficult to draw definitive conclusions about the efficacy of AT.

Linden (1994) reviewed experimental research on AT from both the English and German language literature. Linden supported previous reports (Pikoff, 1984), that AT was effective for treating physical and psychological symptoms associated with insomnia, migraine, and Raynaud's disease, but also found that AT was supported within a broader clinical framework. He concluded that AT may also be effective in the treatment of psychophysiological problems for people with angina pectoris, asthma, hypertension, eczema, infertility, self-perceived stress, anxiety, and tension, and for people recovering from myocardial infarction. Linden also analysed the clinical outcomes of AT in terms of Cohen's (1988) conventions for effect size, and reported that AT was associated with effects in the medium range. Further, he found that comparisons of pre-test versus post-test scores ranged from a \underline{d} of .43 for biological indices to a \underline{d} of .58 for psychological and behavioural indices of change. Similar to the conclusions drawn by Pikoff, Linden also observed that much of the literature is flawed because of the use of variations on the classic AT technique.

More recently, Kanji and Ernst (2000) reviewed the available research examining the effect of AT on self-reported psychological indices of stress and anxiety. They reviewed eight studies from English, Italian, and German publications, and concluded that AT may be an effective stress management strategy in both clinical and non-clinical populations. The authors found that six of the eight studies supported AT as a means for reducing both state and trait anxiety, and psychological stress. The authors of the review, however, concluded that limitations in research design, inherent in most of the literature on AT and stress management, obfuscated the positive results. The main area of concern was that although all the studies described the techniques used as AT, only one actually employed Schultz's six standard verbal formulas without abbreviation or modification. Kanji and Ernst suggested that, as minimum requirement, future research investigating AT should only use the "bona fide" AT technique.

Although much of the available research provides evidence that AT can offset some psychophysiological problems associated with a variety of acute and chronic conditions, some studies have also evaluated the effect of AT on psychosocial aspects of well-being and quality of life. Guenter (1999) found that 20 weeks of AT, combined with psychotherapy, significantly reduced depression in a group of outpatients with depressive disorders, in comparison to psychotherapy alone (N = 55). The results also indicated that continued practice of AT, up to three years after the initial treatment, was associated with lower relapse and treatment re-entry for depressive symptoms. The study, however, was limited in that it lacked a "no treatment" control group. In addition, evaluation of the effectiveness of AT in this population was limited because the relaxation therapy was combined with other psychotherapeutic services.

A number of studies have also investigated the effect of AT on pain perception. Dinges et al. (1997) found that a sample (\underline{N} = 37) of people with sickle cell disease reported a significant reduction in pain over the course of an 18-month AT intervention program. Results indicated that the decrease in self-reported perception of pain was due, in part, to the reduction of some unpredictable episodes of pain associated with the disease. Ashton et al. (1997) found that AT was associated with reduced post-operative pain, demonstrated by decreased pain medication requirements, for individuals recovering from coronary artery bypass surgery. Those participants in the autogenic treatment group also reported greater overall quality of life post-operatively, than those individuals in the control group. Although AT seems to be an effective method for reducing pain, the perception of pain is a complex phenomenon influenced by a combination of social, psychological, and biological factors, and there may be a number of potential explanatory variables.

The available research supports AT as an efficacious relaxation method for offsetting some of the typical physical and psychosocial difficulties involved in living with chronic conditions. Limitations in the literature, however, appear to be is a consistent problem. Much of the research has used modified versions of the classic technique, either by only using some formulas, by changing those formulas, or by adding new ones. Although there is evidence that modified applications of AT may elicit therapeutic benefits, there have been no systematic investigations of the various manipulations of the technique. A further limitation in the AT literature is that many researchers neglect to describe adequately the exact technique that was employed. Several researchers have also commented that the language barrier is one of the major obstacles in the study of AT (Linden, 1990; Pikoff, 1984). AT has a relatively long history as a relaxation therapy in Europe, yet many of the studies have not been translated into English. Nevertheless, a strong foundation for the use of AT, in countries outside of Europe, is growing.

The Use of AT in MS

Despite a recent publication on medical rehabilitation in MS that recommended the use of AT as a means to reduce fatigue and maintain long-term general health (Westarp, 2000), to date, there are no published studies that have examined the effect of AT on the

physical or psychological health of people with MS. There are, however, a number of reasons why AT may be a beneficial relaxation technique for people with MS. First, the benefits of AT, such as reduced depression, pain perception, stress, and anxiety, evident in other illness populations, may be relevant in MS. In particular, the efficacy of AT as a stress management method may have important implications in MS, because of the possible link between psychological stress and symptom exacerbations. Second, previous research has demonstrated that relaxation training in MS can ameliorate some psychosocial problems associated with the disease (Crawford & McIvor, 1987; Foley et al., 1987; Maguire, 1996). The passive element in AT, however, clearly differentiates it from other forms of relaxation therapy such as PMR, which requires dynamic contraction and relaxation of the muscles. It is possible that for people with MS who may be experiencing problems with muscle weakness, coordination, and neurological dysfunction, AT may be a more appropriate technique than relaxation methods that require an active effort. Researchers have also proposed that different relaxation methods may have specific effects (Lehrer, Carr, Sargunaraj, & Woolfolk, 1994). Lehrer et al. indicated that techniques with a strong autonomic component, such as AT, may elicit greater therapeutic benefits in conditions that have some level of autonomic dysfunction. Considering many people with MS report autonomic disturbances, such as bowel, bladder, and sexual dysfunction, AT may be wellsuited to this population.

Finally, the potential benefits of AT in MS may be gleaned, by extrapolation, from studies investigating the effect of classic hypnosis on psychosocial functioning for people with MS. Although there has been some debate over whether AT is comparable with hypnosis (Krenz, 1986), researchers have indicated that both techniques elicit the physiologic changes of the relaxation response (Benson, 1989). In addition, AT was derived from hypnosis, with the most notable difference being that AT was designed to promote self-control and independence from a hypnotherapist. Although the literature, to date, on the use of hypnosis in MS comprises case reports only, there have been some positive results. Dane (1996) reviewed eight published studies, along with an additional case example that examined the use of hypnosis as an adjunct therapy in MS. He found that hypnosis was associated with positive adjustments in a number of psychosocial variables, such as mood, energy, and depressed affect. Dane also reported that hypnosis, for people with MS, was associated with some improvement in MS-related symptoms, such as spasticity, bowel and bladder control, ambulatory ability, muscle coordination, and pain. The individual case study examined by Dane, also used self-hypnotic techniques at the conclusion of the 14-day hypnosis intervention. Results indicated that reduced pain perception and ambulatory ability were consistent with periods when the participant used self-hypnosis. The results may be limited, however, because the participant retrospectively self-reported both usage of selfhypnosis and measures of behavioural indices. The author concluded that, although case reports are limited in terms of generalisability, the positive results indicate that further research is warranted, employing randomised assignment to groups to examine the therapeutic benefits of hetero- and self-hypnosis methods, for people with MS.

For many years, research in MS has primarily investigated pathophysiological manifestations of the disease and the effect of pharmacotherapeutic treatments. The use of psychological interventions in the management of MS, with the aim of enhancing HRQOL and well-being, is a growing area of interest in applied research. Researchers have demonstrated that exercise may be an effective means of ameliorating psychosocial sequelae in a number of chronic diseases (e.g., Baum, Herberman, & Cohen, 1995). Only a few studies, however, have examined the effect of exercise on psychological health status in MS. Cognitive-behavioural techniques, on the other hand, have a long history in MS as adjunct therapies, yet few studies have exclusively examined relaxation techniques. Furthermore, despite strong empirical evidence supporting the therapeutic benefits of AT in various conditions (Guenter, 1999; Kanji & Ernst, 2000; Linden, 1994; Pikoff, 1984), no research to date has examined the effect of AT on HRQOL and well-being in MS. There is an increasing recognition, however, that intervention strategies designed to address quality of life issues are needed, because most people with MS live with the unpredictable effects of the disease for many years (Miller, 1997). In addition, researchers have identified HRQOL as a central outcome assessment in planning, delivering, and examining efficacious research trials in MS (LaRocca et al., 1996).

In summary, the relationship between exercise, relaxation, and physical and psychological health has been widely researched, and theoretical models suggest that exercise and AT have psychological benefits for people with a variety of chronic illnesses. Current models indicate that exercise is associated with several key markers of psychological well-being and HRQOL, and both physiological and psychosocial mechanisms have been posited to explain these psychological health benefits. Much of the research has attempted to isolate single mechanisms (e.g., thermogenic or endorphin hypotheses), yet it is far more likely that different mechanisms work in concert with one another. Researchers have also indicated that social support may mediate psychological responses to exercise among people with MS (e.g., Petajan et al, 1996; Solari et al., 1999). A number of theoretical models have also been posited to explain the psychophysiological benefits of AT, incorporating physiological and cognitive perspectives. Although the exact process by which relaxation methods mediate psychological health benefits is uncertain, the value of AT for enhancing well-being and HRQOL in clinical populations is clear. Current theoretical models posited to explain the psychological health benefits of exercise and AT for individuals with chronic disease inform the research questions in this thesis.

Statistical Concerns

Methodological limitations hamper much of the existing literature on physiological, social, and behavioural research in MS. Issues of low statistical power (e.g., small Ns), possible Type II errors, the unjustifiable equating of "no significant difference" with "no real difference," and the non-existence of power analysis (especially with non-significant results) (Speed & Andersen, 2000) all plague MS research. Clarifying meaningful changes, particularly in measures of self-perceived health status, seem to be universal research problems that are not resolved by employing indicators of statistical significance. For example, what may be clinically important or meaningful may not always be statistically significant, and this issue is particularly relevant in studies using relatively small sample sizes. A number of researchers have recommended the reporting of effect sizes for interpreting the magnitude and meaning of changes in outcome measures (e.g., Andersen & Stoové, 1998; Kazis, Anderson, & Meenan, 1989). Although the abandonment of the use of statistical significance in interpreting the results of research is not advocated, it is perhaps best to consider estimates of significance, combined with indicators of effect size as the necessary statistical tools for judging an intervention to be effective. Finally, the broad use of effect sizes in research, particularly in studies addressing issues such as HRQOL, may

allow for greater understanding of the relative merits of different interventions, because results across studies are more easily interpreted and compared.

Purpose of the Thesis

This thesis aimed to examine the effect of exercise and a relaxation intervention (AT) on the psychological well-being and HRQOL of people with MS. The first study outlines the exercise and physical activity patterns of a sample of people with MS. This study also examined the relationship between self-reported type, frequency, and duration of physical activity, and HRQOL and well-being. It was hypothesised that increased participation in physical activity would be positively associated with HRQOL and psychological well-being. Because this research was purely descriptive, conclusions about causal relationships between exercise and psychological health for people with MS were not appropriate. The second study, therefore, involved a randomised, controlled research design that examined the effect of an exercise program on HRQOL and psychological wellbeing for a group of mild to moderately disabled people with MS. It was hypothesised that people innvolved the exercise group would have higher HRQOL and psychological wellbeing after the intervention than those in the control group. Although previous research has indicated that exercise may have psychosocial benefits (Petajan, 1996), this study aimed to delineate between the effect of the exercise program per se, and the effect of increased social interaction associated with exercising in groups, by controlling for any change in perception of social support. The third study also used social support as a covariate, and examined the effect of an AT program on the HRQOL and psychological well-being of a group of people with MS. It was hypothesised that people with MS in the AT group would have enhanced HRQOL and psychological well-being than those in the control group.

Finally, this thesis aimed to examine the efficacy of the exercise and AT programs for enhancing HRQOL and well-being for people with MS by comparing the exercise and AT groups on the magnitude of changes in the psychosocial variables measured.

CHAPTER 3

HEALTH-RELATED QUALITY OF LIFE AND PSYCHOLOGICAL WELL-BEING FOR PEOPLE WITH MULTIPLE SCLEROSIS: THE INFLUENCE OF PHYSICAL ACTIVITY

Introduction

Living with a chronic and disabling condition, such as MS, often involves adjustments in terms of activity levels. Adjusting to mobility and fatigue-related problems in MS has often led affected individuals to cease recreational physical activities altogether (Ng & Kent-Braun, 1997). In the past, this restriction has been supported by health care professionals, with few other means available for helping people cope with exacerbations and symptoms of fatigue. Currently, approaches to health management for people with MS are changing, with an increasing focus on multidisciplinary care that includes interventions designed to facilitate and enhance HRQOL. Encouraging participation in physical activity may play a role in this new approach with research demonstrating that exercise has physical and psychological benefits for general (Byrne & Byrne, 1993) and disabled populations (Poser & Ronthal, 1991).

A number of studies have indicated that people with MS have much lower average activity levels than the general population, and other people with chronic conditions (Ng & Kent-Braun, 1997; Stuifbergen, 1997). Whether avoiding physical activity is due to diseaserelated problems or other factors, such as advice from physicians, is not clear. It is increasingly apparent, however, that inactivity in MS may exacerbate existing problems relating to physical and psychological health status. For example, limiting physical activity may result in increased muscle impairment, less social interaction, and thus, lower general quality of life and well-being. Research, however, assessing the relationship between physical activity and psychological health status for people with MS is limited. Of the few studies available, results suggest that more physically active people with MS tend to report more positive psychological well-being, than relatively sedentary individuals (Stuifbergen, 1997). Understanding physical activity patterns, and their relationship to psychological health, in persons with MS is an important area of investigation. Knowledge of such factors is essential prior to developing intervention programs that are designed to enhance quality of life and well-being. The purpose of this study was to describe the relationship between HRQOL, psychological well-being, and physical activity in a group of people with MS.

Method

Participants

The participants were 105 people (81 females and 22 males) with confirmed diagnoses of MS. Nearly half of the sample (47%) were diagnosed as having the relapsing-remitting form of the disease. Eighteen people reported diagnoses of medical conditions other than MS, such as migraine and arthritis. A large percentage of the study participants were on a variety of medications (61%). The mean age of the participants was 45.4 years (SD = 10.5), with an average time since onset of MS symptoms of 12.2 years (SD = 8.5) and an average time since confirmed diagnosis of 8.5 years (SD = 7.2).

Measures

Five questionnaires measuring some of the most frequently cited psychosocial problems associated with living with MS were used to determine the relationship between physical activity level, HRQOL, and well-being.

HRQOL. The Multiple Sclerosis Quality of Life Instrument (MSQOL; Vickrey, Hays, Harooni, Myers, & Ellison, 1995) was used to measure HRQOL. The test includes a generic HRQOL instrument (SF-36; Hays, Sherbourne, & Mazel, 1993) with additional items relevant to people with MS (e.g., cognitive and sexual function). The questionnaire was modified, in this study, by omitting one item in the overall quality of life subscale. The graphical scale using faces to represent how a person feels about their life as a whole was deleted in favor of the semantic differential item. The questionnaire, therefore, contained 53 items distributed into 11 subscales: (a) physical health, (b) role limitations due to physical problems, (c) role limitations due to emotional problems, (d) pain, (e) emotional wellbeing, (f) energy, (g) health perceptions, (h) social function, (i) cognitive function, (j) health distress, and (k) sexual function, and three single item subscales: overall quality of life, change in health, and satisfaction with sexual function. Participants responded to "Yes" or "No" questions and items on a Likert scale ranging from three to seven depending on the subscale. Previous research has shown internal consistency reliability estimates ranging from .75 to .96 and test-retest correlation coefficients ranging from .66 to .96 (Vickrey et al., 1995). Only the 11 multi-item subscales were used in the analysis.

Depression. The Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) was employed to measure depressed affect. The CES-D is a 20-item scale with a four-point Likert format ranging from 1 (<u>rarely or none of the time</u>) to 4 (<u>most or all</u> <u>of the time</u>). Responses to statements such as "I was bothered by things that don't usually bother me" indicate how often participants experienced certain depressive symptoms over the past week. The CES-D has shown high internal consistency and reliability in previous research assessing depressive symptomatology in MS populations with correlation coefficients ranging from .78 to .93 (Shnek, Foley, LaRocca, Smith, & Halper, 1995). In addition, the scale is less heavily weighted on somatic aspects of anxiety than some other depression scales (e.g., Beck Depression Scale) and is, therefore, more appropriate for use with an MS population. MS-related fatigue can be easily confounded with depression.

Daily Stressors and Uplifts. Daily stressors and uplifts were measured using the Daily Hassles Scale (DHS; De Longis, Folkman, & Lazarus, 1988). The scale consists of a list of 53 items that can be hassles and uplifts in day to day life (e,g., "your children," "enough money for education," "housework," and "social commitments"). Participants' respond to each item as a hassle or an uplift on two separate three-point Likert scales ranging from 0 (none or not applicable) to 3 (a great deal). An overall score is obtained for hassles and uplifts, with higher scores indicating greater overall perceived intensity. The DHS is increasingly being used in health research to assess stress in people's lives (Cramer, Nieman, & Lee, 1991; Dwyer, 1997; Klemm, 1994).

<u>Mood States.</u> The Profile of Mood States (POMS) is a reliable and well-validated measure of affective states with alpha coefficients ranging from .70 to.93. The Profile of Mood States- Short Form (POMS-SF; Shacham, 1983) consists of 37 adjectives designed to assess the following six moods or affective states: tension, depression, anger, vigor, fatigue, and confusion. Two adjectives were adjusted to suit an Australian sample (i.e., "bushed" was changed to "tired," and "full of pep" was changed to "full of energy"). Responses on a five-point Likert scale indicate the participant's level of agreement with each item ranging from 1 (not at all) to 5 (extremely).

Social Support. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) was used to measure social support. The 12-item scale measures three potential sources of support, namely; family, friends, and significant others. Participants respond to a seven-point Likert format ranging from 1 (strongly disagree) to 7 (strongly agree), with higher scores indicating greater perception of social support. The total score for perceived social support was used in the analysis. Previous research has demonstrated that the MSPSS is a valid and reliable indicator of perceived social support with internal consistency reliability estimates between .89 to .95 (Kazarian & McCabe, 1991).

Physical Activity. Participants responded to questions regarding type, frequency, duration, and intensity of physical activities during the preceding two weeks. Responses allowed self-reported physical activity level to be categorised. Physical activity was divided into three categories, namely, overall, recreational, and work-related activity. Recreational activity was further divided into three subgroups, and was described as either vigorous exercise (e.g., jogging or playing sport, such as football), low to moderate intensity activity (e.g., playing darts, bowling), and walking or self-propelling for recreation or exercise. Work-related exercise was described as an activity that involved physical exertion, but that was not undertaken as a recreational pursuit (e.g., housework) or activities undertaken for employment (e.g., labouring). Categorisation of activity levels via this method has shown to be a valid method of characterising physical activity (Booth, Owen, Bauman, & Gore, 1996).

In addition, demographic items designed to identify aspects that may affect the outcome of the study (e.g., age, time since diagnosis, clinical status, current medication) were collected.

Procedure

The Multiple Sclerosis Society of Victoria (MSSV) supplied a mailing list, and participants received the questionnaires via the mail. A random sample of 300 people with MS received letters detailing the study (see Appendix A), informed consent statements (see Appendix B), and reply-paid envelopes. Those participants who returned the consent forms ($\underline{n} = 167$) were sent questionnaires (see Appendix C) and reply-paid envelopes. Participants completed the questionnaire at home and returned them by mail ($\underline{n} = 110$). Individuals indicating that the frequency and duration of physical activity reported was not indicative of their usual activity level ($\underline{n} = 5$) were excluded from the analysis.

<u>Data Analysis</u>

Because the study was exploratory, a correlational matrix was used to determine the strength of relationships between physical activity, psychological well-being, and HRQOL. Although statistical significance of the correlation coefficients is reported, the description of results primarily focuses on effect size. According to Cohen's (1988) conventions a correlation coefficient <u>r</u> of .10 is small, .30 is medium, and .50 is large.

Results

Descriptive findings from the total sample ($\underline{N} = 105$) are summarised in Table 3.1. Results indicated that over the preceding two-week period, the group participated in an average of 6.8 ($\underline{SD} = 6.3$) sessions of physical activity (frequency), participating for an average of 6.8 ($\underline{SD} = 7.5$) hours (duration). The participants averaged the most time, in terms of frequency and duration, engaged in recreational exercise in comparison to workrelated physical activity. As is evident in Table 3.1, frequency and duration of physical activity showed similar results, indicating that the number of sessions (frequency), over the previous two-week period, closely matched the number of hours (duration) of physical activity reported. Correlational analysis of both frequency and duration of exercise with the psychosocial variables offers limited additional information, and therefore only frequency of physical activity is included in the results. Results are discussed in terms of conventional standards for the effect size $\underline{\mathbf{r}}$.

Table 3.1

<u> </u>	Frequency	(sessions)	Duration (hours)		
Type of Physical Activity	<u>M</u>	<u>SD</u>	M	<u>SD</u>	
Total	6.80	6.33	6.82	7.50	
Total Recreation	5.00	5.71	4.54	6.00	
Vigorous	0.53	1.99	0.50	2.00	
Moderate	0.88	2.05	0.77	1.76	
Walk or Self-Propel	3.60	4.30	3.28	4.56	
Total Work-Related	1.79	2.71	2.29	4.68	

Means and Standard Deviations for Frequency and Duration of Type of Physical Activity

Bivariate correlations indicated that, with the exception of the pain subscale, all dimensions on the MSQOL showed at least a medium effect with frequency of overall activity level. The physical health subscale showed moderate to large effects for frequency of overall, recreational, and work-related physical activity. This result indicated that those people with MS who were more physically active, either in recreational or work-related pursuits, reported better physical function than less physically active individuals. Physical function was the only HRQOL subscale that showed a moderate effect for frequency of work-related exercise. The energy subscale exhibited a large effect for frequency of overall and recreational exercise, but only a small effect for work-related activity. This result indicated that individuals who were more active in recreational physical activity reported increased perception of energy. Role limitations due to either physical or emotional problems (RLPP and RLEP, respectively), health perceptions, and health distress showed moderate correlations with frequency of overall activity and frequency of recreational exercise.

Depressed affect, as measured by the CES-D, showed a medium to large effect with frequency of overall and recreational activity, indicating that increased participation in physical activities for recreation was associated with decreased depressed affect in this sample. There was a distinctly lower correlation for depression and frequency of workrelated exercise. Analysis also revealed recreational exercise to be positively correlated with uplifts as measured by the DHS, but hassles did not follow this trend. Frequency of overall exercise and recreational exercise showed a weak correlation with hassles. There was, however, a small effect for hassles and work-related physical activity, indicating that those people who were more physically active in work-related activities reported increased perception of daily hassles.

All subscales of POMS-SF showed moderate to large effects with frequency of overall and recreational exercise, suggesting more positive mood for those reporting increased levels of recreational exercise. There was a very large effect for vigor and

Table 3.2

Correlation of Frequency of Physical Activity and Psychosocial Variables

Scale	Variable	Overall Physical	Recreational	Work-Related	
		Activity	Activity	Activity	
MSQOL	Energy	.50**	.46**	.19	
	Physical Health	.44**	.33**	.38**	
	Social Function	.36**	.30**	.20*	
	Health Perceptions	35**	34**	11	
	Health Distress	.33**	.28**	.17	
	RLEP	.30**	.28**	.10	
	RLPP	.30**	.25**	.17	
	Emotional Well-Being	.23*	.25*	.02	
	Sexual Function	.21*	.16	.16	
	Cognitive Function	.21*	.14	.20*	
	Pain	11	06	.10	
CES-D	Depression	40**	39**	12	
DHS	Uplifts	.27**	.23*	.14	
	Hassles	03	13	.20*	
POMS-SF	Vigor	.58**	.51**	.30**	
	Depressed Affect	37**	33**	19	
	Tension	27**	29**	03	
	Confusion	27**	26**	09	
	Fatigue	26**	32**	.05	
	Anger	22**	25*	.02	
MSPSS	Social Support	.32**	.33**	.06	

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

frequency of physical activity, regardless of whether exercise was related to recreation or work. Social support, as measured by the MSPSS, showed a moderate effect with overall and recreational exercise, indicating that perceptions of greater social support were related to increased participation in recreational activities. Refer to Table 3.2 for correlation coefficients and significance levels.

Discussion

Overall this descriptive study supports past suggestions (e.g., Stuifbergen, 1997) that exercise and physical activity have important psychosocial consequences in MS. There are, however, a number of issues of note. First, the relatively low response rate (35%) may have influenced results in that individuals who engaged in some form of exercise may have been more likely to respond to a questionnaire about physical activity. Second, the sample demonstrated considerable variability in frequency and duration across all modes of physical activity, as indicated by the large standard deviations (see Table 3.2). This variability is probably typical in an MS population, reflecting the wide range of disabling symptoms affecting participation in physical activity. Third, although participants reported engaging in recreational activity for an average of five sessions over the previous two-week period, the majority of sessions were spent walking or self-propelling for recreation (M = 3.6, SD = 4.3). Few people with MS reported participating in vigorous exercise modes requiring intensive physical exertion, such as jogging, or less vigorous activities, such as bowling or darts. Once again, however, the large standard deviations mean that there was a large range of responses and a large skew among the participants.

Results from the study indicated that type or mode of physical activity may be related to potential psychosocial benefits. Although many of the variables were correlated with overall exercise and with recreational activity, there were distinctly lower correlations with work-related exercise. Moreover, hassles, as measured by the DHS, indicated that physical exertion in work-related exercise may actually increase perception of hassles. Anger and fatigue, as measured by the POMS-SF, also exhibited a similar, although nonsignificant trend (effect sizes in the small range). These results suggest that being physically active in a work environment may not be associated with improvements in some aspects of psychosocial health to the same extent as being active in recreational pursuits. Perhaps many of the activities relating to work are considered necessary demands, and therefore, do not elicit the same psychological responses as those activities undertaken by choice and for enjoyment. Previous researchers have suggested that enjoyment may be an important mediating variable for the psychological health benefits associated with physical activity (Wankel, 1993).

The physical health and social dimensions of the HRQOL measure exhibited strong relationships with both recreational and work-related exercise. It is not surprising that those persons able to partake in physically-demanding tasks for work and recreation would also report higher levels of physical health. Social function may also be related to the ability to work and complete activities of daily living because of the social interaction inherent in many of these types of activities. Vigor as measured by the POMS-SF, and energy, as measured by the MSQOL, showed the strongest relationship with all types of physical activity. The finding that more physically active people with MS reported increased perception of energy and vigor, in comparison to less active individuals, is an important result considering the prevalence of fatigue in the MS population. Some researchers have reported that people with MS may avoid exercise so as to conserve energy for activities of

daily living (Ng & Kent-Braun, 1997; Stuifbergen, 1997). The results from this study indicate that participating in physical activity may moderate fatigue-related problems, by improving energy levels.

Although participants reported general disease course, the study was limited in that specific symptoms and severity of symptoms were not included as measures. Type and severity of physical and neurological impairment may be important variables for assessing ability to engage in physical activity. In addition, although there were a number of significant differences in aspects of HRQOL for those individuals more physically active, in comparison to those who reported lower activity levels, the differences may be due to other, related factors, such as severity of illness and degree of disability. For example, individuals with a high level of physical function are likely to self-report better physical health than those with severe physical deficits, regardless of participation in physical activity. Moreover, differences in one variable (e.g., physical health) may affect other psychological variables, such as health perceptions, energy, fatigue, and depressed affect.

Clinical Implications

Identification of the benefits of physical activity and exercise for people with MS has important implications for health care interventions. The unpredictability and mutability of MS-related disabilities may result in a variety of psychosocial sequelae for affected individuals. Thus, understanding behaviours that influence aspects of HRQOL and psychological well-being is helpful in a population that requires significant levels of service over a long illness trajectory. Results from previous research have indicated that people with MS identify exercise as a health-promoting behaviour, but perceive they lack the knowledge to exercise safely (Stuifbergen, 1995). The results from this study, however,

indicate that simply walking or self-propelling for recreation may be associated with improved perception of HRQOL and well-being. For people with MS, participating in structured exercise or sporting activities may be problematic because of balance, coordination, mobility, and cognitive deficits. Researchers developing intervention strategies for people with MS need to be mindful that physical and psychological benefits may be gained via recreational activities that do not necessarily involve intensive physical exertion or require a high level of physical function.

Conclusion

Overall, the positive results from this study provide encouraging evidence that exercise, particularly undertaken for recreation, can potentially benefit the MS population, not only for reducing the physical limitations imposed by the disease, but also for enhancing psychosocial health. Although knowledge of activity patterns for people with MS, as well as the relationship to HRQOL and well-being is useful, correlational analysis can only describe possible connections. Whether people with MS are more physically active because they have higher perceptions of HRQOL, or whether they have higher HRQOL because they are more active are questions for future experimental studies to attempt to answer. Future research may also need to consider the possibility that the relationship between higher perceptions of HRQOL and increased participation in physical activity may be mediated by a third variable, and thus any association may be non-causal. The positive results from this study, however, lay the foundation for future research assessing the effects of physical activity on quality of life in MS. Specifically, additional research is needed to explore if exercise can actually lead to increased HRQOL and psychological well-being.

CHAPTER 4

THE EFFECT OF EXERCISE ON THE HEALTH-RELATED QUALITY OF LIFE AND PSYCHOLOGICAL WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

Introduction

Exercise is an activity that people with MS have traditionally avoided. With health professionals advising that exercise may intensify MS-related symptoms, it is not suprising that the primary concern of many individuals with MS is to limit activities that may influence the onset of exacerbations and symptoms of fatigue. Unfortunately, physical inactivity may contribute to significant health consequences, such as developing other chronic conditions associated with sedentary living (Pate, Pratt, & Blair, 1995). The unpredictability of MS-related disabilities, combined with the increasing physical limitations of inactivity, may also exacerbate potential psychological problems for affected individuals. The first study in this thesis supported previous research that has shown a positive relationship between physical activity and psychosocial health for people with MS (Stuifbergen, 1997; Petajan et al., 1996). The results of the retrospective, descriptive study, however, may be influenced by other factors, such as severity of impairment interfering with ability to engage in physical activity. In addition, the first study did not provide evidence that increased participation in physical activity was directly related to enhanced psychological health status. There is a need, therefore, to further test the efficacy of exercise for enhancing the physical, mental, and social functionality of people with MS. Thus, if a sedentary group of people with MS begin and maintain an exercise program, what influence will that intervention have on perceived HRQOL and psychological well-being?

Although literature recommending exercise for people with MS has recently emerged (Petajan & White, 1999; Rosenthal & Scheinberg, 1990), research investigating exercise responses of persons with MS is not new. As previously described, a number of studies have employed acute exercise protocols in order to observe manifestations of the disease under physiologically stressful conditions (Foglio et al., 1994; Pepin et al., 1996; Ponichtera-Mulcare et al., 1993; Ponichtera-Mulcare et al., 1995). Other studies have employed long-term exercise programs (four weeks to six months), but have predominantly focused on physiological outcomes, such as VO₂ max (Gappmaier et al., 1994; Gehlson, Grigsby, & Winant, 1984; Ponichtera-Mulcare et al., 1997). Although the research has helped to establish that people with MS can tolerate regular, moderate intensity exercise without detrimental effects to symptom stability, few studies have explored the effects of exercise on psychosocial aspects of health and well-being.

Research investigating the effects of exercise on psychological health in MS is limited. As previously described, the Petajan et al. (1996) study is the only controlled research to date that investigated the effect of exercise training on fitness and HRQOL in MS. The design of the study, however, did not control for initial differences between the treatment and control groups. In addition, the authors concluded that because the exercise program was a social activity, the positive results for psychological function might have been a function of the exercise combined with the effects of enhanced social interaction. Nevertheless, such positive findings provide a foundation for investigating exercise as a complementary therapy for people with MS, not only for counteracting the physical limitations imposed by the disease, but also for enhancing psychological well-being. The purpose of this study was to examine the influence of aerobic exercise on the psychological well-being and HRQOL of individuals affected with MS. Mild to moderately disabled persons participated in 10 weeks of aerobic exercise training to determine the effects on psychological health status. This study, by assessing the effects of exercise on HRQOL of individuals with MS, tested the prediction that exercise can positively affect psychological health.

Method

Participants 1 -

Twenty-two people with MS (12 females and 10 males) participated in the study. Participants were recruited through the Multiple Sclerosis Society of Victoria (MSSV), matched according to age and gender, and randomly assigned to either the treatment ($\underline{n} =$ 11) or control group ($\underline{n} = 11$). Participants were selected according to a clinically confirmed diagnosis of MS, EDSS of 5.0 or less, and they had not been involved in an exercise program for six months prior to the study.

<u>Measures</u>

Four questionnaires assessing psychological health were used to determine the influence of the exercise program on factors relating to HRQOL and well-being. The individual scales were the Multiple Sclerosis Quality of Life Instrument (MSQOL; Vickrey et al., 1995), the Centre for Epidemiology Studies Depression Scale (CES-D; Radloff, 1977), the Daily Hassles Scale (DHS; De Longis, Folkman, & Lazarus, 1988), and the Profile of Mood States-Short Form (POMS-SF; Shacham, 1983). These measures were described in the Method section in Study 1 (see Chapter 3).

The Multidimensional Scale of Perceived Social Support (MSPSS) was used as a statistical control for the potential positive effects of an increased social network associated with exercising in a group. This scale was also described in the Method section of study 1 (see Chapter 3).

<u>Physical fitness.</u> A continuous bicycle ergometer exercise test protocol was used to evaluate changes in aerobic fitness for the exercise group over the course of the training program. The exercise test was only used as a manipulation check to observe any changes in physical fitness as a result of participating in 10 weeks of exercise training, and therefore, participants in the control group did not perform the exercise test.

Procedure

Participants in the study were recruited through the MSSV registration database. People with MS voluntarily register at the MSSV, and because information in the database is confidential, potential participants were sent a letter detailing the study by either the research coordinator or physiotherapists at the MSSV (see Appendix D). Those individuals interested in participating in the study were asked to contact the researcher. All participants agreed to assignment to either the experimental or control group, and the control group participants were offered the opportunity to participate in an exercise program at the conclusion of the study. Participants in the control group also agreed not to alter their current level of physical activity for the duration of the program. Individuals participating in the exercise program obtained medical clearance from their physicians (see Appendix E) and signed informed consent statements (see Appendix F).

All participants were mailed the questionnaires at home (see Appendix C), and returned them either by reply-paid envelopes or directly to the researcher. Participants

completed psychological instruments at baseline and at week 8 of the 10-week intervention. Final measures were taken at week 8 because research has demonstrated that anticipation of the end of an exercise program, together with the removal of social support associated with exercising in a group, might negatively affect aspects of psychological health (Petajan et al., 1996).

Participants in the exercise group performed a continuous, resistance-incremented cycle ergometer submaximal exercise test prior to, and following, the training program. After a warm-up, participants cycled at a workload of 30 W, which was increased to 40 W after the first minute. After each subsequent one-minute interval, the resistance was increased by 20 W, while the speed remained constant. Ratings of perceived exertion (RPE) were measured using the Borg 15-point scale (Borg, 1970) and recorded at each minute until the test was terminated when participants indicated they were working at a rating of 17 (very hard). Time to termination was then recorded, and those data were used to evaluate changes in physical fitness for the treatment group.

The aerobic exercise program consisted of three supervised training sessions per week for ten weeks. Due to unforeseeable circumstances, the pool was unavailable during week 5 and 6 of the program. Apart from five sessions during this period that involved in land-based weight training, the program was conducted in an aquatic environment. The activities undertaken during the sessions included water aerobics, water jogging, and deep water running. As Rosenthal and Scheinberg (1990) stated in their guidelines for exercise prescription for people with MS, exercise in water is the most appropriate exercise modality because it provides maximal total body exercise, minimal joint stress, and optimal heat dissipation. Each 45-minute session included a five-minute warm-up and cool-down, as well as stretching concentrating on the major muscle groups.

Data Analysis

A paired samples <u>t</u> test was conducted on time (minutes) to voluntary termination for the submaximal exercise tests to measure changes in physical fitness. Effect size (Cohen's <u>d</u>) was calculated to examine the magnitude of change.

Analyses of covariance were used to assess group (treatment vs. control) differences for HRQOL and measures of psychological well-being after the intervention. Social support was used as a covariate, along with pre-test measures of HRQOL and psychological wellbeing to control for initial differences between the two groups. By using the above covariates the results presented allow for a quantifiable interpretation of how different the two groups were after the exercise program. The results for the psychological measures primarily focus on effect sizes in the form of η^2 . Although the traditional method of determining significance (p < .05) is also reported, η^2 is a more relevant statistic because it represents the amount of variance in a variable accounted for by group membership (i.e., being in the control or exercise group). Researchers have proposed that η^2 is a useful indicator of effect size because it explains the strength of association between variables (Tabachnick & Fidell, 1996). In the social sciences, if 15% of the variance in a variable is accounted for by group membership ($\eta^2 = .15$), it is considered a medium to large effect (Cohen, 1988).

Results

Participants

All 22 participants originally recruited for the study were included in the analysis. The exercise group adhered well to the program, with participants attending an average of 27 of a possible 30 sessions over the course of the 10-week program. No one participant missed more than three consecutive sessions. Participant characteristics were similar across the treatment and control groups and are summarised in Table 4.1. Differences between groups were analysed using Cohen's \underline{d} and results showed only small to very small effects for the demographic variables at baseline.

Table 4.1

Participant Characteristics

	Exercis	e Group	Non-exercise Group		
-	M	<u>SD</u>	M	<u>SD</u>	
Sex (F/M)	6.	/5	6/5		
Age (yrs)	47.18	4.75	45.45	5.05	
Onset of symptoms (yrs ago)	12.27	8.95	9.27	4.80	
Confirmed diagnosis (yrs ago)	7.00	5.59	6.18	3.63	
Last exacerbation (mths)	11.64	16.70	10.64	15.23	

Physical Fitness

Comparisons of time to voluntary termination of the exercise test at baseline and at week 10 indicated that participants involved in the exercise program improved physical

fitness over the course of the 10-week training period, $\underline{t} = -1.55$, $\underline{p} = .15$, $\underline{d} = .47$ (preexercise $\underline{M} = 5.2$, $\underline{SD} = 1.4$; post-exercise $\underline{M} = 6.0$, $\underline{SD} = 2.0$). Although the change in fitness scores did not reach statistical significance, according to Cohen's conventions (Cohen, 1988), a \underline{d} of .47 is in the medium range, and indicates a difference of 18 percentile points.

Psychosocial Measures

Most of the MSQOL subscales (i.e., 9 of 11) showed at least a medium effect, indicating considerable improvements in physical, social, and psychological health for the exercise group in comparison to the control group. Results showed very large effects for the bodily pain (p = .01, $\eta^2 = .29$), social function (p = .01, $\eta^2 = .29$), and sexual function subscale (p = .04, $\eta^2 = .21$). The energy subscale on the HRQOL measure showed an extremely large effect (p = .0001, $\eta^2 = .51$), with group membership accounting for over 50% of the variance in energy scores. This result indicates that there was a huge improvement in self-reported energy level for those people participating in the exercise program. This substantial effect was replicated on the vigor subscale of the POMS-SF (p = .001, $\eta^2 = .55$). Furthermore, all aspects of mood, as measured by POMS-SF, demonstrated medium effects except for the confusion subscale (p = .64, $\eta^2 = .01$). Depressed affect, as measured by the CES-D, showed a negligible effect ($\underline{p} = .44$, $\eta^2 = .03$) between the exercise group and the control group, indicating that the treatment group did not significantly change level of depressed affect over the 8-week period. The depressed affect subscale of the POMS-SF, however, appeared to contradict this finding. The result on the POMS-SF indicated that participants in the treatment group did improve perception of depressed affect, and that the effect was in the moderate to large range (p = .09, $\eta^2 = .16$).

Daily hassles, as measured by the DHS, showed a small to medium effect (p = .27, $\eta^2 = .07$), and the corresponding daily uplifts scale showed a medium effect (p = .13, $\eta^2 = .12$). Means and standard deviations for each score (pre- and post-intervention) for the treatment and control groups are presented in Table 4.2. F-values, significance levels, and effect sizes for subscales of the psychosocial measures are presented in Table 4.3.

Discussion

The results from this study indicate that aerobic exercise can alter HRQOL and psychological well-being for people with MS. HRQOL measures improved (by effect size standards) for the exercise group in all but the cognitive function and role limitations due to physical problems subscales of the MSQOL. The medium effects for the physical health, health perceptions, and health distress subscales of the MSQOL indicate an increase in overall physical health status for individuals in the exercise group. The positive changes reflect perception of improved health status, as well as a reduction in limitations related to performing day-to-day activities. Improvements in physical fitness observed as a result of the training program more than likely contributed to the positive changes in physicality as measured by the MSQOL. Improved physical function and increases in physical fitness did not seem to affect the way in which participants reflected on role limitations imposed by physical problems. This result suggests that although exercise may reduce perceived limitations in relation to specific physical tasks (e.g., bathing or dressing), it may not necessarily alter the way in which people view the role limitations that are imposed by the physical manifestations of the disease (all the participants had been living with MS for several years).

Table 4.2

Means (M) and Standard Deviations (SD) of Psychosocial Variables for Treatment and

		1	Freatme	ent Grou	р		Contro	l Group	
		Pre-exercise post-exercise		xercise	pre-exercise		post-exercise		
	Variable	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	M	<u>SD</u>	<u>M</u>	<u>SD</u>
MSQOL	energy	12.9	2.7	17.3	3.9	14.3	4.6	14.0	4.4
	pain	10.8	4.4	11.7	2.8	12.7	3.3	11.0	3.9
	social function	10.5	1.9	12.6	2.8	11.4	3.0	10.9	3.1
	sexual function	9.9	3.9	10.9	3.8	12.7	2.7	10.7	4.0
	physical health	15.2	4.6	17.1	4.4	15.4	4.0	15.9	4.0
	health perceptions	12.3	2.3	13.7	3.3	12.5	2.3	12.9	2.8
	emotional well-being	19.6	4.2	22.4	4.1	20.7	5.1	20.8	6.7
	health distress	15.7	5.8	18.7	2.9	15.3	6.2	15.1	6.0
	RLPP	4.9	.94	5.4	1.7	5.7	1.5	5.5	1.7
	RLEP	4.3	1.4	5.3	1.1	5.4	1.0	5.0	1.3
	cognitive function	16.3	4.9	17.5	4.0	19.0	2.5	19.0	2.8
POMS-SF	vigor	5.0	4.1	10.9	5.0	4.2	3.6	3.9	3.7
	tension	7.6	4.3	4.1	3.5	5.7	6.9	5.7	6.9
	fatigue	8.9	3.6	6.7	3.6	8.0	5.4	7.9	5.3
	depressed affect	7.8	6.5	4.5	3.9	6.6	7.2	6.8	7.1
	anger	7.5	6.1	4.6	4.5	5.0	3.8	5.5	4.5
	confusion	4.5	3.3	4.1	3.3	3.5	2.4	3.8	2.4
CES-D	depression	19.2	11.1	13.1	7.8	16.7	9.5	15.7	8.5
DHS	uplifts	29.8	13.1	37.5	11.9	29.5	13.7	28.5	20.3
	hassles	40.2	18.6	34.5	17.7	20.6	10.4	23.9	15.4
MSPSS	social support (c)	59.3	18.9	63.0	14.1	61.6	17.8	60.6	15.8

Control Groups at Pre- and Post-Exercise Program

c = covariate

Table 4.3

F-values, Significance Levels, and Effect Sizes for Psychosocial Instruments Using Social

Support and the Appropriate Baseline Scores as Covariates

Scale	Subscale	F-value	р	η^2
MSQOL	Energy	18.97	.0001	.51
	Pain	7.32	.01	.29
	social function	7.27	.01	.29
	sexual function	4.70	.04	.21
	physical health	4.00	.06	.18
	health perceptions	3.60	.07	.17
	emotional well-being	3.34	.08	.16
	health distress	3.32	.09	.16
	role limitations due to physical problems	2.24	.15	.11
	role limitations due to emotional problems	1.33	.26	.07
	cognitive function	.16	.70	.01
POMS-SF	Vigor	22.00	.001	.55
	Tension	4.27	.05	.19
	Fatigue	4.21	.05	.19
	depressed affect	3.32	.09	.16
	Anger	3.23	.08	.15
	Confusion	.23	.64	.01
CES-D	Depression	.63	.44	.03
DHS	Uplifts	2.51	.13	.12
	Hassles	1.30	.27	.07
MSPSS	social support (covariate)	1.82	.19	.09

This finding coincides with previous descriptive research that has found self-reported limitations in physical function are not correlated with role limitations due to physical problems, particularly in less disabled individuals with MS (Nortvedt, Riise, Myhr, & Nyland, 1999).

A number of disease-related disabilities in MS (e.g., reduced mobility) may lead to a reduction in social interaction and isolation. The large effect on the social function subscale of the HRQOL measure indicates that participants in the exercise group experienced less difficulty in performing social activities. There are several likely factors that contributed to this outcome. Improved physical function more than likely influenced the opportunities to participate in social activities. In addition, reduction in fatigue, and enhanced energy and vigor may have increased the ability of the exercise participants to pursue social contact. Enhanced social function may have also been a potential result of assignment to the exercise group. Because the program was conducted whereby individuals exercised as a group, the participants may have equated the intervention program with increased social activity.

In the HRQOL measures, there were also large effects for the sexual function and bodily pain subscales. From these results, it appears that exercise is a viable therapy for symptoms that are often considered secondary responses to MS in terms of priority for medical treatment. Non-specific chronic pain and sexual dysfunction are symptoms that are commonly reported by people with MS, and have the potential to affect not only well-being, but are also, at least partially, affected by other psychosocial factors (e.g., depressed affect and fatigue). Aspects of HRQOL and mood, therefore, may have been affected by the improvements in pain and sexual function, just as these variables may have had a positive, indirect influence on other psychological factors. With over 90% of men and approximately 70% of women reporting sexual dysfunction with MS (Schapiro, 1994), it is unusual that the relationship between sexual function and quality of life is an area in MS research that is rarely explored.

The energy subscale on the MSQOL showed the largest effects, with over 50% of the variance in this variable accounted for by group membership. The vigor subscale of the POMS-SF also showed an extremely large effect, indicating an improved perception of vigor for the exercise participants. These results have important implications considering that approximately 80% of people with MS report symptoms of fatigue that affect quality of life to varying degrees (Krupp, Alverez, LaRocca, & Scheinberg, 1988). The finding that exercise increases energy and vigor contradicts the commonly held belief that to combat fatigue-related difficulties, people with MS should avoid physical activities. This finding, in conjunction with previous results demonstrating the beneficial effects of exercise on symptoms of fatigue (Petajan et al., 1996), shows that people with MS may benefit from participation in physical activity. It is also probable that the changes in energy and vigor, along with a notable decrease in fatigue, may have affected other positive changes in HRQOL and psychological well-being.

It is likely that change in the level of physical activity for the exercise group affected energy, vigor, and fatigue due to a reversal of some of the effects of sedentary living. It is also worth considering that the way the exercise program was prescribed may have influenced participants' perception of fatigue. The emphasis of the exercise program was based on functional outcomes as measured by the HRQOL scale, rather than physiological outcomes, in that heart rate measures were not recorded and specific training intensity zones were not specified. Physical fitness was a tertiary variable of interest in this study, and the training was designed to be an enjoyable experience in an environment in which people with disabilities felt comfortable. Researchers have indicated that perception of mastery, competence, and enjoyment in physical activity may actually be the source of what is believed to be exercise-induced changes in psychological health (Wankel, 1993). Previous research has also reported that fatigue in MS may be associated with low environmental mastery (Schwartz, Coulthard-Morris, & Zeng, 1996). Although improvements in energy and vigor, along with a reduction in fatigue, evident in this research, may be related to improved fitness, it is also possible that the positive changes may be a function of a sense of mastery and control gained from participating in aerobic exercise. Di Fabio et al. (1997), in their research investigating physical rehabilitation with individuals severely affected with MS, also suggested that mastery may influence fatigue.

Regardless of the mechanism at work, the finding that exercise can reduce fatigue and increase energy is a significant result in the investigation of the effects of exercise on physiological and psychological well-being in MS. The significance of the result is highlighted by research that has demonstrated fatigue, as measured by several different scales, is the single most significant indicator of psychological health status in MS (Ritvo, Fisk, Archibald, Murray, & Field, 1996). The importance of managing fatigue has not been lost on pharmacological companies that have developed drugs to alleviate these symptoms. The clinical trials with these drugs, however, have shown limited success, revealing a number of possible side-effects that potentially affect well-being to the same extent as the fatigue itself (Cohen & Fisher, 1989). The results from this investigation suggest that exercise may help people with MS counteract fatigue-related problems. The exercising participants also experienced a number of improvements in mood as measured by the POMS-SF, which replicated the results of previous research (Petajan et al., 1996). As discussed, the vigor subscale and the fatigue subscale showed very large and large effects, respectively, along with substantial reductions in tension, anger, and depressed mood. Research has not determined whether depression in MS is associated with neurological impairment, psychosocial factors, or a combination of the two (Minden & Schiffer, 1990). In terms of psychosocial factors, research suggests the prevalence of depressed affect in the MS population may be a result of helplessness associated with the unpredictable nature of symptoms and disease progression (Shnek, Foley, LaRocca, Smith, & Halper, 1995). The reduction in depressed mood for the treatment group, as measured by the POMS-SF, may indicate that being physically active promotes a sense of control over some aspects of the disease process, particularly physical health.

Depressed affect, as measured by the CES-D, however, did not coincide with reductions in the depressed mood subscale on the POMS-SF. The difference for depression on the CES-D between the exercise and control group showed a negligible effect. It is possible that the pathology-oriented items in the CES-D were not as sensitive to fluctuations in mood as those items presented in the POMS-SF. Furthermore, a number of items in the CES-D (e.g., "I did not feel like eating; my appetite was poor") may reflect depressive symptomatology manifested in behaviour, and thus, an exercise program may not change some of the inherent and chronic aspects of the disease.

Results indicated that there was an improvement in uplifts as measured by the DHS. Perhaps exercise, and the resultant changes in variables such as physical health, energy, and fatigue may have contributed to how the participants coped with life circumstances, such as family and social commitments. Previous researchers, however, have reported that participation in structured, out of home exercise programs for people with MS may contribute to stress because of added demands of attending a program (Stuifbergen, 1997). The increase in uplifts may indicate that, for exercisers in this study, the training program itself was an uplift.

The findings of this research are distinctive because social support was used as a covariate. Thus, the positive results are more likely to be due to the effects of the exercise program rather than the influence of social interaction on well-being. It is possible that increased physical fitness may have been a mediating factor in the improvements in psychological well-being with aerobic training. Participants in the training program did increase fitness as indexed by improved performance on the cycle ergometer test. Psychological benefits from exercise programs are likely, however, to be mediated by a variety of sources. Previous researchers have indicated that the psychological benefits of exercise may not necessarily be associated with, or dependent on, improved physical fitness (Plante, Lantis, & Giancarlo, 1998; Shepard & Bouchard, 1994). It is possible that other factors, such as increased self-confidence and mastery associated with participating in physical activity, are also responsible for improved HRQOL and psychological well-being.

The small sample size in this research limits the generalisability of the results. In addition, because the participants in this study were relatively ambulatory, the positive results may not be applicable to people with more severe physical and cognitive disabilities. Additional research, therefore, is needed to explore the influence of physical activity on HRQOL for people with MS with a larger range of impairment levels. Although the exercise test was only used as a manipulation check, examination of changes in physical fitness for the control group may have enhanced interpretation of the results considering the unstable nature of physical symptoms in MS. At present, however, exercise appears to be an effective complementary therapy in MS, at least for those with low to moderate EDSS scores.

Clinical Implications

Researchers have recently recognised that treatment and care of individuals with chronic illnesses involve more than the traditional model of intermittent acute care. The results from this study provide evidence of the contribution that exercise can make as a therapy for people with MS. The study demonstrates that exercise may be a beneficial adjunct to medical therapies. Exercise also does not have the negative effects of many of the pharmacological agents designed to alleviate MS symptoms. Because of disabilities, such as spasticity and impaired coordination, land-based aerobic exercise may not always be a viable option for people with MS, but water-based activities offer more possibilities for disabled people to participate in physical activity. This study demonstrates that exercise may make a positive difference in the quality of life for those whose mobility is not severely affected by the disease.

<u>Conclusion</u>

Overall, results from this study indicate that an aerobic exercise program can improve HRQOL and psychological well-being for people with MS. It is possible that changes were mediated by a number of factors including, but not limited to, physical fitness gains. Increases in energy and vigor, and a reduction in fatigue are the most remarkable findings and support the use of exercise as a complementary therapy for counteracting the many difficulties that disrupt day-to-day living for people with MS. This study contributes to the growing body of literature that looks beyond traditional models of care for chronically ill individuals.

Because of the changing and degenerative nature of MS, future outcome studies need to be conducted by employing longitudinal research designs over an extended duration (e.g., two to three years). There remains much scope for research on MS, exercise, and quality of life issues. In particular, there exists the opportunity to explore whether disease progression may be substantially decelerated by participation in long-term, regular physical activity.

Although this study showed that an exercise program may enhance HRQOL and well-being for people with MS, exercise may not be a viable adjunct therapy for all individuals. Some people may not have access to public facilities where swimming and aquatic aerobic programs are available. In addition, common problems associated with the disease, such as bowel and bladder incontinence may contraindicate participation in exercise, and for some people, exercise may simply be an uninviting option. There seems to be a need, therefore, to investigate other alternative therapies, besides exercise. Researchers have indicated that, for many people with MS, the uncertainty of the disease creates a high level of psychological distress that detracts from general well-being (e.g, Murray, 1995). Therapeutic programs, therefore, that are designed to help people cope with stress and anxiety, such as relaxation training, may provide another means by which people with MS can enhance their HRQOL and well-being.

CHAPTER 5

THE EFFECT OF AUTOGENIC TRAINING ON THE HEALTH-RELATED QUALITY OF LIFE AND PSYCHOLOGICAL WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

Introduction

In the late 19th century a physician noted the possible connection between his patient's abrupt onset of disease-related symptoms and the patient's report that he had discovered his wife in bed with another man (Moxon, 1873). There is a long history in MS of anecdotal evidence, such as in this case report, that stress may influence the onset and exacerbation of symptoms. For the most part, clinical studies have not demonstrated a distinct relationship between psychological stress and MS-symptomatology (Goodin et al., 1999). Researchers have indicated, however, that for many people with MS the disease is associated with long-term stress, reduced social interaction, difficulties in activities of daily living, and diminished quality of life and psychological well-being (e.g., Zeldow & Pavlou, 1984). The long-term management of the disease, therefore, should include efficacious treatment strategies aimed at reducing emotional distress and enhancing HRQOL (Murray, 1995; Warren, Warren, & Cockerill, 1991). The second study in this thesis demonstrated that an aerobic exercise program may positively influence psychological well-being and HRQOL for individuals with MS. Yet, a number of issues, such as access and availability of facilities, MS-related disabilities, and motivation to engage in physical activity, may not render exercise an attractive or viable option. There is a need, therefore, to test the efficacy of other therapies for enhancing the physical, mental, and social health of people with MS.

A number of cognitive-behavioural interventions, including relaxation techniques, have demonstrated positive effects on well-being and quality of life for people with chronic illnesses (Baum, Herberman, & Cohen, 1995). In MS, the use of cognitive-behavioural strategies to reduce adverse psychosocial symptomatology dates back to the 1950s, but relatively few studies have used relaxation methods. The limited research available, however, has indicated that relaxation, for people with MS, can positively affect anxiety, psychological stress, ability to cope with stressors, and some aspects of mood, such as tension, vigor, and depressed affect (Crawford & McIvor, 1987; Foley et al., 1987; Maguire, 1996). Although a number of researchers have demonstrated that autogenic training (AT), and modifications of the basic technique, can influence negative physiological and psychological problems associated with various acute and chronic diseases (Ernst & Kanji, 2000; Linden, 1990; Linden, 1994; Pikoff, 1984), no study to date has investigated the effect of AT on psychosocial health for people with MS.

Sachs (1986) proposed that auto-hypnotic techniques were not only one of the easiest ways to induce relaxation, but were also effective in counteracting many psychosocial problems associated with illness. AT is an auto-hypnotic relaxation technique derived in the early part of last century. In AT, the individual passively concentrates on physiologically-oriented phrases in order to bring about sensations associated with the relaxation response. Although there is a limited empirical rationale for the use of AT in MS, there are a number of reasons why it may be an efficacious form of relaxation therapy in this population. Together with the previously described research on the psychosocial benefits of relaxation for people with MS, there are also a number of case reports that have indicated that hetero-hypnosis may positively influence some psychophysiological problems in MS (Dane, 1996). In addition, AT does not require a conscious, active effort to relax the muscles, and thus, may be a viable relaxation method for people with neurological and muscular dysfunction.

The purpose of this study was to examine the influence of AT on the psychological well-being and HRQOL of individuals with MS. Mild to moderately disabled persons participated in 10 weeks of AT to determine the effects on psychological health status. This study tested the prediction that AT can positively affect HRQOL and psychological well-being.

Method

Participants

A group of people with confirmed diagnoses of MS (20 females and 6 males) participated in the study. Participants were recruited from the surrounding community through the Multiple Sclerosis Society of Victoria (MSSV). Participants were selected according to a clinically confirmed diagnosis of MS, EDSS of 5.0 or less, and no history of major cognitive deficits. None of the participants had been involved in cognitivebehavioural programs, including yoga, meditation, hypnosis, or pastoral care services for six months prior to the study.

Measures

Four questionnaires assessing psychological health were used to determine the influence of the AT program on factors relating to HRQOL and well-being. The individual scales were the Multiple Sclerosis Quality of Life Instrument (MSQOL; Vickrey et al., 1995), the Centre for Epidemiology Studies Depression Scale (CES-D; Radloff, 1977), the Daily Hassles Scale (DHS; De Longis, Folkman, & Lazarus, 1988), and the Profile of Mood

States-Short Form (POMS-SF; Shacham, 1983). These measures were described in the Method section in Study 1 (see Chapter 3).

The Multidimensional Scale of Perceived Social Support (MSPSS) was used as a statistical control for the potential positive benefits of social interaction that may be derived from participation in an intervention program in a group setting. Although most forms of relaxtion training are not generally considered group activities, the group sessions of AT in this study concerned discussions about individuals' progress and experiences of AT. Meeting and discussing aspects of the training and potential changes in activities of daily living forms a considerable social component of the intervention. This scale was also described in the Method section of Study 1 (see Chapter 3).

Procedure

Potential participants were identified via the MSSV registration database, and sent letters detailing the study by the research coordinator at the MSSV (see Appendix G). Only those individuals interested in participating in the study were asked to contact the researcher. Participants agreed to assignment to either the experimental or control group, and members of the control group were offered the opportunity to participate in a relaxation training program at the conclusion of the study. Individuals participating in the AT program obtained medical clearance from their physicians (see Appendix H) and signed informed consent statements (see Appendix I). Similar to the design for the second study in this thesis, participants completed psychological instruments at baseline and at week 8 of the 10-week program. Participants in the treatment group received the questionnaires at home, and returned them to the researcher prior to the first session. The control group participants received questionnaires at home, and returned them via reply-paid envelopes. There was no contact, other than to remind individuals to return the questionnaires, with participants in the control group.

The AT program consisted of one supervised training session per week for 10 weeks. The participants were also asked to practice regularly (once a day) for the intervention period, and record their practice, and success or failure experiences in a preprinted diary (see Appendix J). At the beginning of each supervised session, participants reviewed and discussed their past week AT experiences in the group setting. The participants also discussed general training effects, such as change in perception of stress or sleeping patterns, and the instructor highlighted positive experiences. Linden (1994) suggested that discussing the benefits of AT can be used to motivate participants to adhere to the training.

The course of the AT program was relatively slow and deliberate. In the first session, the instructor introduced the participants to AT. The instructor discussed origins of the technique, potential physical sensations, possible problems and solutions. and postural skills. During this session, the instructor introduced the participants to the first two AT formulas (heaviness and warmth in the limbs). At two-week intervals, the physiologically-oriented phrases relating to cardiac regulation (week 3), respiratory control (week 5), and abdominal warmth and coolness of the forehead (week 7) were introduced in the group sessions (see Appendix K for AT script).

<u>Data Analysis</u>

Analyses of covariance were used to assess group (treatment vs. control) differences for HRQOL and measures of psychological well-being, so that results demonstrated how different the two groups were after the intervention. Social support was used as a covariate, as well as pre-test measures of HRQOL and psychological well-being to control for initial differences between the two groups. Although the traditional method of determining significance (p < .05) is reported, the results for the psychosocial measures focus on effect sizes. The effect size in analysis of covariance is η^2 , and it explains the strength of association between the dependent and independent variables (Tabachnick & Fidell, 1996). η^2 represents the amount of variance in a variable accounted for by group membership (i.e., being in the control or AT group). In the social sciences, if 15% of the variance in a variable is accounted for by group membership ($\eta^2 = .15$), it is considered a medium to large effect.

Results

Participants 1 -

Of the 26 participants originally recruited for the study, two participants (one from each of the control and treatment groups) were excluded because their post-intervention questionnaires were not returned. Two additional participants in the treatment group were also excluded. One participant dropped out of the program due to personal reasons unrelated to the training or MS. Another participant experienced an exacerbation during the intervention period that required hospitalisation, and was unable to continue the AT program. Thus, data from 22 participants were included in the analysis (treatment group $\underline{n} = 11$, control group $\underline{n} = 11$).

Participants in the treatment group practiced the AT technique for an average of 27.7 sessions ($\underline{SD} = 12.7$) over the 10-week training period. Participant characteristics for the treatment and control groups are summarised in Table 5.1. Differences between groups were analysed using Cohen's <u>d</u> and results indicated that participants the treatment group

had been living with symptoms of the disease (years since onset of symtpoms) for longer than participants in the control group ($\underline{d} = 1.2$).

Table 5.1

Participant Characteristics

	Treatment Group		Control	Group	
-	M	<u>SD</u>	M	<u>SD</u>	
Sex (F/M)	7.	/4	9/2		
Age (yrs)	43.55	9.47	40.82	6.08	
Onset of symptoms (yrs ago)	17.55	10.31	8.45	4.06	
Confirmed diagnosis (yrs ago)	9.36	6.28	6.45	2.94	
Last exacerbation (mths)	10.64	9.89	6.64	7.47	

Psychosocial Measures

Results indicated improvements in select aspects of HRQOL as measured by the MSQOL for the treatment group in comparison to the control group. There were medium to large effects for the pain (p = .11, $\eta^2 = .13$) and the role limitations due to physical problems subscales (p = .02, $\eta^2 = .19$), as well as a very large effect for the role limitations due to emotional problems subscale (p = .05, $\eta^2 = .25$). The energy subscale on the HRQOL measure also showed a very large effect (p = .01, $\eta^2 = .31$). This result corresponded with medium to large effects for the vigor (p = .06, $\eta^2 = .18$) and fatigue (p = .15, $\eta^2 = .11$) subscales of the POMS-SF. Other subscales of the POMS-SF (depressed affect, tension, confusion, anger) showed negligible effects. Depressed affect, as measured by the CES-D,

however, showed an effect size in the large to very large range (p = .03, $\eta^2 = .22$). Results on the DHS indicated a reduction in hassles in the medium range (p = .16, $\eta^2 = .11$) for the treatment group, but no difference between groups on the uplifts subscale (p = .77, $\eta^2 = .005$). Means and standard deviations for each score (pre- and post AT) for each group (treatment and control) are presented in Table 5.2. F-values, significance levels, and effect sizes for the psychosocial scales are presented in Table 5.3.

Discussion

The results from this study indicate that participation in an AT program can positively affect HRQOL and well-being for people with MS. The medium to large effect for the role limitations due to physical problems subscale of the HRQOL measure indicates the participants in the relaxation program were less limited by physical problems in performing regular daily activities. This finding, however, did not seem to be a reflection of improved physical functioning for the AT group, because results showed that the effect for the physical function subscale of the MSQOL was negligible. Results also indicate a substantial improvement, as evidenced by the very large effect, for the role limitations due to emotional problems subscale for individuals in the AT group. LaRocca, Kalb, Foley, and Caruso (1993) proposed that role functioning is an important and useful outcome measure in psychosocial interventions, because it demonstrates whether a person is coping with the effects of the disease in a way that permits them to function adequately in their work, social, and general activities. The results from this study indicate that participants in the AT program perceived that they were better able to perform day-to-day activities due to positive changes in physical and emotional health. Researchers have found that role performance in

Table 5.2

Means (M) and Standard Deviations (SD) of Psychosocial Variables for Treatment and

	_	-	Freatme	ent Grou	р		Contro	l Group	
		pre-	AT	post	-AT	pre-	-AT	post	-AT
	Variable	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
MSQOL	energy	16.1	3.1	19.7	2.7	17.6	4.3	16.4	4.0
	RLPP	4.9	1.1	6.0	1.7	4.8	1.2	4.4	1.2
	RLEP	4.6	1.4	5.3	1.3	4.5	1.4	4.4	1.5
	pain	9.7	2.7	11.2	2.7	8.5	3.3	8.6	3.6
	sexual function	11.0	3.6	10.6	3.4	8.7	3.9	7.7	3.3
	social function	10.1	2.6	11.8	3.2	9.4	3.0	9.8	3.2
	emotional well-being	21.8	5.4	22.8	4.9	20.8	5.5	20.8	6.0
	health distress	14.7	4.5	16.5	4.3	15.5	5.2	16.3	5.2
	health perceptions	13.9	3.7	13.7	3.1	16.0	5.0	16.0	5.3
	physical health	17.8	5.4	17.4	4.9	16.9	6.4	16.8	5.9
	cognitive function	16.6	4.6	17.8	4.3	16.4	5.2	17.8	5.3
POMS-SF	vigor	5.2	2.8	7.2	4.8	3.4	3.0	3.2	2.7
	fatigue	10.9	4.7	8.8	4.1	11.2	5.8	10.7	6.6
	depressed affect	5.6	5.4	5.0	6.3	8.4	9.3	8.4	9.8
	tension	6.3	4.2	5.3	4.2	7.7	7.1	7.1	7.2
	confusion	3.9	3.1	3.7	3.1	6.1	5.4	5.4	5.7
	anger	5.6	4.7	5.0	4.2	7.3	7.4	7.0	8.9
CES-D	depression	36.7	9.1	34.2	7.9	33.0	17.0	32.7	19.4
DHS	hassles	32.5	14.9	28.0	15.8	31.6	23.8	35.8	28.4
	uplifts	40.7	20.7	41.8	29.4	24.7	19.0	25.8	19.
MSPSS	social support (c)	60.6	21.4	59.5	20.6	61.4	19.7	59.9	19.

Control Groups at Pre- and Post-AT Program

c = covariate

Table 5.3

F-values, Significance Levels, and Effect Sizes for Psychosocial Instruments Using Social Support and the Appropriate Baseline Scores as Covariates

Scale	Subscale	F-value	p	η^2
MSQOL	Energy	8.09	.01	.31
	role limitations due to physical problems	5.94	.02	.25
	role limitations due to emotional problems	4.26	.05	.19
	Pain	2.72	.11	.13
	sexual function	1.85	.19	.09
	social function	1.86	.19	.09
	emotional well-being	1.33	.26	.06
	health distress	.44	.51	.02
	health perceptions	.38	.54	.02
	physical health	.10	.75	.005
	cognitive function	.01	.90	.001
POMS-SF	Vigor	4.04	.06	.18
	Fatigue	2.26	.15	.11
	depressed affect	.21	.65	.01
	Tension	.18	.67	.01
	Confusion	.15	.70	.008
	Anger	.06	.80	.004
CES-D	Depression	5.21	.03	.22
DHS	Hassles	2.12	.16	.11
	Uplifts	.09	.77	.005
MSPSS	social support (covariate)	.03	.87	.002

MS is often compromised because of some of the typical problems associated with living with the disease (Murray, 1995; Miller, 1997). Also, it is likely that improvements in psychosocial factors such as pain, fatigue, energy, and depressed affect, influenced the way in which the AT participants reflected on role limitations.

Although, for many years, pain was not perceived as a major problem in MS, researchers have indicated that non-specific chronic pain is a relatively common sensory symptom that can negatively affect psychosocial health (Archibald, McGrath, Ritvo, Fisk, & Murray, 1994). The medium to large effect on the pain dimension of the MSQOL in this study indicates that AT may be associated with diminished pain perception for people with MS. This finding supports previous research that has demonstrated AT is an effective intervention for treating pain in a variety of acute and chronic illnesses (Dinges, et al., 1997; Spinhoven, Linssen, van Dyck, & Zitman, 1992). Previous case reports have also found that hypnosis, the technique from which AT was derived, may reduce the pain associated with MS (Medd, 1992). The finding that AT is associated with reduced pain may be relevant for people with MS, because routine pain medications often have very little effect (Schapiro, 1994), and thus, individuals may be able to use AT, a technique that they can carry out by themselves, when painful episodes occur.

In the HRQOL measure, the energy subscale exhibited the largest effect, with over 30% of the variance in energy accounted for by group membership. In conjunction with this finding, results also showed that participants in the AT program substantially improved vigor, as measured by the POMS-SF. Previous researchers have suggested that relaxation training for people with MS may be associated with positive changes in vigor, because energy that was previously expended in coping with stressful situations may be redirected

so that individuals can engage in more positive pursuits (Crawford & McIvor, 1997). Thus, improved energy and vigor for participants in the treatment group may have been mediated by the reduction in daily hassles evident in this research. Researchers have also indicated that increased energy and vigor may affect the way in which individuals manage the physical and psychological symptoms of the disease (Murray, 1995). It is likely, therefore. that AT-induced changes in energy and vigor may have a positive, indirect influence on overall psychological health and well-being for people with MS.

Together with increased energy and vigor, results also indicate that the AT program is associated with decreased perception of fatigue, and it is likely that these variables share inverse relationships. There are, however, likely to be other factors associated with AT that may have led to the reduction in fatigue for participants in the AT group. Results from a study, which investigated psychosocial correlates of fatigue in MS. indicated that fatigue severity may be related to low mastery perceptions (Schwartz, Coulthard-Morris, & Zeng, 1996). It is possible that AT may provide a means for mastery experiences, in that the technique is designed to foster a sense of control and independence via the practice of a readily learnable skill. Self-control and independence from feedback devices and therapists clearly differentiate AT from many other relaxation methods, and these differences may partially explain why previous researchers, using other relaxation therapies (i.e., progressive muscular relaxation; PMR) have not found that relaxation reduces fatigue for people with MS (Crawford & McIvor, 1987; Maguire, 1996). The finding that AT may be an efficacious intervention for ameliorating symptoms of fatigue may also have broader therapeutic implications in light of research that identified fatigue as one of the most important indicators of psychological health in MS (Krupp, Alverez, LaRocca, & Scheinberg, 1988).

The large to very large effect for depression, as measured by the CES-D,

demonstrates that the participants involved in the AT program experienced reductions in depressed affect. Examination of the mean change for this variable, however, showed that participants in the AT group reported an overall decrease from pre- to post-intervention of approximately three points. Considering the CES-D has a possible range from 0 to 60, a change of this magnitude does not seem to be meaningful, and is probably not detectable in behaviour. The depressed mood subscale of the POMS-SF also showed that the AT group did not change level of depressed affect. Results from previous research examining the effect of relaxation and other cognitive-behavioural therapies on depression in MS have been equivocal (Crawford & McIvor, 1987; Foley et al., 1987; Larcombe & Wilson, 1984; Maguire, 1996). Although the disparate findings may be due to the different therapies employed, it may also be due to the complex aetiology of depression in MS. Researchers have indicated that the high prevalence of depression among people with MS may be a neurological response to the disease process, and that it is likely that depressed affect is a partial function of the distribution, extent, and severity of cerebral involvement (Feinstein, 1995).

Results indicate that participants in the AT group reduced hassles, as measured by the DHS. Researchers have hypothesised that daily hassles may have more profound effects on general health and well-being than major stressful life events (Kanner, Coyle, Schaefer, & Lazarus, 1981; Lazarus, 1984). Thus, the finding that AT may be associated with reduced daily hassles for people with MS may have important implications, considering the putative links between stress and MS exacerbations. It is also possible that the AT program, and the resultant changes in variables such as pain, fatigue, energy, and vigor, may have contributed to how the participants coped with life circumstances, such as family, work, and social commitments.

One of the major limitations of this research was the small sample size. A larger sample may have permitted examination of other relevant variables, such as frequency of practice of AT. Although results showed that the participants averaged three practice sessions per week (including the group session), the very large standard deviation (SD = 12.7) indicates considerable variability in participants' frequency of practice. Exploration of the frequency of use of AT showed that, although some participants recorded practicing the technique daily, other participants recorded none or few home practice sessions over the 10week training period. Although a number of researchers have suggested that more practice is related to greater benefits (Antoni et al., 1991; Linden, 1996), the small sample size in this research precluded dividing the participants into high and low AT-users, because the subsets would have been extremely small, and results problematic because of issues of low statistical power. A fruitful research path, therefore, may be to use much larger samples to explore the influence of the frequency of use of AT in MS on factors, such as HRQOL and well-being. Although beyond the scope of this research, the apparent variability in frequency of practice also begs the question: what are the reasons some participants with MS practiced the technique regularly, and perhaps incorporated AT into their daily routines, while others did not?

In addition, this research was limited in that the sample was representative of mild to moderate disability, and this restriction of range may preclude generalisation of the results to those people with more advanced illness, particularly people with significant cognitive deficits. Additional research, therefore, is needed to further explore the use of AT on HRQOL for people with MS with a broad range of impairment. Although this study is the first to use AT as a form of relaxation therapy for people with MS, the results represent encouraging evidence that AT may be an effective complementary therapy in MS.

Clinical Implications

There has been an increasing realisation that intervention programs for people with MS need to address the emotional, social, and psychological factors involved in living with a chronic and unpredictable disease. This recognition has led researchers to acknowledge that the comprehensive management of MS requires a more complex and holistic approach to health care (LaRocca et al., 1993). Although research investigating the effect of cognitive-behavioural therapies in MS is not new, few studies have used relaxation training, and in many cases research has been methodologically suspect. The results from this study provide evidence of the contribution that an AT program can make for enhancing HRQOL and psychological well-being for people with MS. It is also possible that participation in an AT program may complement some medical treatments, because recent research has indicated that interventions designed to enhance the coping process may be associated with improved adherence to drug therapies (Mohr et al., 1997). It is also possible that AT represents a viable relaxation method for people with MS across a range of physical disabilities, because it does not require an active effort, and is suitable for people who may be confined to wheelchairs.

<u>Conclusion</u>

Overall, results from this study indicate that 10 weeks of AT can positively affect HRQOL and psychological well-being for people with MS. Changes in perception of role functioning, pain, energy, and fatigue demonstrate that AT may be an efficacious relaxation therapy for counteracting the psychosocial problems that impinge on the quality of life of people living with MS. This study contributes to the growing body of evidence that comprehensive, long-term health care for people with MS needs to address the full range of problems experienced by those individuals living with the disease.

Because this is the first study to use AT as a form of relaxation therapy for people with MS, replication of this research is clearly necessary to extend the knowledge of the beneficial effects in this population. Future outcome studies also need to be conducted by employing longitudinal research designs over an extended period, in order to establish the scope and limits of the observed effects on some of the more complex psychosocial factors, such as depression. Although the use of stress management and relaxation techniques for improving health and well-being for people with MS is recognised, the research is severely limited. Thus, there remains much scope for research investigating the effect of AT on wellbeing and HRQOL for people with MS.

CHAPTER 6

GENERAL DISCUSSION AND CONCLUSIONS

Introduction

The main aim of this thesis was to investigate the effects of exercise and AT on the HRQOL and psychological well-being of people with MS. This discussion chapter briefly compares the efficacy of the exercise and AT interventions for enhancing psychological health for people with MS by examining the treatment groups and the magnitude of changes in the psychosocial variables measured. This comparison is followed by implications for clinical practice and future research, and some concluding remarks.

Comparison of the Effects of Exercise and Autogenic Training

The effect of an exercise and an AT program on HRQOL and psychological wellbeing for people with MS were investigated in two distinct studies. Thus, comparing the effects may be confounded by a number of factors unrelated to the intervention programs, such as participant characteristics, social environment, and contact with the researcher. Of course, these confounds may have also affected results in each intervention study. With this caveat in mind, however, comparison of the effects between the two interventions showed some interesting similarities and differences that may be attributable to the unique contribution of each therapeutic treatment. In addition, the information gained by comparing the effects of these studies may contribute to clinical practice in the choice of behavioural interventions designed to enhance the HRQOL and psychological well-being of people with MS.

The results from the aerobic exercise and AT programs showed a number of similar changes in HRQOL and well-being for those involved in the interventions, including

improved energy and vigor, and reduced fatigue. There were very large effects on the energy subscale of the HRQOL measure, indicating those participants in the treatment groups (either exercise or AT program) substantially improved their energy levels. The magnitude of change for energy, in terms of effect size, was considerably larger for those persons involved in the exercise program. It is possible, however, that the exercising participants experienced larger gains because their mean baseline score for energy was lower than the mean score for those in the AT intervention (exercise group, M = 12.9 vs. AT group, $\underline{M} = 16.1$). The vigor subscale of the POM-SF, however, indicated that, although both groups improved vigor, the exercise intervention was associated with a much larger effect than the AT program, even though mean scores for vigor were similar for the two groups at baseline (exercise group, M = 5.0 vs. AT group, M = 5.2). Results indicated a similar trend for reductions in fatigue. The comparable effects suggest that exercise may be more effective for improving energy and vigor, and reducing fatigue for people with MS, and this result is not unexpected considering the physiological activation associated with aerobic exercise. Yet, because the exercise and AT interventions were both associated with substantial changes in energy, vigor, and fatigue, the mechanisms that govern these positive adaptations may be multifaceted. One theoretical explanation that may account for this finding is Bahrke and Morgan's (1978) distraction hypothesis. The premise of the hypothesis is that cognitive diversion or "time-out" from emotional concerns through any pleasant activity may be the agent responsible for positive changes in psychological affect. The comparable effects between the exercise and AT interventions on measures of energy, vigor, and fatigue lends some support to this premise. Regardless of the mechanism, the finding that both an exercise and an AT program are associated with improved energy and

vigor, and reduced fatigue may be particularly relevant for people with MS. Not only have researchers highlighted the importance of managing fatigue in MS for maintaining quality of life (Murray, 1995; Ritvo et al., 1996), but, considering aerobic exercise may not be a viable intervention for many individuals with severe ambulatory deficits, the comparable results warrant the serious consideration of AT as another means for counteracting some of the typical difficulties imposed by the disease.

Results indicated that an aerobic exercise program may be more efficacious than an AT program for improving the overall physical health status of people with MS. The physical health-related subscales (physical health, health perceptions, health distress), as measured by the MSQOL, showed medium effects for the exercising participants, but effects were negligible for those participants in the AT program. Greater improvements in physical health status due to involvement in an exercise program, in comparison to participation in a relaxation intervention, is not surprising. The exercise program was not only associated with improved physical fitness, which is likely to be reflected in improved perception of physical function, but the positive changes may also have been due to a reversal of some of the effects of sedentary living. Changes in physical function, however, did not seem to be congruent with, or influence, perception of role functioning.

Results indicated that, despite negligible effects on the physical health-related subscales of the MSQOL, the AT program was more effective for reducing role limitations due to physical problems than the exercise program. The physical role limitations subscale of the MSQOL measures how physical problems interfere with regular daily activities, and previous research has indicated that physical abilities may not necessarily be related to the way in which individuals perceive role limitations in relation to physical functioning

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(Nordvedt et al., 1999). Researchers have also suggested that improved role functioning may be indicative of how well individuals are coping with the effects of the disease so that they can function adequately in their activities of daily living (LaRocca et al., 1993). Thus, the positive changes in role functioning for the AT group seem to indicate that the AT program was associated with how the participants handled some aspects of their lives so as to permit them to function in their physical roles. For the participants in the AT program, the reduction in hassles related to family, work, recreational, and social commitments, as measured by the DHS, may have been related to how participants perceived role limitations. Although the exercise program was associated with moderate effects for uplifts, in comparison to negligible effects for the AT group, researchers have indicated that reductions in hassles are more likely to influence psychological well-being than the absence of uplifts (Dwyer, 1997; Lazarus, 1984).

Despite some differences between the two interventions in terms of their influence on HRQOL and well-being, the exercise and AT programs were associated with positive changes in psychosocial health status for participants. The similarities indicate that the mechanics of change in affect may be relevant in both aerobic exercise and AT. It is likely that stress reduction is one of the mechanisms that govern this therapeutic change. Stress management techniques are designed to help people cope with the emotional concerns or stressors in their lives and researchers have indicated that both aerobic exercise and AT are associated with stress-reduction (Baum, Herberman, & Cohen, 1995). In addition, because stress reduction may mediate adaptations in affect, it is likely that the resultant changes in psychosocial health due to the interventions was associated with the autogenic- and exercise-induced reductions in the perception of stress. For example, being able to manage stress successfully may mean that energy that was previously expended in coping with stressful situations is available to the individual for other activities. Although results on the measure of daily stress (DHS) indicated a reduction in hassles for participants in the AT group only, this finding may reflect how different stress management techniques influence the perception of stress. Researchers have indicated that relaxation techniques, such as AT, may actually ameliorate the causes of stress, such as concerns about family, work, and social commitments (Greenberg, 1993). Exercise, on the other hand, may be associated with general resistance to stress via a process of "active toughening" of the body's physiological systems, and thus changes may not be readily apparent by measuring daily hassles. Researchers have suggested that various techniques to help people manage stress do have particular effects, and thus, not only is there a host of methods from which to choose, but strategies used in combination may be the best defence against the debilitating effects of stress (Seaward, 1994).

Overall, the results indicate that an aerobic exercise program may be more effective for enhancing HRQOL and psychological well-being, for people with MS, than an AT program. Comparative results showed that an exercise program was efficacious for improving aspects of health and well-being across a broad spectrum of psychological indices, including physical, social, sexual, and psychological health. Many people with MS, however, may not be keen about exercising, which can be a difficult experience, especially for those with severe ambulatory deficits. For improving these individuals' HRQOL, it seems that interventions with comparable benefits to exercise need to be prescribed. The comparative results demonstrated that an AT program may fulfil this role. Results showed that an AT program may actually be associated with some psychological benefits beyond that which was evident from participating in an exercise program. Thus, because the results showed that exercise and AT may influence distinct aspects of HRQOL and well-being, it may be appropriate for future research to consider the two interventions, not only as complementary therapies in their own right, but as complementary to each other.

Clinical Implications

For people with MS, managing the disease primarily involves dealing with symptoms and the physical, social, and psychological consequences of increasing and unpredictable disability. For many years, therapeutic treatments in MS have focused on intermittent acute care in that symptoms are dealt with when and if they occur. Increasingly, however, attention is shifting from traditional medical treatments, and is being directed towards effective behavioural interventions designed to enhance HRQOL. There may be a number of reasons for this shift to a more holistic approach to health care, including the recognition that many people with MS have near to normal life expectancy, yet are often faced with a wide and confusing variety of symptoms (Olek, 1999). The research in this thesis has shown that an aerobic exercise program may be a beneficial adjunct to medical and pharmaceutical therapies for enhancing psychological well-being. Moreover, previous researchers have shown that people with MS can exercise at an appropriate intensity and duration to achieve short and long-term health benefits without detrimental effects to symptoms and overall disease progression (Gappmaier et al., 1994; Petajan et al., 1996; Ponichtera-Mulcare et al., 1994, 1995, 1997). Although it is unrealistic to suggest that exercise can replace traditional medical care for people with MS, it may serve to enhance other therapies, as well as provide an alternative for those excluded from some treatments.

The research in this thesis demonstrated that a relaxation intervention (AT) may also be an effective means for enhancing HRQOL and well-being for people with MS. Because some of the typical MS-related disabilities include spasticity, impaired coordination, and ambulatory deficits, aerobic exercise may not always be a viable option for people with MS. AT, however, offers possibilities for disabled people to participate in an intervention designed to counteract some of the difficulties imposed by the disease. Although the use of psychotherapeutic interventions has a relatively long history in MS, such interventions seem to have been investigated in a somewhat "ad hoc" manner with little regard to the relative merits of each method. Study 3 in this thesis demonstrated that AT can make some positive changes in psychological health and well-being of people with MS.

Psychosocial interventions designed to facilitate and enhance how people with MS manage the effects of the disease have an important role within an emerging model that embraces the concept of comprehensive and multidisciplinary care. Yet, as more and more interventions are developed within this model, it is important that health professionals identify and demonstrate how each strategy may benefit the MS population. The research in this thesis indicated that both exercise and AT may help individuals with MS improve their psychological health status, and provide people with a choice based on preference and abilities. Although the comparative results are problematic because the interventions were tested in two distinct studies, the findings suggest that an exercise and an AT program for people with MS may actually complement each other in light of some of the distinct effects. These findings have direct implications for clinical practice, and highlight the necessity of approaching the management of MS from a holistic perspective, not just concentrating on the treatment of isolated physical and neurological problems. It seems that health care

professionals working with people with MS have a responsibility to deal not only with MSrelated symptoms and exacerbations, but with psychosocial considerations as well. Thus, exercise, combined with relaxation therapies, such as AT, may be a new focus for health care in MS, because the combination of therapies represent not only a means for reducing physical disabilities, such as fatigue, but may also lead to social and psychological gains.

Implications for Future Research

There is often the tendency in health research investigating chronic illness, such as MS, to concentrate on outcomes measured in terms of disability level. For many years, some of the most common measures used to assess the effectiveness of various treatments in MS have been disease-related outcomes, such as changes in physical and neurological function (e.g., EDSS), or other indicators of disease progression. Although these measures may be relatively easy to obtain and compare, they do not adequately reflect how an individual perceives the effect of illness or disability on their day-to-day lives. Furthermore, it is not likely that such measures best capture the individual's perception of the benefits of different interventions, and thus studies using only physiological or neurological dependent variables seem limited. Participants' perceptions of functioning and well-being are central outcomes of behavioural interventions, such as exercise and AT. The domains associated with HRQOL and psychological well-being provide important "real life" outcomes for people with chronic, degenerative disabilities, such as MS. These measures are also more likely to capture positive aspects of health, and not just the absence of morbidity. Although traditional indicators of disease progression, such as EDSS and MRI, play a role in clinical research, HRQOL variables broaden the focus of outcome measures, and are relevant in terms of everyday issues. Does a person with MS, after an intervention such as exercise or

AT, function better in the physical, mental, and social aspects of life? Or does a person involved in an exercise and AT program feel well enough to perform daily activities? As Kaplan (1990) has argued so convincingly, although biological indices may mediate health outcomes, behavioural measures are the quintessential indicators of health and wellness. It seems that future researchers need to adopt HRQOL and behavioural outcomes in determining the efficacy of complementary therapies in MS.

Study 2 indicated that an aerobic exercise program can positively affect HRQOL and well-being for people with MS. The extreme variability in onset, symptoms, and disease course, however, makes MS one of the more difficult chronic conditions in which to conduct meaningful investigations. In particular, physical fitness, psychological health status, and exercise are important areas for future research to explore, but may be problematic over the short-term. People with MS are prone to exacerbations, without warning, and this unpredictability makes it difficult to draw definitive conclusions about the influence of physical fitness. Future studies need to be extended by employing longitudinal research designs with relatively large sample sizes. There remains much scope for research on HRQOL, exercise, and MS, and research over extended periods may also include investigations into the efficacy of exercise programs for people with MS with a wide range of physical and cognitive impairments, as well as the interaction of drug therapies and regular participation in aerobic exercise. Future studies may also consider the inclusion of measurments (e.g., blood assays) to investigate one, or more, of the mechanisms theoretically posited to mediate exercise-induced affective change.

In addition, the question remains unanswered as to whether disease progression can be decelerated by participation in physical activity. MS is considered an autoimmune disorder, and it is possible that exacerbations occur when the immune system is "unbalanced." Although the available scientific evidence is scant, researchers have found that psychological distress may adversely affect immune function in people with MS (Foley et al., 1988; Foley et al., 1992). Considering that researchers have shown exercise can help modulate immune function by improving psychological well-being (e.g., Kiecolt-Glaser & Glaser, 1992), a line of research on exercise, MS, psychological well-being, and immune function might be a fruitful path to follow. Given the encouraging evidence from related literature on chronic disease, immune function, and exercise, such a line of research would be helpful in designing interventions for MS management over the long-term. Studies of people with HIV/AIDS have shown that participation in moderate aerobic exercise, by reducing psychological distress, can have immunomodulatory effects that may attenuate disease progression (LaPerriere et al., 1992; LaPerriere et al., 1991; Lox, McAuley, & Tucker, 1995). Future exercise and MS research may employ a psychoneuroimmunology model similar to that presented by LaPerriere et al. (1994) in their research on HIV/AIDS. The premise of the model is that improvements in psychological health following exercise will affect neuroendocrine regulators of immune function, and improve the response of the immune system to disease. Although the applicability of this model to the MS population is apparent, research to date has yet to investigate the effect of exercise on immune function in MS.

The role of relaxation in attenuating dysfunctional immunological responses in MS may also be a potential research initiative. Study 3 showed that HRQOL and psychological well-being can be enhanced by participation in a relaxation intervention (AT) program. Although previous researchers have indicated that relaxation techniques may affect components of the immune system, via positive changes in psychological health, in other immunocompromised populations, such as people with HIV/AIDS (Antoni et al., 1991; Eller, 1995; 1999), researchers have not yet addressed this hypothesis in MS. Future research addressing the effect of relaxation training on immunocompetence may be particularly relevant in MS considering the unresolved relationship between stress, immune functioning, and MS exacerbations. Previous research examining the influence of relaxation strategies has also shown that frequency of practice may be a mediating factor in a number of clinical outcomes (Antoni et al., 1999; Milne, Joachim, & Niehardt, 1986). Future research investigating relaxation techniques, such as AT, in MS must employ sufficiently large sample sizes so as to delineate between participants' frequency of practice, regardless of whether the outcomes measured are psychological, immunological, or a combination of the two.

Study 3 in this thesis contributed to the body of literature demonstrating that cognitive-behavioural therapies, and in particular, relaxation strategies, may be efficacious for improving psychological health status for people with MS. Clearly further replication of this study is necessary to establish the scope and limits of the observed effects, as well as examine the mechanisms by which they may occur. The research in this thesis also indicated that despite considerable overlapping effects, the exercise and AT interventions had unique contributions to improving HRQOL and well-being for the participants. Future research should involve studies that combine both exercise and AT for people with MS to examine, not only how each intervention may complement traditional treatments, but also how these interventions may operate in concert to improve the psychosocial problems inherent in the disease.

Concluding Remarks

The primary goal of comprehensive care, which is assuming an increasingly important role in the management of MS, is to help individuals maximise their quality of life given the limitations imposed by the disease. Although psychologically oriented efforts to maintain and improve long-term well-being for people with MS have often been considered as supplementary to drug treatments, more attention is now being directed towards identifying behavioural interventions designed for effective management of psychosocial problems over the long illness trajectory. Results of the present thesis provide support that aerobic exercise and AT programs may fulfil this role as complementary therapies in MS.

It is clear that the unpredictability and multiplicity of disabling symptoms in MS not only disrupt individual's lives, but are associated with a variety of psychological, social, and emotional adjustments for individuals affected by the disease. It is also increasingly apparent that health care strategies that recognise the psychosocial aspects of the disease result in more effective care for those people with MS. The studies presented in this thesis reflect the importance of interventions that look beyond traditional models of care for chronically ill individuals. The studies also highlight the need to define relevant targets of interventions in MS, and to identify effective interventions that contribute to the comprehensive care of people with MS. It is hoped that the results reported in this thesis provide an important step from which research on issues relating to HRQOL and psychological well-being for people with MS can flourish.

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Appendix A: Information Letter to Participants Study 1

Dear Recipient,

We are researchers at Victoria University of Technology investigating the relationship between physical activity levels, well-being, and health-related quality of life of people with multiple sclerosis. Although only a handful of studies have looked at exercise and physical activity for people with multiple sclerosis, it seems that exercise is associated with improved overall well-being and quality of life.

We would like you to be part of this study by completing a questionnaire. The questionnaire asks about your physical activity levels, general health, feelings, and behaviour. Responses to the questionnaire involve ticking boxes and circling numbers. The questionnaire will takes about 40 minutes to complete, although you are under no pressure to complete it within this time. The questionnaire is completely anonymous and all answers you give will remain strictly confidential.

If you are interested in participating in this study, please fill out the consent form overleaf and return it to us in the reply paid envelope enclosed. You do not need to use any stamps. Once you have returned the consent form, a questionnaire will be posted to you in the next few days.

If you are interested in participating, but may require help reading or marking the questionnaire, or if you have any questions regarding the study, please do not hesitate to contact Georgina Sutherland on 9376 2842 or 9248 1133.

Thank you very much for your time.

Yours Sincerely,

Georgina Sutherland

Dr. Mark Andersen Please turn over to fill in the information requested on the consent form

Victoria University of Technology

Consent Form

INFORMATION TO PARTICIPANTS:

We would like to invite you to be part of a study investigating the relationship between physical activity, well-being, and health of people with multiple sclerosis.

CERTIFICATION BY PARTICIPANT:

I, _____

(name)

of ______(address)

certify that I am at least 17 years of age and that I am voluntarily giving my consent to participate in the study entitled: The Relationship Between Physical Activity, Well-Being, and Health of People with Multiple Sclerosis, being conducted at Victoria University of Technology by: Ms. Georgina Sutherland and Dr. Mark Andersen.

I certify that the objectives of the study have been explained to me and that I freely consent to participation.

I certify that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information I provide will be kept confidential.

Signed: _____ Date: _____

Please tick one of the following;

Please send me a questionnaire at the above address

Please send me a questionnaire in <u>large print</u> at the above address.

Please send me a questionnaire at the above address, but I may require help reading or marking the questionnaire.

Please send me a questionnaire at the following address;

Any queries about your participation in this project may be directed to the researchers:

Ms. Georgina Sutherland 9376 2842 Dr. Mark Andersen 9248 1132

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Ethics Committee, Victoria University of Technology,

PO Box 14428 MCMC, Melbourne, 8001. (Telephone no: (03) 9688 4710)

<u>The Multiple Sclerosis</u> <u>Questionnaire</u>

This questionnaire asks about your general health, feelings, and behaviour.

Some of the questions ask about sensitive and personal matters. Please try to answer all the questions as honestly as possible, although if you feel uncomfortable about any question, then move on to the next one.

The questionnaire takes about 40 minutes to complete. If you feel tired before completing the entire questionnaire, please feel free to take a break and complete the remaining sections at another time. Please ask someone to assist you if you need help reading or marking the questionnaire.

All the answers you give will remain strictly confidential.

If you have any questions regarding this questionnaire, please do not hesitate to contact Georgina Sutherland on 9376 2842 or 9248 1133.

Thank-you very much for your time.

1. Age:			
2. Years since onset of MS		3. Years since diagnosis of M	IS
4. Gender: Female •		Male •	
5. Clinical status: (please tick on	e)		
Benign		Exacerbating remitting	
Relapsing progressive		Progressive	
6. Current Medication:			
7. Other Medical Conditions:			

LEVEL OF PHYSICAL ACTIVITY

8. In the **past two weeks**, did you engage in **vigorous** exercise - exercise that made you breathe harder or puff and pant? (e.g., vigorous sports such as football, netball, tennis, squash, or running, jogging, cycling, vigorous swimming etc.).

Yes 🗌
No 🗌
a. If yes, how many sessions of vigorous exercise did you do over the past two weeks ?
b. Please estimate the total number of hours spent exercising vigorously over the past two weeks .
9. In the past two weeks , did you walk or self-propel in a wheelchair for recreation or exercise?
Yes
No 🗌
a. If yes, how many sessions did you do over the past two weeks?
b. Please estimate the total number of hours over the past two weeks .
10. In the past two weeks , did you engage in less vigorous exercise for recreation, sport or health/fitness purposes which did not make you breathe harder or puff and pant? (e.g., throwing the frisbee, playing pool, playing darts, bowling etc.).
Yes 🗌
No 🗌
a. If yes, how many sessions did you do over the past two weeks?
b. Please estimate the total number of hours over the past two weeks .

11. In the past two weeks, did you engage in vigorous activity, apart from exercise, which made you breathe harder or puff and pant? (e.g., carrying loads, heavy gardening, chopping wood, laboring - at home, during employment or anywhere else).

Yes	
No	

a. If yes, how many sessions did you do over the past two weeks?

b. Please estimate the total number of hours over the past two weeks.

12. Is your reported physical activity level over the past two weeks representative of your general or usual activity level?

Yes	
No	

SECTION A

This section asks about your health and daily activities. Please **answer every question** by circling the appropriate number (1, 2, 3,....).

1. In general, would you say your health is: (Circle one number)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now? (Circle one number)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

Please continue to next page.

		Yes,	Yes,	No, not
]		limited a	limited a	limited at
		lot	little	all
3.	Vigorous activities, such as running,	1	2	3
	lifting heavy objects, participating in			
	strenuous sports			
4.	Moderate activities, such as moving a	1	2	3
	table, pushing a vacuum cleaner, bowling,			
	or playing golf			
5.	Lifting or carrying groceries	1	2	3
6.	Climbing several flights of stairs	1	2	3
7.	Climbing one flight of stairs	1	2	3
8.	Bending, kneeling, or stooping	1	2	3
9.	Walking more than a mile (1.6 kilometre)	1	2	3
10.	Walking several blocks	1	2	3
11.	Walking one block	1	2	3
12.	Bathing or dressing yourself	1	2	3

3-12. The following questions are about activities you might do during a **typical day**. Does **your health** limit you in these activities? If so, how much? (Circle 1, 2, or 3 on each line)

13-16. During the **past four weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Circle one number on each line)

		YES	NO
13.	Cut down on the amount of time you could spend on work or other activities	1	2
14.	Accomplished less than you would like	1	2
15.	Were limited in the kind of work or other activities	1	2
16.	Had difficulty performing the work or other activities	1	2

17-19. During the **past four weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious). (Circle one number on each line)

		YES	NO
17.	Cut down on the amount of time you could spend on work or other activities	1	2
18.	Accomplish less than you would like	1	2
19.	Didn't do work or other activities as carefully as usual	1	2

20. During the **past four weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups? (Circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

21. How much **bodily** pain have you had during the **past four weeks**? (Circle one number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very Severe	6

22. During the **past four weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

23-32. These questions are about how you feel and how things have been with you **during the past four weeks**. For each question, please give the one answer that comes closet to the way you have been feeling. (Circle one number on each line)

How much of the time during the past four weeks ...

		All	Most	A good	Some	A	None
		of the	of the	bit of	of the	little	of the
		time	time	the	time	of the	time
				time		time	
23.	Did you feel full of energy?	1	2	3	4	5	6
24.	Have you been a nervous person?	1	2	3	4	5	6
25.	Have you felt so down in the dumps	1	2	3	4	5	6
	that nothing could cheer you up?						
26.	Have you felt calm and peaceful?	1	2	3	4	5	6
27.	Did you have a lot of energy?	1	2	3	4	5	6
28.	Have you felt downhearted and	1	2	3	4	5	6
	blue?						
29.	Did you feel worn out?	1	2	3	4	5	6
30	Have you been a happy person?	1	2	3	4	5	6
31.	Did you feel tired?	1	2	3	4	5	6
32.	Did you feel rested on waking in	1	2	3	4	5	6
	the morning?						

33. During the **past four weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (Circle one number)

195

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

34-37. How TRUE or FALSE is **each** of the following statements to you. (Circle one number on each line).

		Definitely	Mostly	Not	Mostly	Definitely
		true	true	sure	false	false
34.	I seem to get sick a little easier than other people	1	2	3	4	5
35.	I am as healthy as anybody I know	1	2	3	4	5
36.	I expect my health to get worse	1	2	3	4	5
37.	My health is excellent	1	2	3	4	5

38-41. How much of the time during the **past four weeks...** (Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
38.	Were you discouraged by your health problems?	1	2	3	4	5	6
39.	Were you frustrated about your health?	1	2	3	4	5	6
40.	Was your health a worry in your life	1	2	3	4	5	6
41.	Did you feel weighed down by your health problems?	1	2	3	4	5	6

42-45. How much of the time during the past four weeks... (Circle one number on each line)

-	β						
		All of	Most	A good	Some	A little	None
		the	of the	bit of	of the	of the	of the
		time	time	the time	time	time	time
42.	Have you had difficulty	1	2	3	4	5	6
	concentrating and thinking?		c 				
43.	Did you have trouble keeping your	1	2	3	4	5	6
	attention on an activity for long?						
44.	Have you had trouble with your	1	2	3	4	5	6
	memory?						
45.	Have others, such as family	1	2	3	4	5	6
	members or friends, noticed that						
	you have trouble with your memory						
	or problems with your	D					
	concentration?						

46-49. The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function **during the past four weeks only.** (the first set of questions are for **men only** and the second set of questions are for **women only**) How much of a problem was each of the following for you **during the past four weeks**? (Circle one number on each line)

	MEN ONLY	Not a problem	A little of a problem	Somewhat of a problem	Very much a problem
46.	Lack of sexual interest	1	2	3	4
47.	Difficulty getting or keeping an erection	1	2	3	4
48.	Difficulty having an orgasm	1	2	3	4
49.	Ability to satisfy sexual partner	1	2	3	4

	WOMEN ONLY	Not a problem	A little of a	Somewhat of a	Very much a
			problem	problem	problem
46.	Lack of sexual interest	1	2	3	4
47.	Inadequate lubrication	1	2	3	4
48.	Difficulty having an orgasm	1	2	3	4
49.	Ability to satisfy sexual partner	1	2	3	4

50. Overall, how satisfied were you with your sexual function **during the past four weeks**? (Circle one number)

Very satisfied	1
Somewhat satisfied	2
Neither satisfied nor dissatisfied	3
Somewhat dissatisfied	4
Very dissatisfied	5

51. During the **past four weeks**, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family, friends, neighbours, or groups? (Circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

52. During the **past four weeks**, how much did pain interfere with your enjoyment of life? (Circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

53. Which best describes how you feel about your life as a whole? (Circle one number)

Terrible	1
Unhappy	2
Mostly dissatisfied	3
Mixed - about equally satisfied and dissatisfied	4
Mostly satisfied	5
Pleased	6
Delighted	7

SECTION B

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the **past week**.

Please **answer every statement** by circling the appropriate number (1,2,3....).

		Rarely	Some	A	Most
		or	of the	moderate	or all of
		none of	time	amount	the time
		the time		of time	
1	I was bothered by things that usually don't	1	2	3	4
	bother me.				
2	I did not feel like eating; my appetite was poor.	1	2	3	4
3	I feit that I could not shake off the blues even	1	2	3	4
	with help from my family or friends.				
4	I felt that I was just as good as other people.	1	2	3	4
5	I had trouble keeping my mind on what I was	1	2	3	4
	doing.				
6	I felt depressed.	1	2	3	4
7	I felt that everything I did was an effort.	1	2	3	4
8	I felt hopeful about the future.	1	2	3	4
9	I thought my life had been a failure.	1	2	3	4
10	I felt fearful.	1	2	3	4
11	My sleep was restful.	1	2	3	4
12	I was happy.	1	2	3	4
13	I talked less than usual.	1	2	3	4
14	I felt lonely.	1	2	3	4
15	People were unfriendly.	1	2	3	4
16	I enjoyed life.	1	2	3	4
17	I had crying spells	1	2	3	4
18	I felt sad.	1	2	3	4
19	I felt that people dislike me.	1	2	3	4
20	I could not get "going".	1	2	3	4

SECTION C

Below is a list of statements that describe different types of social support. Please read each one carefully. Then circle **one** number to the right to indicate the extent to which you agree or disagree with the statement.

		strongly disagree	disagree	somewhat disagree	neither agree or disagree	somewhat agree	agree	strongly agree
1	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3	My family really tries to help me.	I	2	3	4	5	6	7
4	I get the emotional support I need from my family.	1	2	3	4	5	6	7
5	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6	My friends really try to help me.	1	2	3	4	5	6	7
7	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8	I can talk about my problems with my family.	1	2	3	4	5	6	7
9	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12	I can talk about my problems with my friends	1	2	3	4	5	6	7

SECTION D

The following is a list of things that can be hassles and uplifts in day to day life. You will find that in the course of a fortnight some of these things will only be a hassle for you and others will only be an uplift. Others will have been both a hassle and an uplift.

Please think about how much of a hassle and how much of an uplift **each item** was for you over the **past two weeks**. For example, if "Your Workload" was a major hassle over the past two weeks you would circle 3 in the hassles column on the left-hand side of the page. It would then be likely that in the uplift column on the right-hand side of the page, you would circle zero because if it was a major hassle it is unlikely to be an uplift. On the other hand, with an example like "Social Commitments", it can be somewhat of a hassle, but an uplift as well.

Remember, circle one number on the left hand-side of the page and one number of the right handside of the page for each item.

How much of a **hassle** was this item for you over the **last two weeks**?

- 0 = None or not applicable
- l = Somewhat
- 2 = Quite a bit
- 3 = A great deal

HASSLES

How much of an **uplift** was this item for you over the **last two week**?

- 0 = None or not applicable
- 1 = Somewhat
- 2 =Quite a bit
- 3 = A great deal

UPLIFTS

0	1	2	3	Your child(ren)	0	1	2	3
0	1	2	3	Your parents or parents-in-law	0	1	2	3
0	1	2	3	Other relative(s)	0	1	2	3
	1	2	3	Your spouse/partner		1	2	3
$\left \begin{array}{c} 0 \\ 0 \end{array} \right $	1	2	3	Time spent with family	0	1	2	3
0	1	2	3	Health or well-being of a family	0	1	2	3
		2	5	member	U	ł	2	5
0	1	2	3	Sex	0		2	3
		2			0			3
			3	Intimacy			2	
0	1	2	3	Family-related obligations	0	<u> </u>	2	3
0	1	2	3	Your friend(s)	0	1	2	3
0	1	2	3	Fellow workers	0	1	2	3
0	1	2	3	Client, customer, patient, etc.	0	1	2	3
0	1	2	3	Your supervisor or employer	0	1	2	3
0	1	2	3	The nature of your work	0	1	2	3
0	1	2	3	Your work load	0	1	2	3
0	1	2	3	Your job security	0	1	2	3
0	1	2	3	Meeting deadlines or goals on the job	0	1	2	3
0	1	2	3	Enough money for necessities (e.g., food	0	1	2	3
				clothing, housing, health care, taxes,				
				etc.)				
0	1	2	3	Enough money for education	0	1	2	3
0	1	2	3	Enough money for emergencies	0	1	2	3

HASSLES

UPLIFTS

			<u> </u>					
0	1	2	3	Enough money for extras (e.g.,	0	1	2	3
				vacations, entertainment, recreations				
				etc.)				
0	1	2	3	Financial care for someone who doesn't	0	1	2	3
				live with you	<u> </u>			
0	1	2	3	Investments	0	1	2	3
0	1	2	3	Your smoking	0	1	2	3
0	1	2	3	Your drinking	0	1	2	3
0	1	2	3	Mood-altering drugs	0	1	2	3
0	1	2	3	Your physical appearance	0	1	2	3
0	1	2	3	Contraception	0	1	2	3
0	1	2	3	Exercise(s)	0	1	2	3
0	1	2	3	Your medical care	0	1	2	3
0	1	2	3	Your health	0	1	2	3
0	1	2	3	Your physical abilities	0	1	2	3
0	1	2	3	The weather	0	1	2	3
0	1	2	3	News events	0	1	2	3
0	1	2	3	Your environment (e.g., quality of air,	0	1	2	3
				noise pollution, etc.)				
0	1	2	3	Political or social issues	0	1	2	3
0	1	2	3	Your neighbourhood (e.g., neighbours,	0	1	2	3
				setting, etc.)				
0	1	2	3	Conserving (gas, electricity, water, etc.)	0	1	2	3
0	1	2	3	Bets/Gambling	0	1	2	3
0	1	2	3	Cooking	0	1	2	3
0	1	2	3	Housework	0	1	2	3
0	1	2	3	Home repairs	0	1	2	3
0	1	2	3	Yardwork	0	1	2	3
0	1	2	3	Car maintenance	0	1	2	3
0	1	2	3	Taking care of paper work (e.g., paying	0	1	2	3
				bills, filling out forms, etc.)				
0	1	2	3	Home entertainment (e.g., video, music,	0	1	2	3
				etc.)				
0	1	2	3	Amount of free time	0	1	2	3
0	1	2	3	Recreation and entertainment outside	0	1	2	3
				the house (e.g., movies, sports, eating				
				out, etc.)				
0	1	2	3	Eating (at home)	0	1	2	3
0	1	2	3	Church or community organizations	0	1	2	3
0	1	2	3	Legal matters	0	1	2	3
0	1	2	3	Being organized	0	1	2	3
0	1	2	3	Social commitments	0	1	2	3

SECTION E

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle one number to the right which best describes how you have been feeling during the past week, including today.

		Not	A	Moderately	Quite	Extremely
		at all	little		a bit	
1	Tense	0	1	2	3	4
2	Angry	0	1	2	3	4
3	Worn Out	0	1	2	3	4
4	Unhappy	0	1	2	3	4
5	Lively	0	1	2	3	4
6	Confused	0	1	2	3	4
7	Peeved	0	1	2	3	4
8	Sad	0	- 1	2	3	4
9	Active	0	1	2	3	4
10	On Edge	0	1	2	3	4
11	Grouchy	0	1	2	3	4
12	Blue	0	1	2	3	4
13	Energetic	0	1	2	3	4
14	Hopeless	0	1	2	3	4
15	Uneasy	0	1	2	3	4
16	Restless	0	1	2	3	4
17	Unable to Concentrate	0	1	2	3	4
18	Fatigued	0	1	2	3	4
19	Annoyed	0	1	2	3	4
20	Discouraged	0	1	2	3	4
21	Resentful	0	1	2	3	4
22	Nervous	0	1	2	3	4
23	Miserable	0	1	2	3	4
24	Cheerful	0	1	2	3	4
25	Bitter	0	1	2	3	4
26	Exhausted	0	1	2	3	4
27	Anxious	0	1	2	3	4
28	Helpless	0	1	2	3	4
29	Tired	0	1	2	3	4
30	Bewildered	0	1	2	3	4
31	Furious	0	1	2	3	4
32	Full of Energy	0	1	2	3	4
33	Worthless	0	1	2	3	4
34	Forgetful	0	1	2	3	4
35	Vigorous	0	1	2	3	4
36	Uncertain About Things	0	1	2	3	4
37	Weary	0	1	2	3	4

Did you require help reading or marking this questionnaire? Yes

No

The Effects of Exercise on the Well-Being and Health of People with Multiple Sclerosis. <u>INFORMATION FOR POTENTIAL PARTICIPANTS</u>

(A) About the study:

This study is part of a research project being undertaken at Victoria University of Technology, investigating the effects of exercise on the well-being and health-related quality of life of people with multiple sclerosis. There has been very little research examining the role of exercise for improving well-being for people with multiple sclerosis. The handful of studies available, however, suggest that exercise is associated with improvements in well-being and quality of life. That is, exercise can not only improve physical fitness, but may also alleviate stressors such as worry and fatigue. Unfortunately, no study to date has examined the effects of exercise on the health and well-being of people with multiple sclerosis in Australia.

The following information guide is designed to help you decide if you would like to be part of this research. The project will involve a randomised matched and controlled study. This means that participants in the study will be matched in terms of age and gender and randomly assigned to either a treatment or control group. Those assigned to the treatment group will participate in the exercise program. The control group will not receive any treatment and will be asked not to change their level of physical activity. Both groups will be asked to complete questionnaires throughout the period of the exercise program. The participants in the control group will be offered participation in the second phase of this project, which is a relaxation program or an exercise program at the conclusion of the study. So everyone who participates in the study will, at some point, be part of an exercise or relaxation group.

The project will involve a 10-week aquatic exercise programme, designed for people who are not involved in any form of regular physical activity. Activities will include water aerobics, water jogging, and some swimming. All levels of swimming ability will be accommodated. The program will be in a group setting and will be designed not only to gradually improve participants' fitness levels, but also to be lots of fun. Although the exercise program will be free of charge for those participating, it may involve some small expenses such as swimwear, a swimming cap (if preferred), and transport to and from the pool. Yet, it is hoped that the skills and fitness acquired during the programme will allow participants to continue exercising beyond the duration of the study.

(B) <u>What□ needed?</u>

Participation in the exercise program will need a commitment of time and effort. For the study to be successful, it is important that as many people as possible complete all sessions of the 10-week program. Participants in the exercise program will be asked to attend three, 45 minute sessions per week. At least one hour in total should be set aside for changing, showering, and the exercise programme. The programme will run for 10 weeks, and will begin Tuesday 1st September 1998.

An extra session will be scheduled prior to the commencement of the exercise programme. The session will inform participants, in more detail, about the study. Participants will have the opportunity to meet personally with myself, ask questions, and sign a consent form. Signing the consent form means that each participants understands all aspects of the study. The session will also be held so that participants can perform a test for cardiovascular fitness. The test will be performed, individually, on an exercise bike at low to moderate intensities. The exercise intensity will begin at levels which are easy to accomplish and gradually progress in intensity. The test will be terminated when the participant indicates that they are working at a difficult level. This test will be used to evaluate changes in physical fitness over the course of the training period. During this session participants will also receive a questionnaire to take home and complete assessing well-being and health-related quality of life.

Extra sessions will also be held during week 8 of the exercise program in which participants will perform the test for cardiovascular fitness again. Participants will also be required to complete the questionnaire assessing well-being and health-related quality of life.

Only participants in the treatment group will be asked to attend the session prior to the commencement of the program and the extra session during week 8. Participants in the treatment group will complete the test for cardiovascular fitness and all participants will complete the questionnaire.

(C) Location

The aquatic exercise program will be held at the Melbourne Sports and Aquatic Centre, Albert Park. The main entrance to the pool is on Albert Road and there is plenty of car parking space close to the entrance. If you are relying on public transport, tram numbers 12 or 96 from Bourke Street in the city, run by the Aquatic Centre. If you require a wheelchair or scooter to travel, a bus that can be organised from Flinders or Spencer Street Stations for the cost of a Met ticket.

If a friend or relative is willing to drive a participant to the pool for the exercise program, they are welcome to join the session, although will be required to pay the entrance fee (\$4.00 or \$3.00 conc.).

(D) <u>Risks</u>

Participants in the exercise program should be aware that there are risks involved for people with multiple sclerosis. Specifically, aerobic exercise can result in increased body temperature, which may worsen the signs and symptoms of multiple sclerosis. To reduce this risk, an aquatic exercise programme has been chosen. Water can prevent overheating and minimise the risk of symptoms occurring due to rises in body temperature. In addition, many people with multiple sclerosis report that exercise can worsen fatigue. In most cases, careful pacing of daily activities with appropriate periods of rest will help manage this very common symptom. The exercise testing can also be a risk, in that participants will be working at an increased percentage of aerobic capacity than during the aquatic programme. Experienced staff will be present to ensure exercise testing protocols are strictly followed.

Prior to exercise testing and the program, each participant will be required to obtain medical clearance from their physician. An information sheet with details of the testing and program

protocols will be supplied. This sheet will be available for the participant to organise a consultation with their physician or, if preferred, I can contact the physician personally to arrange medical clearance.

If the exercise program is causing health problems or undue stress for the participant, these problems will be discussed individually. The intensity of the programme can be adjusted or participants may skip some sessions with the possibility of catching up at the end of the program. If an exacerbation occurs during the program and the participant is unable to exercise for an extended period of time, it is possible, with medical clearance, to rejoin the program at a later time. The decision to continue exercising is entirely up to you and you are free to withdraw from the study at anytime. Counselling is available if required.

Finally, I would like to emphasise that participation in this study is voluntary and that you are free to withdraw from the study at anytime. All information collected during this study will be held in the strictest confidence. Participant details and test results will be entered under a code number. Codes and names will be stored separately in a secure location. The information will be used only for the purposes of the proposed study.

If you are interested in participating or would like to ask any questions regarding the study, please do not hesitate to contact me on 9376 2842. If I am unavailable, please leave a message and I will call you back as soon as possible.

Thank you very much for your time.

Georgina Sutherland

Appendix E: Medical Clearance Form Study 2

Dear Physician,

We are researchers at Victoria University of Technology investigating the effects of exercise on the well-being and health-related quality of life of people with multiple sclerosis. The project will involve a 10-week aquatic exercise program, designed for people who are not involved in form of regular physical activity. The program will consist of three supervised training sessions per week. The sessions will be for approximately 45 minutes and will involve a warm-up, cooldown, and stretching.

Prior to the commencement of the exercise program, each participant will be asked to perform a submaximal exercise test. The test will be performed on an exercise bike at low to moderate intensities. Participants' heart rate will be monitored throughout the test. The exercise intensities will begin at levels that are easy to accomplish and will be advanced in stages, depending on functional capacity. The test will be terminated when the participant indicates, on a perceived exertion rating scale, that they are exercising at a level that they perceive to be "very hard". The test will also be terminated if there are any indications of risks to the safety and/or health of the participant.

If you have received this letter, your client has expressed interest in participating in the above mentioned exercise program. Prior to exercise testing and the commencement of the program, participants have been asked to obtain medical clearance from their physician. Participants in the exercise program have been informed of the risks involved for people with multiple sclerosis. In particular, the risks and discomforts that may occur during the exercise test, which will be at an increased percentage of aerobic capacity than during the aquatic program. Although all reasonable precautions will be taken, preliminary screening will help to ensure the safety of the exercise test and program.

We would appreciate your help by completing the medical clearance form on the next page. To assist you there is a checklist of some of the contra-indications to exercise testing and the aquatic exercise program for people with multiple sclerosis. This is only a guide to assist you with your evaluation and does not include every reason why a participant may be excluded from the testing and programme. If you would like to meet with the supervisor of the exercise testing and aquatic programme to discuss the project in more detail, please do not hesitate to contact Georgina Sutherland on 9376 2842 or 9248 1133.

The project has been approved by the Multiple Sclerosis Society of Victoria and the Victoria University Human Research Ethics Committee. Any queries about this project can be directed to the researchers Ms. Georgina Sutherland 9376 2842, Dr. Mark Andersen 9248 1132, or to the Secretary, University Human Ethics Committee, Victoria University of Technology 9688 4710.

Yours Sincerely,

Georgina Sutherland

Dr. Mark Andersen

Medical Clearance Form

A GUIDE TO SOME OF THE CONTRA-INDICATIONS TO

THE AQUATIC EXERCISE PROGRAM

Please mark the box if any of the following apply to your client -

	Acute Infection		Contagious Conditions
	Febrile Conditions		Infected Wounds
	Unstable Epilepsy		Contagious Diseases
	Within 3 Months of Deep X-Ray Therapy		Faecal Incontinence
	Within 3 Weeks of Cerebrovascular Accident		Urine Incontinence
	Subject to Respiratory Distress on Exertion		Open Wounds
	Dermal Sensitivity to Sanitising Chemicals		Renal Failure
	History of Cardiac Conditions (e.g., myocardial		Major Cognitive Deficits
infaı	ction, stroke, angina pectoris, heart murmur,	(e.g	.,severe dementia)
hear	t rhythm disturbances)		

If any of the above conditions apply to your client he/she will be <u>unable</u> to participate in the aqua aerobics program.

If there are is any other reason/s why your client is unable to participate in the exercise program, please state below;

If your client does not have any conditions which may exclude him/her from, please complete the clearance form below;

CERTIFICATION BY PHYSICIAN:

I, of	
(name)	(clinic)
certify that	has been cleared to
Signed:	Date:
Please indicate whether I am able to contact you durin number below;	ng the programme by supplying a contact

Contact Telephone No.: _____

Victoria University of Technology

Consent Form

INFORMATION TO PARTICIPANTS:

We would like to invite you to be part of a study investigating the effects of an exercise program on the well-being and health of people with multiple sclerosis.

CERTIFICATION BY PARTICIPANT:

I certify that the objectives of the experiment, together with any risks to me associated with the procedures listed hereunder to be carried out in the experiment have been fully explained to me by: **Ms. Georgina Sutherland** and that I freely consent to participation involving the use on me of these procedures.

PROCEDURES:

The study involves participation in a 10-week aquatic exercise program. The program will consist of three sessions per week, with each session lasting approximately 45 minutes. Prior to the exercise program an exercise test will be performed in order to evaluate appropriate workloads during the program. A questionnaire designed to assess well-being and health will be administered prior to the commencement and at week eight of the program. All information will remain strictly confidential.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this experiment at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information 1 provide will be kept confidential.

Signed: _____

Date:			

Witness other than the experimenter:

Any queries about your participation in this project may be directed to the researchers: Ms. Georgina Sutherland 9376 2842 Dr. Mark Andersen 9248 1132 If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001. (Telephone no: (03) 9688 4710)

Appendix G: Information Letter to Participants Study 3

The Effect of Autogenic Training on the Well-Being and Health of People with Multiple Sclerosis.

INFORMATION FOR POTENTIAL PARTICIPANTS

(A) <u>About the study:</u>

This study is part of a research project being undertaken at Victoria University of Technology, investigating the effects of autogenic training on the well-being and healthrelated quality of life of people with multiple sclerosis. Autogenic training is a relaxation technique where the participant passively concentrates on body sensations resulting in a deep state of relaxation. Although relaxation interventions have not been extensively studied in multiple sclerosis, research has shown that stress management programs may reduce worry and fatigue for people with multiple sclerosis.

The following information guide is designed to help you decide if you would like to be part of this research. The project will involve a randomised matched and controlled study. This means that participants in the study will be matched in terms of age and assigned to either a treatment and control group. Those assigned to the treatment group will participate in the autogenic training program. The control group will not receive any treatment. Both groups will be asked to complete questionnaires throughout the period of the relaxation program. The participants in the control group will be offered participation in a relaxation program at the conclusion of the study. So everyone who participates in the study will, at some point, be part of a relaxation program.

The project will involve a 10-week autogenic training program, designed for people who are not involved in any form of regular relaxation therapy (e.g., meditation, yoga). In autogenic training, the participant is trained, through the use of verbal instructions (either on tape or from an instructor), to enter into a deep state of relaxation. The verbal instructions are a means of instructing and familiarising participants with the steps for entering into such a deep state of relaxation without the use of tapes or therapists. The exercises are physiologically oriented and focus on the neuromuscular system (feelings of heaviness), the vasomotor system (warmth), the heart, the respiratory system (breathing), warmth in the abdominal area, and cooling of the forehead. Although autogenic training requires several months and regular practice to master, once mastered it may be possible to induce the relaxation response in a matter of minutes. The autogenic training program will be free of charge for those participating. It is hoped that the skills acquired during the programme will allow participants to continue the relaxation technique beyond the duration of the study.

(B) <u>What's needed?</u>

Participation in the autogenic training program will need a commitment of time and effort. For the study to be successful, it is important that as many people as possible practice the autogenic training program for the 10-week duration. Participants in the autogenic training program will be asked to attend one group session per week, lasting approximately one hour. Participants will also be asked to undertake training sessions at home and to keep a diary in which they will record sessions and experiences.

An extra session will be scheduled prior to the commencement of the autogenic training program. This session will inform participants, in more detail, about the study. Participants will have the opportunity to meet personally with myself and the other participants. It will also provide an opportunity to ask questions and sign a consent form. Signing the consent form means that each participants understands all aspects of the study. During this session participants will also receive a questionnaire that assesses psychological well-being and health-related quality of life. The questionnaire is to be completed and returned at the first session. During the group session in week eight, participants will be asked to spend some extra time completing the questionnaire again.

Only participants involved in the relaxation program (treatment group) will be asked to attend the session prior to the commencement of the program. Those assigned to the control group will be posted all the questionnaires throughout the programme and will be asked to complete and return the questionnaires in reply paid envelopes.

(C) Location

The autogenic training programme will be held in a function room at the Melbourne Sports and Aquatic Centre, Albert Park. The main entrance to the centre is on Albert Road and there is plenty of disabled car parking space close to the entrance. If you are relying on public transport, tram numbers 12 or 96 from Bourke Street in the city, run by the Aquatic Centre. If you require a wheelchair or scooter to travel, a bus can be organised from Flinders or Spencer Street Stations for the cost of a Met ticket.

If a friend or relative is willing to drive a participant to the Aquatic Centre for the autogenic training programme, they are welcome to join the session.

(D) <u>Time</u>

Group sessions will be held on the Tuesday of each week of the program. There will be a choice of two sessions; 10.30-11.30am and 11.45am-12.45pm. The program will begin as soon as possible.

(E) <u>Risks</u>

Participants should be aware that, although autogenic training is a standard psychological procedure that rarely causes any negative effects, there can be some unfamiliar sensations, thoughts, and feelings that can occur during the exercises. Prior to the first training session, however, participants will be briefed as to the kind of sensations commonly associated with autogenic training. The participants will be assured that these are normal which will give individuals an expectancy that will help in coping with such sensations associated with deep states of relaxation.

Prior to the autogenic training program, each participant will be asked to obtain medical clearance from their physician. An information sheet with details of the program will be supplied. This sheet will be available for the participant to organise a consultation with their physician or, if preferred, I can contact the physician personally to arrange medical clearance.

If the autogenic training program is causing undue stress for the participant, these problems will be discussed individually. The participant may skip some sessions with possibilities of catching up at the end of the program. If an exacerbation occurs during the programme and the participant is unable to participate for an extended period of time, it is possible to rejoin the program with medical clearance at a later time. The decision to continue the autogenic training program is entirely up to you and you are free to withdraw from the study at anytime. Counselling is available if required.

Finally, I would like to emphasise that participation in this study is voluntary and that you are free to withdraw from the study at anytime. All information gathered during this study will be held in the strictest confidence. Participants details and test results will be entered under a code number. Codes and names will be stored separately in a secure location. The information will be used only for the purposes of the proposed study.

If you are interested in participating or would like to ask any questions regarding the study, please do not hesitate to contact me on 9376 2842 or 9248 1133.

Thank you very much for your time.

Georgina Sutherland

Appendix H: Medical Clearance Form Study 3

Dear Physician,

We are researchers at Victoria University of Technology investigating the effects of autogenic training on the well-being and health-related quality of life of people with multiple sclerosis. The project will involve 10 weeks of autogenic training, designed for people who are not involved in any form of regular relaxation therapy (i.e., yoga, meditation). The program will consist of one group training session per week, lasting approximately one hour. Participants will also be asked to undertake training sessions at home every day.

In autogenic training, the participant passively concentrates on body sensations resulting in a deep state of relaxation. The exercises are physiologically oriented and focus on the neuromuscular system, vasomotor system, the heart, the respiratory system, warmth in the abdominal area, and cooling of the forehead. Autogenic training is a standard psychological procedure that rarely causes negative effects. It is associated with decreases in sympathetic nervous system activity and increases in parasympathetic nervous system activity, and is therefore may affect people with low blood pressure.

Prior to the first session, participants will be briefed as to the kinds of thoughts and feelings commonly associated with autogenic training, providing them with an expectancy about the sensations associated with deep states of relaxation. Participants will also be aware that any sensations associated with deep states of relaxation are transitory and will disappear on opening the eyes and sitting up. If you have received this letter, your client has expressed interest in participating in the above mentioned autogenic training program. Prior to the commencement of the program, participants have been asked to obtain medical clearance from their physician. Participants in the relaxation program have been informed of the risks involved for people with multiple sclerosis. In particular, the unfamiliar sensations, thoughts, and feelings that can occur during the exercises. Although all reasonable care will be taken, preliminary screening will help to ensure that each individual receives maximum benefit from the program.

We would appreciate your help by completing the medical clearance form on the next page. If you would like to meet with the supervisor of the autogenic training program to discuss the project in more detail, please do not hesitate to contact Georgina Sutherland on 9376 2842 (home) or 9248 1133 (university).

The project has been approved by the Multiple Sclerosis Society of Victoria and the Victoria University Human Research Ethics Committee. Any queries about this project can be directed to the researchers Ms. Georgina Sutherland 9376 2842, Dr. Mark Andersen 9248 1132, or to the Secretary, University Human Ethics Committee, Victoria University of Technology 9688 4710.

Yours Sincerely,

Georgina Sutherland

Dr. Mark Andersen

VICTORIA UNIVERSITY OF TECHNOLOGY

Autogenic Training Program

Medical Clearance Form

A GUIDE TO THE REASONS WHY A PARTICIPANT MAY BE EXCLUDED FROM AUTOGENIC TRAINING

- > Previous negative experience(s) with meditation or classical hypnosis
- Major cognitive deficits (e.g., severe dementia)
- Dissociate disorder
- Previous psychotic episodes
- Please note if your client is prescribed anti-hypertensive medication, as the doses may need to be reviewed during the course of the relaxation program.

If any of the above conditions apply to your client he/she may be <u>unable</u> to participate in the autogenic training program.

If there are is any other reason/s why your client is unable to participate in the autogenic training program, please state below;

If your client does not have any conditions which may exclude him/her from autogenic training, please complete the clearance form below;

CERTIFICATION BY PHYSICIAN:

I,	of	
	(name)	(clinic)
certify that		has been cleared to
	(client's name - PLEASE PRINT)	participate in the
autogenic train	ing program.	
Signed:		Date:
Please indicate	whether I am able to contact you dur	ing the program by supplying a contact number
below;	-	
Contact Teleph	none No.:	

Appendix I: Consent Form Study 3

Victoria University of Technology

Consent Form

INFORMATION TO PARTICIPANTS:

We would like to invite you to be part of a study investigating the effects of autogenic training on the well-being and health of people with multiple sclerosis.

CERTIFICATION BY PARTICIPANT:

I, _____ _____ of _____ (town/suburb) (name) certify that I am at least 17 years of age and that I am voluntarily giving my consent to

participate in the experiment entitled: The Effects of Autogenic Training on the Well-Being and Health of People with Multiple Sclerosis, being conducted at Victoria University of Technology by: Ms. Georgina Sutherland and Dr. Mark Andersen.

I certify that the objectives of the experiment, together with any risks to me associated with the procedures listed hereunder to be carried out in the experiment have been fully explained to me by: Ms. Georgina Sutherland and that I freely consent to participation involving the use on me of these procedures.

PROCEDURES:

The study involves participation in a 10-week autogenic training program. The program will consist of one group session per week, with each session lasting approximately one hour. Participants will also be required to practice at home, and keep a diary of sessions and experiences during the 10-week period. A questionnaire designed to assess wellbeing and health will be administered prior to the commencement and at week eight of the program. All information will remain strictly confidential.

I certify that I have had the opportunity to have any questions answered and that 1 understand that I can withdraw from this experiment at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information I provide will be kept confidential.

Signed: _____ Date: _____

Witness other than the experimenter:

Any queries about your participation in this project may be directed to the researchers: Ms. Georgina Sutherland 9376 2842 Dr. Mark Andersen 9248 1132 If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001. (Telephone no: 9688 4710)

AUTOGENIC TRAINING DIARY

This diary is so you can record the number of times you practice the training each week, and your own experiences.

Each week starts from the Wednesday after the group session and ends on the Monday prior to the group session.

You do not need to record the group session each Tuesday.

Write the date or day in the first column, followed by the approximate time you spent on the training (i.e., 25 minutes).

In the column for personal experiences, simply write a brief statement about how you felt during the session. This section is optional. You do not have to record your experiences if you do not wish.

If you have any questions or problems that you would like to discuss with the instructor during the practice sessions at home, please call Georgina on 9376 2842.

AUTOGENIC TRAINING DIARY

Week 1 - Wednesday 15th to Monday 20th March

Date or Day	Time Spent Training	Experiences

Week 2 - Wednesday 22nd to Monday 27th March

Date or Day	Time Spent Training	Experiences
· · · ·		

Week 3 - Wednesday 29th March to Monday 3rd April

Date or Day	Time Spent Training	Experiences

Week 4 - Wednesday 5th to Monday 10th April

Date or Day	Time Spent Training	Experiences

Date or Day	Time Spent Training	Experiences

Date or Day	Time Spent Training	Experiences

Date or Day	Time Spent Training	Experiences

Week 8 - Wednesday 3rd to Monday 8th May

Date or Day	Time Spent Training	Experiences

Date or Day	Time Spent Training	Experiences

Week 10 - Wednesday 17th to Monday 22nd May

Date or Day	Time Spent Training	Experiences

Appendix K: Autogenic Training Script

Autogenic Training Script

Get yourself into a nice, comfortable position, settle back Take a couple of nice deep breaths, take it in & out. Take another nice deep breath, in & out And feel yourself beginning to relax, feel yourself letting go as you continue to breath Feel yourself relaxing as you now focus, very keenly, on your right arm And say to yourself over & over, inside your head My right arm is heavy (repeat x 3) And feel the heaviness spread throughout your right arm and into your shoulder My right arm is heavy (repeat x 3) And feel you right arm comfortably sinking My right arm is heavy (repeat x 3) And that heaviness will continue to grow, as you now move your attention from your right arm to your left arm, and say to yourself

My left arm is heavy (repeat x 3) And feel the heaviness spread from your left arm and into your shoulder My left arm is heavy (repeat x 3) And feel your left arm comfortably sinking My left arm is heavy (repeat x 3) And say to yourself

Both my arms are heavy (repeat x 3) And feel the heaviness spread throughout your arms and into your shoulders Both my arms are heavy (repeat x 3) And feel your arms comfortably sinking Both my arms are heavy (repeat x 3) And that heaviness will continue to grow, as you now move your attention from your arms to your right leg, and say to yourself

My right leg is heavy (repeat x 3) And feel that heaviness spread from your right leg and into your hip My right leg is heavy (repeat x 3) And feel your right leg comfortably sinking My right leg is heavy (repeat x 3) And that heaviness will continue to grow, as you now move your attention from your right leg to your left leg, and say to yourself

My left leg is heavy (repeat x 3) And feel the heaviness spread from your left leg and into your hip My left leg is heavy (repeat x 3) And feel your left leg comfortably sinking My left leg is heavy (repeat x 3) And say to yourself Both my legs are heavy (repeat x 3) And feel that heaviness spread throughout your legs and into your hips Both my legs are heavy (repeat x 3) And feel your legs comfortably sinking Both my legs are heavy (repeat x 3)

And say to yourself My arms & legs are heavy (repeat x 3) And feel that heaviness spread throughout your arms and shoulders, legs and hips My arms & legs are heavy (repeat x 3) And feel your arms and legs comfortably sinking My arms & legs are heavy (repeat x 3) And that heaviness will continue to grow, as you now move your attention once again to your right arm, and say to yourself, over and over

My right arm is warm (repeat x 3) And feel the warmth spread throughout your right arm and into your shoulder My right arm is warm (repeat x 3) And feel the fresh warm blood flowing into your right arm My right arm is warm (repeat x 3) And that warmth will continue to grow, as you now move your attention from your right arm to your left arm, and say to yourself

My left arm is warm (repeat x 3) And feel the warmth spread throughout your left arm and into your shoulder My left arm is warm (repeat x 3) And feel the fresh warm blood flowing into your left arm My left arm is warm (repeat x 3)

And say to yourself Both my arms are warm (repeat x 3) And feel the warmth spread throughout both your arms and into your shoulders Both my arms are warm (repeat x 3) And feel the fresh warm blood flowing into your arms Both my arms are warm (repeat x 3) And that warmth will continue to grow, as you now move your attention from your arms down again to your right leg, and say to yourself

My right leg is warm (repeat x 3) And feel the warmth spread from your right leg and into your hip My right leg is warm (repeat x 3) And feel the fresh warm blood flowing into your right leg My right leg is warm (repeat x 3) And that warmth will continue to grow, as you now move your attention from your right leg to your left leg, and say to yourself

My left leg is warm (repeat x 3) And feel the warmth spread from your left leg and into your hip My left leg is warm (repeat x 3) And feel the fresh warm blood flowing into your left leg My left leg is warm (repeat x 3)

And say to yourself Both my legs are warm (repeat x 3) And feel the warmth spread throughout both your legs and into your hips Both my legs are warm (repeat x 3) And feel the fresh warm blood flowing into your legs Both my legs are warm (repeat x 3)

And say to yourself My arms and legs are warm (repeat x 3) And feel the warmth spread throughout your arms and shoulders, legs and hips My arms and legs are warm (repeat x 3) And feel the fresh warm blood flowing into your arms and legs My arms and legs are warm (repeat x 3)

And say to yourself My arms and legs are warm and heavy (repeat x 3) And feel the warmth and heaviness spread My arms and legs are warm and heavy (repeat x 3) And feel the warmth and heaviness grow My arms and legs are warm and heavy (repeat x 3) And that warmth and heaviness will continue to grow, as you now move your attention to your heart

Feel your heart beat
Maybe you feel it in your chest or down your legs, as you say to yourself
My heartbeat is calm and regular (repeat x 3)
Feel your heart beat
My heartbeat is calm and regular (repeat x 3)
Feel the strong, steady beat
My heart beat is calm and regular (repeat x 3)
And that strong, steady beat will continue, as you no just notice your breathing

Feel your chest rising up, and falling down of its own accord Easy, effortless breathing, as you say to yourself It breathes me (repeat x 3) Like the air is being pushed into you and puled out of you, you are passive It breathes me (repeat x 3) Easy effortless breathing like you have nothing to do with it It breathes me (repeat x 3) And the effortless breathing will continue as you now focus on your solar plexus, and say to yourself

My solar plexus is warm (repeat x 3) And feel the warmth radiating out in all directions, just like a sunburst My solar plexus is warm (repeat x 3) And feel the warmth radiating out My solar plexus is warm (repeat x 3) And feel the warmth growing, as you now move your attention to from your solar plexus to your forehead, and say to yourself

My forehead is cool (repeat x 3) And feel it like a nice cool breeze My forehead is cool (repeat x 3) Just like a cool breeze My forehead is cool