The Neuropsychosocial Sequelae of Multiple Sclerosis and the Impact For Familial Caregivers

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Abstract

Multiple Sclerosis (MS) is the most common neurodegenerative disease diagnosed in young adults. Many people live with the disease throughout their early, middle and late adulthood. It has far-reaching effects for individuals, families, and social networks. The study of its impact is an important precursor to the design of effective, efficient interventions for all concerned. This research sought to examine the physical, cognitive, and psychological effects of MS in a New Zealand community-based sample. Its impact on familial caregivers was also investigated.

One hundred and two people with MS were assessed over a 14-month period. In comparisons with a demographically-matched control group, the cognitive performance of the MS sample was found to be impaired on psychometric measures of current intellectual functioning, learning, retention, delayed recall, recognition memory, and areas of attention/concentration and executive functioning. The MS sample also reported significantly more psychological difficulties than the control group. No statistically significant relationship was found between the cognitive functioning of the MS sample and their physical functioning, time since symptom onset, disease course, level of fatigue, or medication use. However, there was a statistically significant relationship between the sample's cognitive functioning and both their psychological functioning and the time since their MS diagnosis.

Analyses were undertaken with a subset of participants with MS whose cognitive performance was worse than the remainder of the MS sample in relation to the control group. This subset was found to require significantly more changes to their homes and more community services, and they experienced more social handicap than the rest of the MS sample.

Familial caregivers of the participants with MS reported significantly more symptoms of anxiety and insomnia, significantly higher levels of burden, and significantly less satisfaction with the quality of social support that they received, compared to a demographically-matched control group. The caregivers' appraisals of the functional impairments of their family members with MS made the most consistently significant unique contribution to the prediction of these areas of caregiver functioning. The significance of these results for people with MS, their familial caregivers, and society at large are discussed.

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Dedication

This thesis is dedicated to three people :-

My parents, Desmond and Gretchen. Their incredible support has been immense, in this and every other venture I have undertaken in the past 30 years. The safety net that they have provided is made of substantial fibre, covered in the softest down, and has always been palpable. To say thank you feels hopelessly inadequate.

'Lady Clare' of Broomwater, England. Clare is a woman with MS for whom I was a carer in 1993. She has incredible strength and determination, and a wicked sense of humour. Clare is where this story began.

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CHAPTER 1

General Introduction

Multiple Sclerosis (MS) is a degenerative disease which destroys the protective myelin coating of nerve fibres in the human central nervous system (i.e., the brain and spinal cord). Scar-like lesions, called sclerotic plaques, form in areas where demyelination has occurred, causing nerve impulses to become blocked or distorted. MS is a complex disease with clinical manifestations that vary considerably from one person to another. While physical impairments are the most easily identified products of the disease process, it is now recognised that cognitive and affective impairments are also common and add considerably to the distress and disability of the person concerned (Rao, 1986). A brief overview of MS will orient the reader to the experience of people with this disease. This is followed by a summary of current neuropsychological knowledge regarding MS. Finally, the aims and structure of the current research will be outlined.

Overview of MS

Aetiology

While the aetiology of MS remains unknown, the considerable amount of research that has been undertaken to date implicates genetic, environmental, and immunologic variables. For people living in the Western World the lifetime risk of developing MS is approximately 1:800. This increases to 1:50 for the offspring of affected individuals and 1:20 for siblings (Compston, 1994). Twin studies have established that MS affects both twins more frequently in monozygotic than dizygotic dyads (White, Nyenhuis, & Sax, 1992). However, the relatively low concordance rate (approximately 25%) in monozygotic twins has led to the suggestion that MS is a polygenetic condition (Poser, 1994). Women are

approximately twice as likely to develop the disease as men. However, Skegg, Corwin, Craven, Malloch, and Pollack (1987) reported ratios considerably higher than most other studies, with a male-female ratio of 1:2.7 in the northern region of New Zealand and 1:3.0 in the south.

Research findings suggestive of an environmental component in the aetiology of MS have also been reported. For example, prevalence rates of MS have been found to decrease systematically as latitude of habitation nears the equator (e.g., Kurtz, Beebe, & Norman, 1979; Miller, Hammond, McLeod, Purdie, & Skegg, 1990; Skegg et al., 1987). Migration studies have suggested that people who move from a high-risk latitude to a low-risk latitude (e.g., Europeans immigrating to South Africa) or vice versa (e.g., Afro-Asians immigrating to Israel) carry with them some of the risk from their place of origin, but only if this movement occurs after the age of 15 (Knight, 1992). However, Compston (1990) suggested that this migratory evidence is not entirely straightforward, and that the increased risk of MS seen in native people moving out of Africa to the United States correlates with the extent to which Caucasian genes are introduced into the African-American community.

Some indigenous populations (e.g., Eskimos, Japanese, Chinese, American Indians, Asian Indians, Australian Aborigines, New Zealand Maori, Pacific Islanders, and native Africans) have an extremely low incidence of MS (Knight, 1992; Poser, 1994). Skegg et al. (1987) confirmed the clinical impression that MS is rare in the Maori population of New Zealand, as there were no Maori in their MS sample when the expected number of cases (adjusted for age) was 12.

Poser (1994) concluded that while genetic factors seem to be the overriding determinant in the acquisition of MS, environmental factors appear to have more

influence on the clinical onset. For example, the lower prevalence of MS in the white population of Australia and New Zealand compared to the British Isles may be the result of a protective influence in the environment.

Disease Course

The disease process of MS can affect any part of the body's central nervous system, including the optic nerves, brain stem, cerebellum, spinal cord, subcortical white matter, and cortex. The unpredictable nature of the disease trajectory is a particularly distressing feature of MS and a great deal of uncertainty follows the initial symptom onset.

Despite wide variation, the disease course of individual cases is frequently characterised by either a progressive or a relapsing/remitting path. However, these categories are imprecise at best and Lublin and Reingold (1996) noted that, due to the lack of clear biological markers, there had been no common meaning among clinicians for the terms used to distinguish between the various forms of MS. Consequently, an international survey was undertaken to develop a consensus on the definitions and terminology used to describe the forms and clinical stages of MS (Lublin & Reingold, 1996). Agreement was reached about the following definitions:

1. Relapsing/remitting MS - relapses with full recovery or with sequelae and residual deficit upon recovery, periods between relapses characterised by lack of disease progression.
2. Primary/progressive MS - disease progression from onset with occasional plateaux and temporary minor improvements allowed.

3. Secondary/progressive MS - initial relapsing/remitting disease course followed by progression with or without occasional relapses, minor remissions, and plateaux.
4. Progressive/relapsing MS - progressive disease from onset, with clear acute relapses, periods between relapses characterised by continuing progression.
5. Relapsing/progressive MS - though one of the most frequently used terms, no consensus was reached on the definition.
6. Benign MS - disease in which a patient remains fully functional in all neurologic systems 15 years post-onset.
7. Malignant MS - a rapidly progressive course leading to significant disability in multiple neurological systems or death a relatively short time after disease onset.

There is currently no explanation as to what causes the cycles of relapses or remissions, or what determines the rate of disease progression. Nor is there any well established treatment which reverses the effects of MS or halts the process of demyelination.

Two-thirds of people with MS are diagnosed between the ages of 20 and 40 with no definitive reason for onset (White, 1990). A definite clinical diagnosis requires the occurrence of two attacks (i.e., neurological symptoms), caused by lesions in two distinct areas of the central nervous system (e.g., blurred vision and a numb limb), each lasting a minimum of 24 hours and separated by at least a month (Poser et al., 1983). Disease onset before age 15 is rare and late onset (i.e., after 40) is usually characterised by a faster progression of the degenerating process and a shorter length of survival (Rao, 1986). The transient and variable

nature of MS symptoms make it difficult to diagnose and a considerable delay between disease onset and diagnosis is common.

Life expectancy following the onset of MS symptoms is generally estimated to be more than 30 years. Yet, like everything else to do with the disease, this is variable and survival of only a few months has been reported in some cases (White et al., 1992).

Symptoms

Due to the numerous sites in which it is possible for MS lesions to develop, there is wide variation in the symptomatology experienced by different people and changes for each individual over time. Early symptoms of MS commonly include weakness in one or more limbs, incontinence, and retrobulbar or optic neuritis (Knight, 1992). A variety of other symptoms, occurring either singly or in groups, may also signal the onset of MS. These include vertigo, seizures, nystagmus, ataxia, diplopia, hemiplegia, deafness, facial paralysis or facial pain, experiencing 'pins and needles' or numbness in the limbs, gait disturbances, auditory hallucinations, aphasia, and emotional changes (Knight, 1992; White et al., 1992). Initial episodes are often disregarded or not investigated due to their mildness and spontaneous remission.

A latency period, sometimes as long as 10 years, may follow the initial symptom(s) of MS, with more symptoms occurring as the disease progresses. Periods of remission become shorter and exacerbations tend to leave people more impaired than they were previously. As the disease process advances and the involvement of subcortical white matter becomes more widespread, diffuse cognitive changes are more likely to emerge. However, impairment in cognitive functioning has also been reported in the early stages of the disease, so should not

be overlooked in cases where physical disability has not yet advanced (Hotopf, Pollock, & Lishman, 1994; Klonoff, Clark, Oger, Paty, & Li, 1991).

Cognitive difficulties can also be compounded by the emotional symptoms and psychiatric manifestations that sometimes accompany this disease. Debate concerning the nature of psychiatric changes evident in some people with MS has been ongoing. Gerland and Zis (1991) discussed the complexity of separating the effects of biological and psychosocial factors for people with MS who present with major affective disorders. It is likely that psychotic and emotional symptoms are due to an interaction of biological, psychological and social factors.

Neuropsychological Aspects of MS

Since the time of Charcot, the French neurologist credited with first describing the disease in 1877, it has been recognised that MS can result in dementia, particularly in the advanced or end-stages of the disease. However, the comparatively mild, discrete, or subtle cognitive changes that occur for a substantial proportion of individuals with MS throughout their disease experience, have only been understood more recently with the advent of neuropsychological research. This research has largely occurred since the early 1980s and has produced a considerable body of knowledge which, in turn, has assisted people with MS and others around them to become aware of the cognitive sequelae of the disease.

Historically, neurologists have underestimated the prevalence of cognitive dysfunction in people with MS (Rao, 1986). Brief mental status screening questionnaires, such as the Mini Mental Status Exam, need to be supplemented with other measures to reliably detect the cognitive deficits present in many people with MS (Beatty & Goodkin, 1990; Swirsky-Sacchetti, Field, et al., 1992).

MS as a Subcortical Dementia

Rao (1986) proposed that the demyelination process occurring in MS resulted in a form of subcortical dementia (i.e., dementia considered to be caused by pathological changes to subcortical brain structures such as the thalamus, basal ganglia, and related brainstem nuclei). Similar hypotheses had been made about Huntington's disease and Parkinson's disease, distinguishing the cognitive sequelae of these conditions from that of Alzheimer's disease which produces a dementia categorised as cortical. Cortical dementia entails severe aphasia, agnosia, acalculia, and amnesia. In contrast, subcortical dementia results in more subtle cognitive impairment, such as a slowed rate of information processing, impaired attention and conceptual reasoning skills, and memory impairment characterised by retrieval failure but intact encoding and storage. Language skills remain largely unaffected. Subcortical dementias are also hypothesised to consistently result in affective changes such as depression or euphoria, whereas mood is considered to be less reliably affected in cortical dementias.

Effects of MS on Specific Areas of Cognitive Functioning

Intelligence. Cross-sectional studies of intellectual functioning have recorded small but consistent differences between people with MS and normal control participants (e.g., Ron, Callanan, & Warrington, 1991). Significantly greater differences have been recorded on performance IQ scales than verbal IQ scales, likely reflecting sensorimotor impairments in the people with MS. Longitudinal studies have demonstrated a small but significant decline in intellectual functioning over time, with Verbal IQ scores remaining less affected than Performance IQ scores. For example, in a study by Rao, Leo, Bernardin, and Unverzagt (1991), the MS sample averaged 6.3 points lower than the normal

control group on the Verbal IQ score of the Wechsler Adult Intelligence Scale - Revised (WAIS-R). At a three-year follow-up, the scores of the MS sample were essentially unchanged while those of the control group had increased, widening the gap between the two groups (Bernardin et al., 1993). Ron et al. (1991) employed the National Adult Reading Test to obtain estimates of premorbid intellectual functioning in people with (a) definite MS, (b) clinically isolated lesions (evident in the very early stages of disease development), and (c) normal control participants. These scores were compared to current functioning on the Wechsler Adult Intelligence Scale (WAIS). While the WAIS scores of the control group indicated an improvement of 0.7 points, the sample with clinically isolated lesions showed a drop of 2.2 IQ points and the sample with definite MS showed a drop of 6.8 points.

Memory. Memory functioning is one of the most consistently impaired cognitive domains for people with MS, with impairment evident in 40-60% of the total MS population (Rao et al., 1993). Memory is not a unitary function and some components have been found to be more effected by MS than others. Rao et al. (1993) concluded that the memory dysfunction evident in people with MS involves effortful free recall from long-term memory and possibly short-term memory. However, semantic knowledge, storage, the encoding of information into long-term memory, incidental and implicit learning, and recognition memory remain comparably intact. Rao, Leo, and St Aubin-Faubert (1989) likened the memory deficits experienced by people with MS to those evident in people with Huntington's disease (though less severe), closed head injuries, and in healthy elderly people. A more extensive discussion of the range and nature of memory impairments found in people with MS is beyond the scope of this introduction and

the interested reader is directed to the recent review by Brassington and Marsh (1998) for a broader coverage of research findings in this area.

Attention and concentration. Recent research has found the performance of people with MS to be impaired on a number of measures of visual and auditory attention (e.g., Beatty et al., 1996; Diamond, DeLuca, Kim, & Kelley 1997; Kujala, Portin, Revonsuo, & Ruutiainen, 1995; Litvan, Grafman, Vendrell, & Martinez, 1988; Ron et al., 1991). Beatty et al. (1996) considered that the poor performance on the digit span evident in their MS sample may have indicated that observed memory deficits were secondary to attentional dysfunction. Kujala et al. (1995) also examined differences in attentional capacity in people with MS. The 'cognitively preserved' subgroup of their MS sample exhibited signs of motor-related slowness and fatigue, while the 'cognitively deteriorated' subgroup of their MS sample also displayed extensive cognitive slowness. Beatty and Scott (1993) noted that attentional assessment measures that rely on vocal responses rather than motor ones, and accuracy as opposed to speed, provide a purer estimate of attention in people with MS, given their physical impairments. The impaired performance of their MS sample on the two highest speeds of the Paced Auditory Serial Addition Task suggested to Litvan et al. (1988) that people with MS have impaired attentional capacity on complex tests. DeLuca, Johnson, and Natelson (1993) also found that the performance of their MS sample was significantly worse than the performance of a matched control group on all four trials of this test.

The Paced Auditory Serial Addition Task is purported to be a sensitive measure of speed and efficiency of information processing (Gronwall & Wrightson, 1981). Slowed information processing is a major feature of the cognitive profile evident in people with MS. While being exaggerated by physical impairment, it has

been demonstrated to also have a cognitive basis. Rao, St. Aubin-Faubert, and Leo (1989) compared the nature of information processing in people with MS to a matched control group using the Sternberg Memory Scanning Test. The participants with MS exhibited a significantly slower overall reaction time, which included a purely cognitive component that was independent of the effects of physical impairment. Speed of memory scanning was found to be related to disease duration in this sample. Moulthrop and Nudelman (1992) also found evidence of slowed mental processing speed that could not be attributable to motor impairment or lower global cognitive functioning in their MS sample.

Executive functioning. Executive functioning is the name given to a range of cognitive abilities such as abstract and conceptual reasoning, planning, and sequencing. These skills have frequently been reported to be impaired in people with MS (e.g., Beatty, Hames, Blanco, Paul, & Wilbanks, 1995; Beatty & Monson, 1994; Beatty & Monson, 1996; Troyer, Fisk, Archibald, Ritvo, & Murray, 1996). Cognitive inflexibility, similar to that apparent in people with frontal lobe impairment, is commonly found in people with MS upon testing with the Wisconsin Card Sorting Test (Rao, 1986). Beatty (1993) reviews the nature of impairment in memory and executive functioning in people with MS, and discusses the possibility that these deficits stem from impairment at the level of information processing.

Methodological Issues in Neuropsychological Research On MS

The variability and inconsistency of MS that compounds the difficulties experienced by those diagnosed with the disease, also contributes to the complexity of researching its effects. The unpredictable nature of the disease progression necessitates caution when comparing research outcomes across different samples, or generalising findings from a sample to the larger population. Particular caution is

required when research participants have been obtained from hospital or outpatient populations, who are likely to be more severely or acutely impaired than the general MS population. Considerable variation in the cognitive performance of different individuals within the same samples has been a common finding. This variability in the cognitive impairment experienced by different people with MS may parallel the variability of physical impairment. To assist in the comparison of research findings, Rao (1986) recommended that neuropsychological studies about MS should contain a minimal data set. He suggested that this data set include details about the disease course and duration, average and range of physical impairment, and the certainty of diagnosis for the sample investigated.

The relative contribution of motor and sensory impairments to psychometric test scores needs to be ascertained before conclusions can be drawn about MS-related cognitive impairment. Performance measures that are timed and/or require manual dexterity are sometimes inappropriate. Visual impairment and dysarthria may also leave a person with MS at a disadvantage in completing some cognitive tests. The effect of fatigue, which is experienced in differing degrees by a large percentage of people with MS, also needs to be considered in the course of neuropsychological evaluations. Emotional variables can also have an indirect effect on test performance (Peterson & Kokmen, 1989). Consequently, the impact of their affective or psychological functioning on people undergoing a neuropsychological assessment is yet another variable to be accounted for. Appropriate measures of mood need to be obtained in the course of cognitive assessment.

The appropriateness of some psychological assessment tools (e.g., the Beck Depression Inventory and the Minnesota Multiphasic Personality Inventory) needs

to be considered by researchers and health professionals alike, as physical impairments are an independent factor that can influence the validity of some instruments. For example, common motor and sensory impairments experienced by many people with MS can mistakenly be classified as symptoms of depression (e.g., lack of energy).

Ideally, a neuropsychological test battery for the assessment of people with MS needs to be (a) comprehensive, assessing a range of aspects, including cognitive, emotional, and behavioural functioning; (b) sensitive to the types of problems encountered in MS; (c) not totally dependent on sensorimotor functions; and (d) able to be administered in a manner that does not cause excessive fatigue for the person being assessed (Mahler, 1992).

The effects of medication on cognitive test performance need to be considered in the analysis of test results. While it is difficult to avoid this factor without compromising the representativeness of MS samples, Rao (1986) recommended that researchers record the type and dose of medications being taken by participants at the time of evaluation. This information can then be used in the course of data analyses to examine the possible effects of medication.

Relationship Between Cognitive and Affective Functioning

Depression has been a common finding in MS samples. Many studies have reported no association between cognitive impairment and depression in people with MS (e.g., Clark et al., 1992; Gilchrist & Creed, 1994; Krupp, Sliwinski, Masur, & Friedberg, 1994). Some investigations of personality changes in people with MS have employed the Minnesota Multiphasic Personality Inventory, with elevations recorded on the scales of hypochondriasis, depression, and hysteria (the so-called neurotic triad) and the schizophrenia scale (Meyerink, Reitan, & Selz,

1988). However, this profile is a common occurrence in people with central nervous system disease in the absence of psychiatric impairment and is considered to be an artefact of the test items and scale composition (Meyerink et al., 1988).

Formation of the Minimal Record of Disability

The Minimal Record of Disability for MS, published by the International Federation of Multiple Sclerosis Societies (IFMSS, 1984), is the most widely employed scoring system with MS populations (see Appendix C). It was established to provide uniformity of data collection and enable comparison of clinical and research results. The record consists of four rating scales which accommodate the three-tier classification of dysfunction developed by the World Health Organisation (WHO, 1980). As applied to neurological disorders, the three tiers are: (a) impairment - clinical signs and symptoms produced by damage to the nervous system, (b) disability - the personal limitations imposed upon the activities of daily living by the neurological impairment, and (c) handicap - the social and environmental effects of the disability.

Of the Minimal Record of Disability components, the Kurtzke Functional Systems and Kurtzke Expanded Disability Status Scale (EDSS) relate to impairment, the Incapacity Status Scale relates to disability, and the Environmental Status Scale relates to handicap. More detail about the Minimal Record of Disability is presented in Chapter Three, however an introduction to the EDSS is warranted here due to the frequency with which it is mentioned in descriptions of MS research samples.

In 1955 Kurtzke designed the Disability Status Scale, a 10-point rating scale which provided an overall rating of impairment in people with MS. In an attempt to increase its clinical sensitivity, the scale was extended to include half-

point increments in 1983, becoming the Expanded Disability Status Scale (Kurtzke, 1983). This is currently the most widely used scale for the standardisation of research samples of people with MS. The EDSS has been criticised for a number of reasons, including lack of sensitivity to clinical changes not affecting mobility, and inter-rater variability in ratings of people with lower EDSS scores where ambulation is less impaired (Willoughby & Paty, 1988). However, for research purposes the EDSS has remained the gold standard for measuring impairment in people with MS to date.

Rao's (1986) Suggestions for Future Research Directions

At the conclusion of his 1986 review, Rao outlined a number of areas encompassing neuropsychological aspects of MS that, in his opinion, would benefit from further investigation. The six suggestions proposed were:

1. Large-scale, population-based, multicentre collaborative investigations to provide accurate prevalence rates for the cognitive and affective problems experienced by people with MS.
2. More information on the range and severity of cognitive deficits experienced by people with MS, contrasting this with the nature of cognitive impairment evident in other dementing conditions.
3. Information on the rate of progression of cognitive impairment in MS.
4. Correlation of biological markers of disease activity with the cognitive and affective changes evident in MS.
5. Evaluation of the effect of cognitive impairment on the everyday functioning of people with MS (i.e., self-care, independent living, academic and vocational functioning).

6. Additional information on the relationship between the cognitive and affective impairments experienced by people with MS.

Twelve Years On

In 1998, Brassington and Marsh reviewed the neuropsychosocial literature published in the intervening years since Rao's (1986) review. This research is summarised below according to the directions proposed by Rao twelve years earlier.

Large-scale, population based, multicentre, collaborative investigations

In recent years it appears that a number of investigators have made a concerted effort to obtain their MS research samples from community-based populations (e.g., Gulick, 1994; McIntosh-Michaelis et al., 1991; Nyenhuis et al., 1995; Rao et al., 1993; Rao, Leo, Bernardin, et al., 1991; Rodriguez et al., 1994; Skegg, 1993). Consequently, results from these studies have been more representative of the total MS population and, hence, more generalisable than results obtained from hospital and outpatient clinic samples. The methodologies and results of a number of these studies will be considered in detail in the ensuing chapter due to their relevance to the present MS study.

Range and Severity of Cognitive Deficits

There is now a large body of research contributing to our knowledge about specific areas of cognitive deficit experienced by people with MS. The profile that has repeatedly appeared in research is characterised by little or no language impairment; impaired retrieval from long-term memory but normal recognition memory, immediate recall, and rates of forgetting; impaired abstract and conceptual reasoning; slowed rates of information processing; and reduced attentional capabilities. This pattern is consistent with the concept of subcortical

dementia. More recent research has divided MS samples into more cognitively homogeneous groups to gain a better understanding of the nature and pattern of deficits experienced by different clusters of individuals (e.g., Armstrong et al., 1996; Grossman et al., 1995; Kujala, Portin, Revonsuo, & Ruutiaien, 1994; Ryan, Clark, Klonoff, Li, & Paty, 1996).

Comparisons of the cognitive deficits experienced by people with MS with those observed in other disabling conditions have been relatively limited. Recent research has mostly compared the cognitive functioning of people with MS to that of people with Chronic Fatigue Syndrome (e.g., DeLuca, Johnson, Beldowicz, & Natelson, 1995; DeLuca et al., 1993; Krupp et al., 1994; Packer, Sauriol, & Brouwer, 1994). DeLuca et al. (1993) reported significant cognitive impairment both in their participants with MS and in those with Chronic Fatigue Syndrome compared to a normal control group. DeLuca et al. (1995) reported significantly more overall cognitive impairment in the sample with Chronic Fatigue Syndrome than in the MS sample. In comparison, Krupp et al. (1994) found that their sample of people with Chronic Fatigue Syndrome demonstrated more symptoms of depression but less cognitive impairment than their MS sample. The cognitive deficits evident in Krupp et al.'s MS sample were more widespread than those found in the sample with Chronic Fatigue Syndrome and, unlike the Chronic Fatigue Syndrome sample, were independent of depressive symptomatology.

Rate of Progression of Cognitive Dysfunction

The need for longitudinal studies to map the development of cognitive impairments in people with MS has been addressed by a few studies (e.g., Amato et al., 1995; Feinstein, Kartsounis, Miller, Youl, & Ron, 1992). Feinstein, Kartsounis et al. (1992) tracked people who presented with the early signs of MS

(i.e., clinically isolated lesions). At a four and a half year follow-up, they found that approximately half of the people had developed clinically definite MS, with memory deficits becoming apparent. Bernardin et al. (1993) presented results from a three year follow-up study of 84 people with MS. A significant increase in the level of physical impairment was evident, as was statistically significant deterioration in performance on 8 of 29 cognitive measures, including verbal intelligence, memory, and visuospatial perception. The cognitive changes appeared to be independent of disease duration, disease course and changes in physical status.

Neuroanatomical Correlates of Cognitive and Affective Impairment

There has been a proliferation of research conducted in this area in the past decade, particularly since the accessibility of magnetic resonance imaging. The extent and pattern of cognitive impairment evident in people with MS has been found to correlate significantly with the amount and location of white-matter disease in the cerebral hemispheres (Feinstein, Ron, & Thompson, 1993). Rao, Leo, Haughton, Aubin-Faubert, and Bernardin (1989) found that total lesion area was predictive of the cognitive functioning of their MS sample, particularly in the areas of recent memory, abstract and conceptual reasoning, language, and visuospatial problem solving. The size of the corpus callosum predicted cognitive test performance in the areas of information processing speed and rapid problem solving. Huber et al. (1992) found that people with MS who had severe cognitive impairment had significant atrophy of the corpus callosum, compared to people with mild and moderate cognitive impairment. Ryan et al. (1996) recently examined the magnetic resonance imaging profiles of 150 mildly disabled people with relapsing/remitting MS and also concluded that lesion sites were associated with

cognitive impairment. For example, lesions in the white matter of the left parietal region were associated with impaired performance on a test of learning and memory. Both Swirsky-Sacchetti, Mitchel, et al. (1992) and Arnett et al. (1994) have investigated and confirmed the existence of a relationship between frontal lobe white matter lesions in people with MS and impaired conceptual reasoning as demonstrated using the Wisconsin Card Sorting Test.

George, Kellner, Bernstein, and Goust (1994) recently reported a positive correlation between the occurrence of clinical depression in people with MS and lesion load in the left hemisphere cortical white matter. These authors likened this to the finding that clinical depression has been found to be more likely to occur following a left hemisphere stroke than one in the right hemisphere. However, Moller, Wiedemann, Rohde, Backmund, and Sonntag (1994) reported that they were unable to distinguish depressed from non-depressed people with MS on the basis of magnetic resonance imaging results.

Alongside studies which have employed magnetic resonance imaging are a number of studies which have investigated the relationship between event-related potentials and cognitive impairment in MS samples (e.g., Honig, Ramsey, & Sheremata, 1992; Newton, Barrett, Callanan, & Towell, 1989; Ruchkin et al., 1994; Van Dijk, Jennekens-Schinkel, Caekebeke, & Zwinderman, 1992). The generation of event-related potentials is partly dependent on the integrity of the cerebral white matter and so may indicate subtle degrees of cognitive impairment (Newton et al., 1989). Contrasting results have been reported. For example, Van Dijk et al. (1992) reported no significant relationship between event-related potential latencies and psychometric tests, while Honig et al. (1992) reported that

differences in the event-related potentials of people with MS were strongly correlated with cognitive impairment and only weakly associated with the EDSS.

The Effect of Cognitive Impairment on a Person's Everyday Functioning

Detailed examination of the relevant literature will be presented in the next chapter. Suffice to say, there has at last been an increased focus on the practical relevance of the cognitive impairments evident in people with MS. This appears to have followed the identification by many health professionals in the field that this must be the most critical and relevant question from the perspective of people with MS. The combined results of these studies has suggested that the cognitive decline experienced by many people with MS can have a detrimental effect on their social functioning, interpersonal relationships, employment status, affective functioning, and execution of other activities of daily living (Amato et al., 1995; Edgley, Sullivan, & Dehoux, 1991; Gilchrist & Creed, 1994; Rao, Leo, Ellington, et al., 1991).

Relationship Between Cognitive and Affective Impairment

Rao (1986) identified depression and euphoria as mood states often associated with MS, and the need for more information on the relationship between these states and the cognitive changes experienced by people with MS. Recently there have been a number of studies reporting high levels of depression in MS samples, most noting that the depression does not appear to account for impaired cognitive performance (e.g., Clark et al., 1992; Krupp et al., 1994; Moller et al., 1994). The occurrence of euphoria has been less well documented in recent years, which possibly reflects its less common occurrence.

Bernardin, Rao, Ellington, Leo, and Connolly (1992) compared the influence of possible "endogenous" (structural brain changes and cognitive

impairment) and "exogenous" (duration, severity, and course of illness, employment, coping strategies) etiological factors on the severity of emotional disturbance in 100 people with MS. In this research, endogenous variables were found to be most associated with mood disturbance, leading the authors to suggest that these changes may be a direct result of the demyelination process.

Summary and Outline of the Present Research Project

MS is a disease of devastating proportions, with far-reaching effects for individuals and their support networks. It is clear that cognitive and psychological changes are a significant and challenging component of the disease. Significant advances have been made in a number of important areas in recent years, adding to our knowledge of the experience of people with this disease. More recently, there has been a move by neuropsychological researchers to improve the ecological validity of their findings, that is, to determine the actual relevance of cognitive test findings to the daily lives of people with MS (e.g., Rao, Leo, Ellington, et al., 1991).

The principal reasons for undertaking the present study were first, to obtain data pertaining to the physical, psychological, and cognitive functioning of a New Zealand community-based sample of people with MS; and second, to relate this information to the functioning of family members in a caregiving role for this MS sample. Consequently, the project has been divided into two studies. The MS Study (Chapters Two - Five) entails:

1. A detailed description of the impairment, disability, and handicap experienced by a New Zealand community-based MS sample, employing the Minimal Record of Disability.

2. Comparison of the cognitive and psychological functioning of this New Zealand MS sample with the functioning of a matched normal control group.
3. Examination of the relationship between the cognitive functioning of the MS sample and other disease variables, including the sample's physical and psychological functioning, the number of years since disease onset and MS diagnosis, disease course, fatigue, and medication use.
4. Comparison of the disability, handicap, and psychological functioning of people in the MS sample who were cognitively impaired, with people in the MS sample who were comparatively cognitively intact.

Following this, the Caregiver Study (Chapters Six - Nine) consists of two parts:

1. Comparison of the functioning of people in a caregiving role for a family member with MS, with the functioning of a matched normal control group. Domains of comparison include psychological functioning, expressed burden, and social supports.
2. Examination of the relationship between the psychological functioning and burden reported by the caregiver sample, and (a) the clinically-assessed functioning of the MS sample, (b) the caregivers' appraisal of the functioning of the MS sample, and (c) the social support experienced by the caregiver sample. The ability of these variables to predict the well-being and burden expressed by familial caregivers of people with MS is also examined.

The results of these studies are then discussed within the framework of the caregiver stress response model outlined by Knight (1992), based on the work of Lazarus and Folkman (1984).

MS STUDY

CHAPTER 2

Introduction

Rao's (1986) review of the literature on the neuropsychological sequelae of MS caught the beginning of a wave of research examining the cognitive changes experienced by people with this disease. A large body of research has examined in detail, the functioning of people with MS in specific cognitive domains (e.g., Arnett et al., 1997; Beatty & Monson; 1996; DeLuca, Barbieri-Berger, & Johnson, 1994; Rao, Leo, & St. Aubin-Faubert, 1989; Rao, St. Aubin-Faubert, et al., 1989). However, more relevant to the current study are the half dozen large-scale, population-based investigations of the global cognitive functioning of people with MS (i.e., Heaton, Nelson, Thompson, Burks, & Franklin, 1985; Klonoff et al., 1991; McIntosh-Michaelis et al., 1991; Rao, Leo, Bernardin, et al., 1991; Rao, Leo, Ellington, et al., 1991; Rodriguez et al., 1994). These studies were undertaken to provide more accurate estimates of the range and severity of cognitive impairments experienced by people with MS. Some of these studies have gone a step further and examined the effects of these impairments for people with MS. The methodologies and outcomes of these studies will be presented, followed by an outline of the aims of the current MS study.

The Colorado Study

In 1985, Heaton et al. identified four methodological limitations of earlier neuropsychological research which cast doubt on the conclusions drawn from those studies regarding the prevalence and nature of cognitive deficits in MS. The first of these limitations was that prior research on MS had utilised samples of fewer than 50 people and/or relatively brief neuropsychological test batteries of 1-2 hours

duration which, considering the variability of MS, was unlikely to portray the diverse effects of the disease. The second limitation of earlier studies, identified by Heaton et al., was that research participants had been obtained via referrals for neuropsychological assessments, and consequently were likely to be more cognitively impaired than the general MS population. Third, participants experiencing acute exacerbations of their MS had not been excluded from the testing process in previous research, which is likely to have lead to inflated estimates of impairment. And fourth, medication effects had not previously been considered during data analysis.

Heaton et al. (1985) compared the neuropsychological functioning of 100 people with MS to that of an equally large, normal control group. In addition, within the MS sample, they compared the cognitive functioning of people with a relapsing/remitting disease course with those who had a chronic/progressive disease course. Finally, Heaton et al. assessed the relationship between the neuropsychological results obtained by the people with MS and their disease duration, age, medication status, degree of physical disability, and mental-status evaluation.

The MS sample in Heaton et al.'s (1985) study was not a community sample, however neither was it obtained specifically from referrals for neuropsychological assessments. Rather, the sample was obtained from all consecutive admissions to an MS Centre who were aged between 20 and 50, resided in the local area, could be confidently classified as having a relapsing/ remitting or chronic/progressive disease course, and had no history of other neurological insults (e.g., significant head trauma or substance abuse). One hundred and seventy-two people met these criteria, of whom 10 refused to

participate and 28 were excluded because of a tumultuous disease course at the time that the research was being undertaken. A further 34 people were excluded because the severity of their impairments were such that they were considered incapable of providing valid results on the neuropsychological battery.

The mean Kurtzke Disability Status Scale (Kurtzke, 1955) score for the 100 remaining participants with MS was 3.10 (*SD* = 2.09), indicating mild to moderate neurological impairment for the majority of the sample. Fifty-seven of these participants had a relapsing/remitting disease course and forty-three had a chronic/progressive disease course. Forty of the participants with MS were not taking any medication at the time of assessment. The remaining 60 participants were being prescribed various combinations of the following types of medication: antianxiety/sedative-hypnotics (*n* = 27), muscle relaxants/antispasticity (*n* = 19), steroids (*n* = 7), anticonvulsants (*n* = 4), antidepressants (*n* = 4), and miscellaneous (lithium carbonate, Talwin, Norflex; *n* = 4).

The MS group consisted of 25 males and 75 females, with a mean age of 37 years (*SD* = 8), a mean education of 14 years (*SD* = 2), and a mean disease duration of 9 years (*SD* = 6). The authors note that while the two subgroups of MS participants were comparable with respect to gender distribution and years of education, the chronic/progressive subgroup was significantly older, had had MS for longer (an average of 6 and a half years longer), and had more neurological impairment as assessed by the Kurtzke scale. Disease duration was controlled for using covariance procedures in all neuropsychological comparisons between the chronic/progressive and relapsing/remitting subgroups.

The healthy control group consisted of 100 participants who had no history of neurological illness, significant head trauma, or substance abuse. They were 79

males and 21 females with a mean age of 33 years (*SD* = 14) and a mean education of 14 years (*SD* = 3). Age was covaried in all comparisons between the control group and the chronic/progressive subgroup as the former were significantly younger than the latter. The control group also had a significantly higher percentage of males than either of the MS subgroups. Consequently, gender was covaried in all MS-control group comparisons of tests for which sex differences were known to occur.

All 200 research participants were administered the WAIS and the standard Halstead-Reitan Battery. A number of other tests were added to the battery to extend its assessment of abilities that may be affected by MS. These additional tests included the Grooved Pegboard and Hole-Type Steadiness tests from the Klove-Matthews Motor Steadiness Battery, the Wisconsin Card Sorting Test, the Thurstone Word Fluency Test, the Tonal Memory Test, and modified versions of Reitan's Story Memory Test and the visual reproduction component of the Wechsler Memory Scale.

Analyses of covariance revealed significant overall differences between the three groups on each of the five neuropsychological summary scores (i.e., WAIS Verbal IQ, WAIS Performance IQ, Halstead Impairment Index, Average Impairment Rating, and clinician global judgment). The two MS groups performed significantly worse than the control group on each of the five summary scores and the chronic/progressive subgroup performed significantly worse than the relapsing/remitting subgroup on all measures except the WAIS Verbal IQ score.

In the course of their data analysis, Heaton et al. (1985) gave separate consideration to tests which assessed cognitive functioning without significant sensorimotor components, tests which measured both cognitive and sensorimotor

components, and tests which measured sensory-perceptual or motor functioning. On each group of tests the same pattern was observed, i.e., the MS sample performed significantly worse than the control group, and the chronic/progressive subgroup of the MS sample performed significantly worse than the relapsing/ remitting subgroup. Degree of neuropsychological impairment in the MS sample was found to be significantly correlated with disease duration but unrelated to medication use. Medication use was also found to be unrelated to the neurological impairment ratings of the MS sample.

Heaton et al. (1985) concluded that MS disease course is an important factor in determining neuropsychological outcome in MS, with people who have a chronic/progressive disease course particularly likely to show significant cognitive impairment upon testing. Further, while the results of neurological examinations were found to be highly correlated with the motor and sensory components of cognitive testing, such examinations were inadequate for determining the cognitive status of people with MS.

The Milwaukee Study: Frequency, Patterns and Prediction

Another notable study in this area of research was conducted by Rao, Leo, Bernardin, et al. (1991). Their aims were to establish the frequency of cognitive dysfunction in a community-based MS sample which closely resembled the general MS population; gain a better understanding of the patterns of cognitive breakdown in MS; and develop a brief cognitive testing instrument that could be used to predict cognitive dysfunction. People with MS were randomly recruited from the membership listing of a local MS society. After excluding people who did not meet the diagnostic criteria for MS; had a history of alcohol or drug abuse, or a 'nervous system disorder other than MS'; had severe motor or visual impairment that might

interfere with cognitive testing; resided in an institutional setting and could not easily be evaluated at the Wisconsin medical centre; or had previously undergone neuropsychological evaluation at the centre, they were left with a sample of 100 people. Evaluations were conducted over a two-day period to minimise fatigue, and included a neurological examination, magnetic resonance imaging, and a neuropsychological assessment.

Of the 100 participants with MS, the disease course of 39 people was described as relapsing/remitting, while 19 people had a chronic/progressive course and 42 had a chronic/stable course. Two of the participants with a relapsing/ remitting disease course were experiencing a clinical exacerbation at the time of evaluation. The average number of years since symptom onset was 14 (*SD* = 10, range = 1 - 49), average number of years since diagnosis was 10 (*SD* = 9, range = 1 - 43), and the average EDSS score for the sample was 4.1 (*SD* = 2.2, range = 0 - 8.0). Forty-three people in the sample were taking prescribed medications at the time of evaluation.

One hundred healthy adults were recruited from newspaper advertisements. They were individually matched to the participants with MS based on age, education, and gender. Control participants were excluded if they had a history of substance abuse, psychiatric disturbance, head injury, any other 'nervous system disorder', or required the use of prescription medication. Both groups of 100 participants consisted of 75 women and 25 men, with an average age of 46 years (*SD* = 11) and an average of 13 years of education (*SD* = 2). Both groups had a mean estimated premorbid intelligence (calculated from demographic variables) of 106 (*SD* = 7). One participant with MS and one control participant were described as being non-white.

In determining the frequency of cognitive dysfunction in their sample, Rao, Leo, Bernardin, et al. (1991) converted raw cognitive test scores to standardised residual scores. The fifth percentile of residual scores of the control group was used as the cut-off for determining the number of participants who "failed" each test. Thirty-one cognitive test indices were examined, consisting of a dementia screen (Mini-Mental Status Examination), verbal intelligence (Verbal IQ subtests and summary score from the WAIS-R), immediate memory (WAIS-R Digit Span and Brown-Peterson Interference Test), recent memory (Buschke Verbal Selective Reminding Test, Story Recall Test and 7/24 Spatial Recall Test), remote memory (President's Test), verbal fluency (Controlled Oral Word Association Test), abstract reasoning (Wisconsin Card Sorting Test, Booklet Category Test, and Standard Raven Progressive Matrices), attention/concentration (Simple versus Two-Choice Reaction Time, Sternberg Memory Scanning Task, Paced Auditory Serial Addition Task, and Stroop Color/Word Interference Test), language (abbreviated Boston Naming Test and Oral Comprehension), and visuospatial perception (Hooper Visual Organisation Test, Judgment of Line Orientation, Facial Recognition, and Visual Form Discrimination).

The participants with MS 'failed' a significantly greater number of tests (M = 4.64, SD = 4.9) compared to control participants (M = 1.13, SD = 1.8). Using a cutoff of four or more failed tests, 48% of the MS sample was classified as cognitively impaired. The most sensitive measures of cognitive impairment were found to be recent memory (consistent long-term retrieval from the Selective Reminding Test and total recall from the 7/24 Spatial Recall Test) with 31% of the MS sample failing those tests. One-quarter of the MS sample was impaired on measures of sustained attention (Paced Auditory Serial Addition Task) and verbal

fluency (Controlled Oral Word Association Test), while one-fifth were impaired on measures of conceptual reasoning (Raven Progressive Matrices) and visuospatial perception (Benton Facial Recognition Test). The Verbal IQ summary score from the WAIS-R and four of its subtests identified 15 - 21% of the MS sample as cognitively impaired. While the Mini Mental State Examination statistically discriminated between the two groups, it only identified 11% of the MS sample as impaired.

These authors found that severity of physical impairment (as measured by the Kurtzke EDSS) was significantly correlated with cognitive functioning (i.e., number of failed tests) in the MS sample (Rao, Leo, Bernardin, et al., 1991). However both duration of illness and MS disease course were not significantly correlated with cognitive functioning. There was a trend for people with MS taking prescribed medication and/or classified as depressed (using the Zung Depression Scale) to fail more of the cognitive tests, but in neither case did this difference reach statistical significance.

The Milwaukee Study: Impact on Employment and Social Functioning

In a closely related publication employing the same research samples, Rao, Leo, Ellington, et al. (1991) examined the impact of cognitive dysfunction on the psychosocial functioning of people with MS. They utilised the four components of the Minimal Record of Disability (i.e., the Kurtzke Expanded Disability Status Scale, the Kurtzke Functional Systems, the Incapacity Status Scale, and the Environmental Status Scale); an occupational therapy evaluation involving the Barthel Index and the Klein-Bell Activities of Daily Living Scale; self-report measures including ratings of depression (Zung Depression Scale) and anxiety (State-Trait Anxiety Inventory) and the Sickness Impact Profile; and finally, a

rating of the person's emotional adjustment obtained from a close relative or friend using the Katz Adjustment Scale. Rao, Leo, Ellington, et al. employed a conservative alpha level of $p = .01$ in light of the large number of comparisons made, however they also reported nonsignificant trends (where $.01 < p < .05$).

The results of this study demonstrated no significant difference between the cognitively intact ($n = 52$) and cognitively impaired ($n = 48$) subgroups of the MS sample on the overall degree of physical disability as measured by the EDSS. However, as would be expected, on the Kurtzke Functional Systems the cognitively impaired group rated as more impaired on the Cerebral scale ($p < .002$) which measures mentation. This group of participants was also rated as more impaired on the Cerebellar and Brainstem scales ($p < .01$), but was similar to the cognitively intact group on the remaining Functional Systems scales.

On the Incapacity Status Scale (a measure of disability), the cognitively impaired group was rated as significantly more disabled on the Mentation scale ($p < .01$). There was a nonsignificant trend for the cognitively impaired participants to be more disabled on the Bathing ($p < .03$) and Sexual Function ($p < .02$) scales. Results from the Environmental Status Scale (a measure of handicap) indicated that the cognitively impaired group of participants were less likely to be working and required greater personal assistance than the cognitively intact group. There was also a nonsignificant trend ($p < .05$) for the cognitively impaired group to be engaged in fewer social activities than the cognitively intact group.

On the Barthel Index, cognitively impaired participants were rated as significantly ($p < .01$) more dependent in their activities of daily living than the cognitively intact participants. There was a nonsignificant ($p < .02$) trend on the Klein-Bell scale for the cognitively impaired participants to experience more

difficulty with bathing and personal hygiene than the cognitively intact participants. No significant group differences were observed on the self-report measures of depression and anxiety or the Sickness Impact Profile, however again there was a trend for the cognitively impaired participants to report a greater impact on their work-related activities than did the cognitively intact group.

Finally, close relatives or friends were found to report that the cognitively impaired participants with MS exhibited significantly greater confusion and were rated less emotionally stable than the cognitively intact participants. There was also a nonsignificant trend for the cognitively impaired participants to be rated as more helpless and socially withdrawn than the cognitively intact participants.

In conclusion therefore, the findings from this study suggest that people with MS who have significant cognitive impairment experience a greater disturbance in activities of daily living than people with MS who are comparatively cognitively 'intact'. Furthermore, these group differences emerge despite similarities in the two groups with regard to physical disability, duration of illness, MS disease course, and demographic variables. The hypothesis that cognitive deficits in MS are a result of emotional distress was not supported by this study, as the self-report ratings of depression and anxiety made by the cognitively impaired participants did not differ significantly from those made by the cognitively intact participants.

The Southampton Study

McIntosh-Michaelis et al. (1991) also employed a community-based sample to gain an estimate of the prevalence of cognitive impairment in the MS population and examine the relationship between neuropsychological functioning and other disease variables (e.g., physical disability and disease duration). Their sample of

147 people with MS had an average age of 48 years (range = 21 - 80) and a gender ratio of 1:1.8 men to women. The average disease duration for their sample was 13 years and the median EDSS score was 6.0 (indicating moderate neurological impairment). Family members were also interviewed wherever possible, resulting in caregiver ratings and associated data from 109 relatives. Results from this caregiver data are discussed in Chapter Six. The control group for this study consisted of 34 people with rheumatoid arthritis who did not differ from the MS sample in terms of gender and education, but were significantly older (M = 55 years, range = 33 - 79) than the MS sample.

The neuropsychological assessments were conducted in participants' homes and consisted of psychometric measures least reliant on motor function, to reduce possible confounding by physical impairment. The test battery assessed memory (Rivermead Behavioural Memory Test), frontal lobe functioning (the modified Wisconsin Card Sorting Test and the Controlled Oral Word Association Test), and general intellectual functioning (the verbal scales from the WAIS-R and the Raven's Standard Progressive Matrices). Nine participants from the MS sample were unable to perform some or all of the tests due to physical impairments such as ataxia, quadriplegia, and severe visual impairment. Mood was examined using the General Health Questionnaire -28 and the Hospital Anxiety and Depression Scale. The Rosenberg Self-Esteem Questionnaire was also employed.

Forty-nine (34%) of the participants in the MS sample were found to have memory impairment compared to 4 (12%) participants from the control group. For 13 (9%) of the MS sample this impairment was classified as severe. Twenty-one (15%) of the MS sample were impaired on the Wisconsin Card Sorting Test compared to none of the controls. Thirty-four (23%) of the MS sample scored in

the borderline range or worse on the Controlled Oral Word Association Test. In comparison, none of the control sample scored as low as the borderline range on this test. General intellectual functioning was impaired in 22% of the MS sample. The mean Verbal IQ for the MS sample was 97.6 (SD = 14.8) while for the control sample it was 101 (SD = 10.8). There was a significant difference between the two groups on two of the WAIS-R subtests: Digit Span ($p < .05$) and Arithmetic ($p < .01$).

Sixty-two (46%) of the participants in the MS sample demonstrated impairment in one or more of the cognitive domains compared to 4 (12%) participants from the control group. Of the 135 people with MS who completed all of the tests, 36 (27%) were impaired on more than one test and 17 (13%) were impaired in all three test areas. Regression analyses were undertaken to determine the relative contributions of disease-related variables to the presence of memory and frontal lobe impairment. People with EDSS scores of 6.0 or more, or a disease duration of 10 years or more, were twice as likely to have impaired memory functioning as people with EDSS scores of less than 6.0 or disease duration of less than 10 years. Similarly, people with EDSS scores of 6.0 or more were four times as likely as those with scores less than 6.0 to be impaired on one or both tests of frontal lobe functioning. Clearly, disease duration and extent of physical impairment were related to cognitive functioning in this MS sample.

The British Columbia Study

Klonoff et al. (1991) investigated the neuropsychological functioning of people with mild MS (i.e., minimal neurological impairment). They compared a sample of 86 people with mild relapsing/remitting MS to 46 demographically matched normal control participants on an extensive neuropsychological

assessment consisting of 42 variables. The MS participants were volunteers from the University of British Columbia MS Clinic. Two-thirds of the sample were female, and they had an average age of 37 years and an average of 14 years of education. The mean age at which MS symptoms were first experienced by the sample was 26 years and the mean age at diagnosis was 31 years. The average EDSS score for the sample was 2.08, indicating minimal overt symptomatology with limited functional disability. All participants with MS were in remission at the time of assessment and none were taking prescribed medications.

The neuropsychological battery included the following tests: the WAIS-R, the Benton Visual Retention Test, the Controlled Oral Word Association Test (using the letters F, A, S), a shortened form of the Halstead Category Test, the Finger Tapping Test, Strength of Grip, Sentence Repetition, Tactual Performance Test, Paired Associate Learning, Trail Making Test, Speech Perception, Memory for Objects, Klove Grooved Pegboard, Klove Motor Steadiness Maze, and Klove Static Steadiness. The authors report that this battery took approximately three hours to complete and the administration order of the tests was randomized.

The MS sample performed significantly worse ($p \leq .05$) than the control group on 21 of the 42 variables. While eight of the significant differences in performance were on measures of pure motor functions and a further six were on measures with a motor component, six other measures assessed cognitive function without motor components (e.g., the Similarities subtest from the WAIS-R and the Controlled Oral Word Association Test). Klonoff et al. (1991) note that while these tests measured different aspects of cognitive functioning (e.g., learning, verbal fluency, and memory), they all required effortful processing of new or novel material. In comparison, the MS sample did not differ significantly from the control

group in their WAIS-R Verbal IQ results, which employs skills largely measuring previously learned material (e.g., general knowledge and vocabulary).

Klonoff et al. (1991) concluded that cognitive changes do occur even in relatively mild cases of MS. They suggested that an indication of the effect of these deficits was illustrated by the differences in the employment status of the MS sample and control group. Sixty-six percent of the control group were employed full-time compared to only 38% of the MS sample. Of the people with MS, 21.5% described themselves as unemployed or retired due to ill-health, whereas no-one in the control group came under this classification. Klonoff et al. note that as the sclerotic plaques are distributed throughout the brain of people with MS, there may be qualitatively different cognitive changes dependent on the location(s) and size(s) of the lesions. Consequently, by examining group differences, overall decreases in cognitive functioning can be determined, but not how these changes differ for different people with the disease.

The Minnesota Study

A somewhat different study was conducted by Rodriguez et al. (1994), who employed the Minimal Record of Disability to report on the functioning of 179 people with MS living in Olmsted County, Minnesota. Rodriguez et al. considered that while earlier studies had emphasised impairment, primarily as defined by the Kurtzke EDSS, they had not analysed measures of handicap and disability, such as activities of daily living, work status, and sexual functioning. Understandably, these areas are of fundamental importance for people with MS and health care planners.

Rodriguez et al. (1994) utilised a computerised central diagnostic index at the Mayo Clinic to identify all known cases of MS in the delineated population of Olmsted County (a population of approximately 100,000 people in 1991). A total

of 162 people with definite diagnoses of MS were identified. One hundred and twenty-two (75%) of these people were female. The average age of the population at disease onset was 29 years (range = 14 - 66 years) and their average age at diagnosis was 35 years (range = 16 - 66 years). Ninety-four (58%) people had a relapsing/remitting disease course, 22 (14%) had a primary progressive disease course, and 46 (28%) had a secondary progressive disease course. The average EDSS score was 3.5 (range = 1.0 - 9.5).

Results from the Kurtzke Functional Systems component of the Minimal Record of Disability indicated that 33% of the population experienced marked paraparesis, paraplegia, hemiplegia, or quadriplegia (scores of 4 - 6 on pyramidal functioning). On the cerebellar scale, 13% of the population displayed moderate or worse truncal or limb ataxia, or severe ataxia in all limbs (scores of 3 - 5). On the scale measuring brainstem functioning, 13% of the population displayed severe brainstem abnormalities such as extraocular motor weakness, dysarthria, and dysphagia (scores of 3 - 5). Twenty-two percent of the population displayed severe loss of vibration, proprioception, or pain sensation (scores of 3 - 6 on the sensory functional system). A quarter of the population experienced frequent urinary incontinence, the need for almost constant catheterisation, or the need for constant use of measures to evacuate stool (scores of 3 - 6 on the bowel and bladder functional system scale). Almost 10% of the population had corrected visual acuity worse than 20/100 in either eye (scores of 4 - 6 on the visual functioning scale). Four percent of the population had experienced a severe decrease of mentation or dementia (scores of 4 - 5 on the scale of mental functioning). Finally, 27% of the population lived with severe spasticity which resulted in major interference with

physical functioning (a score of 3 on the spasticity scale). These results provided a picture of the neurological functioning of the population.

Rodriguez et al. (1994) reported a bimodal frequency distribution for this MS population on the EDSS, with a mean of 4.3 (*SD* = 2.7). At the higher (i.e., more impaired) end of the scale, 14% of the population functioned exclusively from a wheelchair or were restricted to bed most of the day (scores of 8.0 - 9.5).

The Incapacity Status Scale provided a summary of the level of disability experienced by the MS population studied by Rodriguez et al. (1994). The results of this scale indicated that 58% of the population reported the need for assistance in stair climbing or were unable to perform this task (scores of 2 - 4). Aids such as wheelchairs were required for locomotion by 41% of these people. Most of the population reported normal or minimal problems with bowel (72%) or bladder (51%) functioning (scores of 0 and 1). Human assistance (scores of 3 and 4) was required by a number of the population for various activities of daily living, i.e., bathing (23%), dressing (20%), grooming (14%), and feeding (9%). Twelve percent of the population reported being able to read only very large print or were legally blind (scores of 3 and 4). Dysarthria interfered with the communication (scores of 2 - 4) of 14% of the population. Most people (83%) had appointments with their physicians less than once every 3 months (scores of 0 and 1). Four percent of the population experienced mood or thought disturbances for which they received psychotherapy or hospitalisation (scores of 3 and 4). Disturbance of mentation severe enough to interfere with everyday activities (scores of 2 - 4) was reported by 19% of the population. Finally, fatigue troublesome enough to cause impairment of functioning (scores of 2 - 4) was reported by 43% of the population.

The Environmental Status Scale provided a summary of the handicap experienced by this MS population. The results of this scale indicated that 53% of the population were working full-time (scores of 0 and 1). Sixty percent (24/40) of men and 45% (55/122) of women were employed. Almost everyone (98%) had been employed previously. Most people (77%) maintained their usual financial standard without external support (scores of 0 - 2). No personal assistance or only minor personal assistance was required by 62% of this population (scores of 0 and 1). Most people (63%) were able to drive with no difficulties or only minor difficulties and without the need for hand controls (scores of 0 and 1). Community services of more than an hour per week (scores of 3 - 5) were utilised by one-fifth of the population. The majority of the population (62%) reported normal or minimal difficulties with social activities (scores of 0 and 1). Nineteen people (12%) did not respond to the item regarding sexual concerns and 71 - 85% of the population expressed no concern in the 12 areas of inquiry of sexual functioning.

These results from the Incapacity Status Scale and the Environmental Status Scale are considered by Rodriguez et al. (1994) to be limited in that they were graded on the basis of self-report by the people with MS or their family members. The authors caution that a self-report bias may have been particularly evident in the low reporting of cognitive deficits by the cohort. However Rodriguez et al. also suggest that this population-based study demonstrates a more favourable disease progression than "the exaggerated preconception of poor clinical course based on hospital or MS clinic series" (p.32). They present the findings of half a dozen studies which have reported approximately one-third of their MS samples as having a "benign" MS disease course. A benign disease course was loosely defined as being "free of disability", or walking around without aids, or

having an EDSS score of less than 3.0 - 4.0, usually up to 10 or 15 years post-diagnosis. In Rodriguez et al.'s population, 49 (30%) people had an EDSS score of 4.0 or less.

Conclusion

These studies provide a basis with which to compare the functioning of a New Zealand community-based sample of people with MS to that of MS populations elsewhere in the world.

Methodological Evaluation of Previous Studies

Each of the studies reviewed here employed research samples of more than 50 people and extensive cognitive test batteries, thereby addressing the first limitation of prior research identified by Heaton et al. (1985).

The studies by Rao, Leo, Bernardin, et al. (1991), Rao, Leo, Ellington, et al. (1991), McIntosh-Michaelis et al. (1991), and Rodriguez et al. (1994) all employed community-based MS samples. Heaton et al. (1985) and Klonoff et al. (1991) obtained their research samples from consecutive admissions to MS clinics. Both of these options are more preferable than the recruitment of research participants from neuropsychological waiting lists as they avoid the referral bias outlined in Heaton et al.'s critique of earlier MS research.

Two participants in the MS sample studied by Rao, Leo, Bernardin, et al. (1991) and Rao, Leo, Ellington, et al. (1991) were experiencing an exacerbation of symptoms at the time of their involvement in the research project. In comparison, neither Heaton et al. (1985) nor Klonoff et al. (1991) included any people with MS who were experiencing an exacerbation in their research samples. McIntosh-Michaelis et al. (1991) did not specify whether or not their research participants were experiencing an exacerbation. Given the nature of the study by Rodriguez et

al. (1994) it was unnecessary to omit people experiencing an exacerbation of their MS symptoms.

Finally, as advised by Heaton et al. (1985), some of these studies accounted for the effects of medication use on the obtained neuropsychological test results. Heaton et al. reported no relationship between medication use and cognitive impairment. Rao, Leo, Bernardin, et al. (1991) found a non-significant trend for medication use to correlate with worse neuropsychological test performance. The MS sample studied by Klonoff et al. (1991) were not taking any prescribed medications.

It is clear from this evaluation that the five research projects reviewed here have made an effort to circumvent the limitations of earlier neuropsychological research with MS samples.

Findings on Patterns of Cognitive Impairment in MS Samples

As is evident from the studies presented, the cognitive functioning of people with MS has repeatedly been found to be impaired in comparison with normal control groups. The cognitive domains most consistently found to be impaired were retrieval from long-term and possibly short-term memory, attention/ concentration (including speed of information processing), and executive functioning. Areas found to be unimpaired or comparatively less impaired were immediate recall, recognition memory, naming ability, and visuospatial functioning. Some of these studies found a statistically significant correlation between the physical and cognitive functioning of their MS samples (e.g., Rao, Leo, Bernardin, et al., 1991; McIntosh-Michaelis et al., 1991). However, impairments were evident on psychometric tests measuring pure cognitive ability as well as those tests with sensorimotor components (Heaton et al., 1985; Klonoff et al., 1991).

Consequently, the cognitive impairments evident in many people with MS cannot be considered to arise solely from sensory and motor impairments. The degenerative MS disease process clearly effects cognitive, as well as physical, functioning.

Several studies found that cognitive screening by means of the Mini-Mental Status Examination underestimated the proportion of people with MS experiencing cognitive impairment (Heaton et al., 1985; Rao, Leo, Bernardin, et al., 1991). Using neuropsychological assessments, Rao, Leo, Ellington, et al. (1991) classified 48% of their MS sample as cognitively impaired in relation to a normal control group. This compared to only 11% of their MS sample who were classified as cognitively impaired by the Mini-Mental Status Examination. McIntosh-Michaelis et al. (1991) found 34% of their MS sample to be impaired on tests of memory, while 21% were impaired on tests of frontal lobe functioning, and 22% demonstrated impaired general intellectual functioning.

Two studies reported on the relationship between cognitive test performance and MS disease course. Heaton et al. (1985) found that participants with a chronic/progressive disease course consistently performed worse than participants with a relapsing/remitting disease course on cognitive tests. In comparison, Rao, Leo, Bernardin, et al. (1991) found that disease course was not significantly correlated with cognitive test performance in their MS sample. In general, longer duration of the disease was found to correlate with more cognitive impairment (Heaton et al., 1985; McIntosh-Michaelis et al., 1991). However, Rao, Leo, Bernardin, et al. (1991) reported no significant correlation between cognitive functioning and disease duration.

The study by Rao, Leo, Ellington, et al. (1991) investigated the relationship between cognitive and affective functioning in their MS sample. They reported no significant difference between the cognitively impaired and cognitively intact MS subgroups on ratings of depression and anxiety.

Rao, Leo, Ellington, et al. (1991) led the way in describing some of the effects of cognitive impairment on the lives of people with MS. Their results indicated that, compared to people with MS who were cognitively intact, people with MS who were cognitively impaired experienced a greater need for personal assistance, were less likely to be working, and tended to engage in fewer social activities. Furthermore, family members of the cognitively impaired MS subgroup rated them as experiencing greater confusion and less emotional stability than the cognitively intact MS subgroup. Klonoff et al. (1991) reported that only 38% of their MS sample were employed full-time compared to 66% of the normal control group. This was despite their MS sample being in the early stages of MS, without physical impairment severe enough to limit normal daily activity.

From these studies we can see a pattern emerging which describes the disease experience of people with MS. However, discrepancies remain in a number of areas, with conflicting results evident in the literature (e.g., the nature of the relationship between cognitive functioning and disease duration, disease course, medication use, and affective functioning). The conflicting classification of psychometric tests by different researchers creates difficulty in the comparison of outcomes and identifies a limitation of current neuropsychological knowledge. For example, while Rao, Leo, Bernardin, et al. (1991) classified the Controlled Oral Word Association Test as a measure of recent memory and verbal fluency,

McIntosh-Michaelis et al. (1991) considered this test to be a measure of frontal lobe functioning.

Despite these limitations, neuropsychological research findings have utility when the relationship between cognitive test performance and everyday activities is determined (Heaton & Pendleton, 1981). Cognitive functioning is an integral component of everyday functioning and one which is easy to take for granted until impairments are experienced. Studying the effects of cognitive impairment is important to increase our knowledge of how best to assist people experiencing deficits.

Aims of the Current MS Study

1. Employ the four components of the Minimal Record of Disability to describe the level of impairment, disability, and handicap experienced by a New Zealand community-based sample of people with MS.
2. Establish the range and severity of cognitive and psychological impairment experienced by a New Zealand community-based sample of people with MS.
3. Ascertain whether there is a relationship between the cognitive impairment evident in this MS sample, and other aspects of their well-being and MS disease experience, such as physical and psychological functioning, fatigue, medication use, disease duration, and disease course.
4. Compare the functioning of people with MS who are cognitively impaired with those who are comparatively cognitively intact, in the areas of disability, handicap, psychological functioning, and cognitive-behavioural ratings by family members.

CHAPTER 3

Method

Participants

Over the course of 14 months (February 1996 - March 1997) 102 people with MS and 73 control participants were assessed. Inclusion criteria for the people with MS required that they had a definite neurological diagnosis of MS. Inclusion criteria for the control participants required that neither they nor their relatives have MS, and that they not have any other serious neurological disorder or impairment. Of the 102 people with MS; 6 were excluded from the study due to having received a significant head injury which involved loss of consciousness and required hospitalisation, 2 due to a pre-MS psychiatric history requiring hospitalisation, 1 due to a history of substance abuse requiring inpatient treatment, and 1 due to the absence of a neurological diagnosis of MS. Of the 73 control participants, four were excluded from further analysis due to a history of significant head injury and one due to a psychiatric disorder.

Of the remaining 92 people with MS, all partook in the structured clinical interview and examination process required to obtain data for the Minimal Record of Disability. For all additional data analysis however, data from a further 14 of the people with MS were not incorporated for the following reasons: (a) the extensive physical impairments (i.e., EDSS score ≥ 8.5) of six participants with MS were considered to have rendered any neuropsychological test results invalid; (b) the fatigue experienced by three of the remaining participants was such that they reported being unable to undertake the cognitive and psychological assessment process; (c) the extensive vertigo experienced by a further two participants prevented them from being able to undertake the neuropsychological assessment;

and (d) three participants were judged to be incapable of comprehending the test instructions due to advanced cognitive impairment or dementia.

The remaining 78 people with MS and 68 control participants were matched on the variables of age, gender, years of education, socioeconomic status, and National Adult Reading Test error score. Matching on years of education resulted in the removal of one participant with MS who had a significantly low number of years of education and one control participant who had a significantly high number of years of education. The remaining 77 people with MS and 67 control participants constituted the final groups for this study. Caregiver ratings by family members living in the same households were available for 52 of the participants with MS and 42 people in the control group. Further details about these family members are provided in Chapter Seven.

There were no significant differences between the MS sample and control group on the matching variables of gender, $\chi^2(1) = 0.73$, $p > .05$, age, $t(142) = 0.64$, $p > .05$, years of education, $t(142) = -1.84$, $p > .05$, SES, Mann-Whitney U, $z = 0.68$, $p > .05$, or National Adult Reading Test error score, $t(138) = 1.24$, $p > .05$. Data on these matching variables are presented in Table 3.1.

MS Sample

Of the 77 participants with MS, 62 (81%) were female. The mean age of the participants was 51 years (SD = 11, range = 22 - 74). The mean years of education was 12 (SD = 2, range = 9 - 18). The mean EDSS score for the sample was 5.16 (SD = 1.90, range = 1 - 8.0). The mean age at MS symptom onset was 33 years (SD = 10, range = 15 - 58 years) and the mean time since MS symptom onset was 19 years (SD = 12, range = 2 - 51). The mean time since MS diagnosis for the sample was 12 years (SD = 10, range = 1 - 38 years). Employing the definitions

Table 3.1

Matching Variables for the 77 Participants with MS and 67 Control Participants

Variable	MS Sample	Control Sample
Gender:		
Female	62 (81%)	54 (81%)
Male	15 (19%)	13 (19%)
Age: (years)		
Mean	51.03	49.82
SD	11.37	11.27
Years of Education:		
Mean	12.10	12.79
SD	2.20	2.28
Ethnicity:		
New Zealand European	60 (78%)	56 (84%)
New Zealand Maori	2 (3%)	1 (1%)
Other	15 (19%)	10 (15%)
Socioeconomic Status:		
1	1 (1%)	7 (10%)
2	4 (5%)	12 (18%)
3	7 (9%)	6 (9%)
4	2 (3%)	5 (7%)
5	1 (1%)	3 (4%)
6	1 (1%)	4 (6%)
Unclassified	61 (79%)	30 (45%)
NART Error Score:		
Mean	21.82*	20.10
SD	8.41	7.96

Note. NART = National Adult Reading Test

*N = 73

outlined by Lublin and Reingold (1996), 41 participants were classified as having a relapsing/remitting disease course, 24 participants had a primary/progressive disease course, 7 participants had a secondary/progressive disease course, 3 participants had a progressive/relapsing disease course, and 2 participants had a benign disease course.

Socioeconomic status (SES) was ascertained using the socioeconomic indices created by Johnston (1983). These indices rank occupational skills from upper SES = 1; such as professional/technical occupations, to lower SES = 6; representing production workers, labourers etc. One (1%) of the participants with MS was classified as SES level 1, four (5%) as level 2, seven (9%) as level 3, two (3%) as level 4, one (1%) as level 5, and one (1%) as level 6. Sixty-one people in the MS sample (79%) were not able to be classified as they were not in paid employment at the time of testing.

In regard to the level of educational attainment or occupational training qualifications, 32 participants (42%) had no qualifications, 14 (18%) had obtained secondary school qualifications, 27 (35%) had completed polytechnic qualifications, and 4 (5%) had completed university qualifications. Sixteen (21%) participants were in paid employment at the time of assessment, 13 (17%) were occupied full-time managing their households, 6 (8%) classified themselves as unemployed, 20 (26%) were retired, and 22 (29%) participants were receiving an Invalid's Benefit.

Seventy-four (96%) of the participants with MS were right-handed and 3 (4%) were left handed. Sixty participants (78%) were of New Zealand European origin, while 2 (3%) classified themselves as New Zealand Maori. The remaining 15 (19%) were other ethnicities including English, Scottish, Welsh, Irish, Dutch,

Danish, Croatian, and North American. Fifty (65%) of the participants with MS were married or in a de facto relationship at the time of assessment, while 10 (13%) had never been married, 11 (14%) were separated or divorced, and 6 (8%) were widowed. Sixteen (21%) participants were living alone, 31 (40%) were living with a partner only, 24 (31%) were living as part of a family unit, 1 (1%) lived with other relatives, 2 (3%) lived in a flatting situation, and 3 (4%) lived in a nursing home. Twenty-four (31%) of the participants with MS had dependent children at the time of assessment.

Fifty-two (68%) of the participants with MS were taking medication at the time of assessment. The majority of medication was prescribed for MS-related symptoms, such as muscle spasms, urinary tract infections, constipation, nausea, inflammation, and pain. Eight participants were prescribed anti-depressant medication and two participants were taking anti-psychotic medication, one for manic depression and the other for schizophrenia.[1] Other medication was prescribed for asthma, migraines, ulcers, insomnia, high blood pressure, and hormone replacement therapy.

Control Sample

Of the 67 participants making up the control sample, 54 (81%) were female. The mean age of these participants was 50 years (*SD* = 11, range = 22 - 78) and the mean years of education was 13 (*SD* = 2, range = 9 - 18). Using Johnston's (1983) socioeconomic indices, 7 (10%) of the control participants were classified as level 1, 12 (18%) were classified as level 2, 6 (9%) were classified as level 3, 5 (7%) were classified as level 4, 3 (4%) were classified as level 5, and

[1] The psychiatric conditions for which these medications were prescribed occurred post-MS diagnosis.

another 4 (6%) participants were classified as level 6. Thirty (45%) participants were not able to be classified as they were not in paid employment at the time of the assessment.

Sixteen (24%) of the control participants had no academic training qualifications, 16 (24%) had obtained secondary school qualifications, 26 (39%) had completed polytechnic qualifications, and 9 (13%) had completed university qualifications. Thirty-seven (55%) participants were in paid employment at the time of assessment, 12 (18%) were occupied full-time managing their households, 2 (3%) were full-time students, 1 (1%) participant was unemployed, and 15 (22%) were retired.

Sixty-three (94%) of the control participants were right-handed and 4 (6%) were left-handed. Fifty-six (84%) were of New Zealand European origin and 1 (1%) was of New Zealand Maori origin. The remaining 10 (15%) control participants were other ethnicities including English, Dutch, and Scottish. Forty-four (66%) of the control participants were married or in a de facto relationship at the time of assessment, 4 (6%) had never been married, 12 (18%) were separated or divorced, and 7 (10%) were widowed. Eight (12%) of the control participants were living alone, 23 (34%) were living with a partner only, 29 (43%) were living as part of a family unit, 5 (7%) lived with other relatives, and 2 (3%) control participants lived in a flatting situation. Twenty-seven (40%) of the control participants had dependent children at the time of assessment.

Twenty-eight (42%) of the control participants were taking medication at the time of the assessment. Medication was prescribed for asthma, hypertension, arthritis, and hormone replacement therapy.

Measures

Interview

All participants underwent a semi-structured interview for the purpose of obtaining demographic and medical information (see Appendices A and B). For the participants with MS, the interview also covered information about their MS disease history, e.g., date of initial symptom onset, number of years since diagnosis, disease course, and current disease status.

Clinical Rating Scales

The four clinical rating scales of the Minimal Record of Disability (International Federation of Multiple Sclerosis Societies, 1984) were completed with the participants with MS. The scales comprising the Minimal Record of Disability are the Kurtzke Functional Systems, the Kurtzke Expanded Disability Status Scale, the Incapacity Status Scale, and the Environmental Status Scale (see Appendix C). Approximately 30 minutes is required to complete the record. The use of these internationally employed rating scales assists in the comparison of the present data with that obtained in overseas research of people with MS.

Neurologic dysfunction. Neurological functioning in the participants with MS was graded using the Kurtzke Functional Systems (Kurtzke, 1983). The format for completion of the Functional Systems follows a standard neurological examination, assessing eight functional groups: Pyramidal, Cerebellar, Brainstem, Sensory, Bowel and Bladder, Visual, Cerebral, and Other (e.g., spasticity). Each functional system is independent of the others and together they embody all of the neurological abnormalities attributable to MS. Each function is graded from 0 to 5 or 6, with higher ratings indicating more severe impairment in that domain. While training was received to enable the researcher to assess these functional systems,

this did not extend to the assessment of visual functioning. Consequently, this domain of the Functional Systems scale was not completed in the course of the current study. The various components of the Functional Systems rating scale are not additive. For this reason the EDSS was employed as the overall measure of physical impairment.

Impairment. The Kurtzke Expanded Disability Status Scale was employed as a global rating of physical impairment for the participants with MS. The scale consists of a 0 - 10 rating scale with half point increments. Zero refers to a normal neurological exam and 10.0 indicates death as a result of MS. At the lower end of the scale particularly, the EDSS is heavily reliant on a standard neurological examination, as encapsulated by the Kurtzke Functional Systems, hence the two rating systems are complementary.

Disability. Personal limitations in the daily lives of the participants with MS, resulting from MS, were assessed using the Incapacity Status Scale. This scale assesses functional disability in 16 areas of daily living: stair climbing, ambulation, toilet/chair/bed transfer, bowel function, bladder function, bathing, dressing, grooming, feeding, vision, speech and hearing, medical problems, mood and thought disturbance, mentation, fatiguability, and sexual function. Each area is graded on a 0 - 4 scale, with higher scores indicating more disability.

Handicap. The nature and extent of handicap experienced by the participants with MS as a result of their MS, was assessed using the Environmental Status Scale. This scale encompasses seven areas: work status, financial/economic status, changes required to personal residence/home, personal assistance required, transportation needs, community services, and social activity. Each area is graded on a 0 - 5 scale, with higher scores indicating more handicap.

A structured interview protocol was developed by LaRocca and Foley (1984) to provide a standardised method for procuring the information necessary to complete the Incapacity Status Scale and Environmental Status Scale. This interview protocol was utilised for rating these two scales.

In 1983 preliminary field testing of the Minimal Record of Disability was conducted at eight medical centers in the United States and Canada, coordinated by the Research and Training Centre at Albert Einstein College of Medicine at Yeshiva University. Assessments by neurologists and allied health professionals were completed on 249 people with a diagnosis of definite MS (LaRocca, Scheinberg, & Slater, 1984). Two-thirds (60%) of the sample were females and the average age of participants was 42 years. The average age of symptom onset for the sample was 30 years and the average duration of their symptoms was 12 years. Quantitative analysis revealed high internal reliability of both the Incapacity Status Scale and the Environmental Status Scale (Cronbach's alpha of .93 and .83 respectively), and high correlations with established measures of impairment were reported. Inter-rater agreement for both scales was also high (.94 and .97 respectively). Caution has been advised when interpreting the Incapacity Status Scale and Environmental Status Scale as composite scores given the heterogeneous nature of the content. While the Incapacity Status Scale primarily measures disability in mobility and self-care functions, and the Environmental Status Scale measures social handicap, neither scales were designed to be summative.

Neuropsychological Measures

Tests chosen to assess core areas of neuropsychological functioning conformed, wherever possible, to the core battery proposed by Peyser, Rao, LaRocca, and Kaplan (1990). Areas assessed included general intellectual

functioning, learning and memory, attention and concentration, executive functioning, language, and visuospatial perception. The following psychometric tests were completed by the participants with MS and the matched control group (see Appendix D). All testing occurred individually.

Premorbid intellectual functioning. The National Adult Reading Test (Nelson, 1991) was used to estimate premorbid intellectual functioning. This test consists of an A4 sized word card on which 50 'irregular' words are printed; that is, 50 words whose pronunciation is unable to be deciphered by applying the common rules of phonetic analysis. For example, the correct pronunciation of 'ache' would not be deduced without prior familiarity with the word. The words are listed in order of increasing difficulty and participants are asked to read each word aloud, guessing at the pronunciation of words that they do not know.

The National Adult Reading Test was administered according to the instructions provided in the test manual. As participants pronounced each word, their responses were marked as correct or incorrect on the answer sheet. The number of incorrect responses were totaled and recorded as the error score, with a possible range of 0 to 50. Scoring was based on correct New Zealand pronunciation of the words, as established by a professional linguist who had been recorded reading a pronunciation guide for the New Zealand context (Fisher, 1996). Clinical judgment was used when assessing participants with mild dysarthria and those for whom English was not their first language. Regression equations and tables provided in the test manual enable the error score to be converted into predicted WAIS and WAIS-R Full-Scale, Verbal, and Performance IQ scores. For the purposes of the current research, the predicted WAIS-R Full-Scale IQ score was employed as an estimate of premorbid intellectual functioning.

The 1991 edition of the National Adult Reading Test manual presents restandardization data based on 182 participants, aged between 20 and 70 years of age. Seven WAIS-R subtests were also administered: Arithmetic, Similarities, Digit Span, Vocabulary, Picture Completion, Block Design, and Picture Arrangement. From the results of these subtests, the Verbal, Performance and Full-Scale IQ's were prorated and regression equations developed. Crawford, Parker, Stewart, Besson, and De Lacey (1989) conducted a cross-validation study and developed new regression equations based on the combination of the standardisation and cross-validation samples ($N = 271$). Correlations of the National Adult Reading Test IQ score estimates with the WAIS and WAIS-R Full-Scale IQ scores range from .72 to .81 (Crawford et al., 1989). Test-retest reliability is extremely high, with a correlation coefficient of .98 reported by Crawford and colleagues. These authors also report high inter-rater reliability, with correlations coefficients ranging between .96 and .98.

Current intellectual functioning. The WAIS-R (Wechsler, 1981) is a standard measure of verbal and performance intellectual ability. In order to keep testing time to a manageable length while maintaining an accurate estimate of intellectual ability, a short-form of the WAIS-R was employed for the current research. The triad recommended by Cyr and Brooker (1984) combines the Information and Vocabulary subtests from the Verbal Scale, and the Block Design subtest from the Performance Scale. The Information subtest consists of 29 general knowledge questions which are read aloud to the participant. Responses are recorded verbatim. For the present research, the New Zealand version of the Information subtest was used (Petrie, Dibble, Long-Taylor, & Ruthe, 1986). The Vocabulary subtest consists of 35 words of increasing difficulty, which are

presented both orally and visually. Participants are required to provide meanings for each word and responses are again recorded verbatim. The Block Design subtest consists of a set of cards printed with red and white designs, and a set of identical one inch blocks. Participants are required to use up to nine blocks to reproduce the printed designs on the cards.

Each of the three subtests was administered and scored in accordance with the WAIS-R manual. The maximum score for the Information subtest is 29. Each answer is marked correct or incorrect with one mark given for each correct answer. The maximum score for the Vocabulary subtest is 70, with each of the 35 items marked 2, 1, or 0. All standard dictionary meanings are acceptable, however poverty of content is penalised to some extent (i.e., by obtaining a score of 1). General scoring principals and examples of responses worth 2, 1, and 0 are provided in the test manual. The Block Design subtest consists of nine designs which are presented in order of increasing difficulty. Each trial is timed, with time bonuses allotted for quick, perfect assembling of designs. The maximum score for the Block design is 51. The three subtest scores were converted to age-scaled scores using the tables provided in the test manual (Wechsler, 1981, pp. 142-150). These three scaled scores were then summed and converted to Full-Scale IQ scores using the table presented by Brooker and Cyr (1986). Tellegen and Briggs (cited in Brooker & Cyr, 1986) report that none of the IQ equivalents computed using this method are in error by more than one point.

The WAIS-R was standardised between May 1976 and May 1980 on 1880 American citizens aged between 16 and 75 years of age. The sample was stratified on the variables of age, gender, race, geographical region, occupation, education, and urban/rural residence, using the 1970 United States Census and more recent

population reports as they became available. Scaled scores enable conversion of raw scores for each subtest to a scale having a mean of 10 and a standard deviation of 3. IQ equivalents with a mean of 100 and a standard deviation of 15 are provided in the test manual for each of nine age groups. Split-half (or test-retest in the case of the Digit Span and Digit Symbol subtests) reliability coefficients reported in the manual range from .52 to .96. Reliability coefficients for Verbal, Performance, and Full-Scale IQ's across each of the nine age groups were very high, with average coefficients of .97, .93, and .97 respectively.

Memory and learning. The Rey Auditory-Verbal Learning Test (Rey, 1964, cited in Spreen & Strauss, 1991) yields information about participants' immediate memory, short and long-term retention, retrieval efficiency, learning, and recognition memory. It consists of a 15-word list which is read to participants five times (Trials 1 - 5). Following each presentation of the list, participants are required to repeat out loud as much of the entire list as they can recall. After the fifth presentation, a second list of 15 words is read once (Trial B) and participants are required to repeat as many of these words as they can remember. Without the examiner repeating the original list, participants are asked to recall as many words from that list as they can remember (Trial 6). After 20 minutes participants are again asked to recall as many words from the first list as they can remember (Trial 7). Finally, participants are presented with a page of 50 typed words, containing all the words from the first list, all the words from the second list, plus some words that are semantically associated or phonemically similar to the words from those two lists. Participants are required to circle all the words which they recognise from the first list only (Recognition Trial).

The number of words recalled from Trial 1 is a measure of immediate recall. The sum of all words correctly recalled over the first five trials provides a measure of verbal learning. The number of words recalled in Trial 6 is a measure of retention and the number of words recalled in Trial 7 is a measure of delayed recall. The final score obtained from the Auditory Verbal Learning Test is that of recognition memory, calculated as the total number of words correctly circled by participants on the printed word list.

Test-retest reliability of the Auditory Verbal Learning Test following a 12-month interval was computed by Snow, Tierney, Zorzitto, Fisher, and Reid (1988, cited in Spreen & Strauss, 1991). Correlation coefficients of between .38 (for Trial B) and .70 (for Trial 5) were reported. Factor analytic studies have found significant correlations between the learning measures of the Auditory Verbal Learning Test and other learning measures, in the range of .50 to .65 (e.g., Ryan, Rosenberg, & Mittenberg, 1984, cited in Spreen & Strauss, 1991). A factor analytic study by Vakil and Blachstein (1993) produced three main factors from Trials 1, 5, B, 6, 7, Recognition, and a temporal order measure: acquisition, storage, and retrieval.

Attention/concentration. Three measures of attention and concentration were administered. The Stroop Color and Word Test (Golden, 1978) was the first of these. Lezak (1995) considers that the Stroop test also measures the ability of participants to ward off distractions. The test consists of three A4 sized pages printed with a 5 by 20 matrix of items. The items on the first page are the words "RED", "GREEN", and "BLUE" arranged randomly and printed in black ink. The items on the second page are all written as "XXXX", printed in either red, green, or blue ink. The items on the third page consist of the words from the first page

printed in the colours from the second page. Addressing each page in turn, participants are instructed to read down each column as quickly and accurately as they can. Participants are timed for 45 seconds on each page of the test and are required to read aloud the items on page one, name the colour of the items on page two, and name the colour of the ink the items on page three are printed in.

The Stroop test was administered and scored in accordance with instructions provided in the test manual. Three main scores are yielded from the test. The Word score is the number of items correctly read aloud from the first page within the 45-second time limit. The Color score is the number of items correctly read aloud from the second page within the time limit, and the Color-Word score is the number of items correctly read aloud from the third page within the time limit. Raw scores can be converted into *T*-scores with a mean of 50 and standard deviation of 10, using tables provided in the test manual. For the purposes of the present research however, raw scores were used.

Information regarding the standardisation sample is absent in the test manual. Examination of test-retest reliability reported correlation coefficients of .86, .82, and .73 for the Word, Color, and Color-Word scores respectively, from individual administration, and comparable coefficients from group administrations (Golden, 1975). More recently, Franzen, Tishelman, Sharp, and Friedman (1987) investigated the test-retest reliability of the Stroop test across both one and two week intervals. Correlation coefficients ranged from .92 for the Word score across the two week interval to .55 for the Color-Word score across the two week interval. Age related decrements have been consistently documented (e.g., Cohn, Dustman, & Bradford, 1984), most prominently on the Color-Word interference trial. Cohn et al. recommend that clinicians develop norms for the Stroop tests

which they administer, as the test is unusually sensitive not only for detection of cerebral dysfunction but for the effect of aging also.

The second measure of attention/concentration employed was the d2 Concentration Endurance Test developed by Brickenkamp (1981, cited in Spreen & Strauss, 1991). The test assesses sustained attention and visual scanning ability and consists of an A4 page printed with 14 rows of 'd's' and 'p's', with 47 letters making up each row. Each letter has from one to four dots placed above and/or below each letter. Participants are required to put a strike through all the 'd's' that have two dots - either two dots above, two dots below, or one dot above and one dot below a 'd'. Participants are instructed not to put a strike through any of the 'p's' no matter how many dots they have and not to put a strike through any 'd's' that have more or less than two dots. Each line is timed for 20 seconds after which the examiner says "next line", whereupon participants drop to the line below and continue the same process at the beginning of that line. Participants are instructed to work as quickly and accurately as they can and to put a second strike, forming an 'X', through any letter which they realise they have incorrectly marked. The test continues without a break until 20 seconds into the 14^{th} row of letters.

Scoring of the d2 concentration test considers both speed and accuracy, and a total of eight scores can be calculated. For the purposes of the present study, only the total score (i.e., the total number of letters marked) minus the number of errors (i.e., omissions and additions) was used. Omissions are 'd's' with two dots that have not been crossed out. Additions are any 'p's', or 'd's' with more or less than two dots that have been crossed out.

Test-retest reliability coefficients between .89 and .92 for the Total Score were recorded by Brickenkamp after an interval of five hours. A correlation

coefficient of .92 is recorded for the Total Score Minus Errors. Correlations between .31 and .72 have been recorded when comparisons are made with other tests of attention and concentration (Spreen & Strauss, 1991). Factor analytic studies identify high loadings on an attentional factor. The standardisation sample (described in German in the test manual) is made up of 3132 participants aged 9 - 60 years. Tables are provided in the test manual for converting scores into percentiles, standard scores, stanines, and scaled scores. Normative data are also provided by Spreen and Strauss (1991) from a sample of 80 adults aged 50 - 85 years.

The third measure of attention and concentration employed was the Paced Auditory Serial Addition Task (Gronwall, 1977). This test is also considered to be a sensitive measure of information processing speed (Gronwall & Wrightson, 1981). The test consists of 61 single digits, pre-recorded on a cassette tape. Participants are required to add each successive number to the one presented just before it, giving their answer aloud. Four trials are presented, each at slightly faster rates of speed (2.4, 2.0, 1.6, and 1.2 second pacings). A practice trial of ten digits recorded at 2.4 second intervals is initially presented to participants and this is repeated if further illustration of the task is required. Each successive trial is presented to participants after a 60 second break. Upon presentation of the trials, participants are informed that the following trial will be slightly faster than the one preceding it. The test is discontinued if participants are unable to achieve a minimum of 20 correct responses on the 2.0 second trial.

Scoring of the Paced Auditory Serial Addition Task involves totaling the number of correct responses at each pacing speed. The average time per correct response can also be computed by dividing total trial time by the number of correct

items for each of the four pacings and dividing this by the total number of trials to give a composite score (Gronwall, 1977). This process enables direct comparison of tests where different numbers of trials are given.

The Paced Auditory Serial Addition Task has high internal consistency, as indicated by a split-half reliability coefficient of .96 (Spreen & Strauss, 1991). The standardisation sample provided by Gronwall (1977) consists of 90 control participants aged between 14 and 55 years. Stuss, Stethem, and Pelchat (1988, cited in Spreen & Strauss, 1991) also provide test and retest (with a time interval of 1 week) means and standard deviations for three age groups, based on the performance of 90 adults aged 16 to 69 years. One difficulty with the Paced Auditory Serial Addition Task is its reliance on fast-speed responses which disadvantages people with dysarthria or other speech impediments (Spreen & Strauss, 1991).

Executive functioning. This was assessed using two measures. The first was the Wisconsin Card Sorting Test (Heaton, 1981). The test consists of two identical decks of 64 cards and four stimulus cards. On each card is printed one to four symbols (triangle, star, cross, or circle) in one of four colours (red, green, yellow, or blue). The four stimulus cards consist of one red triangle, two green stars, three yellow crosses, and four blue circles. Employing first one deck and then the other, participants are asked to place each card from the deck below the stimulus card that they think it matches, to which the examiner responds 'right' or 'wrong'. Being guided by the examiner's responses, participants are required to deduce the first matching principle. After ten consecutive correct responses, the examiner changes the matching principle. The only indication for participants of each change of the matching principle is the change in correct and incorrect responses being

provided by the examiner. If participants decipher each of the matching principles before exhausting the two decks of cards, the process is repeated again until all two decks of cards are used or the three matching principles (colour/shape/ number) have been worked through twice. There are a total of 128 trials and six categories.

Six major scores result from administration of the Wisconsin Card Sorting Test: total number of correct responses, total number of errors, number of perseverative responses, number of nonperseverative errors, number of perseverative errors, and number of categories completed. Two of these scores were utilised in the present study: number of perseverative responses and number of categories completed. Heaton (1981) considers the perseverative response score to be the most clinically useful. To overcome the ambiguity and variability that have previously existed in the derivation of this score, the diagrammatic procedure outlined by Berry (1996) was followed.

The standardisation sample for this test contained 208 people with cerebral lesions and 150 normal control participants. Means and standard deviations for all test scores and both sample groups are provided in the test manual. Satisfactory inter-rater reliability has been reported (Lezak, 1995). Test-retest reliability is not usually relevant with the Wisconsin Card Sorting Test as retesting participants who have deduced the matching principle is not meaningful.

The second measure of executive functioning to be used in the present research was the Controlled Oral Word Association Test (Spreen & Benton, 1977, cited in Spreen & Strauss, 1991). This test consists of three one minute word-naming trials, in which participants are provided with a letter of the alphabet (trial one, F; trial two, A; trial three, S), and asked to produce as many words as they

can think of that begin with that letter. Proper nouns, numbers, and the same word with a different suffix are excluded. The verbatim instructions employed in the administration of this test are included on the appended recording form (see Appendix D).

The Controlled Oral Word Association Test score is the total number of suitable words produced over the three trials. Spreen and Strauss (1991) present means and standard deviations for each of the three trials for five age ranges between 15 and 40 years. Means and standard deviations for the total score of the combined trials is also provided. Snow et al. (1988, cited in Spreen & Strauss, 1991) reported test-retest reliability coefficients of .70 and .71 after an interval of one year, while desRosiers and Kavanagh (1987, also cited in Spreen & Strauss, 1991) recorded a retest correlation of .88 following an interval of 19 - 42 days. Concurrent validity has been established and interscorer reliability is recorded as near perfect (Spreen & Strauss, 1991).

Language. Receptive language was assessed using a 39-item short form of the Token Test, originally developed by De Renzi and Vignolo (1962). Lesser (1976) notes that this test also involves immediate memory span. Twenty plastic tokens in five colours (red, white, blue, green, and yellow), two sizes (small, approximately 2cm in diameter; and large, approximately 3cm in diameter), and two shapes (circles and squares) are arranged in a predetermined order in front of participants. Thirty-nine commands of increasing length are read aloud to participants who are graded on the accuracy with which they execute each instruction. The 39 commands are divided to six trials.

The seven statements in the first trial are worth one point each. The four statements in trial two are marked out of two points each. The four statements in

trial three are each marked out of three points, and the four statements in trial four are each marked out of four points. The five statements in trial five and the sixteen statements in trial six are each marked out of six points. This yields a possible total score of 163 points.

Because of the ceiling effects present with normal adults and older children, reported retest reliability coefficients have been low, e.g., .50 recorded by Snow et al. (1988, cited in Spreen & Strauss, 1991). However, Gallagher (1979, cited in Spreen & Strauss, 1991) has reported retest correlations of .92 and .94 with aphasic participants following a three day interval. Validation data are readily available from a variety of sources. Spreen and Strauss (1991) provide normative data for both children and adults, with a mean score for adults recorded as 161. Scores below 157 are virtually absent in normal adult populations.

Naming ability was assessed using the Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983). This test consists of a booklet containing 60 line drawings arranged in order from the most to the least common object. For non-aphasic adult participants the test is administered from item 30 (harmonica) onwards until participants make six consecutive errors. If any of the first eight items are incorrect, the items are presented in reverse order from number 29 until eight consecutive items are passed, at which point a forward direction is resumed. Two cues are given if required. The first, a stimulus cue, is read to participants if they do not recognise or apprehend an item, e.g., for item 51, 'Latch', the stimulus cue is 'part of a door'. Participants are given 20 seconds to respond with the correct response after a stimulus cue is provided. If no response is forthcoming, a phonemic cue is issued. The phonemic cue consists of the examiner providing the

opening sound of the target word. The item is then marked "correct with phonemic cue" if the answer is supplied, or "failed" if it is not supplied.

Scoring of the Boston Naming Test considers the number of items correct without assistance, the number of stimulus cues given, the number of items correct following a stimulus cue, the number of phonemic cues given, and the number of items correct following a phonemic cue. The total naming score is derived from the number of correct answers given without assistance, plus those given following a stimulus cue, plus the number of items preceding the baseline. This total naming score was used in the present study.

While test-retest reliability data are not available, Huff, Collins, Corkin, and Rosen (1986, cited in Spreen & Strauss, 1991) found reliability coefficients of .81 for normal control participants and .97 for people with Alzheimer's disease, using alternate forms of the test. The coefficient alpha between the two forms was .96. Other studies employing short forms as alternate forms have produced similar results. Normative data in the test booklet is brief, however Borod, Goodglass, and Kaplan (1980) provide age-graded norms for the number of items identified, based on a normal control sample aged between 25 and 85 years.

Visuospatial perception. The Hooper Visual Organisation Test (Hooper, 1958) was employed as a measure of visual perception. The test consists of a booklet containing 30 pictures of commonly recognised objects which have been cut into several pieces resembling a jig saw puzzle. Participants are required to name what each item would make if the pieces are fitted together.

Each correctly named object is worth one mark. For ten of the objects, half marks are given for answers closely resembling the correct answer (e.g., a response

of "glove" for the picture of "fingers" would receive half a mark). The total possible score is 30.

The standardisation sample described in the test manual consists of 166 college students with a mean age of 22 years. Split-half reliability was recorded as .82. Lezak (1995) reported a test-retest correlation coefficient of .86 following three repeat administrations of the Hooper Visual Organisation Test, at six and twelve months. Validation studies are reported in the test manual.

Self-Report Questionnaires

Fatigue. The Fatigue Severity Scale (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989) was used to measure the impact of fatigue on participants' daily life. The scale consists of nine written statements to which participants indicate their level of agreement by placing a tick in the appropriate box along a seven-point Likert scale (see Appendix D). Responses range from 1-"strongly disagree" to 7-"strongly agree".

The Fatigue Severity Scale has demonstrated sensitivity to the fatigue problems experienced by people with MS. The standardisation sample contained 25 people with chronic/progressive MS and EDSS scores ranging from 3.0 to 6.5, plus 29 people with systemic lupus erythematosus and 20 healthy adults. Means and standard deviations for the groups are provided (Krupp et al., 1989). The Fatigue Severity Scale was found to have high internal consistency, yielding a Cronbach's alpha of .81 with the MS sample and .88 overall. Test-retest reliability of the scale over a time interval of 5 to 33 weeks yielded no significant change in the group of participants with MS in which there was no clinical reason to expect a change in their fatigue level (Krupp et al., 1989).

Psychological symptoms. The psychological functioning of the participants with MS and the matched control participants was measured using the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1992). The checklist consists of 90 items relating to medical and psychiatric symptoms. Participants' rate the extent to which they have been distressed by each of the symptoms in the previous seven days, using a five-point Likert scale, ranging from 0 -"not at all" to 4 -"extremely".

Scoring of the SCL-90-R yields nine "primary symptom dimensions". These are Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. Three global indices can also be calculated: The Global Severity Index is a measure of the overall level of distress; the Positive Symptom Distress Index is calculated as the average symptom distress level across items; and the Positive Symptom Total is the sum of the number of items for which any level of distress is reported.

Internal consistency measures for the nine dimensions were calculated from 219 volunteers. Coefficient alphas ranging from .77 to .90 are reported. Test-retest reliability was assessed with 94 psychiatric outpatients with a time interval of one week. Correlation coefficients range from .78 to .90. Derogatis (1992) reports excellent levels of invariance for all nine dimensions, and high levels of agreement between males' and females' structural definitions on all dimensions except Paranoid Ideation, which yielded a moderate level of agreement. Validation studies involving both psychiatric and medical samples have demonstrated the sensitivity of the SCL-90-R to emotional and adjustment problems.

Caregiver Rating Scale

The Cognitive Behavior Rating Scale (Williams, 1987) is a psychometric approach to gathering pertinent information about a patient from a reliable

observer. It requires the observer to rate the presence and severity of cognitive impairment, behavioural deficits, and observable neurological signs. The rating scale consists of 116 items and incorporates nine scales: Language Deficit, Apraxia, Disorientation, Agitation, Need for Routine, Depression, Higher Cognitive Deficits, Memory Disorder, and Dementia. For items 1 - 104, raters indicate using a Likert scale of 1 (not at all like this person) to 5 (very much like this person), the applicability of each statement to the person that they are rating. Items 105 - 116 are used to rate specific skills and abilities (e.g., reading and arithmetic) on a Likert scale where 1 indicates superior skill and 5 indicates very poor skill. The Cognitive Behavior Rating Scale usually requires 15 - 20 minutes to complete.

By summing the ratings across or down columns as specified on the rating form, raw scores are obtained for each of the nine scales. Tables provided on the final page of the Rating Booklet enable the transformation of raw scores to *T*-scores ($M = 100$, $SD = 15$) and percentile scores. However, for the purposes of the present study only the raw scores were used.

The 116 items of the Cognitive Behavior Rating Scale were gathered from sources with experience of dementia-related illnesses, such as scientific literature, family guide books, and interviews with families. Test-retest reliability was examined using 31 normal participants and a one-week retest interval, yielding coefficients from .61 to .94 for the nine scales. Internal consistency reliability was calculated from 400 normal participants, with alpha coefficients ranging from .78 to .92 for the nine scales. Concurrent validity studies comparing ratings of matched normal participants with ratings of people with dementia revealed significantly lower ratings for the people with dementia on all scales except Depression. The

normative sample contained 688 people aged between 30 and 89 years, recruited mostly from newspaper advertisements. Further demographic data for the sample are not provided. Means and standard deviations for each of the nine scales for five age groups, plus the total sample, are presented in the manual.

Procedure

Data Collection

This study was approved by the Waikato Ethics Committee (see Appendix E) and the Ethics Committee of the Department of Psychology, University of Waikato.

Members of local branches of the Multiple Sclerosis Society of New Zealand Incorporated, who had a diagnosis of MS, were recruited to take part in the study by their MS Society Field Officer. Field Officers in the Waikato, Coromandel, Rotorua, Tauranga, and Whakatane regions of New Zealand disseminated the Information Sheet (see Appendix F) outlining the research project to their clientele during the course of routine home visits. The names and contact details of clients who agreed to take part in the research were then made available to the researcher. All volunteers with a neurological diagnosis of MS underwent the assessment process involved in the research. In addition to their own participation, volunteers with MS were requested, where possible, to enlist the participation of friends without MS but of a similar age, gender, and background, to undergo the same assessment procedure as control participants. A similar Information Sheet was provided for control participants (see Appendix G).

All participants were telephoned prior to the visit in which the assessment would take place, to answer any further questions that participants had regarding their involvement in the research and arrange a time which was convenient for them

to undergo the assessment procedure. Control participants were contacted only after their agreement to participate in the research project had been obtained by the person putting forward their names. Participants were advised that, in its entirety, the assessment procedure would require approximately three hours of their time, but that they could terminate the session at any time. Participants were given the option of being interviewed in their own homes, at the University of Waikato in Hamilton, or at their MS Society branch office. All participants chose for the assessment to be undertaken in their own homes.

At the time of the visit to the home of each research participant, prior to beginning the assessment procedure, the nature of the research was again outlined and any additional questions raised by participants or other members of their households were answered. All participants were assured of the anonymity of their responses. Following this, each participant signed and dated a consent form (see Appendix H) confirming that he or she understood the nature of the project and agreed to take part. Participants were reminded of their right to withdraw from the research project at any stage.

The assessment process began with the semi-structured interview to obtain demographic data. In the case of the participants with MS, this was followed by details of their MS disease history and the completion of the four Minimal Record of Disability clinical rating scales.

The psychometric measures were administered in the same order for each participant. In an attempt to minimise monotony for the participants, the tests were ordered in a manner which varied the nature of the responses required by the participant. For example, a self-report inventory was followed by a test requiring manual manipulation, which in turn was followed by a test requiring verbal

responses, and so forth. The set order of test administration (and approximate time required for each test) is displayed in Table 3.2. All assessments were conducted by the same researcher to ensure uniformity of the assessment process across participants.

If participants from the MS sample or the control group had a family member willing to take part in the Caregiver Study, this person also completed the Cognitive Behavior Rating Scale at the time of their participation.

Data Analysis

All data analysis was completed using Statistica (Statsoft, Incorporated, 1994). Following the example of Rao, Leo, Bernardin, et al. (1991), a conservative alpha level of .01 was used in statistical analyses which compared the participants with MS to the control group. An alpha level of .05 was used during 'within MS sample' statistical analyses. In those instances where $p < .01$ or $p < .05$ respectively, the exact obtained alpha level is reported.

Following the data screening considerations recommended by Tabachnick and Fidell (1989), data were checked to ensure accurate input and missing data were identified. Cases with missing data were excluded from correlational and regression analyses.

Tabachnick and Fidell (1989) recommend checking data for normality of distribution, and outliers. Previous research has indicated that the concept of normal distribution in clinical populations is unrealistic (Scheffe, 1959; Tiku, Tan, & Balakrishnen, 1986) and that it is acceptable to use the robust parametric tests to analyse data that is not normally distributed (Kraemer, 1981; Scheffe, 1959; Tiku et al., 1986). Therefore, the present study used parametric testing where necessary, regardless of the normality of the data under analysis.

Table 3.2

Administration Order and Approximate Time Required for Psychometric Assessment.

Psychometric Measure	Administration Time (minutes)
Fatigue Severity Scale	5
Wisconsin Card Sorting Test	30
National Adult Reading Test	5
Wechsler Adult Intelligence Scale-Revised (Short Form)	25
Token Test	15
Rey Auditory-Verbal Learning Test	20
Symptom Checklist-90-Revised	15
Boston Naming Test	5
Stroop Color/Word Test	5
Controlled Oral Word Association Test	5
d2 Concentration Test	10
Hooper Visual Organisation Test	5
Paced Auditory Serial Addition Task	20
	Total = 2 hours 45 minutes

Tabachnick and Fidell (1989) outline four possible explanations for outliers. As the data was checked for errors, missing data were accounted for, and all data belonged to the intended population of interest, the only remaining explanation for

any outliers was that they were extreme values and did not belong to a normal distribution. As explained above, it was considered unnecessary to normalise the clinical data obtained in the present study. Therefore any outliers were not altered or deleted to conform to normality of distribution. In addition, Wilcox (1998) has suggested that outliers are an important source of information.

The suggestion has been made that, regardless of normality, parametric tests are not always robust against unequal variances (Kraemer, 1981; Scheffe, 1959; Tiku et al., 1986). The present study has addressed this issue where possible. Where *t* tests were required and variances were unequal, *t* tests for separate variance estimates were used.

Clinical interpretation of scores obtained by the MS sample was undertaken using comparison with the normal control group. Scores lying at, or greater than (or less than, depending on the direction indicating more impairment), one standard deviation from the mean obtained by the control group were considered to reflect "mild" impairment. Scores equal to, or greater than (or less than), two standard deviations from the mean obtained by the control group were considered to reflect "severe" impairment.

Data were described using the following procedures: mean (*M*), standard deviation (*SD*), and range. Data were analysed using the following statistical procedures: two-tailed independent *t* test, *t* test for separate variance estimates, two-tailed dependent *t* test, Pearson product-moment correlation, point-biserial correlation (r_{pb}; used where one variable was dichotomous), and one-way repeated measures analyses of covariance (ANCOVA).

CHAPTER 4

Results

Description of MS Sample Employing Minimal Record of Disability

Results of the four components of the Minimal Record of Disability (i.e., the Kurtzke Functional Systems, Kurtzke Expanded Disability Status Scale, Incapacity Status Scale, and Environmental Status Scale) are presented for the 92 participants with MS.

Kurtzke Functional Systems

Participants' ratings on each of the seven functional systems assessed are presented in Table 4.1. Thirty-nine percent of the participants displayed marked paraparesis, paraplegia, hemiplegia, or quadriplegia (scores of 4 - 6 on the pyramidal scale). On the cerebellar scale, 14% of participants displayed moderate or worse truncal or limb ataxia, or severe ataxia in all limbs (scores of 3 - 5). The cerebellar functioning of three participants was not able to be adequately assessed due to their severe neurological impairment in other areas of function. Nineteen percent of participants displayed severe brainstem abnormalities such as nystagmus, dysarthria, and dysphagia (scores of 3 - 5). On the sensory scale, 28% of the participants displayed moderate to severe loss of vibration, proprioception, and/or pain sensation (scores of 3 - 6). On the bowel and bladder rating scale, 25% of the participants experienced dysfunction ranging from frequent urinary incontinence to complete loss of bowel and bladder functioning (scores of 3 - 6). The visual functioning of the sample was not able to be assessed by the researcher. Four percent of the participants had experienced a severe decrease of mentation or dementia (scores of 4 - 5 on the cerebral scale). Finally, 18% of the participants

had severe spasticity (a score of 3) which resulted in major interference with their physical functioning.

Table 4.1

Results of Neurological Assessment with Kurtzke Functional Systems ($N = 92$)

	Increasing severity of impairment ⇒						
Functional System	0	1	2	3	4	5	6
Pyramidal	5 (5%)	6 (7%)	18 (20%)	27 (29%)	16 (17%)	18 (20%)	2 (2%)
Cerebellar*	28 (30%)	13 (14%)	35 (38%)	11 (12%)	2 (2%)	0 (0%)	-
Brainstem	19 (21%)	23 (25%)	33 (36%)	8 (9%)	9 (10%)	0 (0%)	-
Sensory	15 (16%)	17 (18%)	34 (37%)	12 (13%)	10 (11%)	2 (2%)	2 (2%)
Bowel/Bladder	12 (13%)	25 (27%)	31 (34%)	8 (9%)	3 (2%)	10 (11%)	3 (3%)
Visual	-	-	-	-	-	-	-
Cerebral	23 (25%)	13 (14%)	40 (43%)	11 (12%)	3 (3%)	1 (1%)	-
Spasticity	38 (41%)	22 (24%)	15 (16%)	17 (18%)	-	-	-

*$N = 89$

Kurtzke Expanded Disability Status Scale

Graphical analysis of the distribution of EDSS scores for the 92 participants with MS is presented in Figure 4.1. The mean EDSS score for the group was 5.60 ($SD = 2.04$, range 1.0 - 9.0). At the more severely impaired end of the scale, 17 (18%) of the participants functioned exclusively from a wheelchair or were restricted to bed for most of the day (scores of 8.0 or more). At the other end of

the scale, 31 (34%) of the participants were fully ambulatory without aid, and able to work a full day (scores of 4.5 or less).

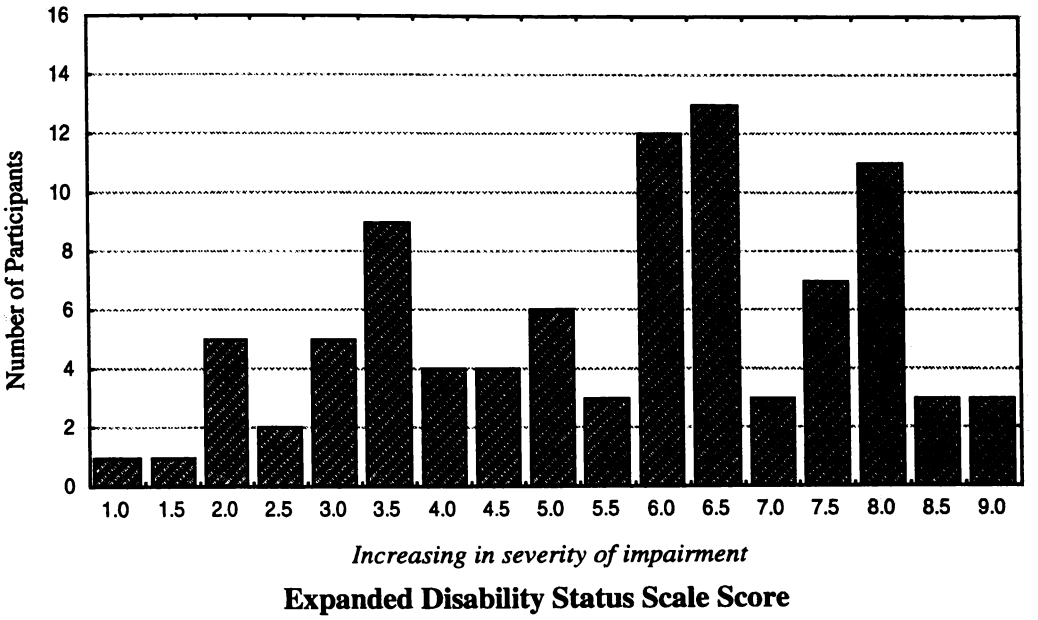

Figure 4.1. Frequency of Expanded Disability Status Scale scores in MS sample ($N = 92$).

Incapacity Status Scale

Results of the Incapacity Status Scale are presented in Table 4.2. The results of this scale indicated that 68% of the participants with MS required assistance in stair climbing or were unable to perform this task (scores of 2 - 4). Walking aids or wheelchairs were required by 64% of participants. The majority of the sample reported normal, or only minimal problems with, bowel (69%) and bladder (55%) functioning (scores of 0 and 1). Human assistance (scores of 3 and 4) was reported as necessary for various activities of daily living, i.e., bathing (22%), dressing (18%), grooming (17%), and feeding (3%). A few people (3%)

reported either being able to read only very large print, experiencing constant double vision, or legal blindness (scores of 3 and 4). Dysarthria or deafness which interfered with communication (scores of 2 - 4) was reported by 10% of the sample. Most participants (87%) did not require active medical care and saw their physicians less than once every 3 months (scores of 0 and 1). One participant (1%) experienced mood/thought disturbance that required consistent professional intervention beyond maintenance medication (a score of 3), however no participants reported experiencing mood/thought disturbance severe enough to preclude their day-to-day functioning (a score of 4). Disturbance in mentation severe enough to interfere with everyday activities (scores of 2 - 4) was reported by 28% of the sample. Fatigue troublesome enough to cause impaired functioning (scores of 2 - 4) was reported by 63% of participants. Finally, sexual dysfunction which caused concern (scores of 2 - 3) was reported by 15% of the sample.

Environmental Status Scale

Results of the Environmental Status Scale are presented in Table 4.3. The results of this scale indicated that 32% of the sample were working full-time (scores of 0 and 1). This definition included participants involved full-time as homemakers or students. The majority of participants (66%) reported maintaining their usual financial standard without external support (scores of 0 - 2). No personal assistance, or only minor personal assistance, was required by 56% of the sample (scores of 0 and 1). Most participants (53%) were able to drive with no or only minor difficulties, and without the need for hand controls (scores of 0 and 1). Community services for more than an hour per week (scores of 3 - 5) were utilised by 48% of the sample. Normal functioning, or only minimal difficulty, with social activities (scores of 0 and 1) were reported by 35% of the participants.

Table 4.2

Frequency Ratings for MS Sample on the Incapacity Status Scale ($N = 92$)

	Rating				
	Increasing in severity of disability ⇒				
Domain:	0	1	2	3	4
Stair Climbing	10 (11%)	19 (21%)	27 (29%)	10 (11%)	26 (28%)
Ambulation	18 (20%)	15 (16%)	24 (26%)	19 (21%)	16 (17%)
Toilet/Chair/Bed Transfer	37 (40%)	26 (28%)	13 (14%)	4 (4%)	12 (13%)
Bowel Function	42 (46%)	21 (23%)	20 (22%)	4 (4%)	5 (5%)
Bladder Function	15 (16%)	36 (39%)	19 (21%)	10 (11%)	12 (13%)
Bathing	30 (33%)	29 (32%)	13 (14%)	8 (9%)	12 (13%)
Dressing	32 (35%)	32 (35%)	11 (12%)	5 (5%)	12 (13%)
Grooming	44 (48%)	32 (35%)	1 (1%)	8 (9%)	7 (8%)
Feeding	51 (55%)	27 (29%)	11 (12%)	0 (0%)	3 (3%)
Vision	58 (63%)	27 (29%)	4 (4%)	1 (1%)	2 (2%)
Speech and Hearing	47 (51%)	36 (39%)	8 (9%)	0 (0%)	1 (1%)
Medical Problems	45 (49%)	35 (38%)	8 (9%)	2 (2%)	2 (2%)
Mood and Thought Disturbance	37 (40%)	39 (42%)	15 (16%)	1 (1%)	0 (0%)
Mentation	29 (32%)	38 (41%)	19 (21%)	6 (7%)	0 (0%)
Fatiguability	13 (14%)	21 (23%)	25 (27%)	14 (15%)	19 (21%)
Sexual Function	43 (47%)	20 (22%)	9 (10%)	5 (5%)	15 (16%)

Table 4.3

Frequency Ratings for MS Sample on the Environmental Status Scale ($N = 92$)

	Rating					
	Increasing in severity of handicap ⇒					
Domain:	0	1	2	3	4	5
Actual Work Status	23 (25%)	6 (7%)	15 (16%)	12 (13%)	15 (16%)	21 (23%)
Financial Status	34 (37%)	19 (21%)	7 (8%)	10 (11%)	14 (15%)	8 (9%)
Personal Residence	32 (35%)	19 (21%)	18 (20%)	8 (9%)	7 (8%)	8 (9%)
Personal Assistance	23 (25%)	38 (41%)	8 (9%)	6 (7%)	6 (7%)	11 (12%)
Transportation	32 (35%)	17 (18%)	5 (5%)	26 (28%)	11 (12%)	1 (1%)
Community Services	35 (38%)	5 (5%)	8 (9%)	20 (22%)	16 (17%)	8 (9%)
Social Activity	8 (9%)	24 (26%)	28 (30%)	15 (16%)	17 (18%)	0 (0%)

Comparison of MS Sample ($N = 77$) with Control Group ($N = 67$) on Measures of Cognitive and Psychological Functioning

Cognitive Functioning

The MS sample in this study performed significantly worse than the matched control group on 8 of the 15 cognitive test indices examined. These results are summarised in Table 4.4. Compared to the control group, the MS sample was found to be significantly impaired in the following areas: current intellectual functioning, learning, retention, delayed recall, recognition memory, sustained attention/concentration (i.e., the Paced Auditory Serial Addition Task),

one measure of executive functioning (the Controlled Oral Word Association Test), and one aspect of language functioning (i.e., receptive language). In addition, there was a trend towards significant impairment of the MS sample in the areas of immediate recall and the remaining two measures of attention and concentration (with $p = .01$ on the Auditory Verbal Learning Test trial 1, the Stroop Color/Word trial, and the d2 Concentration Test total score minus errors). No significant difference between the two groups was found on the second measure of executive functioning (i.e., the Wisconsin Card Sorting Test), one aspect of language (i.e., naming ability), and visuospatial functioning, with $p > .01$ in each case.

Furthermore, there was no statistically significant difference within the MS sample on their results obtained for the National Adult Reading Test estimated premorbid IQ and the WAIS-R IQ, $t\ (68) = .37$, $p > .05$. This suggests that there had been no decrease in general intellectual functioning in the MS sample as a whole. However, in comparison, there was a statistically significant difference in favour of the current intellectual functioning of the control group, as determined by the WAIS-R IQ, when compared to their National Adult Reading Test estimated IQ, $t(65) = -4.11$, $p = .0001$. Therefore, the National Adult Reading Test under-estimated IQ obtained by the three subtest short-form of the WAIS-R employed in this study.

For the majority of the tests there were some participants with MS who were unable to undertake the test, for a variety of reasons. These reasons and the number of participants who did not complete each test are summarised in Appendix I. On the Paced Auditory Serial Addition Task, 30 participants did not complete the test. However, for the remainder of the tests, the number of missing

Table 4.4

Analysis of Cognitive Functioning of MS Sample and Matched Control Group

Measure	MS Group Mean	*SD*	Control Group Mean	*SD*	*t*	*p*
General Intelligence						
WAIS-R Short Form	102.56	10.25	109.88	11.61	-3.91	.0001
Memory & Learning (AVLT)						
Immediate Recall	5.90	1.92	6.70	1.83	-2.57	NS
Learning	45.38	10.25	51.51	8.92	-3.80	.0002
Retention	8.70	3.18	10.67	2.70	-3.97	.0001
Delayed Recall	8.42	3.50	10.52	2.72	-4.03	.00009
Recognition Memory	11.99	2.94	13.42	1.43	-3.73	.0003
Attention / Concentration						
Stroop Color/Word trial	35.00	8.83	39.07	9.76	-2.59	NS
d2 Total Score - Errors	136.85	40.20	154.42	38.90	-2.55	NS
PASAT Total	94.47	39.81	119.72	37.54	-3.22	.002
Executive Functioning						
WCST PR	31.78	20.86	25.91	18.18	1.78	NS
WCST Categories	3.39	2.13	4.04	2.03	-1.86	NS
COWAT Total	35.00	12.02	42.52	12.15	-3.73	.0003
Language						
Token Test Total	161.25	3.38	162.49	1.15	-2.99	.004
Boston Naming Test	55.17	3.72	56.36	3.76	-1.89	NS
Visuospatial Functioning						
HVOT Total	24.53	3.77	25.57	2.62	-1.93	NS

Note. NS = Not significant ($p > .01$); WAIS-R = Wechsler Adult Intelligence Scale-Revised; AVLT = Auditory Verbal Learning Test; PASAT = Paced Auditory Serial Addition Task; WCST = Wisconsin Card Sorting Test; COWAT = Controlled Oral Word Association Test; HVOT = Hooper Visual Organisation Test.

participants ranged from ten people for the d2 Concentration Test (four people due to motor impairment and six people due to visual impairment), to one person for the Wisconsin Card Sorting Test.

The significant difference between the two groups on the measure of receptive language (i.e., the Token Test) raised concerns regarding the ability of the participants with MS to understand test instructions. Consequently, a breakdown of the six trials of the Token Test was undertaken to analyse this difference. The results of this breakdown are presented in Table 4.5.

Table 4.5

Analysis of Performance by the MS Sample ($N = 75$) and Matched Control Group ($N = 67$) on All Token Test Trials

	MS Group		Control Group			
Measure	Mean	*SD*	Mean	*SD*	*t*	*p*
Token Test						
Trial 1	7.00	0.00	7.00	0.00	--	--
Trial 2	8.00	0.00	8.00	0.00	--	--
Trial 3	11.97	0.16	12.00	0.00	-1.35	NS
Trial 4	15.95	0.23	15.93	0.26	0.52	NS
Trial 5	23.65	0.92	23.87	0.39	-1.82	NS
Trial 6	94.68	3.02	95.70	0.87	-2.80	.006
Total Score	161.25	3.38	162.49	1.15	-2.99	.004

Note. NS = Not significant ($p > .01$)

There was no significant difference between the two groups on Trials 1 - 5. A significant difference in the functioning of the two groups was only evident on the final trial, for which participants are required to recall six components of a verbal instruction delivered only once. The group difference on this trial was hypothesised to be a consequence of the memory component emphasised by the final trial as a result of its length. When the difference between the groups was reanalysed in an ANCOVA with verbal memory (i.e., the sum of the first five Auditory Verbal Learning Test trials) as a covariate, no significant difference remained on either Trial 6 of the Token Test, F (1,139) = 3.92, $p > .05$, or the total score of the Token Test, F (1, 139) = 3.06, $p > .05$.

Table 4.6 shows the degree of impairment for the MS sample in the areas of cognitive functioning in which they were found to have performed statistically significantly worse than the control group. Participants with scores lying at or beyond one standard deviation from the mean (in the direction indicating more impairment) obtained by the control group were classified as "mildly" impaired. Participants with scores lying at or beyond two standard deviations from the mean (in the direction indicating more impairment) obtained by the control group were classified as "severely" impaired. Across the different domains, between 17 (37%) and 32 (42%) participants were categorised as impaired. On each test index, between 8 (11%) and 24 (31%) participants were categorised as mildly impaired, and between 2 (3%) and 17 (23%) participants were categorised as severely impaired.

Psychological Functioning

The self-reported psychological functioning of both the MS sample and control group are presented in Table 4.7, along with self-reported fatigue ratings

for each group. All participants from both groups completed these components of the assessment. Significant differences between the two groups were evident on eight of the nine primary symptom dimensions and all three global indices of the

Table 4.6

Degree of Clinically Significant Cognitive Impairment in MS Sample

Cognitive Measures	*N**	Mild *n* (%)	Severe *n* (%)	Total *n* (%)
General Intelligence				
WAIS-R Short Form	71	22 (31%)	2 (3%)	24 (34%)
		8 (12%) #	*2 (3%)*	*10 (15%)*
Memory & Learning (AVLT)				
Learning	77	22 (29%)	10 (13%)	32 (42%)
		10 (15%)	*1 (1.5%)*	*11 (16%)*
Retention	76	15 (20%)	13 (17%)	28 (37%)
		6 (9%)	*3 (4%)*	*9 (13%)*
Delayed Recall	76	14 (18%)	17 (22%)	31 (40%)
		7 (10%)	*2 (3%)*	*9 (13%)*
Recognition Memory	74	8 (11%)	17 (23%)	25 (34%)
		7 (10%)	*2 (3%)*	*9 (13%)*
Attention/Concentration				
PASAT Total	47	12 (26%)	5 (11%)	17 (37%)
		11 (16%)	*0 (0%)*	*11 (16%)*
Executive Functioning				
COWAT Total	77	24 (31%)	5 (6%)	29 (37%)
		10 (15%)	*2 (3%)*	*12 (18%)*

Note. WAIS-R = Wechsler Adult Intelligence Scale-Revised; AVLT = Auditory Verbal Learning Test; PASAT = Paced Auditory Serial Addition Task; COWAT = Controlled Oral Word Association Test.

**N* differs as not all participants with MS were able to complete each test.

Italicised rows = number of control participants whose performance fell within each category.

Table 4.7

Analysis of Psychological Functioning for MS Sample (N = 77) and Matched Control Group (N = 67)

	MS Group		Control Group			
Measure	Mean	*SD*	Mean	*SD*	*t*	*p*
Symptom Checklist-90-Revised						
Somatization	10.88	8.20	4.46	5.52	5.57	.0000001
Obsessive Compulsion	10.77	7.81	5.91	4.61	4.61	.00001
Interpersonal Sensitivity	5.60	5.51	3.04	3.06	3.49	.0007
Depression	12.03	10.50	4.96	4.95	5.27	.000001
Anxiety	5.08	5.96	1.78	2.09	4.55	.00002
Hostility	2.48	3.26	1.31	1.49	2.82	.006
Phobic Anxiety	1.78	3.06	0.33	0.68	4.05	.0001
Paranoid Ideation	2.23	3.25	1.55	2.04	1.53	NS
Psychoticism	3.39	5.03	0.91	1.58	4.10	.00008
Global Severity Index	0.66	0.53	0.31	0.24	5.28	.000001
PSD Index	1.72	0.54	1.30	0.30	5.84	.000001
Positive Symptom Total	31.43	19.16	19.88	12.72	4.31	.00003
Fatigue						
Fatigue Severity Scale	47.13	13.84	25.82	10.16	10.62	.000001

Note. NS = Not significant ($p > .01$); PSD = Positive Symptom Distress

SCL-90-R, with the MS sample indicating a greater degree of psychopathology on each dimension. The only dimension on which the MS sample was not found to significantly differ from the control group was Paranoid Ideation, $p > .01$. On the self-report measure of fatigue, the MS sample reported experiencing significantly more fatigue than the control group.

Table 4.8 presents the degree of impairment of the MS sample in those areas of psychological functioning and fatigue in which they were found to be statistically significantly different to the control group. Between 24 (31%) and 38 (49%) of the participants with MS were classified as experiencing significant psychological impairment on the dimensions of the SCL-90-R. Between five (6%) and 19 (25%) of these participants were classified as mildly impaired on the nine dimensions, while between 11 (14%) and 28 (36%) participants were classified as severely impaired.

Sixty-one (79%) of the participants with MS indicated significant impairment on the Fatigue Severity Scale. Sixteen (21%) of these participants were classified as mildly impaired on this measure and 45 (58%) were classified as severely impaired.

Relationship Between Neuropsychological Functioning and Other Disease Variables for MS Sample

The relationship between neuropsychological functioning in the MS sample and other disease variables was examined. Following DeLuca et al. (1995), a global cognitive rating was calculated for each participant by assigning them a value of 1, 2, or 3 for each of 14 individual test indices. The Paced Auditory Serial Addition Task was not included in this calculation due to the large proportion of missing data in both the MS sample and control group on this measure. If a participant

scored within the normal range (i.e., within one standard deviation of the control group's mean for that test score), a value of 1 was attributed to the person for that test. If a participant scored in the mildly impaired range (i.e., between one and two

Table 4.8

Degree of Clinically Significant Psychological Impairment in MS Sample ($N = 77$)

Measure	Mild	Severe	Total
	n (%)	*n* (%)	*n* (%)
Symptom Checklist-90-Revised			
Somatization	14 (18%)	21 (27%)	35 (45%)
	6 (9%) [#]	*4 (6%)*	*10 (15%)*
Obsessive Compulsion	17 (22%)	18 (23%)	35 (45%)
	8 (12%)	*4 (6%)*	*12 (18%)*
Interpersonal Sensitivity	8 (10%)	16 (21%)	24 (31%)
	4 (6%)	*4 (6%)*	*8 (12%)*
Depression	14 (18%)	24 (31%)	38 (49%)
	7 (10%)	*5 (8%)*	*12 (18%)*
Anxiety	5 (6%)	28 (36%)	33 (42%)
	3 (4%)	*7 (10%)*	*10 (15%)*
Hostility	19 (25%)	11 (14%)	30 (39%)
	5 (7%)	*4 (6%)*	*9 (13%)*
Phobic Anxiety	0 (0%)	26 (34%)	26 (34%)
	0 (0%)	*6 (9%)*	*6 (9%)*
Psychoticism	10 (13%)	21 (27%)	31 (40%)
	5 (7%)	*3 (4%)*	*8 (12%)*
Global Severity Index	11 (14%)	26 (34%)	37 (48%)
	8 (12%)	*3 (4%)*	*11 (16%)*
Positive Symptom Distress Index	11 (14%)	29 (38%)	40 (52%)
	9 (13%)	*2 (3%)*	*11 (16%)*
Positive Symptom Total	16 (21%)	19 (25%)	35 (46%)
	10 (15%)	*3 (4%)*	*13 (19%)*
Fatigue			
Fatigue Severity Scale Total	16 (21%)	45 (58%)	61 (79%)
	7 (10%)	*4 (6%)*	*11 (16%)*

[#] Italicised rows = number of control participants whose performance fell within each category.

standard deviations of the control group's mean for that test score), a value of 2 was attributed to the person for that test. If a participant's score fell within the severely impaired range (i.e., two or more standard deviations from the control group's mean on that test score), a value of 3 was attributed to the person for that test. Hence, the global cognitive rating scores for the sample had a total possible range of 14 (i.e., for participants who obtained 'normal' scores on all 14 of the test indices) to 42 (i.e., for participants who obtained scores in the 'severely impaired' range on all 14 test indices). Higher global cognitive ratings, therefore, were indicative of more extensive or severe cognitive impairment.

Sixty-four participants with MS did not have missing data on any of the 14 test indices. Data from the 13 participants with MS who had some missing cognitive test data were not included in this section of the analysis. There were no statistically significant differences between these 13 participants and the remainder of the MS sample on the following variables: psychological functioning, disease duration (including 'number of years since symptom onset' and 'number of years since MS diagnosis'), medication use, and self-reported experience of fatigue ($p >$ .05 for each variable). However, there was a statistically significant difference in the physical functioning of the two groups, $t(75) = -2.92$, $p = .005$. The 13 participants with incomplete cognitive data were significantly more physically impaired than the remainder of the MS sample. This was to be expected, since it was as a result of advanced physical impairment that each of these 13 participants had some missing cognitive test indices.

The mean global cognitive rating for the 64 participants in the MS sample included in this section of the data analysis was 19.20 ($SD = 4.12$, range = 14 - 35). In comparison, the mean global cognitive rating for the control group was 16.48

(SD = 3.12, range = 14 - 30). There was a statistically significant difference between the global cognitive ratings of the MS sample and the control group, t (117.42) = 4.23, $p < .001$.

The relationships of seven MS disease variables with cognitive functioning were analysed (see Table 4.9 and Table 4.10). The first of these was degree of physical disability (i.e., EDSS score) which was not significantly correlated with global cognitive functioning, $r = .18$, $p > .05$. The relationship between cognitive functioning and disease duration was examined in relation to two variables:

Table 4.9

Correlational Analyses Relating the Cognitive Functioning of the Participants With MS (N = 64) With Other Disease Variables

Variable	1	2	3	4	5	6	7
1. GC Rating	--						
2. EDSS Score	.18	--					
3. Symptom Onset	.14	.32*	--				
4. Years Since Diagnosis	.29*	.23	.69*	--			
5. SCL-90-R GSI	.31*	.02	.04	.04	--		
6. Fatigue Rating	.23	.24	-.19	-.21	.31*	--	
7. Medication Use	-.11	-.33*	-.41*	-.47*	-.21	-.09	--

Note. GC Rating = Global Cognitive Rating; EDSS = Expanded Disability Status Scale; SCL-90-R GSI = Symptom Checklist 90-Revised Global Symptom Index.

*$p < .05$.

number of years since symptom onset and number of years since MS diagnosis. The first of these was not found to be significantly correlated with global cognitive functioning, $r = .14$, $p > .05$. However, the number of years since MS diagnosis was significantly correlated with global cognitive functioning, $r = .29$, $p = .019$.

The psychological functioning of the participants with MS (for which the Global Symptom Index of the SCL-90-R was utilised) was statistically significantly correlated with global cognitive functioning, $r = .31$, $p = .013$. Fatigue ratings were not statistically significantly correlated with global cognitive functioning, $r = .23$, $p > .05$, and neither was medication use, $r_{pb} = -.11$, $p > .05$.

Finally, no significant relationship was found between the global cognitive functioning of the MS sample and their MS disease course. This relationship was examined first with the five disease course categories, $F(4, 59) = .95$, $p > .05$. It was then examined again after collapsing the five disease course categories into two main categories, one distinguished by a relapsing course (i.e., relapsing/ remitting) and the other by a progressive course (i.e., primary/progressive and secondary/progressive), $F(1, 58) = .008$, $p > .05$ (see Table 4.10).

Comparison of the Functioning of Cognitively Impaired Versus Cognitively Intact People With MS

Following the example of Rao, Leo, Ellington, et al. (1991), to determine the impact of cognitive impairment on other areas of functioning, the MS sample was divided into two subgroups: 'cognitively impaired' and 'cognitively intact'. This was undertaken on the basis of their global cognitive rating scores. Participants with MS who had a global cognitive rating score equal to, or more than, 1.5 standard deviations above the mean of the control group's cognitive global rating scores were classified as 'cognitively impaired'. Participants whose

Table 4.10

Means and Standard Deviations for Global Cognitive Ratings in MS Sample for Analysis of Variance of MS Disease Course

		Global Cognitive Rating	
Disease Course	*N*	Mean	*SD*
Part I			
Relapsing/Remitting	36	19.39	4.28
Primary/Progressive	19	18.63	3.82
Secondary/Progressive	5	21.80	4.76
Primary/Relapsing	2	16.00	1.41
Benign	2	18.00	2.83
Part II			
Relapsing	36	19.39	4.28
Progressive	24	19.29	4.13

global cognitive rating was less than 1.5 standard deviations above the mean of the control group's global cognitive rating scores were classified as 'cognitively intact'.

For each of the 13 participants with MS who had one or more missing test scores, the mean and standard deviation of the control group's global cognitive rating was calculated individually, having removed the relevant (missing) test score(s) pertaining to that participant's cognitive performance. These 13 participants were then able to be classified as cognitively intact or cognitively

impaired in the same manner as the other participants with MS, i.e., by comparing their performance to that of the relevant mean for the control group.

This computation classified 28 (36%) participants with MS as cognitively impaired and 49 (64%) participants with MS as cognitively intact. The same method classified four (6%) control participants as cognitively impaired and 63 (94%) control participants as cognitively intact.

There were no significant differences between the cognitively intact and cognitively impaired MS groups on the matching variables of gender (79% of the cognitively impaired MS group were female, compared to 78% of the cognitively intact MS group); years of education, $t(75) = -.74$, $p > .05$; premorbid intellectual functioning (i.e., National Adult Reading Test error score), $t(71) = .97$, $p > .05$; number of years since initial MS symptom onset, $t(75) = 1.63$, $p > .05$; medication use, $\chi^2(1) = 2.45$, $p > .05$; and fatigue, $t(75) = 1.54$, $p > .05$.

However statistically significant differences were found between the cognitively intact and cognitively impaired MS groups on the variables of age, $t(75) = 3.31$, $p = .001$; number of years since diagnosis, $t(75) = 2.20$, $p = .03$; and degree of physical impairment (i.e., EDSS score), $t(75) = 3.09$, $p = .003$. The cognitively impaired MS group were significantly older, had had a diagnosis of MS for significantly longer, and were significantly more physically impaired than the cognitively intact group. Data on these matching variables are presented in Table 4.11.

Analysis of Disability in Cognitively Impaired and Cognitively Intact Participants with MS Using the Incapacity Status Scale

Table 4.12 presents a breakdown of the 16 items of the Incapacity Status Scale, the measure of MS-related disability from the Minimal Record of Disability.

Table 4.11

Matching Variables for Cognitively Impaired (N = 28) and Cognitively Intact (N = 49) Participants With MS

Variable	Cognitive Status: Impaired	Intact
Gender:		
Female	22 (79%)	38 (78%)
Male	6 (21%)	11 (22%)
Age: (years)		
Mean	56.36	47.98
SD	8.50	11.75
Years of Education:		
Mean	11.86	12.24
SD	2.29	2.17
NART Error Score:		
Mean	23.07	21.09
SD	7.77	8.76
Years Since Symptom Onset:		
Mean	21.64	17.24
SD	11.02	11.61
Years Since MS Diagnosis:		
Mean	14.71	9.81
SD	9.31	9.49
Medication Use:		
Yes	19 (68%)	33 (67%)
No	9 (32%)	16 (33%)
Fatigue Severity Scale Rating:		
Mean	50.32	45.31
SD	11.27	14.92
EDSS Score:		
Mean	6.00	4.68
SD	1.61	1.90

Note. NART = National Adult Reading Test; EDSS = Expanded Disability Status Scale

Statistically significant differences (i.e., $p < .05$) between the cognitively intact and cognitively impaired MS groups were evident in 6 of the 16 areas. These were Stair Climbing, Ambulation, Toilet/Chair/Bed Transfers, Bathing, Speech and Hearing, and Fatigue. With each of these items, the cognitively impaired MS group reported more disability (i.e., greater difficulty climbing stairs, more difficulty walking without aid, less ability to transfer unaided between toilet/chair/bed, more difficulty bathing without assistance from other people, more difficulty in verbal communication, and more debilitating fatigue) than the cognitively intact MS group.

When the differences between the groups on these six variables were reanalysed in an ANCOVA with age, number of years since MS diagnosis, and degree of physical impairment as covariates, significant differences between the two groups remained only for Speech and Hearing, $F(1, 72) = 4.92$, $p = .03$.

Analysis of Handicap in Cognitively Impaired and Cognitively Intact Participants with MS Using the Environmental Status Scale

Table 4.13 presents a breakdown of the items of the Environment Status Scale, the measure of MS-related handicap from the Minimal Record of Disability. Statistically significant differences (i.e., $p < .05$) between the cognitively intact and cognitively impaired MS groups were evident in the areas of Change Required to Personal Residence/Home, Community Services Required, and Social Activity. With each of these items, the cognitively impaired MS group reported more handicap (i.e., a greater number of changes required to personal residences, more community services required, and more restrictions to social activity) than the cognitively intact MS group.

Table 4.12

Analysis of Disability in Cognitively Impaired (N = 28) and Cognitively Intact (N = 49) Participants with MS

	Cognitive Status:					
	Impaired		Intact			
Incapacity Status Scale:	Mean	*SD*	Mean	*SD*	*t*	*p*
Stair Climbing	2.46	1.26	1.69	1.18	2.69	.009
Ambulation	2.18	1.16	1.47	1.31	2.38	.02
Toilet/Chair/Bed Transfer	1.25	1.14	0.63	0.97	2.51	.01
Bowel Function	1.07	1.09	0.61	0.93	1.96	NS
Bladder Function	1.71	1.08	1.22	1.03	1.97	NS
Bathing	1.50	1.20	0.73	0.91	3.16	.002
Dressing	1.11	1.10	0.78	0.98	1.36	NS
Grooming	0.75	0.84	0.49	0.87	1.28	NS
Feeding	0.57	0.69	0.29	0.50	1.92	NS
Vision	0.43	0.63	0.39	0.79	0.23	NS
Speech and Hearing	0.71	0.76	0.35	0.52	2.26	.03
Medical Problems	0.68	0.82	0.53	0.58	0.84	NS
Mood/Thought Disturbance	1.00	0.67	0.71	0.79	1.61	NS
Mentation	1.14	0.97	0.80	0.64	1.69	NS
Fatiguability	2.46	1.26	1.76	1.25	2.39	.02
Sexual Function	1.41	1.58	0.92	1.24	1.49	NS

Note. NS = Not significant ($p > .05$)

When the differences between the groups on these three variables were reanalysed in an ANCOVA with age, number of years since MS diagnosis, and degree of physical impairment as covariates, significant differences remained between the two groups for Changes Required to Personal Residence/ Home, F (1, 72) = 9.55, p = .003; and Social Activity, F (1, 72) = 4.23, p = .04. A trend towards a significant difference between the two groups remained for Community Services Required, F (1, 72) = 3.99, p = .05.

Table 4.13

Analysis of Handicap in Cognitively Impaired (N = 28) and Cognitively Intact (N = 49) Participants with MS

	Cognitive Status:					
	Impaired		Intact			
Environmental Status Scale:	Mean	*SD*	Mean	*SD*	*t*	*p*
Actual Work Status	2.82	1.74	2.04	1.74	1.89	NS
Financial/Economic Status	2.07	1.88	1.59	1.73	1.13	NS
Personal Residence/Home	2.18	1.66	0.80	.96	4.05	.0002
Personal Assistance Required	1.64	1.54	1.02	1.11	1.87	NS
Transportation	1.64	1.45	1.22	1.37	1.26	NS
Community Services	2.57	1.73	1.16	1.48	3.78	.0003
Social Activity	2.39	1.26	1.57	0.94	3.26	.002

Note. NS = Not significant (p > .05)

Analysis of Psychological Functioning of Cognitively Impaired and Cognitively Intact Participants with MS Using the Symptom Checklist-90-Revised

Table 4.14 presents a breakdown of the nine dimensions and three summary scores from the SCL-90-R, a measure of self-reported psychological functioning. No statistically significant differences between the cognitively intact and cognitively impaired MS groups were evident in any of these areas.

Analysis of Caregiver Ratings of Cognitively Impaired and Cognitively Intact Participants With MS Using the Cognitive Behavior Rating Scale

Table 4.15 presents a breakdown of the items of the Cognitive Behavior Rating Scale, a measure completed by a family member of the participant with MS. Statistically significant differences (i.e., $p < .05$) between the cognitively intact and cognitively impaired MS groups were reported on the Need for Routine scale and the Higher Cognitive Deficits scale. On both of these scales, the family members of the cognitively impaired MS group reported more impairment (i.e., a greater need for routine, and more higher cognitive deficits) than the cognitively intact MS group. There was also a trend in the same direction for a significant difference between the family members ratings of the two groups on the Disorientation scale, $p = .06$.

When the differences between the groups on these three variables were reanalysed in an ANCOVA with age, number of years since MS diagnosis, and degree of physical impairment as covariates, a significant difference remained between the two groups on the Need for Routine scale, $F(1, 41) = 5.95$, $p = .02$; and the Disorientation scale, $F(1, 41) = 7.03$, $p = .01$. No significant difference remained between the two groups on the Higher Cognitive Deficits scale, $F(1, 41) = 3.68$, $p > .05$.

Table 4.14

Analysis of Psychological Functioning in Cognitively Impaired (N = 28) and Cognitively Intact (N = 49) Participants with MS

	Cognitive Status:					
	Impaired		Intact			
SCL-90-R:	Mean	*SD*	Mean	*SD*	*t*	*p*
Somatization	11.14	7.69	10.73	8.56	0.21	NS
Obsessive-Compulsive	12.32	8.10	9.88	7.58	1.33	NS
Interpersonal Sensitivity	6.43	6.36	5.12	4.96	1.00	NS
Depression	12.86	10.61	11.55	10.52	0.52	NS
Anxiety	5.46	6.71	4.86	5.55	0.43	NS
Hostility	2.82	4.47	2.29	2.34	0.59	NS
Phobic Anxiety	2.25	2.89	1.51	3.15	1.02	NS
Paranoid Ideation	2.57	4.24	2.04	2.56	0.60	NS
Psychoticism	4.21	6.81	2.92	3.64	0.93	NS
Global Severity Index	0.72	0.55	0.63	0.52	0.74	NS
PSDI	1.87	0.57	1.63	0.50	1.88	NS
Positive Symptom Total	31.96	18.31	31.12	19.81	0.18	NS

Note. SCL-90-R = Symptom Checklist-90-Revised; PSDI = Positive Symptom Distress Index; NS = Not significant ($p > .05$)

Table 4.15

Analysis of Caregiver Ratings of Cognitively Impaired (N = 28) and Cognitively Intact (N = 49) Participants with MS

	Cognitive Status:					
	Impaired		Intact			
CBRS:	Mean	*SD*	Mean	*SD*	*t*	*p*
Language Deficit	21.87	5.97	19.19	6.01	1.42	NS
Apraxia	12.33	3.60	12.35	4.44	-0.02	NS
Disorientation	8.40	4.19	6.10	1.56	2.06	NS
Agitation	13.67	6.22	11.03	4.30	1.67	NS
Need for Routine	14.67	6.17	10.61	3.52	2.36	.03
Depression	47.33	17.60	41.90	12.47	1.21	NS
Higher Cognitive Deficits	27.47	5.77	23.26	5.34	2.44	.02
Memory Disorder	38.80	14.65	31.74	11.06	1.82	NS
Dementia	48.47	12.88	41.55	11.46	1.84	NS

Note. CBRS = Cognitive Behavior Rating Scale; NS = Not significant ($p > .05$)

CHAPTER 5

Discussion

A consistent theme encountered by the researcher throughout the data collection process was the willingness of both the participants with MS and the control participants to give freely of their time and energy during the course of this research. Many of the participants reported finding the assessment process both interesting and stimulating, if not somewhat wearying. The opportunity to conduct the assessments in people's homes was beneficial. As well as minimising disruption for the research participants (many of whom were extensively physically disabled), it also provided the researcher with an insight into the participants' functioning in their usual environment. Participants were friendly and welcoming, which kept to a minimum the unavoidable tediousness that is a part of any extensive data collection process such as was involved in the present study. Many of the participants with MS expressed gratitude that someone was taking an interest in their plight, while the control participants expressed a willingness to be involved in a project which aimed to assist the general MS population.

MS is a disease which infiltrates all areas of a person's life. The courage, determination, and sense of humour that were characteristic of many of these research participants left me feeling humble. I have huge respect for them. While there is undoubtedly a great deal of distress that accompanies a diagnosis of MS; as with many of life's trials, the challenge of the disease can also bring out the most admirable qualities of a person and their support network. These can be qualities that psychometric test results do not demonstrate.

Minimal Record of Disability Ratings in People With MS

The results obtained on the Kurtzke Functional Systems neurologic ratings for the 92 participants with MS were similar to those reported by Rodriguez et al. (1994) in their population-based study of 162 people with MS. In the present sample, 39% of participants had marked pyramidal impairment, 14% had moderate or worse ataxia, 19% displayed severe brainstem abnormalities, and 28% had moderate to severe sensory impairment. This compares with 33% of the participants in the study by Rodriguez et al. who had marked pyramidal impairment, 13% who had moderate or worse ataxia, 13% who showed severe brainstem abnormalities, and 22% who demonstrated severe loss of sensory function. In both samples, 25% of participants experienced bowel and/or bladder impairment to the extent of frequent incontinence or the need for almost constant catheterisation. Four percent of the population studied by Rodriguez et al. had experienced a severe decrease of mentation or dementia, as was the case for 4% of the sample described here. Finally, 27% of the population described by Rodriguez et al. experienced spasticity to the extent that it resulted in major interference of function, compared to 18% of the current sample.

Despite these similarities, a larger percentage of the participants in the present study obtained moderate ratings (3 - 4) in the Kurtzke Functional Systems, while participants in the population studied by Rodriguez et al. (1994) more frequently obtained ratings in the normal to mild range (0 - 2). That the sample described here was somewhat more neurologically impaired overall is reflected in their EDSS scores (M = 5.60, SD = 2.04), compared to that of the population described by Rodriguez et al. (M = 4.3, SD = 2.7). While both groups had a similar proportion of people who functioned exclusively from a wheelchair or were

restricted to bed most of the day (18% in the current study compared to 14% in the population studied by Rodriguez et al.), there were substantially more people in the population described by Rodriguez et al. who were fully ambulatory without aid, and able to work a full day (57%, compared to 34% in the present study). Consequently, more people in the present sample were ambulatory to some degree, but living with impairment severe enough to prevent them participating fully in their usual daily activities.

Mostly similar results were found between the sample in this study and the population described by Rodriguez et al. (1994) on the Incapacity Status Scale and the Environmental Status Scale. However some notable differences in the results of the two samples on the Incapacity Status Scale occurred in the areas of Ambulation, Vision, Mentation, and Sexual Function. These differences are likely to have been a result of the more advanced neurological impairment of the sample in the present study. For example, 51% of the population studied by Rodriguez et al. reported that they experienced no disability in the area of ambulation, compared to 20% of the current sample. Fifty-seven percent of the population studied by Rodriguez et al. reported no observable problem in the area of mentation, compared to 32% of the present sample. While 24% of the population studied by Rodriguez et al. reported the presence of disturbance in mentation without interference of performance in everyday activities, significantly more (41%) of the current sample reported this experience. Sixty-two percent of the population studied by Rodriguez et al. reported experiencing no problems in sexual functioning, compared to 47% of the current sample. Furthermore, only 9% of the Rodriguez et al. population reported being less sexually active than before and/or

experiencing some sexual problems (without being concerned about this), compared to 22% of the current sample.

On the Environmental Status Scale, notable differences were evident between the present MS sample and that of Rodriguez et al. (1994) in the areas of Work Status, Financial Status, Personal Assistance Required, Community Services, and Social Activity. Thirty-nine percent of Rodriguez et al.'s population reported normal work status, compared to 25% of the present sample. Fifty-five percent of the population studied by Rodriguez et al. reported no MS-related financial problems, compared to 35% of the present sample. Forty-nine percent of the population studied by Rodriguez et al. reported no requirement for personal assistance, compared to 25% of the present sample. Thirteen percent of the Rodriguez et al. population reported requiring only minor help (i.e., the involvement of a relative but personal independence maintained), compared to 41% of the present sample. Seventy-five percent of the Rodriguez et al. population reported that they required no community services, compared to 38% of the present sample. And finally, 40% of the population described by Rodriguez et al. reported being as socially active as before they had MS, with no changes to their usual pattern of social activity and no difficulty maintaining that pattern, compared to only 9% of the present sample.

As with the population-based study by Rodriguez et al. (1994), the present study included participants with MS who resided in nursing homes in the community. However, while Rodriguez et al. determined the disability of all people with MS in a geographical region (by way of a computerised central diagnostic index), the MS sample involved in the present study did not represent the entire MS population of the region and only incorporated people whose names were

registered with their local MS Society. It is entirely possible that some people with MS only seek or require the services offered by their local branch of the MS Society as their disease advances. Furthermore, involvement with one's local MS Society suggests a certain amount of acceptance of one's diagnosis which may not be common in the very early stages of the disease for many people. Consequently, the somewhat more impaired, disabled, and handicapped constitution of the MS sample presented here (rated using the Minimal Record of Disability) may be a consequence of the recruitment via MS Societies. Even so, people at all stages of the disease were represented in this community-based MS sample, ranging from an EDSS of 1.0 (equating to no disability and minimal neurological abnormality in one functional system) to an EDSS of 9.5 (equating to a person who has been rendered completely helpless by the disease, retains no voluntary movement, and is unable to effectively communicate, eat, or swallow).

When the MS sample was reduced to 77 participants for the analyses of cognitive and psychological functioning, the mean EDSS score for the group (M = 5.16, SD = 1.90, range = 1.0 - 8.0) was higher (i.e., indicative of more extensive neurological impairment) than that reported for the sample studied by Klonoff et al. (1991), who researched the functioning of participants with mild MS (EDSS M = 2.08). It was also higher than that of the sample studied by Rao, Leo, Bernardin, et al. (1991), for whom the mean EDSS score was 4.1 (SD = 2.2); and that of the sample employed by Heaton et al. (1985), whose mean Disability Status Scale score was 3.10 (SD = 2.09) for their sample of 100 participants with MS. Of the studies reviewed here, only McIntosh-Michaelis et al. (1991) described a sample who were slightly more neurologically impaired than the sample presented here, with their median EDSS rating of 6.0 for 147 participants with MS.

Similarly, the average age of the present MS sample (M = 51 years) was older than the average age of the MS samples studied by Heaton et al. in 1985 (M = 37 years), Klonoff et al. in 1991 (M = 37 years), McIntosh-Michaelis et al. in 1991 (M = 48 years), Rao, Leo, Bernardin, et al. in 1991 (M = 46 years) and Rodriguez et al. in 1994 (M = 48 years). It follows, therefore, that the present sample also had a longer average MS disease duration (M = 12 years) compared to the MS samples studied by Heaton et al. (M = 9 years), Klonoff et al. (M = 6 years), and Rao, Leo, Bernardin, et al. (M = 10 years). The mean disease duration of the sample studied by McIntosh-Michaelis et al. (1991) was 13 years. The average age of MS symptom onset for the various samples was comparable: 33 years in the present sample, 28 years in Heaton et al.'s (1985) sample, 26 years in Klonoff et al.'s (1991) sample, 35 years in McIntosh-Michaelis et al.'s (1991) sample, 32 years in Rao, Leo, Bernardin, et al.'s (1991) sample, and 29 years in Rodriguez et al.'s (1994) sample.

Overall, therefore, the current sample was slightly older and more physically impaired than most of the other samples discussed here. As the assessment process for the present research took place in the participants' homes, this may have increased the likelihood of involvement by people with MS with more extensive physical impairments, who may have declined to participate if they had been required to attend an in- or out-patient clinic setting. Also, the average age of the present sample is closest to that of the samples studied by Rao, Leo, Bernardin, et al. (1991), Rodriguez et al. (1994), and McIntosh-Michaelis et al. (1991). These studies also recruited community-based samples via local MS Society listings, while Klonoff et al. (1991) and Heaton et al. (1985) recruited their samples from clinic admissions. This supports the finding by Nelson et al. (1988)

that MS samples obtained from referral centres or clinics tend to be younger than those obtained from population-based groups.

The universal use of the Minimal Record of Disability rating scales, even when only the EDSS was reported, proved to be useful for making comparisons across research samples.

Cognitive Functioning in People With MS Compared to Normal Control Groups

The results from the assessment of the cognitive functioning of the MS sample demonstrated that they performed significantly worse than the control group in the areas of current intellectual functioning, learning, retention, delayed recall, recognition memory, sustained attention, and on a task of executive functioning, i.e., verbal fluency. While a significant difference was found between the two groups on a measure of receptive language, this difference was accounted for by the MS sample's impaired retention of the instructions for the final Token Test trial, rather than indicating an impairment in receptive language per se. Trends towards a significantly worse performance by the MS sample were also evident in the areas of attention/concentration and immediate recall. No statistically significant difference between the MS sample and the control group was evident in the areas of naming ability and visuospatial functioning. Compared to the control group, the MS sample also did not demonstrate a statistically significant worse performance on the Wisconsin Card Sorting Test, a measure of executive functioning.

This relatively widespread cognitive impairment in the present MS sample, in comparison with the normal control group, was also found by Heaton et al. (1985) in their sample of 100 people with MS, who performed significantly worse than a normal control group on all five summary measures of their cognitive test

battery: the WAIS Verbal IQ, WAIS Performance IQ, Halstead Impairment Index, Average Impairment Rating, and clinician global judgment.

The pattern of cognitive impairment found in the present MS sample is also similar to that reported by Rao, Leo, Bernardin, et al. (1991). Their MS sample also performed significantly worse than a normal control group on WAIS-R subtests, the Controlled Oral Word Association Test, the Paced Auditory Serial Addition Task, the Stroop Color/Word Test, and on alternative measures used to assess the areas of recent memory and attention/concentration. Both MS samples were also found not to be significantly impaired on the Boston Naming Test, the Hooper Visual Organisation Test, and measures of receptive language ability. Differences to the results reported by Rao, Leo, Bernardin, et al. include the impaired performance of their MS sample on the Wisconsin Card Sorting Test, other measures of abstract/conceptual reasoning, and measures of visuospatial perception other than the Hooper Visual Organisation Test.

Comparison of the National Adult Reading Test estimated premorbid IQ with the results of the WAIS-R short-form indicated that, overall, the present MS sample had not experienced a global decline in intellectual functioning. However, in comparison, the results of the control group on these measures indicated a significant increase in the control group's intellectual functioning. Previous research findings have reported small but significant declines in the intellectual functioning of people with MS over time (Bernardin et al., 1993; Rao, 1986). For example, Ron et al. (1991) reported a drop of 6.8 points between the IQ scores obtained on the National Adult Reading Test and the WAIS for an MS sample. The lack of a significant difference in the results of these measures for the MS sample in the present study may be a consequence of having employed a short-form of the

WAIS-R. In the present study, the short-form was used instead of the full WAIS-R, to shorten the length of the psychometric assessment for the participants, as many people with MS experience quite debilitating fatigue. The results of this study are similar, however, to those reported by Bernardin et al. (1993), who, at a three-year follow-up, found that the WAIS-R IQ scores of their MS sample had remained essentially unchanged, while those of the normal control group had increased, thus widening the gap between the two.

Degree of Cognitive Impairment in MS Sample

On those tests for which their mean performance differed significantly from that of the control group, between 34% and 42% of the participants in the MS sample were found to be experiencing some degree of cognitive impairment. This is similar to the findings of Rao, Leo, Bernardin, et al. (1991), who reported that 40% of their sample showed evidence of cognitive impairment. It is also similar to the findings of McIntosh-Michaelis et al. (1991), who reported cognitive impairment in 46% of their MS sample. McIntosh-Michaelis et al. reported memory impairment in 34% of their sample, which compares to memory impairment in 34% - 42% of the present sample (depending on the particular aspect of memory functioning being examined). McIntosh-Michaelis et al. reported that for 12% of their sample this memory impairment was severe, which compares to the severe memory impairment found in 13% - 23% of the present sample. McIntosh-Michaelis et al. reported that the performance of 23% of their MS sample was impaired on the Controlled Oral Word Association Test, compared to 37% of the MS sample in the present study.

Overall, the cognitive functioning of the New Zealand community-based MS sample presented here was found to be very similar to the cognitive

functioning of other MS populations detailed in the neuropsychological literature. One area of difference, however, was the absence of a significant difference between the functioning of the MS sample and the control group on the Wisconsin Card Sorting Test. This measure of executive functioning has previously been reported to differentiate MS samples from normal control groups, and has been hypothesised to be indicative of deficits in frontal lobe functioning. It is possible that the statistically significant, worse performance of the MS sample on the second measure of executive functioning may, in fact, be attributable to a slowed rate of information processing, as the Controlled Oral Word Association Test is a timed test while the Wisconsin Card Sorting Test is not. The worse performance of the MS sample (compared to the control group) on the Paced Auditory Serial Addition Task indicates a slower rate of information processing by the MS sample compared to the control group.

This difficulty in defining what (combination of) cognitive domain(s) a psychometric test is actually assessing is one of the greatest areas of frustration within the field of neuropsychology. In the field of rehabilitation, the utility of neuropsychological tests is maximised when their direct relationship with everyday functioning (i.e., their ecological validity) is known (Deaton, 1993; Marsh & Kersel, 1993). For example, Ruff et al. (1993) found that speed, rather than accuracy rate, on neuropsychological variables was a more critical determinant of returning to work following head injury.

Psychological Functioning of People With MS Compared to Normal Control Groups

The MS sample in the present study were found to differ significantly from the control group in their self-reported symptomatology on all dimensions of the

SCL-90-R except Paranoid Ideation. In comparison, Jean, Beatty, Paul, and Mullins (1997) found that their MS sample did not differ significantly from their normal control group on four of the SCL-90-R dimensions: Interpersonal Sensitivity, Anxiety, Hostility, and Paranoid Ideation. As noted by Jean et al., this significantly higher level of psychological distress is consistent with the published literature. The absence of a statistically significant difference between the two groups on the dimension of Paranoid Ideation indicated that the MS sample did not feel significantly distrustful or suspicious of other people. This scale is comprised of items such as: "Feel that most people cannot be trusted", "Feel others are to blame for most of your troubles", and "Feel that people will take advantage of you if you let them".

Degree of Psychological Impairment in MS Samples

Between 31% and 49% of the MS sample indicated psychological 'distress' or impairment on the dimensions of the SCL-90-R. The highest percentage of impairment was recorded on the Depression dimension with the self-report ratings of almost half of the MS sample (49%) equal to or greater than one standard deviation above the mean of the control group; and 31% of the MS sample's ratings equal to or greater than two standard deviations above the mean of the control group. Previous research has also reported finding high levels of depression in MS samples (Clark et al., 1992; Krupp et al., 1994). Clearly, MS is a major stressor in the lives of people with MS and the source of significant psychological distress.

Relationship Between Cognitive Functioning and Other Disease Variables

There have been conflicting findings in the literature about the relationship between the cognitive impairment caused by MS and other disease variables such

as disease duration, disease course, psychological functioning, fatigue, medication use, and physical impairment. The relationship between cognitive functioning and each of these variables is now considered in turn.

Physical Impairment

The physical functioning of this MS sample was found not to be statistically significantly correlated with their cognitive functioning. Despite this, when the sample was divided into 'cognitively intact' and 'cognitively impaired' subgroups on the basis of their global cognitive rating, there was a significant difference in the degree of physical impairment of the two subgroups. These conflicting results are likely to have arisen because of the inclusion of the 13 participants with missing cognitive test data, in the latter calculations. The physical impairment of these 13 participants was more advanced, as, it would appear, was the extent of their cognitive impairment. Interestingly, the studies by Rao, Leo, Bernardin, et al. (1991) and Rao, Leo, Ellington, et al. (1991) also reported inconsistency in this area. While both studies utilised the same MS sample, the correlation of cognitive functioning with severity of physical impairment reported in Rao, Leo, Bernardin, et al. was reported to be statistically significant. Yet when the MS sample was subdivided, no statistically significant difference in physical functioning was evident between the 'cognitively intact' and 'cognitively impaired' MS groups (Rao, Leo, Ellington, et al., 1991). This contradiction may indicate a lack of robustness in these particular findings.

McIntosh-Michaelis et al. (1991) found cognitive functioning to be significantly correlated with the physical functioning of their MS sample, while Heaton et al. (1985) found no correlation between these variables in their MS sample. It is possible that as the MS disease process advances, the different

domains of impairment become more highly correlated, as the deterioration of the central nervous system becomes more widespread.

Disease Duration

In the present study, no statistically significant relationship was found between the cognitive functioning of the MS sample and the number of years since the onset of their MS symptoms, however there was a significant relationship between their cognitive functioning and the number of years since their MS diagnosis. These differing results may be an artefact of the retrospective nature of participants' recall regarding MS symptom onset. Given the confusing and transient nature of early MS symptomatology, it would be easy and understandable for people to later attribute to MS, all vague somatic and cognitive complaints previously experienced. Therefore, the number of years since MS diagnosis may be a more accurate indication of actual disease duration for the overall sample. If this is the case, disease duration was indeed significantly related to the degree of cognitive impairment in the present MS sample. If the cognitive impairment experienced by people with MS has mostly neurological origins (as recent research employing Magnetic Resonance Imaging has indicated), and given that the disease is progressively degenerative, it follows that cognitive impairments become more evident and severe as time passes and the disease process advances.

Heaton et al. (1985) and McIntosh-Michaelis et al. (1991) also both found cognitive functioning in their MS samples to be significantly correlated with MS disease duration. Alternatively, Rao, Leo, Bernardin, et al. (1991) found no relationship between cognitive impairment and disease duration in their MS sample.

Disease Course

No significant relationship was found between MS disease course and the cognitive functioning of the present MS sample. This contrasts with the findings of Heaton et al. (1985), who reported MS disease course to be an independent determinant of cognitive impairment. However, Rao, Leo, Bernardin, et al. (1991) also found MS disease course to be unrelated to the cognitive functioning of their MS sample although they did report a tendency for participants with a relapsing/ remitting disease course to fail fewer cognitive tests than participants with a chronic/progressive or chronic/stable disease course. This trend was not found in the sample assessed in this study. One explanation for this could be the manner in which MS disease course was determined. As access to neurologists' notes and medical records was not available for the present study, disease course was established from descriptions by the participants with MS, and members of their family if any were present. The extent to which these description were accurate is unknown.

Psychological Functioning

Emotional functioning can have an indirect effect on cognitive test variables (Peterson & Kokmen, 1989). This needs to be considered with the present MS sample, as their cognitive functioning was found to be significantly related to their self-reported psychological functioning. Interestingly, however, when the MS sample was divided into 'cognitively intact' and 'cognitively impaired' subgroups on the basis of their global cognitive rating scores, there was no significant difference between the two groups in their self reported psychological functioning.

Again, these results are somewhat similar to those of the Milwaukee study (Rao, Leo, Bernardin, et al., 1991; Rao, Leo, Ellington, et al., 1991). Rao, Leo,

Bernardin, et al. reported a non-significant trend for people in their MS sample classified as depressed (using the Zung Depression Scale) to fail more cognitive tests. However, when this MS sample was divided into cognitively intact and cognitively impaired subgroups, there were no significant subgroup differences on the self-report measures of depression and anxiety (Rao, Leo, Ellington, et al., 1991). Several other studies have reported that depression has not accounted for the impaired cognitive performance demonstrated by MS samples (Clark et al., 1992; Krupp et al., 1994).

Medication Use

As recommended by Heaton et al. (1985) and Rao (1986), the effect of medication use on cognitive test results was considered in the present study. Sixty-eight percent of the MS sample was taking prescribed medication at the time of assessment. No relationship was found between cognitive functioning and medication use. This finding is the same as that reported by Heaton et al. (1985), McIntosh-Michaelis et al. (1991), and Rao, Leo, Bernardin, et al. (1991), who all found no relationship between the cognitive functioning and medication use in their MS samples.

Summary

In conclusion, there is consistency in the reports from various studies regarding the lack of a relationship between medication use and cognitive functioning in people with MS. However there are conflicting reports regarding the relationship between cognitive functioning and physical functioning, emotional functioning, disease course, and disease duration in MS samples. The variability of the MS disease experience between individuals is likely to contribute to this inconsistency in research findings.

Comparison of Functioning of 'Cognitively Intact' and 'Cognitively Impaired' Participants with MS

Thirty-six percent of the present MS sample were classified as cognitively impaired, compared to 48% of the sample studied by Rao, Leo, Ellington, et al. (1991). While Rao, Leo, Ellington, et al. reported no significant difference in the physical functioning of their two MS subgroups, there was a significant difference in the physical functioning of the two subgroups in the present study. There was also a significant difference in the age and number of years since MS diagnosis between the cognitively impaired and cognitively intact subgroups in the present study. Consequently, when differences were found between the two groups on measures of disability, handicap, and cognitive-behavioural ratings by family members, these three variables on which the groups differed were incorporated as covariates to determine their contribution.

Incapacity Status Scale

Rao, Leo, Ellington, et al. (1991) reported a significant difference between their cognitively impaired and cognitively intact MS samples on the Incapacity Status Scale in the area of Mentation and a non-significant trend on the Bathing and Sexual Function scales. While differences between the cognitively impaired and intact groups were evident on half a dozen scales in the present study, the only statistically significant difference that remained when differences in the participants' age, years since MS diagnosis, and physical functioning were accounted for, was Speech and Hearing. Therefore, differences on the other five variables were attributable to the effects of the three covariates. The reason for the significant difference in the speech and hearing of the two groups is unclear. Self-report bias

or lack of insight may be the reason for the absence of a significant difference between the two groups on the Mentation scale.

Environmental Status Scale

On the Environmental Status Scale, the two MS subgroups differed in the changes they had required to their personal residences and the amount or kind of social activity that they engaged in. They also differed in the extent of community services that they required. The finding that people with MS who were comparatively more cognitive impaired engaged in fewer social activities was also reported by Rao, Leo, Ellington, et al. (1991). Clearly, cognitive impairment translates to increased handicap for some people with MS.

The absence of a statistically significant difference between the work status of people with MS who were cognitively impaired and those who were cognitively intact may be a consequence of the low level of employment in the MS sample as a whole (approximately 20%). This high rate of unemployment in the MS sample is likely to have resulted from MS-related factors.

Psychological Functioning

The absence of a statistically significant difference between the cognitively intact and cognitively impaired MS subgroups on all nine dimensions of the SCL-90-R suggests that their differences in cognitive functioning cannot be attributed to their psychological functioning. This finding was also reported by Rao, Leo, Ellington, et al. (1991).

Cognitive-Behavioural Ratings by Family Members

Statistically significant differences in the cognitive-behavioural ratings by family members of the two MS subgroups were evident in the domains of needing routine, and disorientation. As with the self-report ratings by the two MS

subgroups, there was no significant difference in the ratings by family members of the level of depression evident in the two groups. This differs from the finding of Rao, Leo, Ellington, et al. (1991) who reported that close relatives or friends of cognitively impaired people with MS were more likely to rate that person as less emotionally stable (on the Katz Adjustment Scale) than were close relatives and friends of cognitively intact people with MS. However 'emotional stability' and depression may not be comparable constructs in these studies.

Interestingly, there was no difference in the ratings by family members of the two groups, in the domains of memory disorder and higher cognitive deficits (e.g., social judgment). Intact language and verbal skills can disguise other cognitive impairments. This can result in family members being largely unaware of the cognitive deficits that are a common feature of MS. Lack of awareness may, in turn, lead to unrealistic expectations, misunderstandings, and frustration for both family members and people with MS.

Conclusion

This study has clearly demonstrated the high prevalence of cognitive deficits in people with MS. A number of the participants in the MS sample of this study mentioned that cognitive impairment was one of their major concerns about the disease and they were very much aware of their impaired cognitive abilities compared to their previous level of functioning. This impairment was a source of frustration for them as they carried out their usual daily activities.

There has been greater awareness by researchers in the past 10 to 15 years of the occurrence of cognitive impairments in people with MS, leading to a greater public awareness and understanding of this component of the disease. Among other things, the present study has contributed a New Zealand flavour to the literature.

CAREGIVER STUDY

CHAPTER 6

Introduction

Caregiving is a normal part of relationships in which the people involved care about each other. Whereas caring refers to the affective component of a relationship, caregiving is defined as the behavioural component (Pearlin, Mullan, Semple, & Skaff, 1990). Consequently, most people engage in the process of informal caregiving on a regular basis. However, in some circumstances this normal exchange of caring and caregiving can become unbalanced. This is often the case for people rendered severely impaired due to an accident or illness. The role of one party to the relationship predominantly becomes that of caregiver, while the role of the other becomes care-receiver. The change in roles requires adjustment by both people.

Informal family caregiving is not an uncommon experience (Brody, 1985). In fact, for recent generations, informal caregiving arrangements may have been on the increase due to the reduction in institutional care facilities, and medical advances increasing the longevity of people with even the most severe physical impairments. Research into caregiving processes has increased greatly since Fengler and Goodrich (1979) referred to caregivers as the "hidden patients". Possible negative outcomes of caregiving include a sense of burden, depression, reduced well-being, physical ill-health, emotional distress, and social isolation (Knight, 1992). Particular attention in psychological literature has been accorded to caregiver stress or burden.

The term "caregiver burden" has become employed to refer to the range of difficulties that can be experienced by people caring for an impaired family

member. These difficulties can be physical, psychological or emotional, social, and/or financial in nature. Since Hoenig and Hamilton's (1969) work with caregivers of people with psychiatric illness, a distinction has been made between objective and subjective burden. Objective burden refers to observable changes in the environment (e.g., financial changes, changes in routine and activities of daily living) and the care recipient (e.g., physical, cognitive, psychological, and social changes), while subjective burden refers to the feelings, attitudes, and thoughts of caregivers with regards to their caregiving role (Chwalisz, 1992).

Numerous studies have found that variables contributing to objective burden (e.g., illness/injury severity, degree of physical and cognitive impairment) have not been reliable predictors of subjective burden (e.g., Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; George & Gwyther, 1986; Marsh, Kersel, Havill, & Sleigh, 1998; Zarit, Reever, & Bach-Peterson, 1980). Montgomery, Gonyea, and Hooyman (1985) found that while measures of objective and subjective burden were correlated, different factors predicted the two different aspects of caregiver burden. For example, caregiver reports of subjective burden were related to caregivers' age and income, while caregivers' reports of objective burden were related to the type of caregiving tasks performed (Montgomery et al., 1985). Burden experienced by caregivers is clearly not commensurate to objective events or care-receiver characteristics (Chwalisz, 1992). Pearlin et al. (1990) comment that "it is useful to think of caregiver stress not as an event or as a unitary phenomenon. It is, instead, a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that consequently vary in their impact on caregivers health and behaviour" (p. 591).

To better understand the nature of caregiver burden or stress, researchers have frequently utilised the transaction theory of Lazarus and Folkman (1984). Their model of stress and coping hypothesises that a critical determinant of the effects of objective stressors is a person's appraisal of those stressors. Knight (1992) outlines a model of stress response in caregivers, based on the work of Lazarus and Folkman, whereby the effect of objective stressors is mediated by three factors: caregivers' appraisal of stressors, caregiver coping strategies, and caregiver social support (Figure 6.1).

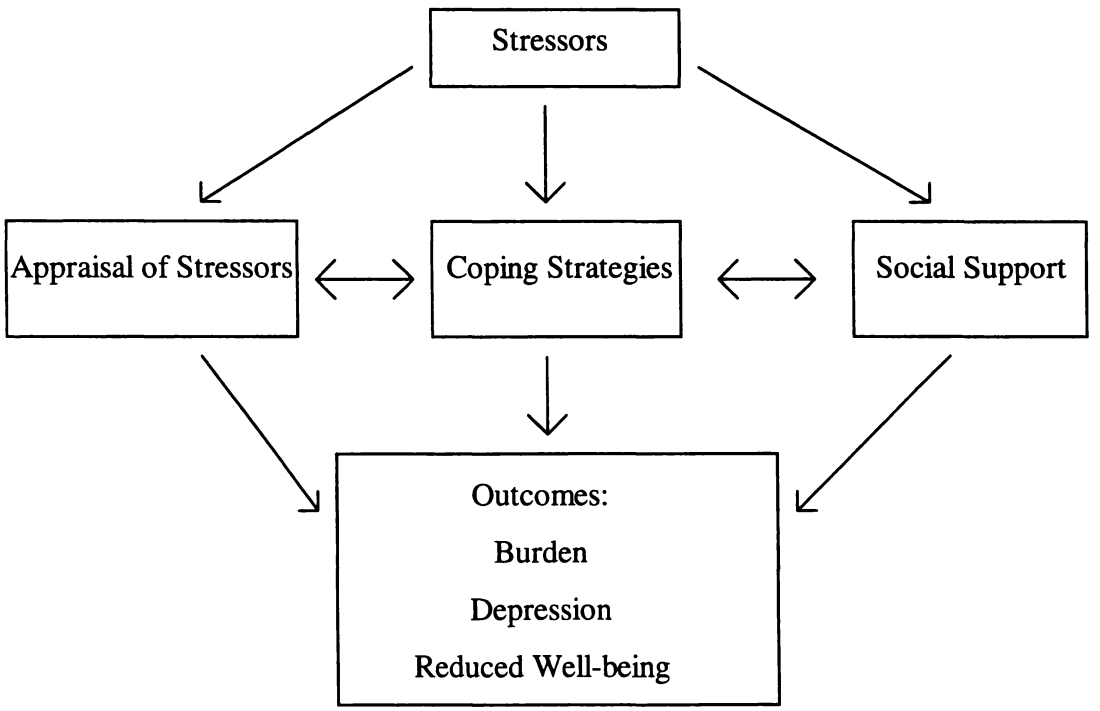

Figure 6.1. Knight's (1992) model of stress response in caregivers.

A large body of research has investigated the positive mediating effects of social support, coping, and appraisal of stressors. Much of this research has involved people in a caregiving role for a family member with Alzheimer's Disease

or other forms of dementia. For example, Zarit et al (1980) studied 29 primary caregivers of people with senile dementia. Severity of behavioural problems in the people with dementia was not associated with the report of higher levels of burden by the caregivers. However, the caregivers' experience of burden was less when more visits were paid to the person with dementia by other relatives, highlighting the buffering effect of social support.

An investigation by George and Gwyther (1986) into the well-being of 510 family caregivers of older adults with memory impairments found that in comparison with a community sample, the caregivers were more likely to experience problems with mental health and social participation. Measures of the caregivers' well-being were significantly related to their perceived need for more social support. This was the case even when the actual amount of social support being received was controlled for. Caregivers who did not perceive a need for more social support reported more favourable well-being than caregivers who perceived the need for more support from family and friends. In this study, illness characteristics of the care receiver were not found to be important predictor variables of caregiver well-being.

Zarit, Todd, and Zarit (1986) reported results from a study of 64 spousal caregivers of people with dementia, whereby the decision by caregivers to place their spouse in a nursing home was associated with subjective factors such as caregivers' perceived level of burden. Severity of the care-receivers' symptoms did not differentiate between caregivers who placed their relative in a nursing home and those who did not. In this study no relationship was found between social support and burden or the placement decision.

Broadhead, Gehlbach, de Gruy, and Kaplan (1988) described two categories of social support measures. One assesses quantitative or structural aspects of social support networks, such as size, frequency, and density. The other examines qualitative or functional aspects of supportive relationships. Broadhead et al. reviewed research findings which have indicated that quality of social support is a stronger predictor of health outcome than quantity and that the latter is often not significantly related to well-being.

In summary, there has been undisputed evidence that caregivers experience stress or burden as a consequence of their caregiving role. Aspects of caregiver burden and the mediating effects of several variables have also been investigated for several caregiving populations. However, to date, there has been scant research specifically examining the well-being of caregivers of people with MS. There are unique features about a diagnosis of MS that make the study of its impact for caregivers deserving of individual analysis. These features include the unpredictable disease trajectory; the waxing and waning nature of the symptomatology; the combination of motor, sensory, and cognitive impairments; and the comparatively early age of the person at the time of disease onset.

Caregiving and MS

MS is the most common degenerative disease diagnosed in young adults, with the majority of people diagnosed between 20 and 40 years of age. Therefore, when people are first advised that they have the disease, they are commonly engaged in life tasks centering around the establishment of a long-term relationship with a partner, raising a young family, establishing a career, and/or meeting financial commitments such as house repayments. MS challenges a person's coping resources and family members are a feature of most people's coping resources.

Frequently one family member (often a spouse) becomes established as the primary caregiver.

The waxing and waning nature of MS symptoms creates additional difficulties in the adjustment process for both caregivers and care receivers, with impairments changing in frequency, intensity, and duration at irregular intervals. Aronson (1997) found that an unstable disease course was associated with poorer quality of life among people with MS. The unseen nature of some impairments (e.g., cognitive impairment and fatigue) can result in confusion and misattributions.

Two studies have directly set out to investigate the impact of MS for familial caregivers. The first of these was conducted by Cockerill and Warren (1990). In an earlier study by these authors (Warren, Cockerill, Paterson, & Patterson, 1986) family members were identified as providing the majority of help with personal care, household tasks, and transportation for people with MS, with relatively little assistance provided by friends, paid employees, volunteers, and government agencies. In 1990, Cockerill and Warren reported on the amount of time that their sample of caregivers spent contributing to the care of their family member with MS, the impact that providing this caregiving had on the lifestyle of the caregivers, and the caregivers' use of respite services.

The average age of the caregivers in Cockerill and Warren's (1990) study was 48 years and 52% of the sample were female. The number of caregivers who participated in the study was not provided. Ninety-six percent of the caregivers were related to the people with MS, with the majority of them (66%) being spouses. Thirty-five percent of the caregivers reported spending 90 minutes or more providing personal care for their relative with MS on a daily basis. Fourteen percent of the caregivers reported spending more than five hours a day providing

this personal care. Ninety-five percent of the caregivers reported helping with homemaking activities, with 21% reporting that they provided five or more hours assisting in this area. Seventy-eight percent of caregivers reported providing assistance with communication and related activities, with 10% spending more than five hours per day assisting with tasks in this area.

There was a discrepancy between the perceptions of the people with MS and the caregivers regarding how much assistance was provided by the caregivers. On 21 of the 22 activities measured, a smaller percentage of the people with MS than the caregivers reported that assistance was always required from the primary caregiver. These results suggested that either the participants with MS underestimated the care they required or their caregivers overestimated the care that they provided, or both.

The caregivers in this study were questioned about the degree to which caregiving for their relative with MS had curtailed their level of involvement in other areas of activity (i.e., entertaining at home, taking holidays, attending social activities, participating in recreational activities, and visiting family). In all of these areas but one (visiting family), the majority of caregivers indicated some degree of curtailment. For example, 28% of the sample indicated that their ability to take holidays had been 'greatly' curtailed, while 42% of the sample considered themselves to have been 'somewhat' curtailed in this area and 30% of the caregiver sample considered that their ability to take holidays had not been curtailed. Similarly, 21% of the caregivers rated their participation in social activities as having been 'greatly' curtailed, while 41% of the sample considered their participation in social activities to have been 'somewhat' curtailed and 38% did not consider their participation in social activities to have been curtailed. Only 55% of

the caregivers who looked after their relative with MS at home had used any form of respite care (e.g., hospital admittance, hiring assistants, or calling on friends and family). Cockerill and Warren (1990) concluded that the caregivers in their sample were providing a substantial amount of support for their family members with MS and that this was provided at some cost to the caregivers, by way of curtailment of the caregivers' usual activities.

The second investigation into the experience of people living with someone diagnosed with MS was conducted by O'Brien (1993). Being guided by Lazarus and Folkman's (1984) theoretical model of stress and coping, O'Brien's aims were to describe the stressors experienced by spousal caregivers, identify coping behaviours used, and explore the relationship between caregiver stressors and caregiver coping behaviours.

O'Brien's sample of 20 people included 9 caregiving wives and 11 caregiving husbands, ranging in age from 36 to 70 years, with a mean age of 52. On average, caregivers had been providing care for their spouses for 8 years, with a range of 1 to 25 years. Ninety percent of the caregivers performed some personal care tasks for their spouses. Typical caregiving tasks included assistance with bathing, dressing, toileting, and feeding. The caregivers completed measures of caregiver stress and coping.

The mean stress score for the caregiver sample was 28.80 out of a possible range of 0 to 52, indicating that the caregivers experienced a moderate level of stress. Changes in personal plans and confinement were found to be the major stressors for the majority of caregivers in this study, indicating that the provision of physical care was less burdensome than restrictions on personal freedom. For example, 80% of the caregivers reported that demands placed on their time

interfered with their obligations to other family members, friends, and careers. Seventy percent of the caregivers described being confined frequently to their homes because their spouse with MS could not be left unattended for extended periods of time.

Sixty-five percent of the caregivers in O'Brien's (1993) study reported experiencing emotional adjustments due in part to feelings of helplessness because of the progressive nature of MS, the uncertainty of the future, and their inability to control or predict the course of the disease and its adverse affects for their spouse. Sixty-five percent of the caregivers reported that the physical and cognitive changes in their spouse had altered the quality of their previous relationship. Seventy-five percent of the caregivers found that the cognitive impairment of their spouse was especially upsetting because of the effect on marital, family, and social interactions. Bowel and bladder dysfunction, which necessitated frequent assistance with toileting, was also particularly upsetting and 45% of the caregivers frequently experienced disturbed sleep primarily due to their spouses' need for toileting. Financial burdens were reported by 70% of the caregivers. Fifty-five percent of the caregivers in O'Brien's study reported being overwhelmed with the sheer magnitude of their spouses deficits and 65% felt inconvenienced as caregiving became more time consuming and confining, and as infringements on personal time and lifestyle began to escalate.

Results from this study indicated that the caregivers engaged in more problem-focused coping strategies than emotion-focused coping strategies. O'Brien (1993) reported positive correlations between the stress scores of the caregivers and several forms of coping behaviour (i.e., detachment, problem-focused coping, wishful thinking, tension reduction, keeping to oneself, and

focusing on the positive), indicating that as stress increased so did these kinds of coping behaviours. O'Brien's findings support conclusions made by Anderson (1977) and Lazarus and Folkman (1984) that when few possibilities for change exist (as may be the case for people faced with a progressive degenerative condition), and with high levels of stress, people tend to resort more to emotion-focused coping strategies.

In their population-based study which examined the relationship between impaired cognitive functioning in people with MS and other disease variables, McIntosh-Michaelis et al. (1991) briefly discussed reports by relatives who had rated the cognitive impairment of the MS sample. Of the people with MS who were impaired on one or more of the psychometric tests, 74% of the relatives reported memory impairment. Forty-one percent of relatives reported memory impairment in their relative with MS when test results had not indicated memory impairment. 'Personality change' in the person with MS was reported by 66% of the relatives of the cognitively impaired people with MS and by 50% of the relatives of cognitively intact people with MS.

McIntosh-Michaelis et al. (1991) reported no significant correlations between poor performance on cognitive measures by the participants with MS and their relatives' Hospital Anxiety and Depression Scale scores. However, the authors considered that the cognitive changes evident in many people with MS do cause stress in personal relationships and a reduction in the quality of life for people with the disease and their families. They advocated further research into this area so that interventions with this population can be better informed, with steps taken to minimise the handicap resulting from cognitive impairment.

Conclusion and Aims

Clearly, a caregiving role brings with it numerous challenges and potential stressors. The increase in research undertaken in this area in recent decades has demonstrated recognition of this fact. Cockerill and Warren (1990) and O'Brien (1993) have investigated the well-being of people engaged in a caregiving role for a family member with MS. The caregiver samples in both these studies reported stress or burden in relation to their caregiving role. O'Brien also examined the coping strategies utilised by spousal caregivers, concluding that as stress in their caregiving role increased, there was an increase in both problem-focused and emotion-focused forms of coping behaviour.

No attention has been paid, as yet, to the influence of social support and appraisal of stressors on the well-being and burden experienced by familial caregivers of people with MS. Neither has the well-being and burden expressed by caregivers of people with MS been compared to that of a normal control group. Consequently, the aims of this study were as follows:

1. Comparison of the well-being, stress/burden, and social support networks of familial caregivers of people with MS with that of a normal control group.
2. Following Knight's (1992) model, the examination of the contributions of: (a) clinically determined impairment in people with MS, (b) caregivers' appraisal of the functioning of their family members with MS, and (c) social support, in determining caregivers' self-reported psychological functioning and experience of burden.

CHAPTER 7

Method

Participants

Fifty-eight of the people with MS who had participated in the MS Study had a family member who agreed to participate in the Caregiver Study. Of the 73 control participants in the MS Study, 42 had family members who agreed to participate as controls in the Caregiver Study. The data of six caregiver participants were not included in the data analysis because their family member with MS had a history of head injury, substance abuse, or a psychiatric history predating the onset of MS. Consequently, the final samples for the Caregiver Study consisted of 52 family members of the participants with MS who had taken part in the MS Study and 42 family members of the control participants from the MS Study. There were no statistically significant differences between the two groups on the matching variables of age, $t(92) = 0.15$, $p > .05$; gender, $\chi^2(1) = 0.32$, $p > .05$; and socioeconomic status, Mann-Whitney U, $z = 0.51$, $p > .05$. For a summary of this demographic information see Table 7.1.

Caregiver Sample

Of the 52 caregiver participants, 48 (92%) were the spouse of the participant with MS, two (4%) were parents, one (2%) was a child, and one (2%) was a relative of the participant with MS. Nineteen (37%) of the caregiver participants were female. The mean age of the caregiver participants was 52 years (SD = 14, range = 14 - 81). According to Johnston's (1983) socioeconomic indices five (10%) of the caregiver participants were classified as SES level 1, five (10%) were classified as level 2, another five (10%) as level 3, six (12%) were classified as level 4, one (2%) as level 5, and one (2%) was classified as level 6. Twenty-nine

Table 7.1

Matching Variables for Caregiver Sample ($N = 52$) and Control Group ($N = 42$)

Variable	Caregiver Sample	Control Group
Gender:		
Female	19 (37%)	13 (31%)
Male	33 (63%)	29 (69%)
Age (years):		
Mean	52.40	51.98
SD	14.01	12.73
Socioeconomic Status:		
1	5 (10%)	7 (17%)
2	5 (10%)	7 (17%)
3	5 (10%)	8 (19%)
4	6 (12%)	9 (21%)
5	1 (2%)	1 (2%)
6	1 (2%)	0 (0%)
Unclassified	29 (56%)	10 (24%)

(56%) of the caregiver participants were not able to be classified as they were not in paid employment at the time of assessment.

Twenty-three (44%) participants from the caregiver sample were in paid employment, seven (13%) were fully occupied managing their households, two (4%) were full-time students, 19 (37%) were retired, and one (2%) was receiving an Invalid's Benefit. Forty-four (85%) of the sample classified their ethnic origin as

New Zealand European and two (4%) as New Zealand Maori. The remaining six (12%) caregiver participants were English, American, or Dutch. Forty-nine (94%) of the caregiver participants were married or in a de facto relationship at the time of assessment and three (6%) had never been married. One (2%) caregiver participant was living alone (while his relative with MS was residing in a nursing home), 31 (60%) of the caregiver participants lived with a partner only, 19 (37%) lived as part of a family unit, and 1 (2%) participant lived in a flatting situation. Seventeen (33%) of the caregiver participants had dependent children at the time of assessment.

Control Group

Forty-two control participants from the MS Study had family members living with them who were willing to take part in the Caregiver Study as control participants. Of these 42 control participants, 13 (31%) were female. The mean age for this sample was 52 years (SD = 13, range = 14 - 74). Seven (17%) of the control participants were classified as SES level 1 using Johnston's (1983) socioeconomic indices. Seven (17%) participants were classified as level 2, eight (19%) as level 3, and nine (21%) as level 4. One (2%) participant was classified as level 5. Ten (24%) participants were not able to be classified as they were not in paid employment at the time of assessment.

Thirty-two (76%) of these participants were in paid employment at the time of assessment, one (2%) was occupied full-time managing the household, one (2%) was a full-time student, one (2%) was unemployed, and seven (18%) control participants were retired. Thirty-eight (90%) of this sample were of New Zealand European origin. The remaining four (10%) were English, German, or Canadian. Thirty-nine (93%) of the control participants were married or in a de facto

relationship at the time of assessment, one (2%) participant had never been married, and two (5%) were widowed. Twenty (48%) of the control participants were living with a partner only, 19 (45%) were living as part of a family unit, one (2%) lived in a flatting situation, and two (5%) lived with other relations. Thirteen (31%) of the control participants had dependent children at the time of assessment.

Measures

Interview

The same semi-structured interview protocol that was used for the control group from the MS Study was followed to obtain demographic information from the caregiver and control participants (see Appendix B).

Caregiver Rating Questionnaire

The Cognitive Behavior Rating Scale (Williams, 1987) was introduced in the MS Study methodology. This 116 item rating scale obtains information from an observer regarding cognitive and behavioural deficits, and observable neurological signs for a patient. The questionnaire is comprised of the following nine scales: Language Deficit, Apraxia, Disorientation, Agitation, Need for Routine, Depression, Higher Cognitive Deficits, Memory Disorder, and Dementia. See Chapter Three for more psychometric details about this measure.

Self-Report Questionnaires

A variety of measures of caregiver experience were employed to gather standardised information about the caregiving process for these participants (see Appendix J).

Psychological functioning. The General Health Questionnaire (Goldberg & Williams, 1988) is a self-administered screening test aimed at detecting psychiatric disorders among participants in community settings. For the present research the

28-item version was used. This contains 28 questions about particular symptoms or behaviours. The questions are divided into four groups, each containing seven items, representing four dimensions of symptomatology: somatic symptoms (scale A), anxiety and insomnia (scale B), social dysfunction (scale C), and severe depression (scale D). Participants are required to indicate the extent to which they have experienced each item in the previous few weeks, using a Likert scale ranging from "Not at all" to "Much more than usual". Item responses were scored 0, 1, 2, or 3, with higher scores indicating more symptomatology.

The questionnaire manual details the statistical properties of several versions of the General Health Questionnaire (e.g., 60, 30, 28, and 12 item versions). Reliability coefficients ranging from .75 (test-retest) to .94 (split-half), and validity percentages ranging from 80% (specificity) to 96% (sensitivity) are recorded. Factor analysis of the General Health Questionnaire - 28 identified four factors: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression (Goldberg & Hillier, 1979). These subscales are not independent of each other and do not necessarily correspond to psychiatric diagnoses. Validation of the four subscales and the total score was examined using the 60-item General Health Questionnaire and Clinical Interview Schedule ratings of 200 participants in the original normative sample. Correlation coefficients ranging between .21 and .76 are reported.

Social support. Two measures of social support were utilised, one a measure of qualitative or functional social support, and the other a measure of quantitative or structural social support.

The measure of qualitative social support employed was the Duke-University of North Carolina Functional Social Support Questionnaire (Broadhead

et al., 1988). This is a self-administered questionnaire requiring participants to rate eight statements along a five point Likert scale, where 1 translates to "As much as I would like" and 5 is "Much less than I would like". Higher scores indicate less satisfaction with the quality of social support received.

The normative sample consisted of 401 people presenting to a family medical centre in Durham, North Carolina between November 1983 and May 1984. The average age of the sample was 36 years (range 18 - 44 years) and participants were predominantly female and Caucasian. The mean scores for the original 14 items of the questionnaire ranged from 3.54 to 4.34 (*SD* = .99 to 1.41). Following reliability and factor analyses, the questionnaire was reduced to its current eight item form. Test-retest reliability following an average interval of 13 days yielded a correlation coefficient of .66. Factor analysis revealed two major factors: Confidant Support (five items) and Affective Support (three items), yielding internal consistency coefficients of .62 and .64 respectively. Significant relationships were found between the items of this social support measure and other measures of general health.

The measure of quantitative social support employed in the current research was the Social Health Battery developed by Donald and Ware (1984). The original Social Health Battery consisted of 11 items, however one item (about writing letters) was discontinued as it was considered invalid (McDowell & Newell, 1987). Consequently, the questionnaire used in this study contained only 10 items. The Social Health Battery is a self-administered questionnaire which requires both forced choice and open ended responses. It provides an indication of the quantity of a person's social network by inquiring about social resources and frequency of social contact in the areas of home and family, friendships, social, and community

life. Donald and Ware provide a scoring format to recode the questionnaire's response options. Two subscales can be calculated: frequency of social contacts (the total of items 3, 4, and 5) and group participation (the sum of items 9 and 10). A measure of overall quantity of social support was derived from the total scores of these two subscales, together with the responses to questions 1, 2, 6, and 8. Question 7 was excluded from the final analysis as it has been found to be unreliable (Wilkin, Hallam, & Doggett, 1992). Higher scores on this questionnaire are indicative of more favourable levels of social resources and social interaction.

The questionnaire was normed on adults aged 14 to 61 years. Test-retest reliability following a one-year interval recorded coefficients of .55, .68, and .68 for the social contacts subscale, the group participation subscale, and the total social support index respectively. Coefficients for the individual items ranged from .23 to .80. Inter-item correlations were low with only 5 of 45 correlations exceeding .40. Internal consistency was recorded as .72 for the social contacts subscale, .84 for the group participation subscale, and .68 for the overall social support index.

Caregiver burden. Montgomery et al. (1985) developed a questionnaire for the purposes of detecting burden experienced by family members assuming a caregiver role for an elderly relative. Their measure is divided into two sections: objective and subjective burden. Objective Burden was defined as "the extent of disruptions or changes in various aspects of the caregivers' life and household" (p.21), while Subjective Burden was defined as "the respondents' attitudes toward, or emotional reactions to, the caregiving experience" (p.21).

The Objective Burden scale consists of nine questions regarding aspects of the caregiver's life most frequently identified by previous research to be affected by the caregiving experience. Thirteen questions related to feelings and attitudes make

up the Subjective Burden measure. Both measures employ a five-point Likert response scale. Scores on the Objective Burden scale have a possible range of 9 - 45, with one point given for each rating of 'a lot more/better' through to five points given for each rating of 'a lot less/worse'. Scores on the Subjective Burden scale have a possible range of 13 - 65, with one point allocated for each rating of 'rarely or never' through to five points allocated for each rating of 'most of the time'.

The measures of Objective and Subjective Burden were developed in a study of 80 individuals who were involved to varying degrees in caring for an elderly relative. Cronbach's alpha was used to test the reliability of both scales, yielding an alpha equal to .85 for the Objective Burden scale and .86 for the Subjective Burden scale.

Procedure

Data Collection

If family members who had volunteered to take part in the research as caregiver participants were in the house at the time of the assessment of the person with MS, any questions they had about the research were addressed before they signed a consent form and underwent the semi-structured interview to obtain their demographic details. These participants then completed the self-report questionnaires and the Cognitive Behavior Rating Scale requiring about 40 minutes of their time.

If caregiver and caregiver control participants were not home at the time of the assessment of their family member, the consent form, demographics form, and caregiver questionnaires were left at the house in a stamped addressed envelope, to be completed by the participant and returned by mail. This was the case for 15 of

the caregiver participants and 21 of the control participants. The researcher's contact telephone number was made available in case questions arose as these participants completed their forms.

Data Analysis

Data was described using the following descriptive procedures: mean (*M*), standard deviation (*SD*), and range. Statistical analyses were completed using the following procedures: independent *t* test, *t* test for unequal variance estimates, Pearson product-moment correlation, and hierarchical regression. Prior to conducting regression analyses variables were screened for multicollinearity. Following the suggestion of Tabachnick and Fidell (1989), variables with a correlation greater than .70 were combined. An alpha level of .05 was used to determine statistical significance. In those instances where $p < .05$, the exact obtained alpha level is reported.

Following Knight's model, the hierarchical regressions were performed with three clinically-determined variables of impairment in the MS sample (i.e., stressors) added in step one, caregivers' appraisal of the impairment of the MS sample (i.e., appraisal of stressors) added in step two, and caregivers' reports of quantity and quality of social support added in step three.

CHAPTER 8

Results

Caregiver Sample Compared With Control Group

Data from all 52 participants in the caregiver sample and all 42 participants in the control group were included in this section of the analysis. Table 8.1 summarises the results of the cognitive-behavioural ratings of the participants in the MS Study by their family member. Table 8.2 summarises the results of the comparison between the caregiver sample and the control group on the measure of psychological functioning, the two social support measures, and the caregiver burden questionnaire.

Cognitive Behavioural Ratings of Participants in MS Sample and Control Group by Family Members

The results of the Cognitive Behavior Rating Scale completed by a family member for 52 of the participants in the MS sample and 42 of the control participants in the MS Study are presented in Table 8.1. Significant differences on the ratings made by the family members of each group are evident on all nine dimensions of the Cognitive Behavior Rating Scale. In each of these areas, participants in the MS sample were rated by their family members as more impaired compared to the ratings made by the family members of control participants.

Psychological Functioning

There was a significant difference between the two groups on the anxiety/insomnia dimension of the General Health Questionnaire-28, with the caregiver sample reporting significantly more symptoms of anxiety and insomnia than the control group ($p = .006$). There was no statistically significant difference between the groups on the dimensions of somatisation, social dysfunction, and

Table 8.1

Analysis of the Cognitive Behavior Rating Scale Completed by a Family Member for Participants in the MS Sample ($N = 52$) and Control Group ($N = 42$)

	MS Group		Control Group			
Measure	Mean	*SD*	Mean	*SD*	*t*	*p*
Cognitive Behavior Rating Scale						
Language Deficit	21.50	7.34	17.26	4.85	3.35	.001
Agitation	11.96	5.02	7.52	2.38	5.64	.0000001
Need for Routine	12.83	5.58	9.10	3.79	3.85	.0002
Depression	44.94	14.59	28.36	12.22	5.89	.0000001
Higher Cognitive Deficits	26.31	7.56	19.76	5.35	4.91	.000004
Memory Disorder	36.90	15.26	26.69	10.62	3.82	.0002
Dementia	46.17	14.44	29.83	12.41	5.80	.0000001
Apraxia	13.19	4.75	6.57	2.04	9.07	.0000001
Disorientation	7.58	3.69	5.45	2.33	3.40	.001

severe depression ($p > .05$ in each case), although there was a trend towards a significant difference on the Depression scale with the caregiver sample reporting more symptoms of depression than the control group ($p = .07$).

Consequently, while the caregivers reported significantly more symptoms of anxiety and insomnia, and somewhat more symptoms of depression, they did not differ from the control group in their report of somatisation and social functioning.

Social Support Measures

The results of the quantitative measure of social support, the Social Health Battery, show no significant difference between the caregiver sample and the control group on either of the two subscales or the overall score on this measure ($p > .05$ in each case). This indicates that there was no notable difference between the two groups in the amount of social activity in which they were engaged.

However, on the measure of qualitative social support, there was a significant difference between the two groups on one of the subscales, Affective Support ($p = .02$), and on the overall score ($p = .03$). There was also a trend towards a significant difference on the second subscale, Confidant Support ($p = .06$). On each of these scales the caregiver sample indicated less satisfaction with the quality of social support that they received compared to the control group.

Consequently, these results suggest that while both groups reported engaging in the same amount of social activity, the caregiver sample reported less satisfaction than the control group with the quality of the social support that they received.

Caregiver Burden Questionnaire

There was a significant difference between the two groups on both the Objective Burden scale ($p < .001$) and the Subjective Burden scale ($p < .001$) of this measure. The caregiver sample reported experiencing more of both aspects of burden.

Inspection of the individual items of the Objective Burden scale revealed significant differences in the same direction on all of the scale items except the eighth (i.e., there was no statistically significant difference between the two groups in their responses to the item about their relationships with other family members).

However, the remainder of items on this scale indicated that the caregiver sample experienced significantly less time to themselves, less personal freedom, less money to meet expenses, less vacation activities and trips, etc. The mean score of 31 for the caregiver sample on this scale was considerably less than the scale maximum of 45, indicating that while the caregiver sample considered their current situation to be somewhat worse than previously, on average they did not consider it to be a lot worse.

Inspection of the individual items of the Subjective Burden scale revealed that the two largest differences between the caregiver sample and the control group were on items 1 and 3, indicating that the caregivers found it painful to watch their family member with MS age ($p < .001$) and that they felt afraid for what the future held for their family member with MS ($p < .001$). Caregivers also indicated feeling more strain in their relationship with their family member with MS than the control participants felt regarding their relationship with their family member ($p < .001$).

Again, however, the average score of 27 for the caregiver sample on the Subjective Burden scale was substantially less than the maximum possible subjective burden score of 65. This indicates that while the caregiver sample felt significantly more burdened than the normal control group, they did not rate themselves as feeling the most burdened that they conceived it was possible to be.

Table 8.2

Analysis of Psychosocial Functioning for Caregiver Sample (N = 52) and Matched Control Group (N = 42)

	Caregivers		Control Group			
Domain	Mean	*SD*	Mean	*SD*	*t*	*p*
Psychological Functioning (GHQ)						
Somatisation	4.02	3.17	3.86	3.79	0.23	NS
Anxiety/Insomnia	4.81	4.26	2.79	2.68	2.80	.006
Social Dysfunction	6.75	2.02	6.81	1.84	-0.15	NS
Severe Depression	1.12	2.59	0.38	1.15	1.83	NS
Social Support						
SHB: Social Contacts	7.63	2.23	7.76	1.96	-0.29	NS
SHB: Group Participation	3.94	2.44	3.98	2.04	-0.07	NS
SHB: Total	23.96	6.20	24.71	5.87	-0.60	NS
FSSQ: Confidant Support	9.73	4.24	8.19	3.33	1.92	NS
FSSQ: Affective Support	5.48	2.49	4.45	1.68	2.38	.02
FSSQ: Total	15.21	6.48	12.64	4.52	2.26	.03
Caregiver Burden						
Objective Burden	31.35	5.08	26.69	4.55	4.63	.000012
Subjective Burden	27.27	8.22	20.45	6.20	4.45	.000024

Note. GHQ = General Health Questionnaire; FSSQ = Functional Social Support Questionnaire; SHB = Social Health Battery; NS = Not significant ($p > .05$).

Within MS Caregiver Sample Analyses

Correlational Analysis

The family members with MS of 11 of the caregiver participants were unable to participate in some or all of the cognitive and psychological assessment due to motor-sensory impairments, severe vertigo, or dementia. These caregivers were excluded from the correlational analyses due to the incomplete data regarding the person for whom they were caring. Therefore, 41 caregivers of people with MS were included in the correlational analyses that follow.

For the purposes of these analyses, the nine dimensions of the Cognitive Behavior Rating Scale completed by caregivers were collapsed into one overall score, consisting of the total of the nine subscales. This total Cognitive Behavior Rating Scale score represented the caregivers' appraisal of the functioning of their family members with MS. Five clinically-assessed measures of the functioning of the MS sample were also included. These consisted of (a) the Expanded Disability Status Scale score as a measure of overall neurological functioning; (b) the global cognitive ratings as a measure of overall cognitive functioning; (c) the Global Symptom Index from the Symptom Checklist-90-Revised as a measure of overall psychological functioning; (d) the combined total of the ratings of the 16 areas of inquiry in the Incapacity Status Scale from the Minimal Record of Disability, as a measure of disability; and finally (e) the combined total of the ratings of the seven areas of inquiry in the Environmental Status Scale from the Minimal Record of Disability, as a measure of handicap.

Table 8.3 displays the results of the correlational analyses. The relationships between the physical, cognitive, and psychological functioning of the MS sample; the caregivers' appraisal of the MS sample's impairments; the six variables of

caregiver social support; and the six variables relating to the psychological functioning of the caregiver sample and their expressed level of burden are detailed below:

Somatic complaints. Caregiver reporting of somatisation was significantly correlated with the psychological functioning of the MS sample ($r = .45$, $p = .003$). Caregivers' somatic functioning was also significantly correlated with their appraisal of the functioning of the MS sample ($r = .47$, $p = .002$) and the extent of the caregivers' participation in social groups ($r = -.36$, $p = .021$). Therefore, caregivers who (a) were living with someone with MS who was psychologically impaired, (b) were living with someone with MS whom the caregiver perceived to be functionally impaired, and/or (c) participated less in group social contact, were more likely to report somatic complaints. The somatic functioning of the caregivers was not significantly related to the remaining variables.

Anxiety/insomnia complaints. The amount of anxiety and insomnia reported by the caregivers was significantly correlated with their appraisal of the functioning of the MS sample ($r = .63$, $p < .001$). Caregiver report of anxiety and insomnia was also significantly related to their self-reported satisfaction with the quality of confidant support ($r = .35$, $p = .027$), affective support ($r = .32$, $p = .041$), and overall functional social support ($r = .34$, $p = .028$) that they received. Therefore, caregivers who perceived their family member with MS to be less impaired, and/or who reported satisfaction with the quality of social support that they received, also reported fewer symptoms of anxiety and insomnia than caregivers who perceived their family member with MS to be more impaired and/or were less satisfied with the quality of social support that they received. The amount of anxiety and

insomnia reported by the caregiver sample was not significantly related to the remaining variables.

Social dysfunction. The extent of social dysfunction reported by the caregiver sample was significantly related to the cognitive ($r = .38$, $p = .015$) and psychological ($r = .32$, $p = .044$) functioning in the MS sample. Caregivers' report of social dysfunction was also significantly correlated with their appraisal of the functional impairment of the MS sample ($r = .36$, $p = .021$). Therefore, caregivers of family members with MS who were cognitively and/or psychologically impaired, and caregivers who perceived their family member with MS to be functionally impaired, reported more social dysfunction than caregivers of family members with MS who were less cognitively and psychologically impaired, and caregivers who rated their family member with MS to be less functionally impaired. Caregivers' report of social dysfunction was not significantly related to the remaining variables.

Depression. Caregivers' report of depressive symptomatology was significantly correlated with both the cognitive ($r = .36$, $p = .019$) and psychological ($r = .47$, $p = .002$) functioning of the MS sample, and the caregivers' appraisal of the functional impairment of their family member with MS ($r = .60$, $p < .001$). Therefore, caregivers of family members with MS who were cognitively and/or psychologically impaired, and caregivers who rated their family member with MS as more functionally impaired, reported more symptoms of depression than caregivers of family members with MS who were less cognitively and/or psychologically impaired, and caregivers who rated their family member with MS as less functionally impaired.

Depression reported by the caregivers was also significantly related to the caregivers' reported frequency of social contact ($r = -.37$, $p = .017$), satisfaction

with confidant support ($r = .37$, $p = .017$), and their satisfaction with the overall quality of social support that they reported they received ($r = .35$, $p = .024$). Therefore, caregivers who engaged in social contact more frequently, were satisfied with both the quality of confidant support and the overall quality of functional social support that they received, also reported fewer and/or less severe symptoms of depression.

Depression reported by the caregiver sample was not significantly related to the physical impairment, disability, or handicap of the MS sample ($p > .05$), or to the amount of group participation or satisfaction with affective support that the caregivers' reported experiencing ($p > .05$).

Objective burden. The amount of objective burden reported by caregivers was significantly related to their appraisal of the functional impairment of their family member with MS ($r = .57$, $p < .001$). The more impaired the person with MS was perceived by their caregiver to be, the more objective burden was reported by the caregiver. The amount of objective burden reported by the caregivers was also significantly related to caregivers' satisfaction with confidant support ($r = .60$, $p < .001$), affective support ($r = .57$, $p < .001$), and their satisfaction with the overall quality of functional social support ($r = .60$, $p < .001$) that they received. Caregivers who reported satisfaction with the quality of social support that they received also reported experiencing less objective burden than caregivers who were less satisfied with the quality of social support that they experienced. Caregiver report of objective burden was not significantly related to the remaining variables.

Subjective burden. The amount of subjective burden reported by caregivers was significantly related to the cognitive impairment of the MS sample ($r = .32$, $p = .045$). More subjective burden was reported by caregivers of cognitively impaired

Table 8.3

Correlational Analyses of Variables Relating to Participants With MS and Their Caregivers ($N = 41$)

Variable	1	2	3	4	5	6	7	8	9
1. EDSS	--								
2. GC Rating	.06	--							
3. SCL - 90-R: GSI	-.04	.34*	--						
4. ISS (Disability)	.71*	.11	.23	--					
5. ESS (Handicap)	.73*	.19	.21	.90*	--				
6. CBRS: Total	-.07	.36*	.31	.04	-.03	--			
7. SHB: Social Contacts	.25	-.01	-.04	.09	.18	-.14	--		
8. SHB: Group Participation	.33*	-.13	-.19	.14	.11	-.20	.04	--	
9. SHB: Total	.34*	.09	-.12	.21	.21	-.05	.74*	.48*	--
10. FSSQ: Confidant Support	-.07	.06	-.05	-.08	-.05	.40*	-.35*	.06	-.25
11. FSSQ: Affective Support	.07	.10	-.07	.02	.06	.30	-.25	-.02	-.22
12. FSSQ: Total	-.02	.08	-.06	-.05	-.01	.37*	-.32*	.03	-.25
13. GHQ: Somatic	-.22	.30	.45*	-.02	.03	.47*	-.01	-.36*	-.21
14. GHQ: Anxiety/Insomnia	-.02	.23	.30	.07	.08	.63*	-.24	-.26	-.19
15. GHQ: Social Dysfunction	-.03	.38*	.32*	.08	.17	.36*	-.19	-.04	-.08
16. GHQ: Depression	-.19	.36*	.47*	-.03	.03	.60*	-.37*	-.20	-.29
17. Objective Burden	.01	.26	.08	.17	.17	.57*	-.30	-.11	-.10
18. Subjective Burden	-.14	.32*	.12	-.02	.02	.55*	-.27	-.14	-.23

Table 8.3 (continued)

Correlational Analyses of Variables Relating to Participants With MS and Their Caregivers ($N = 41$)

Variable	10	11	12	13	14	15	16	17	18
10. FSSQ: Confidant Support	--								
11. FSSQ: Affective Support	.90*	--							
12. FSSQ: Total	.99*	.96*	--						
13. GHQ: Somatic	.19	.15	.18	--					
14. GHQ: Anxiety/Insomnia	.35*	.32*	.34*	.64*	--				
15. GHQ: Social Dysfunction	.21	.14	.19	.47*	.30	--			
16. GHQ: Depression	.37*	.30	.35*	.66*	.77*	.54*	--		
17. Objective Burden	.60*	.57*	.60*	.20	.42*	.28	.41*	--	
18. Subjective Burden	.48*	.45*	.48*	.40*	.59*	.31	.59*	.50*	--

Note. GC Rating = Global Cognitive Rating; SCL-90-R GSI = Symptom Checklist 90-R Global Symptom Index; EDSS = Expanded Disability Status Scale; ISS = Incapacity Status Scale; ESS = Environmental Status Scale; CBRS = Cognitive Behavior Rating Scale; SHB = Social Health Battery; FSSQ = Functional Social Support Questionnaire; GHQ = General Health Questionnaire.
*$p < .05$.

family members with MS than by caregivers of comparatively cognitively intact family members with MS. Subjective burden was also significantly correlated with the caregivers' appraisal of the functional impairment of their family member with MS ($r = .55$, $p < .001$).

The amount of subjective burden reported by caregivers was also significantly related to their satisfaction with the quality of confidant and affective support that they experienced (r = .48, p = .002 and r = .45, p = .003 respectively), and their satisfaction with the overall quality of social support that they received (r = .48, p = .002). Therefore, caregivers reporting satisfaction with the quality of social support that they received reported less subjective burden than caregivers who were unsatisfied with the quality of social support that they received. The amount of subjective burden reported by the caregiver sample was not significantly correlated with any of the remaining variables.

Regression Analyses

Hierarchical regressions were performed to determine the extent to which variables relating to (a) the clinically-assessed functioning of the MS sample, (b) the appraisals of the functioning of the MS sample by the caregiver sample, and (c) aspects of the social support networks of the caregivers, predicted each of the six variables relating to the psychological functioning of the caregiver sample and their reports of subjective and objective burden. Despite the fact that there was only a statistically significant difference between the caregiver and control groups on three of the six outcome variables (Table 8.2), given the exploratory nature of this research it was decided to conduct regression analyses on all six outcome variables.

Bivariate correlations among the predictor variables were examined for evidence of multicollinearity. Due to the high correlation of the Incapacity Status Scale total score and the Environmental Status Scale total score with each other (r = .90) and with the EDSS score (r = .71 and r = .74 respectively), the former two variables were not included in the regression analyses. Similarly, the high correlation of the two subscale scores of the Functional Social Support

Questionnaire with each other (r = .90) and with the total score of this measure (r = .99 and r = .96) meant that only the latter score was used in the regression analyses. The Social Contacts subscale of the Social Health Battery was highly correlated with the Total Scale score of this measure (r = .74). Consequently, only the latter score and the second subscale score (i.e., group participation) were utilised in the course of the regression analyses.

Each of the ensuing six tables pertaining to the regression analyses displays the unstandardised (B) and standardised (β) regression coefficients, R^2 for step 1, and the change in R^2 (ΔR^2) after entry of the additional blocks of independent variables.

Somatic Functioning

Results from the regression analysis for the somatic functioning of the caregiver sample are presented in Table 8.4. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained 27% of the variance in the Somatic scale of the General Health Questionnaire, F (3, 37) = 4.54, p = .00832. Therefore, the functioning of the MS sample accounted for a significant amount of the variance in caregiver somatic functioning.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 36% of the variance in the Somatic scale, F (4, 36) = 5.09, p = .00235. The caregiver ratings of the functioning of the MS sample alone accounted for 9% of the variance at this step. The addition of the caregiver ratings of the functioning of the MS sample resulted in a significant increment in R^2 (p = .028659).

At step 3, the social support variables alone accounted for only 4% of the

Table 8.4

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Somatic Functioning ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	-0.23	0.29	-.12
	Cognitive	0.05	0.11	.07
	Psychological	1.81	0.91	.30
Step 2	CBRS Total	0.02	0.01	.27
Step 3	Quantity of Social Support			
	Group Participation	-0.29	0.24	-.20
	Total Social Contact	-0.003	0.10	-.01
	Quality of Social Support	0.04	0.08	.09

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .27$ for Step 1 ($p = .00832$),

$\Delta R^2 = .09$ for Step 2 ($p = .028659$),

$\Delta R^2 = .04$ for Step 3 ($p > .05$).

variance at this step. The resulting change in R^2 was not significant. Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 40% of the variance in the Somatic scale, F (7, 33) = 3.13, $p = .012$.

Therefore, in total, the five independent variables explained 40% of the variance in the Somatic scale of the General Health Questionnaire. The variables included in the regression equation did significantly predict the caregivers' report of somatic functioning. Furthermore, the unique contribution of the psychological functioning of the participants with MS to the somatic functioning of their caregivers approached statistical significance, $p = .05$.

Anxiety and Insomnia

Results from the regression analysis for anxiety and insomnia reported by the caregiver sample are presented in Table 8.5. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained 11% of the variance in the Anxiety/Insomnia scale of the General Health Questionnaire, F (3, 37) = 1.55, $p > .05$.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 41% of the variance in the Anxiety/Insomnia scale, F (4, 36) = 6.25, $p = .00063$, and the caregiver ratings of the functioning of the MS sample alone accounted for 30% of the variance at this step. The addition of the caregiver ratings of the MS sample resulted in a significant increment in R^2 ($p = .000139$).

At step 3, the social support variables alone accounted for only 5% of the variance at this step. Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 46% of the variance in the Anxiety/Insomnia scale, F (7, 33) = 4.01, $p = .00279$.

Therefore, in total, the five independent variables explained 46% of the variance in the Anxiety/Insomnia scale of the General Health Questionnaire. The

Table 8.5

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Anxiety and Insomnia ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	0.27	0.37	.10
	Cognitive	-0.03	0.14	-.03
	Psychological	1.07	1.17	.13
Step 2	CBRS Total	0.04	0.01	.52 *
Step 3	Quantity of Social Support			
	Group Participation	-0.28	0.31	-.14
	Total Social Contact	-0.06	0.13	-.07
	Quality of Social Support	0.10	0.10	.15

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .11$ for Step 1 ($p > .05$),

$\Delta R^2 = .30$ for Step 2 ($p = .000139$),

$\Delta R^2 = .05$ for Step 3 ($p > .05$).

*$p < .05$.

variables included in the regression equation did significantly predict caregiver report of anxiety and insomnia symptomatology. The results also indicated that the caregivers' appraisal of the functioning of their family member with MS made a significant unique contribution to the amount of anxiety and insomnia reported by the caregivers, $p = .002433$.

Social Dysfunction

Results from the regression analysis for the social dysfunction reported by the caregiver sample are presented in Table 8.6. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained 18% of the variance in the Social Dysfunction scale of the General Health Questionnaire, F (3, 37) = 2.76, $p > .05$.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 22% of the variance in the Social Dysfunction scale, F (4, 36) = 2.58, $p > .05$, and the caregiver ratings of the MS sample alone accounted for 4% of the variance at this step. The addition of the caregiver ratings of the functioning of the MS sample did not result in a significant increment in R^2 ($p > .05$).

The social support variables alone accounted for only 2% of the variance at step 3. Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 25% of the variance in the Social Dysfunction scale, F (7, 33) = 1.54, $p > .05$.

Therefore, in total, the five independent variables explained only 25% of the variance in the Social Dysfunction scale of the General Health Questionnaire. The variables included in the regression equation did not significantly predict caregiver report of social dysfunction.

Depression

Results from the regression analysis for severe depression reported by the caregiver sample are presented in Table 8.7. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained 30% of the variance in

Table 8.6

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Social Dysfunction ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	-0.03	0.19	-.03
	Cognitive	0.11	0.07	.27
	Psychological	0.61	0.58	.18
Step 2	CBRS Total	0.01	0.01	.20
Step 3	Quantity of Social Support			
	Group Participation	0.11	0.16	.13
	Total Social Contact	-0.04	0.06	-.11
	Quality of Social Support	0.02	0.05	.07

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .18$ for Step 1 ($p > .05$),

$\Delta R^2 = .04$ for Step 2 ($p > .05$),

$\Delta R^2 = .02$ for Step 3 ($p > .05$).

the Depression scale of the General Health Questionnaire, F (3, 37) = 5.39, p = .00352.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 48% of the variance in the Depression scale, F (4, 36) = 8.41, p = .00007, and the caregiver ratings of the MS

sample alone accounted for 18% of the variance at this step. The addition of the caregiver ratings of the MS sample resulted in a significant increment in R^2 (p = .001154).

At step 3, the social support variables alone accounted for 7% of the variance at this step. Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 55% of the variance in the Depression scale, F (7, 33) = 5.85, p = .00018.

Therefore, in total, the five independent variables explained 55% of the variance in the Depression scale of the General Health Questionnaire. The variables included in the regression equation did significantly predict caregiver report of depressive symptomatology. These results also indicated that the psychological functioning of the people with MS and the caregivers' appraisal of the functioning of their family member with MS each made significant unique contributions to the amount of depression reported by the caregivers, with p = .034487 and p = .007817 respectively.

Objective Burden

Results from the regression analysis for the objective burden reported by the caregiver sample are presented in Table 8.8. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained just 7% of the variance in the Objective Burden scale, F (3, 37) = 0.89, $p > .05$.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 34% of the variance in the Objective Burden scale, F (4, 36) = 4.69, p = .00379. The caregiver ratings of the MS sample alone accounted for 28% of the variance at this step, resulting in a

Table 8.7

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Depression ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	-0.19	0.22	-.11
	Cognitive	0.09	0.08	.15
	Psychological	1.51	0.69	.29 *
Step 2	CBRS Total	0.02	0.01	.41 *
Step 3	Quantity of Social Support			
	Group Participation	0.12	0.18	.09
	Total Social Contact	-0.11	0.07	-.22
	Quality of Social Support	0.06	0.06	.15

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .30$ for Step 1 ($p = .00352$),

$\Delta R^2 = .18$ for Step 2 ($p = .001154$),

$\Delta R^2 = .07$ for Step 3 ($p > .05$).

*$p < .05$.

significant increment in R^2 ($p = .000426$).

At step 3, the social support variables alone accounted for 17% of the variance, resulting in a significant increment in R^2 ($p = .015919$). Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver

Table 8.8

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Objective Burden ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	0.14	0.37	.05
	Cognitive	0.09	0.14	.09
	Psychological	-0.34	1.17	-.04
Step 2	CBRS Total	0.03	0.01	.36 *
Step 3	Quantity of Social Support			
	Group Participation	-0.18	0.31	-.09
	Total Social Contact	0.04	0.13	.05
	Quality of Social Support	0.33	0.10	.47 *

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .07$ for Step 1 ($p > .05$),

$\Delta R^2 = .28$ for Step 2 ($p = .000426$),

$\Delta R^2 = .17$ for Step 3 ($p = .015919$).

*$p < .05$.

ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 52% of the variance in the Objective Burden scale, $F(7, 33) = 5.05$, $p = .00057$.

Therefore, in total, the five independent variables explained 52% of the variance in the Objective Burden scale. The variables included in the regression equation did significantly predict caregiver report of objective burden. The results also indicated that the caregivers' appraisal of the functioning of their family member with MS, and the caregivers' satisfaction with the quality of social support that they received made significant unique contributions to the amount of objective burden reported by the caregivers, with $p = .020646$ and $p = .002261$ respectively.

Subjective Burden

Results from the regression analysis for the subjective burden reported by the caregiver sample are presented in Table 8.9. At step 1, the MS sample variables of physical, cognitive, and psychological functioning explained 12% of the variance in the Subjective Burden scale, $F(3, 37) = 1.76$, $p > .05$.

At step 2, the MS sample variables and the caregiver ratings of the functioning of the MS sample explained a total of 34% of the variance in the Subjective Burden scale, $F(4, 36) = 4.61$, $p = .00414$, and the caregiver ratings of the MS sample alone accounted for 21% of the variance at this step. The addition of the caregiver ratings of the functioning of the MS sample resulted in a significant increment in R^2 ($p = .001594$).

At step 3, the social support variables alone accounted for 11% of the variance. Together, the physical, cognitive, and psychological functioning of the MS sample, the caregiver ratings of the MS sample's functioning, and the social support variables of the caregivers explained a total of 44% of the variance in the Subjective Burden scale, $F(7, 33) = 3.77$, $p = .00418$.

Therefore, in total, the five independent variables explained 44% of the variance in the Subjective Burden scale. The variables included in the regression

Table 8.9

Summary of Hierarchical Regression Analysis for MS and Caregiver Variables Predicting Caregiver Subjective Burden ($N = 41$)

	Variable	*B*	*SE B*	β
Step 1	Physical	-0.38	0.69	-.08
	Cognitive	0.36	0.26	.20
	Psychological	-0.91	2.16	-.06
Step 2	CBRS Total	0.06	0.02	.39 *
Step 3	Quantity of Social Support			
	Group Participation	0.18	0.58	.05
	Total Social Contact	-0.24	0.24	-.17
	Quality of Social Support	0.33	0.19	.27

Note. CBRS = Cognitive Behavior Rating Scale

$R^2 = .12$ for Step 1 ($p > .05$),

$\Delta R^2 = .21$ for Step 2 ($p = .001594$),

$\Delta R^2 = .11$ for Step 3 ($p > .05$).

*$p < .05$.

equation did significantly predict caregiver report of subjective burden. The results also indicated that the caregivers' appraisal of the functioning of their family member with MS made a significant unique contribution towards the amount of subjective burden reported by the caregivers, $p = .019293$.

CHAPTER 9

Discussion

Previous research has clearly demonstrated that caregiving for an impaired family member can have negative consequences for the caregiver (e.g., Fengler & Goodrich, 1979; Zarit, Reever, & Bach-Peterson, 1980). These consequences can include feelings of stress or burden, social isolation, depression, and health problems (Haley, Levine, Brown, & Bartolucci, 1987). MS brings unique challenges for family members as well as for people diagnosed with the disease. These challenges include the time of life that the disease symptoms begin (i.e., early adulthood), the waxing and waning nature of symptoms, and the uncertain prognosis. MS does not necessarily shorten a person's life-span. Consequently, 30 to 40 years of adapting and readapting to a disease which progresses in an unpredictable manner and at an unpredictable pace, follows diagnosis. It is important that people diagnosed with the disease, and their families, are supported as effectively as possible.

This caregiver study consisted of two parts. First, a sample of caregivers who were living with their family member with MS, were compared with a matched control group in the areas of psychological functioning, social support, and experience of burden or stress. Ratings made by participants in these two groups regarding the functioning of their family member who participated in the MS Study, were also compared. Following this, an investigation was undertaken to determine the relative contribution of several factors to the psychological functioning and burden reported by the caregiver sample. In line with Knight's (1992) model of caregiver functioning, the factors investigated were (a) three clinically-assessed areas of functioning of the family members with MS (i.e., their

level of physical, cognitive, and psychological impairment), (b) the caregivers' appraisal of the functioning of their family member with MS, and (c) the social support received by the caregivers.

Comparison of the Caregiver Sample with the Matched Control Group Cognitive-Behavioural Ratings of Family Members

On all nine dimensions of the Cognitive Behavior Rating Scale the people with MS were rated as significantly more impaired by their family members than the control participants in the MS Study were rated by their family members. That is, the people with MS were considered by their family members to exhibit more language deficits and agitation, more need for routine, more symptoms of depression, more memory impairments and higher cognitive deficits, and more symptoms of dementia, apraxia and disorientation. These differences in ratings by family members were to be expected, given the reality of the impairments experienced by the MS sample. Taylor (1990) found that ratings by family members of the everyday cognitive functioning of people with MS showed a stronger relationship with performance on objective neuropsychological tests than did ratings made by people with MS themselves regarding their own everyday cognitive functioning. Taylor also found a relationship between the size of this discrepancy (i.e., between the ratings made by family members and those made by the people with MS) and the functioning of the MS sample on tests considered to be sensitive to frontal lobe impairment. This suggested that some people with MS may not be the best judge of their own cognitive impairment, perhaps for reasons such as lack of insight or awareness.

It is important to acknowledge, however, that caregiver ratings are also not objective measures, as they are affected by caregivers' perceptions. Some

caregivers find minor impairment in a family member difficult to cope with or adapt to and, therefore, may consider that person to be more severely impaired than might another caregiver who is less affected by the same level of impairment. Similarly, some caregivers may cope very effectively with severe impairments in a family member and, consequently, may under-rate the severity of that person's level of impairment. As an example of these differing perceptions, imagine a woman who gains a great deal of pleasure from walking and for whom this has been a shared activity with her husband for many years. She may rate as severe, the mild impairment in his pyramidal functioning if it limits his ability to partake in this mutual form of relaxation. Alternatively, another couple who do not enjoy physical exercise but who gain a great deal of enjoyment playing Bridge together, may find that mild impairment in a spouse's ability to walk for extended periods of time is considered far less bothersome or aggravating than mild impairment in memory functioning which affects Bridge-playing ability. Caregiver ratings provide valuable information about the rater in addition to the information gained about the person being rated. Identifying caregivers who find their current situation stressful or taxing is an important first step for effectively intervening with this population.

Psychological Functioning

Of the four scales comprising the General Health Questionnaire-28, a statistically significant difference between the symptomatology reported by the caregiver sample and the demographically-matched control group was evident on the anxiety and insomnia scale. However, the differences in responses of the two groups also approached statistical significance on the depression scale. The finding that more symptoms of anxiety, insomnia, and depression were reported by the caregivers supports research findings of other caregiving populations which have

found that people in a caregiving role commonly experience negative consequences (e.g., George & Gwyther, 1986; Marsh et al., 1998).

The finding that familial caregivers of people with MS report higher levels of anxiety and insomnia than non-caregiving peers suggests that psychological interventions targeting stress management and anxiety reduction techniques would be beneficial for this population. Empirically validated interventions of this nature are well known and, with funding, could routinely be made available for people in caregiving roles for impaired family members.

While research conducted with other caregiving populations has found that social isolation can also be a consequence of caregiving for an impaired family member, the caregivers comprising the present sample did not have higher scores (i.e., indicating more impairment) than the control group on the Social Dysfunction scale of the General Health Questionnaire-28. However, examination of the seven items of this scale brings into question whether the scale accurately portrays respondents' social functioning. For example, item one from this scale is "Have you recently been managing to keep yourself busy and occupied?" and item two is "Have you recently been taking longer over the things you do?" On the face of it, the items of this scale appear to measure the extent to which respondents feel able to engage in their usual activities of daily living, rather than being a measure of their social functioning per se.

In general, while the family members of people with MS in the present study reported being tense and under more strain, they did not report significantly more physical aches and pains or less ability to undertake their usual activities of daily living than the participants in the control group.

Social Support

No statistically significant difference was evident in the amount or frequency of social activity engaged in by the caregiver sample and the control group. According to the model of caregiver functioning by Knight (1992), social involvement has a buffering effect for caregivers, lessening the negative impact of their caregiving role. Therefore, the social contact that the caregivers in this study engaged in is likely to have been a protective factor, reducing the negative sequelae of their caregiving role.

However, a significant difference was evident between the two groups on the measure of qualitative social support. This difference reached statistical significance on one of the subscales of this measure (Affective Support) and the Total Scale score, and approached statistical significance on the other subscale (Confidant Support). These results suggest that the caregiver sample, while engaging in the same quantity of social contact, felt less supported or less satisfied with the quality of their social relationships than the participants in the control group. This could indicate that (a) the caregivers had a greater need for affective and confidant relationships than their non-caregiving peers, (b) the caregivers were receiving less in the way of this kind of relationship, or (c) a combination of these two scenarios.

Broadhead et al. (1988) discussed the differences in these two components of social support, emphasising the primary importance of qualitative social support for a person's health and well-being, rather than quantitative social support. It is possible that people in a caregiving role for a family member with MS have particular social support needs that are not met by general social contact. For example, a caregiver who lacks contact with other people filling a similar

caregiving role may find their social network to be less empathetic or less understanding, or less able to provide useful information, than if they shared a common caregiving experience. As people in a caregiving role for a family member with MS are more likely to be on the providing end of caregiving behaviour than the receiving end, they may have caregiving needs of their own which are not met in their current social relationships (e.g., somebody to take care of them when they are unwell or someone to talk to about their own worries and concerns). Clearly, it is important to differentiate between the quantitative and qualitative aspects of a person's social support network to identify any deficits and intervene in an effective manner.

One arm of a structured intervention aimed at improving the well-being of familial caregivers could involve an education program for members of their social support networks. Factual information about MS, in addition to information about the processes of caregiving and social support will help to equip support persons with knowledge of how or when they might best be of assistance. Linked to this, educational programs for caregivers could be implemented to provide information about the 'psychology of caregiving' and skills to assist caregivers to maintain their own physical and psychological well-being, whilst caring for their family member.

A number of carer support groups already operate within New Zealand, mostly on an informal basis. A nation-wide evaluation of these programs would help to determine their most effective components whilst also examining how to improve their effectiveness. Further, these programs need to be made available for all caregivers who will benefit from them - a goal which is likely to require some additional funding. Like parenting, caregiving is a role that people often find themselves immersed in with no formal training or preparation. Also like parenting,

caregiving can be conducted in an effective and beneficial way or it can be an ineffective, negative experience for the parties involved. The deciding factor may be education, support, and role models.

Caregiver Burden

Statistically significant differences were evident in the amount of objective and subjective burden reported by the caregiver sample and the control group. The caregiver sample reported experiencing more subjective burden and more objective burden. These results support prior research findings which have indicated that caregivers in general, and people caregiving for a family member with MS specifically, experience burden in connection with their caregiving role (e.g., Cockerill & Warren, 1990; Zarit et al., 1980; Zarit et al., 1986). Practical support (e.g., respite care facilities, home help) can assist in reducing aspects of objective burden such as less personal freedom, less time to oneself, and less vacations.

On average, however, the caregiver sample studied in the present research did not report the most extreme amounts of either type of burden. The average amount of objective burden reported was 31 out of a possible 45, while the average amount of subjective burden reported was 27 out of 65, where higher scores on each scale indicate more burden. Therefore, while the caregivers did report experiencing significantly more burden than peers not caregiving for a family member with MS, they did not report the most extreme amounts of burden. This may have been an indication that the majority of caregivers' (a) had adequate coping skills to manage their current level of burden, (b) received adequate social support, or (c) perceived their current situation as tolerable. Caregivers not able to cope with their current predicament would be more likely to report more extreme amounts of burden. Identifying the factors that caregivers consider make their

current situation tolerable would be useful for intervention purposes, as attempts could be made to replicate these factors for caregivers reporting more extreme levels of burden.

Within MS Caregiver Sample Analyses

An overview of the results of the correlational and regression analyses is presented below, along with their implications.

Somatic Functioning

The caregivers' report of their somatic functioning on the General Health Questionnaire-28 was significantly correlated with three variables: the psychological functioning of the MS sample, the caregivers' appraisal of the functioning of the MS sample, and the amount that caregivers participated in group social contact. As the psychological impairment of the MS sample increased, and the caregivers' ratings of the MS sample's functioning indicated more impairment, and the caregivers participated in less group social contact, the severity of somatic complaints reported by the caregivers increased.

Overall, the variables measured in this study were able to account for a significant proportion of the somatic functioning of the caregivers. For example, the three clinically-assessed stressors (i.e., the physical, cognitive, and psychological impairment of the MS sample) explained a statistically significant proportion of the somatic complaints reported by the caregiver sample. Similarly, the caregivers' ratings of the MS sample's functioning also accounted for a statistically significant amount of the caregivers' report of somatic complaints. This information can be used to help identify caregivers at higher risk of developing somatic complaints who may benefit from a tailored intervention program. However, the social support received by the caregivers did not account for a

significant portion of their somatic complaints, indicating that this would be a less effective target for interventions aimed at reducing the negative somatic sequelae for family members in a caregiving role.

Anxiety and Insomnia

The caregivers' report of anxiety and insomnia on the General Health Questionnaire-28 was significantly correlated with their ratings of the MS sample's functioning and the caregivers' satisfaction with the quality of social support that they received. Therefore, the caregivers who reported more symptoms of anxiety and insomnia also rated their family member with MS as more impaired and reported less satisfaction with the quality of the social support that they received.

Overall, the variables measured in this study did account for a significant proportion of the anxiety and insomnia reported by these caregivers. The three clinically-assessed stressors relating to the functioning of the MS sample did not account for a statistically significant proportion of the anxiety and insomnia reported by the caregiver sample. However, the caregivers' ratings of the functioning of the MS sample did account for a statistically significant amount of the anxiety and insomnia reported by the caregivers. This provides valuable information about appropriate forms of interventions for reducing caregivers' experience of anxiety symptomatology (i.e., techniques for assisting positive cognitive change). These results also signal that the impairment severity of a person with MS is not necessarily a good indicator of the level of anxiety that may be experienced by that person's primary caregiver.

As with the caregivers' somatic functioning, social support variables did not account for a significant proportion of the caregivers' report of anxiety and insomnia. Consequently, changing characteristics of caregivers' social support

networks would appear to be a less effective means of reducing their experience of anxiety.

Social Dysfunction

The caregivers' responses on the Social Dysfunction scale of the General Health Questionnaire-28 were significantly correlated with the clinically-assessed cognitive and psychological functioning of the MS sample and the caregivers' ratings of the functioning of the MS sample. That is, as the cognitive and psychological impairment of the MS sample increased and as the caregivers rated their family member with MS as more functionally impaired, the caregivers reported experiencing more dysfunction on the items contained in the Social Dysfunction scale. However, as discussed in the results section, a perusal of the seven items of this scale suggests that it measures respondents' ability to carry out their usual activities of daily living rather than their social functioning per se. Further investigation of this is warranted.

Despite the relationship between the caregivers' responses on this scale and some aspects of the MS sample, the clinically-assessed impairment variables did not account for a statistically significant proportion of the social dysfunction reported by the caregiver sample. The caregivers' ratings of the functioning of the MS sample and the social support variables also did not account for a significant proportion of the caregivers' report of social dysfunction. These results indicate that the variables measured in this study were not able to account for a significant proportion of the caregivers' social functioning. Consequently, any intervention aimed at improving this area of functioning for the caregivers of family members with MS (if it is, in fact, warranted) would first need to determine the appropriate

targets for change. The variables measured in the present research do not appear to be significantly influential in this area of caregiver functioning.

Depression

The caregivers' responses on the Depression scale of the General Health Questionnaire-28 were significantly correlated with (a) the cognitive and psychological functioning of the MS sample, (b) the caregivers' ratings of the functioning of the MS sample, (c) the frequency of social contact that the caregivers engaged in, and (d) the caregivers' satisfaction with the quality of their social relationships. Therefore, caregivers of cognitively and psychologically impaired family members with MS, and caregivers who rated their family member with MS as functionally impaired reported more symptoms of depression, as did caregivers who engaged in less social activity and caregivers who were less satisfied with the quality of social support that they received.

Overall, the variables measured in this study were able to significantly predict depressive symptomatology in the caregivers of family members with MS. The three clinically-assessed stressors relating to the functioning of the people with MS explained a statistically significant proportion of the variance on the Depression scale, as did the caregivers' ratings of the MS sample's functioning. These results assist in the identification of caregivers who are more at risk of experiencing depression (i.e., those whose family members with MS are more severely physical, cognitively, and psychologically impaired). Familial caregivers of psychologically impaired people with MS are particularly at risk. The significant unique contribution made by the caregivers' ratings of the functioning of the MS sample also suggests that cognitive strategies would be valuable techniques to

employ in interventions targeted at reducing the caregivers risk of developing depression.

The social support variables did not account for a statistically significant proportion of the depressive symptomatology reported by the caregiver sample. This indicates that targeting social networks during interventions aimed at the reduction of caregiver depression would not be the most efficient or effective use of resources.

Objective Burden

The amount of objective burden reported by the caregiver sample was significantly correlated with their ratings of the functioning of the MS sample and with the caregivers' satisfaction with the quality of their social relationships. Therefore, caregivers who rated their family member with MS as more functionally impaired and caregivers who were less satisfied with the quality of their social relationships, also reported higher amounts of objective burden.

Overall, the variables measured in this study did significantly predict the amount of objective burden reported by these caregivers. However, the three clinically-assessed stressors relating to the functioning of the people with MS did not account for a statistically significant proportion of the objective burden reported by their caregivers. Interestingly, this indicates that the severity of impairment in people with MS does not predict the amount of objective burden reported by familial caregivers. However, the caregivers' ratings of the functioning of the MS sample did account for a statistically significant amount of the caregivers' objective burden. Clearly, in this study, the caregivers' perceptions were an important determinant of their experience of objective burden.

Aspects of the social support networks of the caregivers also accounted for a significant proportion of their reports of objective burden. Qualitative features of the caregivers' social support made a significant unique contribution. This indicates that interventions targeted at improving the quality of the social support received by caregivers of family members with MS would be effective in reducing their objective burden. These results also indicate that interventions aimed at altering quantitative features of the caregivers' social support networks are likely to be less effective at reducing their level of objective burden.

Subjective Burden

The amount of subjective burden reported by the caregivers was significantly correlated with the clinically-assessed cognitive impairment of the MS sample, the caregivers' ratings of the functioning of their family member with MS, and the caregivers' satisfaction with the quality of social support that they received. Therefore, caregivers of a cognitive-impaired family member with MS and caregivers who rated their family member with MS as more functionally impaired reported more subjective burden, as did caregivers who were less satisfied with the quality of social support that they received.

Overall, the variables measured in this study were able to significantly predict the amount of subjective burden reported by these familial caregivers. As with the objective burden scale, the three clinically-assessed stressors relating to the functioning of the people with MS did not account for a statistically significant proportion of the subjective burden reported by the caregiver sample. However, again, the caregivers' perception of the functioning of the MS sample did account for a statistically significant amount of the caregivers' reported subjective burden. Unlike the caregivers' report of objective burden, however, the social support

received by the caregivers did not account for a significant proportion of their reports of subjective burden.

These results suggest that the amount of subjective burden a caregiver feels can not be predicted by the severity of the impairments of their family member with MS. The caregivers' perceptions of the impairment of their family member is more predictive of the amount of subjective burden that they feel. Again, cognitive strategies are likely to be an effective intervention technique to incorporate in interventions aimed at reducing the amount of subjective burden experienced by these caregivers. Based on the findings of the present research, interventions targeting aspects of the caregivers' social support networks are likely to be less effective at reducing their subjective burden.

Summary

Overall, the psychological functioning and burden experienced by the caregiver sample were most consistently related to their perceptions or appraisal of the functioning of their family member with MS, and their satisfaction with the quality of the social support that they received. None of the six variables of caregiver functioning were significantly correlated with the clinically-assessed physical functioning of the MS sample. Findings of earlier research undertaken with other populations of caregivers (e.g., caregivers of people who have had a traumatic brain injury) have also reported that physical impairment has not been predictive of caregiver reports of stress and burden (e.g., Marsh, Knight, & Godfrey, 1990).

The two other clinically-assessed areas of functioning of the MS sample were significantly correlated with some aspects of caregivers' functioning. Cognitive impairment in the MS sample was significantly related to higher scores

by the caregivers on the General Health Questionnaire-28 scales of social dysfunction and depression, and the subjective burden scale. Psychological impairment in the MS sample was significantly related to higher scores by the caregivers on the General Health Questionnaire-28 scales of somatic functioning, social dysfunction, and depression. The psychological functioning of the participants with MS was also found to make a significant unique contribution in the prediction of the caregivers' self-reported level of depression. The higher profile of the cognitive and psychological functioning of the MS sample with regards to the well-being of their familial caregivers is in line with prior research which has found that changes in the behaviour and emotions (often conceived as 'personality changes') of impaired persons is a stronger determinant of caregiver burden than physical impairment (e.g., Marsh et al., 1998).

The quantity of social support that the caregivers took part in appeared to be less related to their psychological well-being and burden than qualitative aspects of social support. These results support the assertion made by Broadhead et al. (1988) that it is important to differentiate between types of social support and that quantitative social support is often not significantly related to well-being. As with the present study, Broadhead et al. reported that qualitative social support is a stronger predictor of health outcome than quantitative social support.

The results of both the correlational and regression analyses identified the important role of the caregivers' appraisal of the functioning of their family member with MS in determining the caregivers experience of burden and psychological well-being. This variable made a significant unique contribution in explaining the caregivers' self-reported level of anxiety and insomnia, depression, objective and subjective burden. This supported Knight's (1992) model of

caregiver functioning as well as the findings of research undertaken with other caregiving populations (e.g., Chwalisz, 1992; Haley et al., 1987). Haley et al. also reported little direct relationship between stressors and outcome variables of caregiver well-being and burden, while measures of caregiver appraisal and coping were consistently related to caregiver outcome. Further, Haley et al. reported that higher levels of social network size, activity, and satisfaction with social network were related to better caregiver outcomes.

Five of the six outcome variables of caregiver well-being and burden were able to be significantly predicted by the combination of variables measured in this study. To recap, these five areas were the caregivers' self-reported level of somatic functioning, anxiety/insomnia, and depression; and the caregivers' self-reported level of subjective and objective burden. Only the caregivers' report of social dysfunction was not significantly accounted for by the variables measured in this study. However, as discussed earlier, this scale of the General Health Questionnaire -28 may not be a comprehensive measure of the caregivers' social functioning.

Conclusions

In conclusion, while MS is a degenerative disease with some unique features, it is apparent that the caregiving experience for family members of people with this disease has similarities to that of other caregiving populations. As with other caregivers, the amount of caregiver burden and the psychological well-being reported by this caregiver sample was not equal to the objective stressors relating to the people with the disease. Mediating factors, such as the caregivers' appraisal of the stressors and their satisfaction with the social support that they received, had an important role in determining the psychological well-being and extent of burden that the caregivers reported.

CHAPTER 10

General Discussion

Recapitulation

The first major objective of this research was to investigate the physical, cognitive, and psychological functioning of a New Zealand community-based sample of people with MS. The second major objective was to investigate the well-being of familial caregivers of people with MS and relate this to Knight's (1992) model of caregiver functioning.

The MS Study

The MS Study demonstrated that the sample of 92 participants with MS represented people from across the neurological spectrum of the disease, ranging from no disability with minimal signs of neurological impairment in only one area of functioning, through to severe impairment in all areas of neurological functioning. The neurological impairment, disability, and handicap of this sample were similar to that of MS populations elsewhere in the world which have been described earlier in the literature. Similarly, the pattern and prevalence of cognitive impairment in the sample of 77 participants with MS were akin to that of earlier studies in this area. For example, the absence of statistically significant differences between the functioning of the MS sample and the normal control group on the measures of language and visuospatial functioning. Between 30% and 40% of the MS sample were found to be mildly or severely impaired on tests of general intelligence, memory and learning, attention/concentration, and one measure of executive functioning. The absence of a statistically significant difference between the functioning of the MS sample and the demographically-matched control group on the Wisconsin Card Sorting Test was unexpected, as previous research has

consistently reported impaired performance by MS samples on this test of frontal lobe functioning.

Between 30% and 50% of the MS sample in this study reported mild to severe impairment on eight of the nine dimensions of the Symptom Checklist-90-Revised, indicating a high level of psychological distress in comparison to the control group. The psychological functioning of the MS sample was found to be significantly correlated with their cognitive functioning. The cognitive functioning of the MS sample was also found to be significantly related to the number of years since the diagnosis of MS had been made. Fatigue, medication use, physical impairment, disease course, and the number of years since initial symptom onset were not significantly related to the cognitive functioning of this MS sample.

However, when the MS sample was divided into a 'cognitively intact' subgroup and a 'cognitively impaired' subgroup, there was a statistically significant difference between the two groups in the severity of physical impairment. There was also a significant difference between the groups in the number of years since MS diagnosis and the age of the participants. The participants in the cognitively impaired subgroup were significantly older, had had their diagnosis of MS for longer, and were more physically impaired. There was no statistically significant difference in the psychological functioning of the two subgroups or in most areas of disability and handicap as measured by the Minimal Record of Disability. The exceptions were in the domains of speech and hearing, changes required to personal residences, and social activity. The cognitively impaired subgroup had more difficulties with speech and hearing, had required more changes to their personal residences, and took part in less social activity than the cognitively intact subgroup.

The Caregiver Study

The results of the Caregiver Study demonstrated that the 52 participants in a caregiving role for a family member diagnosed with MS reported significantly more symptoms of anxiety and insomnia than the demographically-matched control group. There was no statistically significant difference between these two groups in their self-reports of somatisation, social dysfunction, and depression. There was also no difference between the groups regarding the quantity of social contact in which they engaged. However, there was a statistically significant difference between the caregiver sample and the control group in their level of self-reported satisfaction with the quality of their social relationships. There was also a difference between the two groups in the amount of subjective and objective burden that participants reported. Participants in the caregiver sample reported significantly less satisfaction with the quality of their social relationships and significantly more burden than people in the control group.

All areas of caregiver functioning measured in this study, except social dysfunction, were able to be significantly predicted by the combination of the three clinically-assessed stressors (i.e., the neurological, cognitive, and psychological functioning of the MS sample), the appraisal of the stressors by the caregiver sample, and the caregivers' experience of social support. Correlational and regression analyses demonstrated that the impact of the stressors on the psychological functioning and level of burden expressed by the caregivers was mediated by the caregivers' appraisal of the stressors and aspects of social support. This finding supported the model of caregiver functioning outlined by Knight (1992).

Implications of Results For People With MS

The similarity of the functioning of this New Zealand MS sample with reports of the functioning of MS samples elsewhere in the world indicates that research findings stemming from overseas are also directly applicable to our national MS population. For example, the finding by Aronson (1997) that a poorer quality of life among people with MS was associated with unemployment, MS symptoms of moderate or worse, fatigue, mobility limitations on stairs, a disease course other than stable, and particularly, interference by MS in social activities, is likely to be equally applicable to our NZ MS population. Consequently, the difference found in the social activity of the cognitively intact MS subgroup and the cognitively impaired MS subgroup is likely to indicate, and contribute to, a lower quality of life amongst cognitively impaired people with MS in New Zealand. Quality of life was not directly measured in the present study however. The similarity of the functioning of the present MS sample to overseas MS populations also indicates that the findings of the present research are likely to be applicable for people with MS living elsewhere in the world.

The finding that family members of people with MS reported more burden than matched control participants is not surprising. Normal relationship exchanges of caring and caregiving are disrupted when one person develops a serious chronic illness. The imbalance experienced by primary caregivers whereby they provide more caregiving than they receive, often leads to feelings of burden and reduced well-being. This has implications for the people being cared for. First, a caregiver who feels burdened may in turn become physically and/or psychologically impaired due to the stress or burden experience. If this is the case, the caregiver may be less able to fill the caregiving role for his or her family member. The well-being of the

caregiver effects the person with MS as well as visa versa. It is beneficial for both people involved in a relationship if both feel that their needs are being met. Therefore, people with MS have a vested interest in ensuring that the caregiving needs of their family members are also met. This may involve relationship counselling, encouraging their family member(s) to be involved in support groups, finding caregiving activities that they are able to carry out for their loved one(s), and so forth. Actively encouraging their family member(s) to utilise respite care options may also be necessary. Several studies have reported that family members in a caregiving role under utilise respite care services due to feelings of guilt.

Implications of Results for Familial Caregivers of People With MS

The results of the Caregiver Study demonstrated that caregivers' appraisals of the functional impairment of their family member with MS greatly impacted on the caregivers' experience of burden and their psychological well-being. For example, the caregivers' ratings of the functional impairment of the MS sample accounted for 30% of the variance on the Anxiety and Insomnia scale and 18% of the variance on the Depression scale of the General Health Qustionnaire-28 completed by the caregivers. These caregivers' ratings also accounted for 28% of the variance on the Objective Burden scale and 21% of the variance on the Subjective Burden scale. The caregivers' ratings of the functional impairment of the MS sample were not strongly correlated with the clinically-assessed variables of neurological, cognitive, and psychological impairment in the MS sample, with r = -.07, .36, and .31 respectively. This suggests that aspects of the caregivers' own outlook or experience affected their appraisal of their family member with MS, and thus in turn, their level of stress or burden in their caregiving role. Consequently, cognitive interventions which examine caregivers' cognitions and belief systems

relating to aspects of caregiving, and the nature and consequences of a family member's impairment may assist in reducing the level of burden experienced by caregivers. Cognitive styles have a major impact on our psychological well-being and experience of the world (Beck, 1976; Ellis, 1962). A combination of group interventions and more tailored individual programs may prove to be the most appropriate protocol.

The results of the Caregiver Study also highlighted the need to assess different aspects of the social support received by caregivers. Satisfaction with the quality of social relationships was clearly a stronger determinant of caregiver well-being and stress than quantity of social contact. The quality of social relationships for caregivers of family members with MS may be improved with the help of relationship counselling and education about MS and caregiving, for the caregiver, the person with MS, and possibly other people in the caregiver's social support network. Research investigating effective methods of improving the quality of social support for caregivers is warranted.

In some parts of New Zealand, support groups have been set up specifically to help meet the social support needs of people in a caregiving role for someone with MS. An nation-wide evaluation of these groups would help to standardise their most beneficial components for implementation throughout the country. Further, research on additional psychological treatment strategies for caregivers could be conducted to determine the most effective forms of intervention and service delivery for this population.

Implications of Results For Service Providers

Without informal caregiving arrangements, the need for institutional care facilities is higher. Therefore, the provision of effective means of support for

people caregiving for a chronically ill family member is a cost-saving venture. Interventions could include educational programmes for different target groups (e.g., people with MS, family members, other people in support roles); the provision of psychological services for individuals, couples, or family groups; recreational and respite activities and facilities. It is important to acknowledge that in many parts of the country some of these services are already available and being executed effectively. Further, the Field Officers of each local MS Society branch provide an important and highly-regarded service. However, regular evaluation and modification of services is warranted at a national level, alongside a needs assessment in each region, to ensure the standardisation in service provision.

Recent Research Developments

Since the commencement of this research three studies have been published which have examined aspects of caregiver functioning in relation to MS. Like the present research, Knight, Devereux, and Godfrey (1997) investigated the psychosocial consequences of caring for a family member with MS. Participants were 55 spouses of people with MS, ranging in age from 29 to 74 years. Participants completed a mailed questionnaire which investigated the domains of caregiver burden, distress, health, coping, social support, and quality of life.

The caregivers in this study were found to be experiencing a range of negative effects related to the MS symptoms of their spouse, such as motor problems, sudden mood changes, incontinence, pain, and interpersonal conflict (Knight et al., 1997). The aspects of burden most frequently reported by the caregivers were worry and pessimism about the future, and time burden. Neither the age of the people with MS, the length of time since their MS diagnosis, nor the work status of the caregivers were significantly predictive of the amount of burden

experienced by the caregivers. Unlike the findings of the present research, Knight et al. (1997) found that the caregivers' appraisal of the severity of their spouse's MS symptoms was not strongly predictive of the caregivers' reports of burden. In their study, the most significant predictors of caregiver burden were the caregivers' satisfaction with their ability to cope and their satisfaction with social support. This latter finding, i.e., that the caregivers' satisfaction with social support was a significant predictor of their report of burden, was also found in the present Caregiver Study.

Knight et al. (1997) concluded that their results were consistent with theories of stress in that the role of perceived coping abilities and satisfaction with social support as significant determinants of caregiver burden was confirmed. These conclusions are also supported by the results of the current research project.

Another study which employed the use of mailed questionnaires was published by Aronson (1997) who investigated quality of life among people with MS and their caregivers. Aronson found that poorer quality of life among caregivers of people with MS was associated with (a) being a spouse, (b) longer duration of caregiving, (c) moderate or worse MS symptoms in the care recipient, and (d) the care recipient's current disease course, if it was unstable. Finances were also an area of low satisfaction identified by the caregivers.

The third study in this area to come to light recently was undertaken by Pakenham (1998). Forty-five couples affected by MS were interviewed and completed questionnaires relating to coping style and adjustment. Pakenham was interested in the psychosocial impact of MS on caregiver- care receiver dyads and also the congruence of their coping processes. Pakenham predicted that the psychological distress scores of people with MS would be positively correlated

with those of their caregivers. Results from the study supported this hypothesis. The people with MS reported significantly more global distress and depression than their caregivers, and the psychological distress scores of the people with MS were positively correlated with those of their caregivers. More problem-focused coping by couples was related to lower collective global stress, while more emotion-focused coping by couples was related to higher collective global distress. In the present research, the self-reported psychological functioning of the MS sample was significantly positively correlated with the caregivers' report of somatic complaints, social dysfunction, and depression. Further, the psychological functioning of the MS sample made a significant unique contribution in the prediction of caregiver depression.

Limitations of Present Research Project

The following limitations have been identified. First, as recent neurological examinations were unavailable for the majority of the participants with MS, the classification of their MS disease course was determined by the participants' self-report of symptomatology. These classifications were vulnerable to self-report bias. Second, some researchers in recent years have utilised cluster analyses to identify subgroups of people with MS with distinct profiles of cognitive impairment (e.g., Beatty et al., 1996; Ryan et al., 1996). A cluster analysis in the present MS Study may have contributed information than was not unearthed during the analysis of the 'cognitively intact' and 'cognitively impaired' categories employed here. Third, no measure of the caregivers' satisfaction with their ability to cope was utilised. Therefore, the contribution of this to caregiver well-being and burden was not able to be ascertained in the Caregiver Study. Finally, the number of caregivers with complete data to be analysed in the correlational and regression computations (N =

41) was too small for structural equation modeling which may have been a more informative way of examining Knight's (1994) model.

Future Research Directions

As already outlined, the logical next step in this research is the compilation of a treatment package aimed at benefiting both people with MS and their familial caregivers. Such a package would need to be trialed and evaluated, before being disseminated nation-wide. The treatment package would involve the following components:-

- Educational seminars for people with MS and their families on psychological aspects of caregiving for a family member.
- Information seminars for the support persons of families affected by MS.
- Cognitive therapy, in group and individual format, for caregivers of people with MS.
- Stress reduction and anxiety management training for caregivers of people with MS.

In addition to these treatment strategies, research needs to be undertaken to investigate methods for improving the quality of social support for people in a caregiving role for a family member.

Conclusions

In conclusion, this research investigated the physical, cognitive and psychological functioning of a New Zealand community-based sample of people with MS. The psychosocial functioning of family members in a caregiving role for people with MS was also investigated.

In the MS Study, the performance of the MS sample was found to be impaired in a number of areas of cognitive functioning in comparison to the

demographically-matched control group. Psychological difficulties were also reported significantly more by the MS sample than the control group. The cognitive functioning of the MS sample was found to be related to time since MS diagnosis and psychological functioning. Cognitive functioning in the MS sample was found not to be related to the physical functioning of the sample, time since MS symptom onset, disease course, level of fatigue, or medication use. A subset of participants with MS who were comparatively more cognitively impaired in relation to the performance of the control group were found to require more changes to their homes and more community services. They also experienced more social handicap than the remainder of the MS sample.

In the Caregiver Study, the familial caregivers of people with MS reported significantly more anxiety and insomnia, higher levels of burden, and less satisfaction with the quality of their social support than the demographically-matched control group. Of the factors measured in this study, the caregivers' appraisal of the functional impairments of their family member with MS was most influential in predicting caregiver functioning.

The results of this research identify a number of practice recommendations to assist people with MS, their familial caregivers, and the wider community. It has been proposed that these recommendations form the basis of a treatment package to be offered to people affected by MS.

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APPENDICES

Appendix A

The following structured interview protocol was employed to obtain demographic information from the participants with MS.

MULTIPLE SCLEROSIS NEUROPSYCHOLOGICAL STUDY

(University of Waikato & Multiple Sclerosis Society)

Participant ID:_____

Name: _____

Address: _____

Date: _____ **Time:** _____

Date of Birth: _____ **Age:** _____

Gender: 1. Female 2. Male [ ]

Dominant Hand: 1.Right 2. Left [ ]

Ethnicity: [ ]

1. NZ European/Pakeha 2. NZ Maori
3. Pacific Islander 4. Other - Specify: _____

Marital Status: [ ]

1. Never married 2. Married/De facto
3. Separated/Divorced 4. Widowed
5. Other - Specify: _____

Relationship to Other Person Being Assessed: [ ]

1. Spouse/Partner 2. Parent
3. Son/Daughter 4. Other relative
5. Friend 6. Other - Specify: _____

Education:

Years of secondary education: _____

Years of tertiary education: _____

Age when left school: _____

Years of education: _____

Occupational Status: [ ]

1. Student 2. Unemployed
3. Homemaker 4. Sickness Beneficiary
5. Retired
6. Paid employment - Specify: _____ [ ]

Occupational Training Qualifications: [ ]

1. Nil
2. School Certificate
3. U.E./Sixth Form Certificate
4. HSC/Bursary
5. Trade - Specify: _____
6. Professional - Specify: _____
7. Tertiary - Specify: _____
8. Other - Specify: _____

Living Arrangements: (Include number of people living with) [ ]

1. Alone
2. Family
3. Relations
4. Partner
5. Partner plus children
6. Flatmates
7. Other - Specify: _____

Number of Dependent Children: _____

Current Medication: [ ]

1. No
2. Yes - Type: _____

_____

Current Medical Conditions: [ ]

(Do you currently have any condition other than Multiple Sclerosis which affects your eyesight, hearing, sense of smell, or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes - Type: _____

_____

Previous Medical Conditions: [ ]

(Have you ever had any condition other than Multiple Sclerosis which affected your eyesight, hearing, sense of smell or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes - Type: _____

_____

Previous Hospitalisations: [ ]

1. No
2. Yes - Diagnosis: _____

_____

Previous Neurological Complaints: [ ]

(Prior to developing Multiple Sclerosis, did you suffer from headaches, dizziness, fainting spells, or insomnia?)

1. No
2. Yes - If so, how often? _____

Previous Psychiatric History: [ ]

(Prior to developing Multiple Sclerosis, were you ever treated by a Psychiatrist or Psychologist?)

1. No 2. Yes - Diagnosis: _____

Current Psychiatric Treatment: [ ]

(Are you currently being treated by a psychiatrist or psychologist?)

1. No 2. Yes - Diagnosis: _____

History of Multiple Sclerosis

Age at onset of MS symptoms: _____

Years since onset of first MS symptoms: _____

Years since definite formal diagnosis: _____

Course of Multiple Sclerosis: _____

How was Multiple Sclerosis diagnosed? _____

Who diagnosed the condition? _____

Who provides current medical care? _____

Disease Course: [ ]

1. Relapsing/Remitting 2. Chronic/Progressive
3. Benign 4. Acute Progressive
5. Other - Specify: _____

Current Status: [ ]

1. In Remission 2. Exacerbation
3. Other - Specify: _____

Suggested Control Subjects:

Name: _____

Address: _____

_____

Name: _____

Address: _____

_____

Appendix B

The following structured interview protocol was employed to obtain demographic information from the control participants in the MS Study, and both the caregiver and control participants in the Caregiver Study.

MULTIPLE SCLEROSIS NEUROPSYCHOLOGICAL STUDY

(University of Waikato & Multiple Sclerosis Society)

Participant ID:_____

Name: _____

Address: _____

Date: _____ **Time:** _____

Date of Birth: _____ **Age:** _____

Gender: 1. Female 2. Male [ ]

Dominant Hand: 1.Right 2. Left [ ]

Ethnicity: [ ]

1. NZ European/Pakeha 2. NZ Maori
3. Pacific Islander 4. Other - Specify: _____

Marital Status: [ ]

1. Never married 2. Married/De facto
3. Separated/Divorced 4. Widowed
5. Other - Specify: _____

Relationship to Other Person Being Assessed: [ ]

1. Spouse/Partner 2. Parent
3. Son/Daughter 4. Other relative
5. Friend 6. Other - Specify: _____

Education:

Years of secondary education: _____

Years of tertiary education: _____

Age when left school: _____

Years of education: _____

Occupational Status: [ ]

1. Student 2. Unemployed
3. Homemaker 4. Sickness Beneficiary
5. Retired
6. Paid employment - Specify: _____ [ ]

Occupational Training Qualifications: [ ]

1. Nil
2. School Certificate
3. U.E./Sixth Form Certificate
4. HSC/Bursary
5. Trade - Specify: _____
6. Professional - Specify: _____
7. Tertiary - Specify: _____
8. Other - Specify: _____

Living Arrangements: (Include number of people living with) [ ]

1. Alone
2. Family
3. Relations
4. Partner
5. Partner plus children
6. Flatmates
7. Other - Specify: _____

Number of Dependent Children: _____

Current Medication: [ ]

1. No
2. Yes - Type: _____

_____

Current Medical Conditions: [ ]

(Do you currently have any condition which affects your eyesight, hearing, sense of smell, or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes - Type: _____

_____

Previous Medical Conditions: [ ]

(Have you ever had any condition which affected your eyesight, hearing, sense of smell or touch, or conditions of epilepsy, diabetes, etc?)

1. No
2. Yes - Type: _____

_____

Previous Hospitalisations: [ ]

1. No
2. Yes - Diagnosis: _____

_____

Previous Neurological Complaints: [ ]

(Have you ever suffered from headaches, dizziness, fainting spells, or insomnia?)

1. No
2. Yes - If so, how often? _____

Previous Psychiatric History: [ ]

(Have you ever been treated by a Psychiatrist or Psychologist?)

1. No 2. Yes - Diagnosis: _____

Current Psychiatric Treatment: [ ]

(Are you currently being treated by a psychiatrist or psychologist?)

1. No 2. Yes - Diagnosis: _____

Appendix C

The four components of the Minimal Record of Disability are:

1. Kurtzke Functional Systems
2. Kurtzke Expanded Disability Status Scale
3. Incapacity Status Scale
4. Environmental Status Scale

IFMSS Minimal Record of Disability

Neurological assessment

Kurtzke Functional System FS

(WHO Impairment)

1. **Pyramidal Functions:** ☐

0 - Normal

1 - Abnormal signs without disability

2 - Minimal disability

3 - Mild to moderate paraparesis or hemiparesis *(detectable weakness but most function sustained for short periods, fatigue a problem)*; severe monoparesis *(almost no function)*

4 - Marked paraparesis or hemiparesis *(function is difficult)*, moderate quadriparesis *(function is decreased but can be sustained for short periods)*; or monoplegia

5 - Paraplegia, hemiplegia, or marked quadriparesis

6 - Quadriplegia

9 - Unknown

2. **Cerebellar Functions:** ☐

0 - Normal

1 - Abnormal signs without disability

2 - Mild ataxia *(tremor or clumsy movements easily seen, minor interference with function)*

3 - Moderate trunkal or limb ataxia *(tremor or clumsy movements interfere with function in all spheres)*

4 - Severe ataxia in all limbs *(most function is very difficult)*

5 - Unable to perform coordinated movements due to ataxia

9 - Unknown

- Use 1 in adjacent box when weakness (grade three or worse on pyramidal) interferes with testing ☐

3. **Brainstem Functions:** ☐

0 - Normal

1 - Signs only

2 - Moderate nystagmus or other mild disability

3 - Severe nystagmus, marked extraocular weakness, or moderate disability of other cranial nerves

4 - Marked dysarthria or other marked disability

5 - Inability to swallow or speak

9 - Unknown

4. **Sensory Functions:** ☐

0 - Normal

1 - Vibration or figure writing decrease only in 1 or 2 limbs

2 - Mild decrease in touch or pain or position sense, and/or moderate decrease in vibration in 1 or 2 limbs; or vibratory (c/s figure writing) decrease alone in 3 or 4 limbs

3 - Moderate decrease in touch or pain or position sense, and/or essentially lost vibration in 1 or 2 limbs; or mild decrease in touch or pain and/or moderate decrease in all proprioceptive tests in 3 or 4 limbs

4 - Marked decrease in touch or pain or proprioceptive, alone or combined, in 1 or 2 limbs; or moderate decrease in touch or pain and/or severe proprioceptive loss in more than 2 limbs

5 - Loss (essentially) of sensation in 1 or 2 limbs; or moderate decrease in touch or pain and/or loss of proprioception for most of the body below the head

6 - Sensation essentially lost below the head

9 - Unknown

5. **Bowel and Bladder Functions:** ☐

(Rate on the basis of the worse function, either bowel or bladder)

0 - Normal

1 - Mild urinary hesitancy, urgency or retention

2 - Moderate hesitancy, urgency, retention or bowel or bladder or rare urinary incontinence *(intermittent self-catheterization, manual compression to evacuate bladder, or finger evacuation of stool)*

3 - Frequent urinary incontinence

4 - In need of almost constant catheterization *(and constant use of measures to evacuate stool)*

5 - Loss of bladder function

6 - Loss of bowel and bladder function

9 - Unknown

6. **Visual (or Optic) Functions:** ☐

0 - Normal

1 - Scotoma with visual acuity (corrected) better than 20/30

2 - Worse eye with scotoma with maximal visual acuity (corrected) of 20/30 to 20/59

3 - Worse eye with large scotoma, or moderate decrease in fields, but with maximal visual acuity (corrected) of 20/60 to 20/99

4 - Worse eye with marked decrease of fields and maximal visual acuity (corrected) of 20/100 to 20/200; grade 3 plus maximal acuity of better eye of 20/60 or less

5 - Worse eye with maximal visual acuity of better eye of 20/60 or less

6 - Grade 5 plus maximal visual acuity of better eye of 20/60 or less

9 - Unknown

- Use 1 in adjacent box for presence of temporal pallor ☐

7. **Cerebral (or Mental) Functions** ☐

0 - Normal

1 - Mood alteration only (does not affect DSS score)

2 - Mild decrease in mentation

3 - Moderate decrease in mentation

4 - Marked decrease in mentation (chronic brain syndrome-moderate)

5 - Dementia or chronic brain syndrome - severe or incompetent

9 - Unknown

8. **Other functions:** ☐

(Any other neurological findings attributable to MS)

A Spasticity:

0 - None

1 - Mild --- *(detectable only)*

2 - Moderate --- *(minor interference with function)*

3 - Severe --- *(major interference with function)*

9 - Unknown

B Others:

Name of rater: _____ Date: _____

IFMSS Minimal Record of Disability

Neurological Assessment

Kurtzke Expanded Disability Status Scale EDSS

(WHO Impairment)

Note - DSS steps below refer to patients who are fully ambulatory, and the precise step is defined by the Functional System score(s). DSS steps from 5 up are defined by ability to ambulate, and *usual* equivalents in Functional System scores are provided.

☐ ☐ . ☐

0.0 - Normal neurological exam (All grade 0 in FS*)

1.0 - No disability, minimal signs in one FS* (i.e. grade 1)

1.5 - No disability, minimal signs in more than one FS* (more than 1 grade 1) *Excludes cerebral function grade 1

2.0 - Minimal disability in one FS (one FS grade 2, others 0 or 1)

2.5 - Minimal disability in two FS (two FS grade 2, others 0 or 1)

3.0 - Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade, others 0 or 1) though fully ambulatory)

3.5 - Fully ambulatory but with moderate disability in one FS (one grade 3) *and* one or two FS grade 2; *or* two FS grade 3; *or* five FS grade 2 (other 0 or 1)

4.0 - Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1), or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 500 metres.

4.5 - Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterised by relatively severe disability usually consisting of one FS grade 4 (others 0 or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 300 metres

5.0 - Ambulatory without aid or rest for about 200 metres; disability severe enough to impair full daily activities (e.g. to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, other 0 or 1; or combinations of lesser grades usually exceeding specifications for step 4.0)

5.5 - Ambulatory without aid or rest for about 100 metres; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0)

6.0 - Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 metres with or without resting; (Usual FS equivalents are combinations with more than two FS grades 3+)

6.5 - Constant bilateral assistance (canes, crutches, braces) required to walk about 20 metres without resting; (Usual FS equivalents are combinations with more than two FS grade 3+)

7.0 - Unable to walk beyond about 5 metres even with aid, essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day; (Usual FS equivalents are combinations with more than one FS grade 4+; very rarely pyramidal grade 5 alone)

7.5 - Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; May require motorised wheelchair; (Usual FS equivalents are combinations with more than one FS grade 4+)

8.0 - Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms; (Usual FS equivalents are combinations, generally grade 4+ in several systems)

8.5 - Essentially restricted to bed much of the day; has some effective use of arm(s); retains some self-care functions; (Usual FS equivalents are combinations generally 4+ in several systems)

9.0 - Helpless bed patient; can communicate and eat; (Usual FS equivalents are combinations; mostly grade 4+)

9.5 - Totally helpless bed patient; unable to communicate effectively or eat/swallow; (Usually FS equivalents are combinations, almost all grade 4+)

10.0 - Death due to MS

Note - DSS should not change by 1.0 step unless there is a change in the same direction of at least one step in at least one FS. Each step (e.g. 3.0 to 3.5) is still part of prior scale equivalent (i.e. 3). Progression from 3 to 3.5 should be equivalent to the old 3.

IFMSS Minimal Record of Disability

Incapacity Status Scale ISS

(WHO Disability)

In the first box place the score for the item.
In the second box (when applicable) place a 1 if the rating was arrived at through questioning and a 2 if actual testing of the function was done.

1. **Stair Climbing.** (Ability to ascend a flight of stairs of about 12 steps)
   0 - Normal ☐ ☐
   1 - Some difficulty but performed without aid
   2 - Need for canes, braces, prostheses, or dependent upon banister to perform
   3 - Need human assistance to perform
   4 - Unable to perform; includes mechanical lifts

2. **Ambulation.** (Ability to walk on level ground or indoors some 50 metres without rest)
   0 - Normal ☐ ☐
   1 - Some difficulty but performed without aid
   2 - Need for canes, braces, prostheses, or dependent upon banister to perform
   3 - Need for human assistance or use of manual wheelchair which patient enters, leaves, and manoeuvres without aid
   4 - Unable to perform; includes perambulation in a wheelchair and motorised wheelchair

3. **Toilet /Chair /Bed Transfer** (Ability to enter and leave regular toilet and/or chair and/or bed; includes wheelchair transfer as indicated. The worst transfer function determines the grade)
   0 - Normal ☐ ☐
   1 - Some difficulty but performed without aid
   2 - Need for adaptive or assistive devices such as trapeze, sling, bars, lift, sliding board to perform
   3 - Requires human aid to perform
   4 - Must be lifted or moved about completely by another person

4. **Bowel Function**
   0 - Normal ☐ ☐
   1 - Bowel retention not requiring more than fibre diets, laxatives, occasional enemas or suppositories, self-administered

2 - Bowel retention requiring regular laxatives, enemas or suppositories, self-administered in order to induce evacuation; cleanses and disimpacts self

3 - Bowel retention requiring enemas or suppositories administered by another; disimpacted by another; needs assistance in cleansing; occasional incontinence; presence of colostomy tended by self

4 - Frequent soiling due either to incontinence or a poorly maintained ostomy device which patient cannot maintain without assistance

5. **Bladder Function**

0 - Normal (even if maintained by drugs) ☐ ☐

1 - Occasional hesitancy or urgency; occasional need for drugs

2 - Frequent hesitancy, urgency, or retention; use of indwelling or external catheter applied and maintained by self; intermittent self-catheterisation, manual compression to evacuate bladder, regular use of drugs

3 - Occasional incontinence; use of indwelling or external catheter applied and maintained by self; intermittent catheterisation by others

4 - Frequent incontinence; ostomy device which patient cannot maintain without assistance

6. **Bathing**

0 - Normal ☐ ☐

1 - Some difficulty with washing and drying self though performed without aid whether in tub or shower or by sponge-bathing, whichever is usual for the patient

2 - Need for assistive devices (trapeze, sling, lift, shower or tub bar) in order to bathe self; need to bathe self outside of tub or shower if that is the usual method

3 - Need for human assistance in bathing parts of the body or in entry/exit/positioning in tub or shower

4 - Bathing performed by others (aside from face and hands)

7. **Dressing**

0 - Normal ☐ ☐

1 - Some difficulty clothing self completely in standard garments, but accomplished by self

2 - Specially adapted clothing (special closures, elastic-laced shoes, front closing garments) or devices (long shoe horns, zipper

extenders) required to dress self

3 - Need for human aid to accomplish; performs considerable portion him/herself

4 - Need for almost complete assistance; unable to dress self

8. **Grooming** (Care of teeth or dentures and hair, shaving, or application of cosmetics)

0 - Normal ☐ ☐

1 - Some difficulty but all tasks performed without aid

2 - Need for adaptive devices (electric razors or toothbrushes, special combs or brushes, arm rests or slings) but performed without aid

3 - Need for human aid to perform some of the tasks

4 - Almost all tasks performed by another person

9. **Feeding** (Ingestion, mastication, swallowing of solids and liquids, and manipulation of the appropriate utensils)

0 - Normal ☐ ☐

1 - Some difficulty but performed without aid

2 - Need for adaptive devices (special feeding utensils, straws) or special preparation (portions pre-cut or minced, bread buttered) to feed self

3 - Need for human aid in the delivery of food; dysphagia preventing solid diet; esophagostomy or gastrostomy maintained and utilised by self; tube-feeding performed by self

4 - Unable to feed self or to manage ostomies

10. **Vision** (Rate of the basis of the worse of either visual acuity or double vision) ☐ ☐

0 - Normal vision. Can read print finer than standard newsprint with corrective lenses

1 - Cannot read print finer than standard newsprint even with corrective lenses or complains of double vision

2 - Magnifying lenses or large print necessary for reading or double vision interferes with function

3 - Can only read very large print such as major newspaper headlines, constant double vision or movements of objects

4 - Legal blindness

11. **Speech and Hearing** (Verbal output and input for interpersonal communication) ☐ ☐

0 - Normal; no subjective hearing loss; articulation and language

appropriate to the culture

1 - Impaired hearing or articulation not interfering with communication

2 - Deafness sufficient to require hearing aid and/or dysarthria interfering with communication. Needs communication aids such as special keyboards, etc

3 - Severe deafness compensated for by sign language or lip reading facility and/or severe dysarthria compensated for by sign language or self-written communication

4 - Severe deafness and/or dysarthria without effective compensation

12. **Medical Problems** (Presence of general medical and/or neurological and/or orthopaedic disorders; this includes MS and related problems such as decubiti, contractures, and urinary tract infections) ☐ ☐

0 - No significant disorder present

1 - Disorder(s) not requiring active care; may be on maintenance medication; monitoring not required more often than every three months

2 - Disorder(s) requiring occasional monitoring by physician or nurse, more often than every three months but less often than weekly

3 - Disorder(s) requiring regular attention (at least weekly) by physician or nurse

4 - Disorder(s) requiring essentially daily attention by physician or nurse, usually in hospital

13. **Mood and Thought Disturbances** (This includes anxiety, depression, mood swings, euphoria, delusions, hallucinations, and thought disorder. The rating should reflect current behaviour even if the patient is maintained on medication) ☐ ☐

0 - No observable problem

1 - Disturbance is present at times, but does not interfere with day to day functioning

2 - Disturbance does interfere with day to day functioning, but the person can manage without professional assistance except for occasional visits to maintain medication

3 - Disturbance interferes with day to day functioning and consistently requires professional intervention beyond that required to maintain medication; e.g., requires psychotherapy or hospitalisation

4 - Despite medication and/or other intervention, disturbance is severe enough to preclude day to day functioning

14. **Mentation** (Disturbances in memory, reasoning, calculation, judgement or orientation) ☐ ☐

0 - No observable problem

1 - Disturbance is present but does not interfere with performance of everyday activities

2 - Disturbance interferes with performance of everyday activities; the person may need to use lists or other prompting devices, but manages without the help of other people; the person is likely to be a poor historian

3 - Disturbance is severe enough to require prompting or assistance from others for performance of everyday activities

4 - Disturbance precludes the performance of most everyday activities; may include severe confusion, disorientation, or memory loss

15. **Fatigability** (This is a sense of overwhelming weakness or lasitude which dramatically alters baseline motor and coordination (occasionally visual or sensory) functions. It may be transient or persistent for hours or even days, and occurs at varying frequency; a common complaint in MS) ☐ ☐

0 - No fatigability

1 - Fatigability present but does not notably interfere with baseline physical function

2 - Fatigability causing intermittent and generally transient impairment of baseline physical function

3 - Fatigability causing intermittent transient loss or frequent moderate impairment of baseline physical function

4 - Fatigability which generally prevents prolonged or sustained physical function

16. **Sexual Function** ☐ ☐

0 - Sexually active as before and/or not experiencing some sexual problems. (No changes in patient's usual pattern of sexual activity; for example, no changes in frequency and type of sex activities; and no changes in previous genital sensations, erections, and ejaculation in men, and vaginal lubrication and orgasm in women. This includes persons without previous sexual experience or who are voluntarily celibate)

1 - Sexually less active than before, and/or now experiencing some sexual problem(s) but *not* concerned. (Less frequent or less varied sexual activity; and/or some changes in previous genital sensations, erections and ejaculation in men, and vaginal lubrication and orgasm in women but does not consider this an issue. May be using a prothesis or sexual aids.

2 - Sexually less active than before, and now experiencing some sexual problems *and* concerned. (Would like to regain former sexual activity pattern and/or would like to regain previous genital sensation, erection, ejaculations and/or orgasmic experiences). May be using a prothesis or sexual aids

3 - Sexually inactive but still concerned. (Sexual activity has ceased for several months, or years, but wishes to regain previous pattern and functional ability)

4 - Sexually inactive and not concerned. (Sexual activity has ceased for several months, or years, but does not consider this an issue)

Name of rater: _____ Date: _____

Sexual Concern Inquiry (This inquiry focuses on the specific areas about which the person expresses concern. It is intended for use by professionals who need further elaboration for planning specific interventions)

Code as follows: 1 - Does apply 2 - Does not apply

1 - Don't feel like sex ☐

2 - Can't find partner ☐

3 - Can't keep partner ☐

4 - Can't satisfy partner (e.g. erection and orgasmic problems; physical difficulties in hugging, intercourse) ☐

5 - Can't satisfy myself (e.g. sensory and orgasmic problems, pain) ☐

6 - Can't become a father or a mother ☐

7 - Can't be like a man or a woman ☐

8 - Partner doesn't feel like sex ☐

9 - Genitourinary hygiene ☐

10 - Lack of privacy ☐

11 - Other concerns, specify: ☐

Record number corresponding to area of greatest concern: ☐☐

IFMSS Minimal Record of Disability

Environmental Status Scale ESS

(WHO Handicap)

1. **Actual Work Status** (This question also applies to students and homemakers. It describes the overall situation and is not limited to MS related problems) ☐

   0 - Normal or retired for age, e.g. full-time worker, homemaker, or student

   1 - Works essentially full time but in less demanding position

   2 - Works more than half time at job, housework, or school

   3 - Works between one quarter and one half time at job, housework, or school

   4 - Works less than one quarter time at job, housework or school

   5 - Unemployed, not able to do any housework or to attend school at all

2. **Financial / Economic Status** (MS related) ☐

   0 - No MS related financial problems

   1 - Family maintains usual financial standard without external support despite some financial disadvantages resulting from MS

   2 - Family maintains usual financial standard with aid of some external financial support

   3 - Family maintains usual financial standard by receiving basic disability pension as defined in location of residence

   4 - Family maintains usual financial standard only because receiving all available financial assistance

   5 - Family unable to maintain usual financial standard despite receipt of all available financial assistance

3. **Personal Residence / Home** (MS related) ☐

   0 - No change necessary

   1 - Minor modification necessary

   2 - Moderate modification necessary

   3 - Major structural alteration or addition necessary

   4 - Must move to satisfactory person home

   5 - Must live in facility for dependent care because unable to continue in any personal home (institutionalised)

4. **Personal Assistance Required** (MS related) ☐

0 - None

1 - Minor help: Relatives involved but personal independence is maintained

2 - Requires assistance for activities of daily living up to one hour per day from relatives or others in the home

3 - Requires assistance with activities of daily living up to three hours per day from relatives or others in the home

4 - Requires more than three hours of personal assistance per day but is able to live at home and does not need a constant attendant

5 - Requires a constant attendant or care in an institution, i.e. cannot be left alone for more than short periods such as two or three hours

5. **Transportation** (This item refers to transportation problems which are attributable to MS and includes difficulties in both the availability and accessibility of transport). If the person with MS does not know how to drive, the questions on driving should be ignored ☐

0 - Uses public transport with no problems or drives

1 - Uses all forms of transport available despite minor difficulties or drives with minor difficulty, e.g. needs handicapped parking

2 - Uses some public transport despite difficulties or needs hand controls to drive

3 - Cannot use public transport but can use private transport, cannot drive but may be driven by others

4 - Requires community (public or private agency) transport in a wheelchair

5 - Requires ambulance

6. **Community Services** (MS related. Community services may include medical, social, household, personal assistance, or similar services whether administered at home or institution) ☐

0 - None required

1 - Requires service only per month or less frequently

2 - Requires Not more than one hour per week

3 - Requires not more than an average of one hour per day

4 - Requires one to four hours per day

5 - Requires more than four hours per day or institutionalised

7. **Social Activity** ☐

0 - Socially active as before with no changes in the usual pattern of social activity, and no difficulty in maintaining this pattern

1 - Maintains usual pattern of social activity despite some difficulties

2 - Some restrictions on social activity such as change in type or frequency of some activities or increased dependence on others

3 - Significant restrictions of social activity. Largely dependent on actions of others but still able to initiate some activity

4 - Socially inactive except for the initiative of others

5 - No social activity. Does not see friends or family. Social contact is limited to that provided by community service providers, e.g. visiting nurse

Name of rater: _____ Date: _____

Appendix D

Copies of the following measures of the participants' functioning are not included in this appendix due to copyright regulations:

1. Information, Block Design, and Vocabulary subtests of the Wechsler Adult Intelligence Scale - Revised (Wechsler, 1981).
2. National Adult Reading Test (NART; Nelson, 1991)
3. Wisconsin Card Sorting Test (Heaton, 1981)
4. Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983)
5. Stroop Color and Word Test (Golden, 1978)
6. Concentration Endurance Test (d2 Test; Brickenkamp, 1981)
7. Hooper Visual Organisation Test (Hooper, 1958)
8. Symptom Checklist -90- Revised (Derogatis, 1992).

Therefore, this appendix includes the following measures:

1. Fatigue Severity Scale.
2. Token Test.
3. Auditory Verbal Learning Test.
4. Controlled Oral Word Association Test (COWAT).
5. Paced Auditory Serial Addition Task (PASAT).

The FSS Scale

Participant ID: _____

Please indicate by placing a tick in the box under the number that most strongly corresponds with your degree of agreement with each statement.

1=Strongly disagree 2=Disagree 3=Somewhat disagree 4=Neither agree nor disagree 5=Somewhat agree 6=Agree 7=Strongly agree

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

1. My motivation is lower when I am fatigued
2. Exercise brings on my fatigue
3. I am easily fatigued
4. Fatigue interferes with my physical functioning
5. Fatigue causes frequent problems for me
6. My fatigue prevents sustained physical functioning
7. Fatigue interferes with carrying out certain duties and responsibilities
8. Fatigue is among my three most disabling symptoms
9. Fatigue interferes with my work, family, or social life

Token Test

Participant ID: _____

Date: _____

A. *Present all tokens in preset pattern. Instructions may be repeated once*
1. Show me a circle
2. Show me a square
3. Show me a yellow token
4. Show me a red token
5. Show me a blue token
6. Show me a green token
7. Show me a white token
Total A(7)

B. *Present only large tokens. Instructions may be repeated once.*
8. Show me the **yellow square**
9. Show me the **blue circle**
10. Show me the **green circle**
11. Show me the **white square**
Total B(8)

C. *Present all tokens in preset pattern. Do not repeat instructions.*
12. Show me the **small white circle**
13. Show me the **large yellow square**
14. Show me the **large green square**
15. Show me the **small blue square**
Total C(12)

D. *Present large token only. Do not repeat instructions.*
16. Take the **red circle** and the **green square**
17. Take the **yellow square** and the **blue square**
18. Take the **white square** and the **green circle**
19. Take the **white circle** and the **red circle**
Total D(16)

E. *Present all tokens in preset pattern. Do not repeat instructions.*
20. Take the **large white circle** and the **small green square**
21. Take the **small blue circle** and the **large yellow square**
22. Take the **large green square** and the **large red square**
23. Take the **large white square** and the **small green circle**
Total E(24)

F. *Present large tokens only. Do not repeat instructions.*
24. **Put** the **red circle on** the **green square**.
25. **Put** the **white square behind** the **yellow circle**
26. **Touch** the **blue circle with** the **red square**
27. **Touch** the **blue circle and** the **red square**
28. **Pick up** the **blue circle OR** the **red square**
29. **Move** the **green square away from** the **yellow square**
30. **Put** the **white circle in front of** the **blue square**
31. **If** there is a **black circle, pick up** the **red square**
32. **Pick up all squares except** the **yellow one**
33. **Put** the **green square beside** the **red circle**
34. **Touch** the **squares slowly and** the **circles quickly**
35. **Put** the **red circle between** the **yellow square** and the **green square**
36. **Touch all circles, except** the **green one**
37. **Pick up** the **red circle- NO-** the **white square**
38. **Instead of** the **white square, pick up** the **yellow circle**
39. **Together with** the **yellow circle, pick up** the **blue circle**
Total F(96)
Total A-F (163)

Token Arrangement in front of Person

Row 1

Large circles in order: Red, Blue, Yellow, White, Green

Row 2

Large squares in order: Blue, Red, White, Green, Yellow

Row 3

Small circles in order: White, Blue, Yellow, Red, Green

Row 4

Small squares in order: Yellow, Green, Red, Blue, White

Auditory Verbal Learning Test

Instructions: *I am going to read a list of words. Listen carefully, for when I stop, you are to say back as many words as you can remember. It doesn't matter in what order you repeat them. Just try to remember as many as you can.*

(After Trial A1): *Now I am going to read the same words again, and once again when I stop, I want you to tell me as many words as you can remember, including words you said the first time. It doesn't matter in what order you say them. Just as many words as you can remember, whether or not you said them before.*

(After Trial A5): *Now I'm going to read a second list of words. This time, again, you are to say back as many words of this second list that you can remember. Again, the order in which you say the words does not matter. Just try to remember as many as you can.*

(After Trial B): *Now I want you to tell me as many words as you can remember from the first list.*

(After 20 minutes): *I want you to tell me as many words as you can remember from the first list of words that we practiced earlier.*

(After Trial A7): *Here is a list of words. I want you to tell me which words come from the first list of words that we practiced earlier.*

LIST A	LIST B
Drum	Desk
Curtain	Ranger
Bell	Bird
Coffee	Shoe
School	Stove
Parent	Mountain
Moon	Glasses
Garden	Towel
Hat	Cloud
Farmer	Boat
Nose	Lamb
Turkey	Gun
Colour	Pencil
House	Church
River	Fish

Auditory Verbal Learning Test

Participant ID: _____

Date: _____

TRIALS

A1	A2	A3	A4	A5	B	A6	A7

AVLT: Recognition List

Participant ID: _____

Date: _____

Bell	Home	Towel	Boat	Glasses
Window	Fish	Curtain	Hot	Stocking
Hat	Moon	Flower	Parent	Shoe
Barn	Tree	Colour	Water	Teacher
Ranger	Balloon	Desk	Farmer	Stove
Nose	Bird	Gun	Rose	Nest
Weather	Mountain	Crayon	Cloud	Children
School	Coffee	Church	House	Drum
Hand	Mouse	Turkey	Stranger	Toffee
Pencil	River	Fountain	Garden	Lamb

Controlled Oral Word Association Test (COWAT)

Administration Instructions

I will say a letter of the alphabet. Then I want you to give me as many words that begin with that letter as quickly as you can. For instance, if I say 'B', you might give me 'bad', 'battle', 'bed'...I do not want you to use words that are proper names such as 'Boston', 'Bob', or 'Brylcream'. Also, do not use the same word again with a different ending such as 'eat' and 'eating'. Any questions?

Begin when I say the letter. **The first letter is 'F'** (Allow 1 minute):

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Total: _____

The second letter is 'A'. (Allow 1 minute):

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Total: _____

The third and final letter is 'S'. (Allow 1 minute):

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Total: _____

Participant ID: _____

Date: _____

'F' _____

'A' _____

'S' _____

Combined Total: _____

Paced Auditory Serial Addition Task (PASAT)

Oral Demonstration / Instructions

"I am going to ask you to add together pairs of single-digit numbers. You will hear a tape-recorded list of numbers read one after the other. I will ask you to add the numbers in pairs and give your answers out loud. Although this is really a concentration task, and not a test to see how well you can add, it might help to do a little adding before I explain the task in more detail. Please add the following pairs of numbers together as fast as you can, and give your answers out loud":

'3,8' [11]; **'4,9'** [13]; **'7,8'** [15]; **'8,6'** [14]; **'8,9'** [17]; **'5,7'** [12]; **'6,5'** [11]; **'6,9'** [15]; **'4,7'** [11]; **'7,6'** [13]. Good.

"The task that I want you to do involves adding together pairs of numbers, just as you have done, except that the numbers will be read as a list, one after the other. Let me give you an example with a short easy list. Suppose I gave you the following: '1,2,3,4'. Here is what you would do. After hearing the first 2 numbers on the list, which were '1,2', you would add these together and give your answer as '3'. The next number on the list was '3', so when you heard it, you would add this number to the number right before it on the list, which was '2', and give your answer as '5'. Are you following so far? The last number on the list was '4', so you would add '4' to the number right before it, which was '3', and give your answer as '7'."

"The important thing to remember is that you must add each number on the list to the number right before it on the list, and <u>not</u> to the answer you have just given. You can forget your answers as soon as you have said them. All you have to remember is the last digit that you have heard, and add it to the next digit that you hear. O.K.? Let's try that short list again, only this time <u>you</u> say the answers. Ready? '1,2' [3]; '3' [5]; '4' [7]. Now let's try another, longer practice list of numbers, this time the numbers on the list won't be in any particular order. Ready?":

'4,6' [10]; **'1'** [7]; **'8'** [9]; **'8'** [16]; **'4'** [12]; **'3'** [7]; **'8'** [11]; **'2'** [10]; **'7'** [9]. Good.

"Remember I said the numbers would be tape-recorded? The task is not easy, and no one is expected to get all the answers right. The hard part is keeping up with the speed of the recording. However if you can't answer in time, don't worry. Just wait until you hear two more numbers, add them together, and go on from there. O.K? Any questions? I'll play a practice list of numbers, and get you to give me the answers."

Play tape recording: 3,1 [4]; 4 [5]; 2 [6]; 6 [8]; 1 [7]; 8 [9]; 3 [11]; 5 [8]; 6 [11]; 2 [8]; 4 [6].

"You see what I meant about the task measuring how well you can concentrate. It doesn't have anything to do with how smart you are. Now we'll try the first real trial. This trial is just the same as the practice trial you've just done, except that it is six times as long, so it goes for almost two and a half minutes. Don't worry if you make mistakes or miss some answers. This is a difficult task. I want to see not only how long you can keep going without stopping, but also how quickly you can pick up again if you do stop. No one is expected to get all the answers. After this trial, we will take a break and then do another trial at a faster speed. There are 4 trials altogether."

Allow at least 60 seconds between trials. Warn person that next trial will be faster.

PASAT Score Sheet

Participant ID: _____

	2.4"	2.0"	1.6"	1.2"		2.4"	2.0"	1.6"	1.2"		2.4"	2.0"	1.6"	1.2"
7(9)					8(12)					5(13)				
5(12)					7(15)					4(9)				
1(6)					1(8)					8(12)				
4(5)					6(7)					2(10)				
9(13)					3(9)					1(3)				
6(15)					5(8)					7(8)				
5(11)					9(14)					5(12)				
3(8)					2(11)					9(14)				
8(11)					7(9)					1(10)				
4(12)					5(12)					3(4)				
3(7)					3(8)					6(9)				
2(5)					4(7)					2(8)				
6(8)					7(11)					9(11)				
9(15)					1(8)					7(16)				
3(12)					5(6)					8(15)				
4(7)					8(13)					2(10)				
5(9)					3(11)					4(6)				
8(13)					4(7)					7(11)				
6(14)					6(10)					6(13)				
6(14)					8(14)					3(9)				

	Total Correct	z	%ile	Time/Resp.	z	%ile
2.4" pacing	_____	__	____	_____	__	_____
2.0" pacing	_____	__	____	_____	__	_____
1.6" pacing	_____	__	____	_____	__	_____
1.2" pacing	_____	__	____	_____	__	_____

Appendix E

WAIKATO ETHICS COMMITTEE

26 September 1995

Miss J C Brassington
127 Nixon Street
HAMILTON

Dear Miss Brassington

NEUROPSYCHOSOCIAL ASPECTS OF MULTIPLE SCLEROSIS (NO. 036/95:278)

This proposal was considered by the Committee at its meeting on 20 September 1995 and given ethical approval subject to the following:

a) Could you please ensure that consent is obtained not only from the person with MS but also from the parents/caregivers and from the other couple. They should also be provided with the Information Sheet.

b) The freephone number (0800 801 482) of the Health Consumer Service should be included in the Information Sheet.

Would you please inform the Secretary of the actual start date of your study. Any proposed amendments to protocol must be submitted for ethical review and a final report submitted on completion of the study. A form is enclosed for this purpose.

Best wishes for the success of your study.

Yours sincerely

Rosemary J De Luca
Chairperson

P O Box 322 HAMILTON Telephone: 07 846 1539 Fax: 07 846 1496

Appendix F

INFORMATION SHEET: PART 1

Title of project: The Effects of Multiple Sclerosis

Principal Investigator: Jan Brassington
Post-graduate student
Department of Psychology
University of Waikato

Telephone: (07) 8568996

Co-investigators: Dr Nigel V Marsh (University of Waikato)
---------- (Field Officer, MS Society)

This study is concerned with finding out about the types of difficulties faced by people with Multiple Sclerosis (MS). We are also interested in finding out about any problems that may occur for other members of the family.

The reason for this research is so that we are able to get an idea of the impact of these difficulties on the lives of people with MS and their families. In this way we hope to be better able to provide relevant assistance in the future to people with MS and their families.

If you agree to take part in this study the person who has MS and another person who knows them well (and preferably lives with them) will be seen on one occasion. You can be seen at the MS branch office, the University of Waikato, or your own home, depending on which is most convenient for you.

This visit will last about 3 hours. During this visit the person who has MS will be asked a number of questions about how they spend their time and will be asked to take part in a number of puzzle/game-type assessments. Most people completing these assessments find them enjoyable and stimulating. The person who does not have MS will be asked a number of questions about how MS has changed both of their lives. The information that we receive during this visit will remain completely confidential, and you will not be identified in any future use of this information.

You will also be asked if you are willing to contact another couple similar to yourselves but not related to the person with MS, and ask them if they would like to participate in this study. It is necessary that neither person in the couple you contact has MS. This is so that we can gain information on how life for people who have MS is different from life for those who don't have MS.

PTO

INFORMATION SHEET: PART 2

You have been asked to take part in a research project which has been reviewed and approved by the Waikato Ethics Committee.

It is important that you know exactly what your participation in this project means. Therefore, if you are unsure about any part of this research or about what it means for you, please ask the person explaining it to you, or the person in charge of the research project. You may wish to discuss it with your own doctor, a family member or friend. Before you sign the consent form, the person who gave it to you will ask you to tell him or her what you understand your involvement in the research project to be, and how it will affect you.

DO NOT sign the consent form until you understand all the information given.

If you do not want to take part in this research project, or if you sign the form but then change your mind and do not want to continue at any stage, tell the person in charge of the project. In either case, you will still be given the best possible health treatment.

The Health Consumer Service Trust (Telephone: 0800 801 482) is available to all patients in the Midland Regional Health area. Any patient in a research project who has a concern about treatment may contact one of the people listed in the Health Consumer Service pamphlet.

Appendix G

INFORMATION SHEET: PART 1

Title of project: The Effects of Multiple Sclerosis

Principal Investigator: Jan Brassington
Post-graduate student
Department of Psychology
University of Waikato

Telephone: (07) 856 8996

Co-investigators: Dr Nigel V Marsh (University of Waikato)
---------- (Field Officer, MS Society)

This study is concerned with finding out about the types of difficulties faced by people with Multiple Sclerosis (MS). We are also interested in finding out about any problems that may occur for other members of the family.

The reason for this research is so that we are able to get an idea of the impact of these difficulties on the lives of people with MS and their families. In this way we hope to be better able to provide relevant assistance in the future to people with MS and their families.

The reason that we have sought your involvement with the research is to enable us to compare the information we collect from the people with Multiple Sclerosis and their partners, with people who are not affected by MS. In doing this we hope to gain some insight into how life for people who have MS is different from life for those who don't. In order to be useful as a comparison therefore, it is necessary that neither of you have neurological or medical problems.

If you agree to take part in this research you can be seen at the MS branch office, the University of Waikato, or your own home, depending on which is most convenient for you. The visit will last about 3 hours. During this visit one person will be asked a number of questions about how they spend their time and will be asked to take part in a number of puzzle/game-type assessments. Most people completing these assessments find them enjoyable and stimulating. The other person will be asked to complete a number of short questionnaires. This process will be identical to that undergone by the people with MS and their partners taking part in our research project. The information that we receive during this visit will remain completely confidential, and you will not be identified in any future use of this information.

PTO

INFORMATION SHEET: PART 2

You have been asked to take part in a research project which has been reviewed and approved by the Waikato Ethics Committee.

It is important that you know exactly what your participation in this project means. Therefore, if you are unsure about any part of this research or about what it means for you, please ask the person explaining it to you, or the person in charge of the research project. You may wish to discuss it with your own doctor, a family member or friend. Before you sign the consent form, the person who gave it to you will ask you to tell him or her what you understand your involvement in the research project to be, and how it will affect you.

DO NOT sign the consent form until you understand all the information given.

If you do not want to take part in this research project, or if you sign the form but then change your mind and do not want to continue at any stage, tell the person in charge of the project. In either case, you will still be given the best possible health treatment.

The Health Consumer Service Trust (Telephone: 0800 801 482) is available to all patients in the Midland Regional Health area. Any patient in a research project who has a concern about treatment may contact one of the people listed in the Health Consumer Service pamphlet.

Appendix H

Part 3: Consent Form

Researcher's Copy: Consent

Name of Research Project: The Effects of Multiple Sclerosis

Name of Principal Researcher: Jan Brassington

I have received a copy of the information sheet. The researcher and / or MS Field Officer have explained it to me and I have had a chance to discuss it with other people. Any questions have been answered to my satisfaction. I have read and understood all the information concerning my participation in this research project.

I agree to participate in this research project. I understand that I may withdraw at any time.

Signature: _____

Printed Name: _____

Date: _____

----------Detach----------

Participant's Copy: Consent

Name of Research Project: The Effects of Multiple Sclerosis

Name of Principal Researcher: Jan Brassington

I have received a copy of the information sheet. The researcher and / or MS Field Officer have explained it to me and I have had a chance to discuss it with other people. Any questions have been answered to my satisfaction. I have read and understood all the information concerning my participation in this research project.

I agree to participate in this research project. I understand that I may withdraw at any time.

Signature: _____

Printed Name: _____

Date: _____

Appendix I

Summary of Missing Data from the Cognitive Test Analysis

Of the three subtests from the WAIS-R that contributed to the summary score of current intellectual functioning, four participants with MS were unable to undertake the Block Design subtest due to severe motor impairments and one participant due to severe visual impairment. One participant with MS did not undertake the Vocabulary subtest due to English being the person's second language. One control participant refused to undertake the Block Design subtest.

All participants from both groups completed Trials 1 - 5 of the Auditory Verbal Learning Test. However the data of one participant with MS is absent from Trials 6, 7 and the recognition trial of this test due to the testing session being interrupted by the unexpected arrival of family members at that time. The data of an additional two participants with MS is missing from the recognition trial due to their severe visual impairments.

Two participants with MS were unable to undertake the Stroop Word/Color Test due to severe dysarthria, and a further two due to severe visual impairment. The data of one participant with MS was unable to be obtained for the d2 Concentration Test as a result of the unavoidable interruption to the testing session by the routine of the nursing home in which the person resided. A further four participants with MS were unable to complete this test due to severe motor impairments, and six more due to severe visual impairment. One control participant was not able to complete this test due to visual impairment (i.e., cataracts).

Twenty-nine participants with MS chose not to undertake the Paced Auditory Serial Addition Task due to severe fatigue or aversion to the test. One participant with MS was unable to undertake the test due to an unavoidable

interruption of the testing session by the normal routine of the nursing home in which she resided. Seventeen control participants also chose not to undertake this test due to aversion to the test.

The data of one participant with MS is missing from the Wisconsin Card Sorting Test as a result of severe visual impairment. Data from two participants with MS are missing from the analysis of the Token Test, one as a result of severe motor impairment and one as a result of severe visual impairment. One participant with MS was unable to undertake the Boston Naming Test due to severe visual impairment, and another as a result of English being the person's second language. All participants from both groups completed the Controlled Oral Word Association Test. Finally, two participants with MS were unable to complete the Hooper Visual Organisation test as a result of severe visual impairment.

Summary of Missing Cognitive Data from the MS Sample (N = 77)

	Reason for missing data					
Cognitive Measure:	Motor Impairment	Visual Impairment	Dysarthria	English as Second Language	Testing Session Interrupted	Aversion to Test
Wechsler Adult Intelligence Scale						
Vocabulary subtest				1		
Block Design subtest	4	1				
Auditory Verbal Learning Test						
Trial 6					1	
Trial 7					1	
Recognition Trial		2			1	
Stroop Color / Word Trial		2	2			
d2 raw score - errors	4	6			1	
Paced Auditory Serial Addition Task					1	29
Wisconsin Card Sorting Test						
Perseverative Responses		1				
Categories		1				
Token Test	1	1				
Boston Naming Test		1		1		
Hooper Visual Organisation		2				

Appendix J

Copies of the 28-item version of the General Health Questionnaire (GHQ-28; Goldberg & Williams, 1988) and the Cognitive Behavior Rating Scale (CBRS; Williams, 1987) are not included in the appendix of caregiver measures due to copyright regulations.

Therefore, this appendix includes the following measures of caregiver functioning (title on measure is presented here in parenthesis):

1. Measure of Objective and Subjective Burden (Montgomery, Gonyea, & Hooyman).
2. Social Health Battery (Donald & Ware S.H. Battery).
3. Duke-UNC Functional Social Support Questionnaire (Duke-UNC FSS Questionnaire).

Montgomery, Gonyea, & Hooyman

Participant ID: _____

Date: _____

Instruction: For each question please circle the option that you feel best describes your situation.

Section A.

1. Amount of time you have to yourself.

   a lot more a little more the same a little less a lot less

2. Amount of privacy you have.

   a lot more a little more the same a little less a lot less

3. Amount of money you have available to meet expenses.

   a lot more a little more the same a little less a lot less

4. Amount of personal freedom you have.

   a lot more a little more the same a little less a lot less

5. Amount of energy you have.

   a lot more a little more the same a little less a lot less

6. Amount of time you spend in recreational and/or social activities.

   a lot more a little more the same a little less a lot less

7. Amount of vacation activities and trips you take.

   a lot more a little more the same a little less a lot less

8. Your relationships with other family members.

   a lot better a little better the same a little worse a lot worse

9. Your health.

   a lot better a little better the same a little worse a lot worse

Section B.

1. I feel it is painful to watch my relative age.

rarely/never a little of the time sometimes often most of the time

2. I feel useful in my relationship with my relative.

rarely/never a little of the time sometimes often most of the time

3. I feel afraid for what the future holds for my relative.

rarely/never a little of the time sometimes often most of the time

4. I feel strained in my relationship with my relative.

rarely/never a little of the time sometimes often most of the time

5. I feel that I am contributing to the well-being of my relative.

rarely/never a little of the time sometimes often most of the time

6. I feel that my relative tries to manipulate me.

rarely/never a little of the time sometimes often most of the time

7. I feel pleased with my relationship with my relative.

rarely/never a little of the time sometimes often most of the time

8. I feel that my relative doesn't appreciate what I do for him/her as I would like.

rarely/never a little of the time sometimes often most of the time

9. I feel nervous and depressed about my relationship with my relative.

rarely/never a little of the time sometimes often most of the time

10. I feel that my relative makes requests which are over and above what s/he needs.

rarely/never a little of the time sometimes often most of the time

PLEASE TURN OVER

11. I feel that I don't do as much for my relative as I could or should.

rarely/never a little of the time sometimes often most of the time

12. I feel that my relative seems to expect me to take care of him/her as is I were the only one s/he could depend on.

rarely/never a little of the time sometimes often most of the time

13. I feel guilty over my relationship with my relative.

rarely/never a little of the time sometimes often most of the time

The Donald & Ware S.H. Battery

Participant ID: _____
Date: _____

1. About how many families in your neighbourhood are you well enough acquainted with, that you visit each other in your homes?
_____ families (Enter number on line)

2. About how many *close* friends do you have - people you feel at ease with and can talk with about what is on your mind? (You may include relatives)
_____ close friends (Enter number on line)

3. Over a year's time, about how often do you get together with friends or relatives, like going out together or visiting in each other's homes?

	(Circle one)
Every day	1
Several days a week	2
About once a week	3
2 or 3 times a month	4
About once a month	5
5 to 10 times a year	6
Less than 5 times a year	7

4. During the *past month,* about how often have you had friends over to your home? (Do *not* count relatives)

	(Circle one)
Every day	1
Several days a week	2
About once a week	3
2 or 3 times in past month	4
Once in past month	5
Not at all in past month	6

5. About how often have you visited with friends at *their* homes during the *past month*? (Do not count relatives)

	(Circle one)
Every day	1
Several times a week	2
About once a week	3
2 or 3 times in past month	4
Once in past month	5
Not at all in past month	6

PLEASE TURN OVER

6. About how often were you on the telephone with close friends or relatives during the *past month*?

	(Circle one)
Every day	1
Several times a week	2
About once a week	3
2 or 3 times	4
Once	5
Not at all	6

7. In general, how well are you getting along with people these days - would you say better than usual, about the same, or not as well as usual?

	(Circle one)
Better than usual	1
About the same	2
Not as well as usual	3

8. How often have you attended a religious service during the *past month*?

	(Circle one)
Every day	1
Several times a week	2
About once a week	3
2 or 3 times	4
Once	5
Not at all	6

9. About how many voluntary groups or organisations do you belong to - like church groups, clubs or lodges, parent groups, etc. ("Voluntary" means because you want to.)
_____ groups or organisations. (Write in number. If none, enter "0").

10. How active are you in the affairs of these groups or clubs you belong to? (If you belong to a great many, just count those you feel closest to. If you don't belong to any, circle 4).

	(Circle one)
Very active, attend most meetings	1
Fairly active, attend fairly often	2
Not active, belong but hardly ever go	3
Do not belong to any groups or clubs	4

Duke -UNC FSS Questionnaire

Participant ID: _____

Date: _____

Here is a list of some things that other people do for us or give us that may be helpful or supportive. Please read each statement carefully and tick (√) in the blank that is closest to your situation.

HERE IS AN EXAMPLE: I get...	As much as I would like				Much less than I would like
enough vacation time	.	√	.	.	.

If you tick where we have, it means that you get almost as much vacation time as you would like, but not quite as much as you would like.

ANSWER EACH ITEM AS BEST YOU CAN. THERE ARE NO RIGHT OR WRONG ANSWERS.

I get...	As much as I would like				Much less than I would like
1. invitations to go out and do things with other people	.	.	.	.	.
2. love and affection	.	.	.	.	.
3. chances to talk to someone about problems at work or with my housework	.	.	.	.	.
4. chances to talk to someone I trust about my personal and family problems	.	.	.	.	.
5. chances to talk about money matters.	.	.	.	.	.
6. people who care what happens to me.	.	.	.	.	.
7. useful advice about important things in life	.	.	.	.	.
8. help when I'm sick in bed	.	.	.	.	.