

**TRYING TO TAKE CONTROL WHILE ATTEMPTING TO ADAPT:
PERSPECTIVES OF PEOPLE WITH MULTIPLE SCLEROSIS
ON THE
TWELVE MONTHS FOLLOWING DIAGNOSIS**

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ABSTRACT

Multiple Sclerosis (MS) is a neurological condition often characterised by its unpredictability, and lack of known cause or cure. As the leading non-traumatic cause of disability in young adults (Marrie, 2004), a diagnosis of MS is likely to bring uncertainty to those affected, as the future ramifications are unable to be foreseen (Costello & Harris, 2006). Considering the present trend toward self-management in chronic conditions, it is of utmost importance to take the perspectives of people with MS (PwMS) into account when conducting research into behaviour following diagnosis. The current study was exploratory in nature, with a focus on gaining information on individuals' MS related experiences prior to, and at the time of, diagnosis. A further focus of the study was to identify and further clarify the post-diagnosis behaviours and lifestyle changing activities exhibited by individuals in the first 12 months following diagnosis. The 12 months following diagnosis was chosen for examination as it may be a critical time for PwMS to establish the key coping resources, strategies and behaviours needed to adapt to the diagnosis, and has been rarely examined in studies on MS. Another unique feature of the current study was the global representation of PwMS. Participants in the current study were 243 females and 52 males from 18 countries. Both quantitative and qualitative data were obtained using an online self-report measure that was linked to the MS Australia website.

Results showed that participant reports on MS related experiences prior to and during the first 12 months following diagnosis of MS varied widely. Variability included the number of exacerbations prior to diagnosis, and the types of symptoms and whether admission to hospital occurred prior to or at the time of diagnosis. On examination of the behaviour engaged in by PwMS in the 12 months following diagnosis, there was a wide variety of examples given by participants, with information seeking the most identified activity. Lifestyle changing activities reported by participants were also numerous, with changes to diet or vitamin intake the most common.

Three key demographic variables (gender, type of MS, and country of birth) were examined to ascertain their possible effect on MS related experience. Minor differences were found between male and female participants and included a higher proportion of females reporting suspicion of MS prior to diagnosis and an increased interest in spirituality in the 12 months following diagnosis, than males. Generally, the differences found between participants grouped into the five types of MS were expected. There were few differences found between participants based on their country of birth indicating that the experiences of PwMS prior to, and at the time of diagnosis, and in the 12 months following, may be considered somewhat universal.

Qualitative findings were based around participant perspectives of the discussion of diagnosis with another PwMS; the reasons given for disclosure of diagnosis to others; and the factors that participants identified as being of assistance, or hindrance, to their coping within the first 12 months following diagnosis. The prominent theme throughout the qualitative results was participants' desire to take control of lifestyle changing activities post-diagnosis, and further research into the use of taking control as a coping resource by PwMS is warranted. Attempting to take control of an uncontrollable disease during the 12 months following diagnosis seems imperative for most PwMS, and health professionals may be able to take a key role in advising appropriate avenues for this when working with those newly diagnosed with MS.

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This thesis is dedicated to my mum, Sandra Joy Shaw, who would have been so proud of me, and would have read every word. Twice.

DECLARATION

I declare that this report does not incorporate, without acknowledgement, any material previously submitted for a degree in any University or other educational institution and that to the best of my knowledge, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: _____

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CHAPTER ONE

INTRODUCTION AND OVERVIEW OF THE THESIS

1.1 Preamble

While everyone tried to reassure her that it was normal, there was just something about the tiredness that Jane¹ could not put down to ‘being a new mum’. Jane was also experiencing a range of other invisible and curious symptoms. Dizziness, heat intolerance, and pins and needles were among them. A good friend of hers, who was a nurse, suggested that she should not worry about it as the symptoms were probably indicative of the early stages of menopause, but Jane was not so sure. She spent ten years having countless blood tests and medical scans for conditions such as Carpal Tunnel Syndrome, Meniere’s disease, and cancer. When Jane was finally diagnosed with multiple sclerosis (MS) in 1999, her husband of 14 years was not sitting beside her in the neurologist’s office. He had decided to stay at home to mow the lawns because previous test results had always failed to provide answers, and he thought the results of the MRI would be no different. At the time of Jane’s diagnosis they had two sons, aged 8 and 9 years, and she worked part time. Jane and her husband were both surprised by the combination of shock and relief they experienced after receiving the diagnosis. Nevertheless, Jane looks back at the time following her diagnosis of MS as an extremely difficult period in her life, where her uncertainty about the future was at the forefront of her thinking.

¹ Not her real name. ‘Jane’ was born in Australia, and is a woman living with Relapsing Remitting MS. Diagnosed at the age of 38 years, Jane was 41 years old at the time of personal communication with the author.

The current author asked Jane what she remembered of the first 12 months following diagnosis. The following are excerpts taken from her response.

It is like an out-of-body experience when you are first diagnosed. My diagnosing neurologist gave me his normal 15 minute appointment, that's all you get, told me I had MS and that was the last time I saw him. He didn't understand what it would be like for me to hear that diagnosis. It was really hard - the first 12 months were really hard because I thought that life, as I knew it, was over. Sometimes it was all I could think about.

... You don't know anything about MS when you are diagnosed, but people treat you differently straight away. All of a sudden I had been given this label of MS even though I looked the same... People's attitudes toward me changed dramatically.

...The only thing I knew about MS was from my professional experience (nursing) in caring for people with really bad MS. I assumed that that was now going to be the picture for my life... Nobody told me about the 20 or 30 or even 40 years leading up to that point.

...My neuro [sic] didn't give me any info; he gave me the MS Society's phone number on a piece of paper, and I was like 'what do you want me to do with this'? He should have made sure that I had enough information so that I could go home and sleep that night. You need to be able to go home and sleep that night and not feel like you are going to die, or that you want to die.

...Some of the health professionals I came into contact with after my diagnosis didn't seem to be human...they didn't really care about me, and they definitely didn't know anything about MS. I felt like I really needed to have confidence in them because I didn't know what to do or what was going on. Mostly, I felt like I had no control over anything to do with MS (Personal communication with 'Jane', 02.06.02).

As Jane reflected on her experiences of the first 12 months following diagnosis, she highlighted her feelings of uncertainty and being out of control, of not knowing what to do, and her need for information and support. Stories such as Jane's provide researchers and health practitioners with a valuable glimpse into the multiple difficulties inherent in attempting to adapt to a diagnosis of MS. From such stories it can be gleaned that research into the first 12 months following a diagnosis of MS is crucial in order to develop further understanding of this difficult time. It is imperative that those working with people newly diagnosed with MS are aware of the complexities involved and offer, not only information and support, but critical understanding of the issues pertinent to the first 12 months, and suggestions and strategies for successful adaptation to a diagnosis of MS.

1.2 Introduction

Multiple Sclerosis, or MS as it is commonly termed, is the leading non-traumatic cause of disability in young adults (Marrie, 2004), and it affects more young adult Australians than any other neurological condition (Jelinek, 2005). The cause of MS remains elusive, and there is no known cure. All functions controlled by the central nervous system can be affected as MS can cause physical, sensory, affective and cognitive symptoms (Mohr & Cox, 2001; Wassem & Dudley, 2003). Best characterised by its unpredictability, the severity of symptoms varies widely between and within individuals, and the timing and type of symptoms are unable to be foreseen (Costello & Harris, 2006).

A diagnosis of MS is likely to indicate the threat of major changes in an individual's lifestyle. These may include reduced physical abilities, loss of independence, changes to interpersonal roles and relationships, loss of employment, and subsequent financial insecurity (Edgley, Sullivan & Dehoux, 1991; Lyons et al., 1995). In addition, actual changes may be

instigated by the individual soon after the diagnosis for a number of reasons. Individuals may engage in post-diagnosis behaviours, or lifestyle changing activities, in attempts to make sense of the disease, or to cope with the uncertainty a diagnosis of MS can bring. Changes to lifestyle or behaviour may also be observed as individuals attempt to alleviate symptoms or improve their quality of life. Making lifestyle changes in the first 12 months following diagnosis may be difficult as individuals struggle to adapt to the reality of having MS. Adding to this struggle, the early stages are often marked by the threat of loss rather than actual loss, making adaptation to a diagnosis of MS a complex process (Lyons et al., 1995; Sullivan, Edgley, Mikail, Dehoux & Fisher, 1993).

1.3 Significance of the Current Study

The majority of research conducted into MS to date has been approached from a medical, biological, or immunological perspective. In comparison, there is a much smaller amount of research into MS from a psychosocial perspective. A body of work exploring certain aspects of the psychosocial realm of MS research is evident; however, examinations by health psychologists of the behaviour following a diagnosis of MS have been scarce. The literature that does exist tends to focus on information seeking and social support (e.g., Baker, 1998; Pakenham, 1999), and does not seek out additional behaviours that may occur following diagnosis, or invite people with MS (PwMS)² to elaborate on their lifestyle changing activities following diagnosis. This lack of research into behaviour following a diagnosis of MS is paralleled by the paucity of research into individuals' experiences during the first 12 months following diagnosis. Where the experiences of individuals spanning their time since diagnosis has been the focus of most studies, there exists a lack of understanding of the individual's experiences looking specifically at the first

² The abbreviation 'PwMS' is used throughout this thesis to refer to either a 'Person with MS' or 'People with MS'.

12 months following diagnosis. The deficit of such research calls for a broad and explorative study, utilising qualitative techniques, to provide a basis for understanding post-diagnosis behaviour and lifestyle changing activities undertaken within the crucial first 12 months following diagnosis.

Further, an investigation into the differences in behaviour following diagnosis among different demographic groups of people with MS has not yet been conducted. While some gender comparisons have been made in regard to specific behaviours such as information seeking and social support, a broader understanding of the post-diagnosis differences, if any, between groups based on gender, birthplace and type of MS would be beneficial and could aid in the planning and provision of services internationally as well as in Australia.

Within the field of health psychology the importance of the individual's own understanding and explanation of their situation, is acknowledged (Taylor, 1995). Therefore, a focus of research into MS should be placed on what the PwMS views as being of assistance or hindrance to their coping with the diagnosis. Such emphases will add a richer knowledge of post diagnosis behaviour to the area of MS related research, and will assist both health psychologists and other health professionals working with people newly diagnosed with MS. Although recent literature shows increasing recognition by health professionals and researchers that PwMS want to learn more about the disease and play a role in managing their health (Heesen, Köpke, Richter & Kasper, 2007), very little has been clarified from a health psychology perspective about individuals' post-diagnosis behaviour and the lifestyle changing activities engaged in following a diagnosis of MS. The unpredictability of MS, combined with the lack of a cure for the disease, highlights the importance of psychologists and other health professionals working with people newly diagnosed with MS to have a thorough understanding of MS, and a critical appreciation for the complex issues inherent in an individual's ability to adapt to the diagnosis. The present

research is located within the contemporary social context of health care in that the importance of the individual's role is acknowledged, and the individual's view of what they identify as being of assistance following diagnosis is explored.

1.4 The Following Chapters

A review of the literature describing MS is presented in Chapter Two. It includes a description of the disease, the aetiology and epidemiology of MS, and the diagnostic process. The clinical subgroups of MS are discussed, before symptoms and treatment options are explored. The uncertain prognosis of MS is also considered.

In Chapter Three, the literature on post diagnosis behaviour is explored. The uncertainty inherent in a diagnosis of MS is discussed alongside the reported preference for early diagnosis. A review of the empirical studies from the psychological literature on people's experience following a diagnosis of MS is then offered with a focus on post-diagnosis behaviour and lifestyle changing activities.

A discussion detailing the importance of isolating the first 12 months when researching behaviour following diagnosis is presented in Chapter 4. Then, psychosocial factors that may assist or hinder adaptation to diagnosis during this time period are identified and discussed.

In Chapter Five, key demographic variables are identified before the justification for the current study is outlined. The rationale for combining quantitative and qualitative methodologies and the rationale for using an online questionnaire to collect data is explained. The importance of the current study for health psychologists and other health professionals is explored before the research aims are presented.

The methodology of the current study is outlined in Chapter Six. Specifically, the chapter includes an outline of the participants, materials and procedures used, and details of the constructed questionnaire.

The results of the study are presented in Chapter Seven. An overview of how the data is presented, and the manner in which the qualitative responses were thematically analysed, is given. The demographic information of participants at the time of their diagnosis of MS and the MS-related experiences of participants leading up to, and at the time of, the diagnosis is included. Following this, an in-depth qualitative analysis of the responses given to the questionnaire's open ended questions is presented. Participants' experiences of meeting another person or people with MS, reasons for disclosing their diagnosis to others, and the factors participants identified as assisting or hindering their coping with MS in the first 12 months following diagnosis, are explored.

In Chapter Eight, a general discussion is presented drawing together the quantitative and qualitative results, highlighting the main findings, and placing the current research within the recent literature of behaviour following a diagnosis of MS. The broader application of the current research to health psychology theory is then considered before suggestions are offered for health professionals and staff of MS Societies working with people newly diagnosed with MS. The limitations of the present research, together with suggestions for future research are also addressed in this chapter.

CHAPTER TWO

A DIAGNOSIS OF MULTIPLE SCLEROSIS

2.1 Overview of the Chapter

Chapter Two consists of several sections to offer a comprehensive picture of MS. A brief description of the disease is given before research into the complex aetiology and epidemiology of MS is discussed. In the third section of the chapter, the process of diagnosing MS is examined, and an outline of the confirmatory studies involved in this often lengthy and difficult, procedure is given. The five clinical subgroups of MS are then profiled before the numerous symptoms of MS are listed and the most and least commonly reported symptoms are identified. Treatment options, including disease modifying treatments, relapse specific treatments, and complementary treatments are then discussed. In the final section of the chapter, the prognosis, or uncertainty of prognosis, facing people living with MS is considered.

2.2 A Description of the Disease

While a definitive and complete definition of MS remains controversial (Poser & Brinar, 2004), it is widely accepted that MS is a chronic, often disabling disease of the central nervous system (CNS). MS is cited in current literature as an autoimmune disease, where the immune system attacks the myelin sheath of the axons in the brain, spinal cord and optic nerves (Mohr & Cox, 2001). Recently however, Hauser and Oksenberg (2006) reported that the autoimmune model of MS is an “incomplete conceptual framework for understanding the complex array of factors that lead to the loss of immune homeostasis, myelin and axonal injury, and progressive neurological symptoms” (p.61). MS is a multifaceted and complicated disease not yet fully

understood and further research into the possible causes, and the specific disease pathology, is required.

The term multiple sclerosis literally means ‘many scars’ (Multiple Sclerosis International Federation, 2002) and is characterised by the demyelination of nerve fibres in the white matter of the CNS which produces lesions or ‘scarring’. Permanent damage to axons can occur, and may begin earlier in the disease process than originally thought, as damage may be clinically silent (Trapp et al., 1998; Trapp, Bo, Mork & Chang, 1999). As a result of the demyelination process, nerve impulses are interrupted along the nerve fibres, or travel at a reduced speed (Trapp et al., 1999). Common symptoms of MS are wide ranging as all functions controlled by the CNS can potentially be affected (Mohr & Cox, 2001).

MS is usually diagnosed between the ages of 20 and 40 years, with an occasional diagnosis made in childhood or late middle age (Calabresi, 2004). The prevalence of MS among women is generally accepted to be two to three times that found in men (Eeltink & Duffy, 2004). However, more recently, Orton et al. (2006) have demonstrated that the female to male sex ratio by year of birth in Canada has been increasing for at least 50 years and now exceeds 3.2:1. Thus, the gender divide in MS may be increasing.

2.3 Aetiology and Epidemiology of Multiple Sclerosis

There are as many studies reporting associations between the studied risk factors and MS, as there are denying the existence of an association (Hibberd, 1994, p.128).

While the aetiology and epidemiology of MS have been studied intensively, the cause remains elusive. MS has been conceptualised as a complex condition, in which a number of environmental factors act together in a genetically susceptible individual to cause disease

(Dyment, Sadnovich & Ebers, 1997; Marrie, 2004). While understanding of possible genetic and environmental factors that contribute to MS has improved, Kantarci and Wingerchuk (2006) suggest that further research involving longitudinal studies to assess genetic and environmental interactions will provide implications for the prediction of MS susceptibility, the disease course, and response to treatment.

2.3.1 Genetics

MS affects more Caucasians than any other racial group (Williamson, 2006). A suggestion that the Vikings may have been instrumental in disseminating the genetic susceptibility to MS around the world was made by Poser (1994). Poser tracked the path of the Vikings through the areas where the highest prevalence rates for MS are found: Iceland, Scandinavia, and the British Isles, and the countries settled by their descendants such as the United States, Canada, Australia and New Zealand. This 'Viking gene' hypothesis has attracted much interest (Holmoy, 2006) although it remains within the theoretical realm. The variable of race is complicated further by the fact that the susceptibility to MS varies even within Caucasian populations, where individuals of Scottish descent are more likely to develop the disease than any other ethnic group (McLeod, Hammond & Hallpike, 1994). So while there are suggestions of a genetic link in MS, clarification of the exact role genes play in the development of the disease is needed.

Another indication of a possible genetic link in MS is that between 10% and 20% of PwMS report having a relative with MS (Sadovnick, 1994). Compston (2000) reports that studies of genetics in MS indicate that susceptibility may be determined by several genes acting independently, rather than the presence of one 'MS specific' gene. Similarly, Ebers and Dyment (1998) stress the complexity of the genetics of MS in determining familial risk. In a recent study

of concordance for MS in Danish twins by Hansen et al. (2005), it was found that a monozygotic twin whose co-twin has MS, has a 24% risk of developing the disease, while the risk for a dizygotic twin is approximately 3%. This study was of particular importance given that Denmark keeps registries of all PwMS and all twins, and researchers had access to an unbiased sample of MS cases among twins. This study confirmed the results of other twin and genetic studies (Bugeja et al, 2006; Dyment, Sadovnick, Ebers, Sadnovich, 1997; Ebers & Dyment, 1998; Fedetz et al., 2006) in indicating that genetic factors are of significance in assessing an individual's risk of susceptibility to MS.

The higher risk for MS in relatives of PwMS, and in certain racial groups, together with the existence of MS-resistant ethnic groups, supports a potential genetic predisposition (Hagancamp, Rodriguez & Weinshenker, 1997). Although a genetic link in the development of MS appears clear, the low concordance rate among identical twins indicates that there are possibly multiple non-genetic factors involved in influencing an individual's risk of developing MS (Ebers & Sadovnick, 1998; Sadovnick, Yee & Ebers, 2005). While this genetic link is apparent, the exact involvement of genetics is yet to be clarified.

2.3.2 Possible Non-Genetic Factors

While exposure to a single non-genetic or environmental factor has not been consistently identified as a causal factor in MS, numerous potential causal factors have been put forward (Marrie, 2004). These include viral infection, vaccinations, climate, sex hormones, stress, and diet, among others (Marrie, 2004). Coo and Aronson (2004) recently carried out a systematic review of several potential non-genetic risk factors for MS, ranking the plausibility of each. While they did not make comment on all possible environmental factors, they reported that based

on their criteria, the plausibility for solar ultraviolet radiation and sex hormones is good, and the plausibility for dietary fat is fair.

2.3.2.1 Geographical Zones

The prevalence rates of MS vary around the globe. Kurtzke (2000) describes three geographical zones (high, medium and low frequency zones) for MS based on prevalence, where genetics is certainly a confounding factor, but does not explain fully the differences in prevalence found between geographical zones. Most of Europe (including the UK), Israel, Canada, northern USA, south eastern Australia, New Zealand, and eastern Russia are considered to lie within the high frequency zone (prevalence 30+ per 100,000). The medium frequency zone includes southern USA, most of Australia (apart from the south-east), South Africa, the southern Mediterranean basin, central and western Russia, the Ukraine and parts of Latin America. Low prevalence rates of MS (under 5 per 100,000) are found in the rest of Asia, Africa and northern South America. Temporal and geographic variations in disease risk are apparent, and patterns of migration have illustrated how geographical zones may impact on the development of MS. For example, migrants from high to lower risk areas retain the MS risk of their birth place only if they are at least age 15 years at migration (Gale & Martyn, 1995; Kurtzke, 2005). Similarly, Dean et al. (1976) found that those immigrating from areas of low risk to the UK (an area of high risk), retained the low risk of their area of origin. Further research into prevalence differences across geographical zones is needed regarding MS.

2.3.2.2 Climate

The geographic variations in risk of developing MS have prompted much research into climatic factors as causal agents (Marrie, 2004). As MS is more prevalent in the geographic

areas furthest from the equator (Kurtze, 2000), and solar ultra-violet radiation decreases with increasing distance from the equator (Coo & Aronson, 2004), a number of epidemiological studies have looked at the possible effect of exposure to sunlight and prevalence of MS. Research has provided mixed results with the findings of two ecological studies showing strong inverse correlations between levels of ultraviolet radiation and frequency of MS (Leibowitz, Sharon & Alter, 1967; van der Mei, Ponsonby, Blizzard & Dwyer, 2001). No association was found in three studies (Cendrowski et al., 1969; Norman, Kurtzke & Beebe, 1983; Warren, Cockeril & Warren, 1991) and individuals with MS reported more sun exposure than others before disease onset in two studies (Antonovsky et al., 1965; Neutel, 1980).

Studies conducted more recently have demonstrated higher levels of consistency in their findings, with higher sun exposure associated with a reduced risk of developing MS, and mortality from MS negatively associated with exposure to sunlight (Freedman, Dosemeci & Alavanja, 2000; Goldacre, Seagroatt, Yeates & Acheson, 2004; van der Mei et al., 2003). In a case control study conducted in Australia, individuals who reported high levels of sun exposure between the ages of six and fifteen were less likely to have MS (van der Mei et al., 2003). Van der Mei and colleagues suggested that insufficient ultraviolet radiation in childhood and early adolescence may therefore influence the development of MS. Kantarci and Wingerchuk (2006) suggest that as well as exposure to sunlight, which provides the body with vitamin D, dietary vitamin D supplementation is also associated with reduced MS risk. Brown (2006) asserts that vitamin D supplementation may not only help prevent the development of MS, but may also reduce the severity of the disease course, and therefore may be a useful addition to other treatments.

2.3.2.3 Diet

Interest in diet, as both a possible causative factor in MS and a contributing factor to disease mortality, has existed for over fifty years (Swank, 1950). Just as an individual's diet is multifaceted, the variety of hypotheses put forward relating to aspects of diet and MS have been numerous. Significant positive correlations for dietary fat and MS prevalence and MS morbidity, have been reported by a number of studies (Alter, Yamoor & Harshe, 1974; Esparza, Sasaki & Kesteloot, 1995; Nanji & Narod, 1986). Phosphate depletion and its impact on increasing the risk of MS has also been put forward (Haglin, 2004). Similarly, MS has also been associated with magnesium deficiency (Johnson, 2001). Looking more broadly at the types of food included in an individual's diet, Zhang et al. (2001) studied two large cohorts of women (over 150,000 women) and found no association between intake of fruit and vegetables and risk of MS. Similarly, they found no relationship between use of vitamin C, vitamin E, or multivitamin supplements, and risk of MS. The influence of diet on MS is, arguably, unproven (Schwarz, Leweling & Meinck, 2005), and there are a number of methodological challenges facing researchers examining components of diet, including recall bias, sampling bias, and the way diet is measured (Coo & Aronson, 2004). However, diet remains a strong area of interest for both researchers and PwMS in the search for aetiological answers in MS.

Following diagnosis, PwMS may view dietary changes, or the addition of vitamin supplements, as a positive behaviour to engage in, as one study found that two thirds of PwMS made changes to their diet post-diagnosis (Hewson et al., 1984). Examples of dietary changes made by PwMS following diagnosis will be discussed in Chapter Three.

2.3.2.4 Viral Infection

In the search for an environmental factor that may interact with a genetically susceptible individual to cause MS, there have been numerous studies into the effect viral infections may have on the development of MS. Nowark et al. (2006) suggest that viral infections are the most likely environmental factor involved in the development of MS. Soldan et al. (1997) hypothesise that the implication of a viral agent in the development of MS is based on the epidemiological evidence of childhood exposure to infectious agents; geographic association of disease susceptibility with evidence of MS clustering; and analogy with animal disease models whereby viruses can cause disease with long incubation periods, a relapsing remitting course and demyelination. With some 20 bacteria and viruses potentially linked with the development of MS in previous research (Swanborg, Wittum-Hudson & Hudson, 2003); measles, mumps, rubella, canine distemper, sinusitis, retrovirus and herpes are among those studied (Kastrukoff & Rice, 1998). Following a longitudinal study conducted in the Faroe Islands, researchers concluded that there is a specific, widespread, but unidentified viral infection known as the primary multiple sclerosis affection (PMSA) (Kurtzke, 2005). Kurtzke hypothesised that while prolonged exposure is needed to acquire PMSA, a small proportion of persons who have it will develop clinical neurological MS some years later.

Attempts to find a positive and irrefutable link between a specific viral infection and MS has been the basis for many studies. For example, in a recent study by Opsahl and Kennedy (2006), the possible involvement of two herpes viruses (HHV-7 and HHV-8) in MS was considered. Akin to other research on viral infection and MS, they concluded that there was little evidence in their sample of definite involvement of either herpes virus in MS. There is much interest in this line of research in determining further aetiological knowledge on MS, and it is expected that study into possible viral infections, and links to MS, will continue.

Overall, researching the aetiology of MS, and the role of possible environmental risk factors, is difficult to do for several reasons (Marrie, 2004). Exposure to possible risk factors, as outlined above, is likely to exist for large numbers of individuals, with or without MS, which means that sample sizes must be sufficient to identify a possible effect. It may be that a combination of risk factors has to be present to cause MS in a genetically susceptible individual, which makes studying any one of them in isolation complicated (Marrie, 2004). Coo and Aronson (2004) concluded that there is an insufficient number of methodologically rigorous studies to assess the evidence of any risk factor at this time, and that all hypothesised risk factors need further study. As an objectively interesting subject for both clinicians and researchers alike, the search for what may be behind the cause of MS attracts a great deal of international research (Butler & Bennett, 2003). This interest is evident by the 200 research grants and fellowships funded by the National MS Society each year in America alone (NMSS, 1999).

2.4 Diagnosing Multiple Sclerosis

MS is notoriously difficult to diagnose as it has a broad range of presentations, including ‘invisible’ symptoms that often resolve spontaneously in a matter of weeks (Calabresi, 2004). Adding to the difficulty of diagnosis, there is no single reliable test to identify MS (Costello & Harris, 2006; O’Connor, Detsky, Tansey & Kucharczyk, 1994). Also, a number of other conditions can mimic the disease, presenting symptoms commonly found in MS, such as CNS infections, CNS microvascular disease, structural or compressive disorder of the brain or spinal cord, and Vitamin B₁₂ deficiency (Calabresi, 2004). A definite diagnosis of MS can take months, or even years, to make. Frequently, patients are subject to multiple misdiagnoses as general practitioners, neurologists and other health professionals must rule out numerous differential diagnoses before determining the presence of MS (Eeltink & Duffy, 2004). Levin, Mor and Ben-

Hur (2003) looked at patterns of misdiagnosis of MS and found that almost 60% of their sample were initially misdiagnosed, receiving the correct diagnosis of MS an average of three and a half years following the onset of symptoms.

The most recently developed diagnostic criteria for MS are known as the ‘McDonald Criteria’ (McDonald et al., 2001). The McDonald Criteria integrate clinical symptoms, magnetic resonance imaging and para-clinical results in order to facilitate diagnosis (Wiendl et al., 2006). The focus of the diagnosis of MS is, in part, based on the presence of lesions in the CNS that are objectively demonstrated to be disseminated in both time and in space (McDonald et al., 2001). This means that lesions have to occur at least three months apart in different parts of the CNS, with no better explanation for the disease process (Calabresi, 2004). Neurologists must examine clinical features and patient history, and the results of one or more confirmatory studies (to rule out the possibility of other conditions) before confidently diagnosing MS. Dalton et al. (2002) suggest that the McDonald Criteria allows earlier diagnosis in some patients than previous criteria have allowed. The McDonald Criteria have also been reported to provide a more simplified diagnostic process for people with the subgroup of primary progressive MS (Polman et al., 2005). It is widely believed that the once standard, lengthy delay from symptom onset to diagnosis is steadily decreasing in MS due to the McDonald diagnostic criteria and increased imaging technology availability (Marrie et al., 2005).

2.4.1 Confirmatory Studies used in Diagnosing Multiple Sclerosis

In order to exclude other diseases or conditions likely to exhibit symptoms similar to those shown in MS, and to build evidence toward a definite diagnosis of MS, a number of confirmatory studies can be implemented. Among these are magnetic resonance imaging of the

brain and spinal cord, evoked potential testing, cerebrospinal fluid analysis, and serologic testing, described below.

2.4.1.1 Magnetic Resonance Imaging of the Central Nervous System

The ability to diagnose MS, while still difficult, has improved considerably with the availability of magnetic resonance imaging (MRI) technology. An MRI scan of the brain is the most useful confirmatory study in reaching a diagnosis of MS (McDonald et al., 2001). Magnetic resonance imaging is a method of obtaining cross-sectional images (slices) of internal soft body tissue, allowing much more accurate diagnoses of neurological conditions because it allows doctors to ‘see’ into the human brain and spinal cord. An examination of these cross sectional slices enables physicians to identify lesions that could be characteristic of MS. On the MRI scans, lesions characteristic of MS appear as areas of high signal, predominately in the cerebral white matter or spinal cord, on T₂-weighted images (Calabresi, 2004). MRI is highly sensitive in the detection of MS lesions, whether the lesions are clinically symptomatic, or clinically silent (McDonald et al., 2001). With MRI machines now more easily accessible in many countries, all newly diagnosed patients and those with a suspected diagnosis of MS should have an MRI scan if the technology is available (Burks et al, 2002; Fazekas et al., 1999). In addition, a record of MRI scans early in the disease course provides a baseline for meaningful comparison over time (Tintore et al., 2006).

While an MRI scan can be a non-invasive procedure, the patient is required to lie very still in a confined space, for up to an hour, while the scans are being taken. To gain clearer images in the scans, and to provide information about new lesion activity, contrast agents, such as Gadolinium, can be injected intravenously (Traboulsee & Li, 2006). For most, the MRI

experience ranges from tolerable to mildly unpleasant. However, for those who suffer from claustrophobia, this process can be extremely anxiety provoking (Jones, 2006).

2.4.1.2 Evoked Potential Testing

Visual, brainstem auditory, and sensory evoked potential testing may be useful in demonstrating the presence of sub-clinical lesions in sensory pathways (McDonald et al., 2001). Of these, the visual evoked potential is the most useful when testing for MS, as it can provide evidence of a silent optic nerve lesion that may not be evident on an MRI scan (Calabresi, 2004). Visual evoked potentials are tested by measuring the speed at which nerves transmit messages from the eye to the back of the brain. An individual watches an alternating black and white checkered pattern, which generates electrical potentials along the optic nerve and into the brain. Electroencephalographical (EEG) sensors are placed on specific sites on the individual's head to record the neural response (Jones, 2002).

In PwMS, a delayed visual evoked response is found in those reporting optic neuritis, and in almost 50% of those with MS who do not report visual difficulties (Asselman, Chadwick & Marsden, 1975). Evoked potential test results may also be useful in providing neurologists with objective evidence of lesions following patient reporting of clinical, but invisible, symptoms (Calabresi, 2004). Recently, Leocani et al. (2006) reported that evoked potential tests can be a good indicator of the nerve damage in MS, and may also have predictive value regarding the progression of disability. Fraser et al., (2006) studied people who had a confirmed diagnosis of optic neuritis without being diagnosed with MS, and people who had been diagnosed with MS (according to the McDonald criteria), and found a significant difference in the groups' delayed visual evoked responses. Findings suggested that there may be a role for visual evoked potential tests in identifying an individual's risk for future development of MS.

2.4.1.3 Cerebrospinal Fluid Analysis

“Cerebrospinal fluid (CSF) is the bodily fluid closest to the pathology of multiple sclerosis” (Giovannoni, 2006, p.1). Examination of the CSF cannot be used to definitively diagnose nor exclude MS, but the results can be indicative of MS and are often used to support a clinical diagnosis. CFS analysis is most useful for ruling out infectious conditions that share similar presenting symptoms with MS. In approximately 90% of patients with definite MS, the CSF IgG index is increased, relative to other CSF proteins, and CSF gel electrophoresis reveals oligoclonal bands that are not present in a matched serum sample (Cole, Beck, Moke, Kaufman & Tourtellotte, 1998). However, a rise in IgG index and the presence of oligoclonal bands are not necessary for an MS diagnosis, and are therefore not diagnostic of the disease (Calabresi, 2004).

CSF samples are taken via a lumbar puncture, or spinal tap. The lumbar puncture has been reported to be the only diagnostic procedure commonly used for MS that causes significant discomfort (Jones, 2006). A spinal needle is inserted between the 3rd and 4th lumbar vertebrae and a sample of CSF is taken, and the CSF pressure recorded. Although the procedure usually takes approximately 30 minutes, patients must remain horizontal for a number of hours after. Side effects of the procedure may include headache and nausea (Jones, 2006).

2.4.1.4 Serologic Testing

Blood tests are relatively simple procedures that can assist in the elimination of other disease diagnoses when MS is suspected. Testing frequently includes an examination of the level of vitamin B₁₂, and levels of hormones, and antibodies that would indicate a CNS infection or micro-vascular disease (Calabresi, 2004). While serological testing has not been traditionally used to aid in the diagnosis of MS (rather, it assists to eliminate other possible causes of

symptoms), recent research conducted by Avasarala, Wall and Wolfe (2005) has identified a pattern of three biomarkers found in samples of blood from an MS population that is not present in a normal sample. This finding may lead to blood tests being used more effectively to aid in the diagnosis of MS in the future.

2.5 Clinical Subgroups of Multiple Sclerosis

There are a number of possible courses MS can take (Lublin & Reingold, 1996). Different patterns of disease evolution, and variable rates of disability accumulation, are apparent across individuals diagnosed with MS (Confavreux & Vukusic, 2006). Without clear biological markers to distinguish the various subtypes of MS, Lublin and Reingold (1996) created classifications for four subgroups of MS based on clinical course and disease progression. Three subgroups: Relapsing Remitting, Primary Progressive and Secondary Progressive, are widely accepted and referred to by clinicians and researchers (Dujmovic, Mesaros, Pekmezovic, Levic & Drulovic, 2004). The fourth subgroup is Progressive Relapsing MS and is an unusual, and the least common, subgroup of MS (Tullman, Oshinsky, Lublin & Cutter, 2004), with one study unable to distinguish between it and Primary Progressive MS (Andersson, Waubant, Gee & Goodkin, 1999). An additional subgroup, Benign MS, is recognised by a moderate amount of literature on MS, and by the Multiple Sclerosis International Federation (2006). Benign MS is the most contentious subgroup with a large number of researchers and clinicians agreeing that a true diagnosis of Benign MS can only be made retrospectively by examining a patient's clinical history and MRI scans, and determining that the patient remains fully functional 15 years after disease onset (Burks et al., 2002; Lublin & Reingold, 1996). However, as anecdotal evidence suggests that individuals can be provided with a diagnosis of Benign MS by their neurologist at the initial time of diagnosis (personal communication, Dr. E. McDonald, Medical Director, MS

Society of Victoria, 2004), this subgroup was included in the present study. The five subgroups of MS that will be discussed here are Benign, Relapsing Remitting, Primary Progressive, Secondary Progressive, and Progressive Relapsing.

2.5.1 Benign Multiple Sclerosis (Benign MS)

With its contentious status as a subgroup of the disease, the definition of Benign MS is variable, however this diagnosis is commonly attributed to patients with little or no disability. These patients have a low relapse rate, and exhibit good recovery between relapses (Burks et al., 2002). For example, Pittock et al. (2004) completed a 20 year population based follow up study examining people who had lived with Benign MS for more than 20 years. Pittock and colleagues concluded that it is not possible to determine early in the course of the disease (within the first five years), which patients will have Benign MS. However, they also found that the longer the duration of MS (greater than 10 years) and the lower the level of disability, the more likely the patient is to remain stable.

In comparison to the other subgroups, there is little disease activity seen in a Benign course of MS. Estimates of the number of PwMS that fall into this subgroup vary, ranging from 5% to 40% (Hawkins & McDonnell, 1999), while Pittock et al. (2004) reported a 17% prevalence of people with Benign MS in their sample. Most experts agree on an estimate of 10% prevalence of Benign MS (Burks et al., 2002). Lublin and Reingold (1996) warn that the term 'Benign MS' should be used with care in communication with PwMS and family members, as it may not accurately reflect the future course of the disease.

2.5.2 Relapsing Remitting Multiple Sclerosis (RRMS)

Relapsing-Remitting MS is the most common subgroup of the disease, characterised by periods of remission (where the disease is inactive) interrupted by relapses (episodes of symptoms) of the disease (Williams, 2004). A relapse, or an exacerbation, is a sudden worsening of symptoms, which remit partially or completely over the course of a few weeks or months (Mohr & Cox, 2001). To be classified as a relapse, symptoms of a neurological abnormality must be present for at least 24 hours, in the absence of an infection (Polman et al., 2001). Each relapse is unique and unpredictable. A relapse may evoke new symptoms not experienced by the individual before, or it may produce symptoms already experienced by the individual in the past. A level of disability may accumulate if remissions are not complete, but patients remain stable between relapses (Lublin & Reingold, 1996). As the most commonly occurring subgroup of MS, estimates of the number of people diagnosed with RRMS range from 65% (Mohr & Cox, 2001) to 85% (Burks et al., 2002) of the population of PwMS.

2.5.3 Primary Progressive Multiple Sclerosis (PPMS)

Right from the beginning of a Primary Progressive course of MS, there is an absence of exacerbations or relapses, with no periods of remission (Lublin & Reingold, 1996). Patients diagnosed with PPMS experience continual worsening of symptoms and a progressive loss of functioning from the disease outset (Burks et al., 2002). It has been found that PPMS has a lesser female preponderance compared with a general MS population, and a relatively later age of onset (McDonnell & Hawkins, 1998; Noseworthy, Paty, Wonnacott, Feasby & Ebers, 1983). Dujmovic et al. (2004) observed a male to female ratio of 1.3:1 for PPMS, and a mean age at disease onset of 33.2 years. Approximately 10% - 15% of those diagnosed with MS have PPMS (Dujmovic et al., 2004; McDonnell & Hawkins, 1998; Mohr & Cox, 2001).

2.5.4 Secondary Progressive Multiple Sclerosis (SPMS)

Approximately 50% of people diagnosed with RRMS ‘transition’ to SPMS within 10 years of diagnosis, 90% within 25 years of diagnosis (Burks, 2002; Weinshenker, 1995). Exacerbations and periods of remission can occur in SPMS, but patients will rarely recover from the symptoms to their baseline functioning. The level of disability experienced by the person with SPMS will very slowly increase over time, regardless of the presence of exacerbations (Burks et al., 2002). Poser (1992) explains the transition from RRMS to SPMS as a result of the accumulation of damage to the axons in the CNS over time.

2.5.5 Progressive Relapsing Multiple Sclerosis (PRMS)

Characterised by progressive disease, with the addition of clear and acute relapses, PRMS is an unusual subgroup of MS (Lublin & Reingold, 1996). It is similar to PPMS as it exhibits a gradual loss of ability, but PRMS also includes exacerbations where the PwMS may or may not recover to their baseline level of ability between relapses (Lublin & Reingold, 1996). Although often grouped together with PPMS, Tullman, Oshinsky, Lublin and Cutter (2004) suggest that researchers and clinicians differentiate between PPMS and PRMS, as exacerbations in PRMS may occur more frequently than previously thought. If examining exacerbation frequency and response to medication, the subgroup PRMS could alternatively be considered most closely related to SPMS (personal communication, Dr. E. McDonald, Medical Director, MS Society of Victoria, 2004).

2.5.6 Multiple Sclerosis: One Disease or Many?

With such a marked and dramatic difference between the clinical outcomes of the various subgroups of MS, the question has been asked: ‘MS: One disease or many?’ (Compston, 2006;

Weinshenker & Miller, 1996). The differing chronicity and severity of the subgroups of MS has highlighted the possibility of there being a ‘spectrum of MS diseases’, with Benign MS, RRMS and SPMS grouped together, and PPMS singled out as being a different condition (Olerup et al., 1989). The apparent effectiveness of disease modifying therapies in all subgroups of MS (including PRMS) other than PPMS is another example of why all subgroups may not be of the same disease. It has also been postulated that, in the future, the subgroups of MS may be found to be genetically different (Rasmussen & Clausen, 2000). For the time being, the five subgroups of MS, as discussed here, are grouped under one general banner of ‘multiple sclerosis’.

2.6 Symptoms of Multiple Sclerosis

As all functions controlled by the CNS can be affected by MS (Mohr & Cox, 2001), individuals with the disease can experience an array of symptoms. Common symptoms include, but are not limited to, paralysis or loss of function in limbs, weakness, sensory impairment, spasticity, impaired coordination and balance, dizziness or vertigo, heat sensitivity, bladder urgency or retention, constipation, numbness or pins and needles, paroxysmal pain such as trigeminal neuralgia or Lhermitte’s sign (electrical sensation down the spine on neck flexion), sexual dysfunction, depression, debilitating fatigue, visual impairment or blindness, communication difficulties, cognitive dysfunction, and emotional changes (Calabresi, 2004; Mohr & Dick, 1998; O’Hara, Cadbury, De Souza & Ide, 2002). While the above symptoms are all possible in a course of MS, the above is not a ‘shopping list’ for PwMS and any single individual is unlikely to experience all possible symptoms in the course of the disease.

The symptoms experienced, and the severity of their effect on the body, varies widely among individuals (Costello & Harris, 2006). Common symptoms at onset include visual impairment (16%) and numbness and tingling of the extremities (33%); and multiple symptoms

can appear simultaneously at the onset of the disease, or during an exacerbation (Paty, 2000). Fatigue is the most commonly reported symptom across the course of MS, and is also one of the most disabling aspects of MS, affecting an estimated 70-90% of people living with MS (Costello & Harris, 2003). On the other hand, the symptoms believed to be traditionally under reported by PwMS include pain, sexual dysfunction, and bladder management issues. Solaro (2006) reports the prevalence of pain in MS as 40%, and considers that the lack of clear clinical treatment guidelines and the lack of understanding of the mechanisms of pain in MS, adds to the reasons for the under reporting of this symptom. In a case control study, Zorzon et al. (1999) found the prevalence of sexual dysfunction in PwMS to be 73.1%, as opposed to 39.2% of people with other chronic conditions, and 12.7% of matched healthy controls. Foley, LaRocca, Sanders and Zemon (2001) found that sexual satisfaction, marital satisfaction, problem solving communication and affective communication can be improved in PwMS and their partners through education, improved management of symptom treatment regimens, and counselling including cognitive behavioural therapy with a focus on improving communication skills. Similarly, Demirkiran et al. (2006) reported that sexual dysfunction is an underestimated but common symptom of MS that, if treated and managed appropriately, can improve the quality of life for PwMS. A third common but often under reported symptom of MS is bladder dysfunction, and Wollin, Bennie, Leech, Windsor and Spencer (2005) found that the reasons for PwMS not accessing support regarding continence issues included participants feeling that they were 'managing ok'; participants that 'didn't think it would help'; and participants that were 'embarrassed' or 'too busy' to have an appointment with a continence nurse. However, new and existing treatments can be highly effective in relieving PwMS of what can be considered an invisible yet embarrassing symptom (Kalsi & Fowler, 2005). The invisibility of these symptoms may lead to the under reporting of them, as health professionals may fail to ask about symptoms

that they cannot see. Similarly, PwMS may be hesitant to speak about symptoms that could be considered embarrassing, or of an extremely personal nature.

2.7 Treatments for Multiple Sclerosis

2.7.1 Disease Modifying Therapies

Over the past 10 years, four disease modifying therapies, or immunomodulating medications, have been approved for the treatment of RRMS and SPMS in Australia. All four medications are also available in Canada, the United Kingdom, and the United States of America, among others (Burks et al., 2002). These are interferon beta-1a (Avonex), another interferon beta-1a (Rebif), interferon beta-1b (Betaferon), and glatiramer acetate (Copaxone). Other countries may have access to only one, two or three of these medications. A fifth immunomodulating medication, Natalizumab (Tysabri), has just been approved through the U.S.A Food and Drug Administration in mid 2006, but will not be discussed in detail here due to its recent availability. While the price of distributing the interferon and glatiramer acetate medication is high (approx AU\$1055 per month), there exists varying levels of government support around the world (from nil to complete), to reduce the cost to the consumer.

In Australia, all four medications are available, and are subsidised by the Pharmaceutical Benefits Scheme (PBS) at a cost of approximately AU\$29.50 per month (Schedule of [Australian] Pharmaceutical Benefits Scheme, 2006) for those with RRMS or SPMS who meet the criteria as set out by the PBS.

In Canada, all four medications are available, and the Canadian government's PharmaCare agency subsidises between 70-100% of the cost of medication to the consumer (Multiple Sclerosis Society of Canada, 2005). The amount of subsidy offered, and eligibility

criteria, depend on which province of Canada the PwMS resides in. In general, the criteria include those with RRMS, and in some instances, SPMS.

In the United Kingdom, all four medications are available, and the UK government's National Health Scheme (NHS) subsidises the medication to those with RRMS and SPMS who fit strict criteria (estimated at approximately 12-15% of the population of people living with MS) (UK Department of Health, 2005). As part of the NHS's 'Risk Sharing Scheme', a cohort of patients receiving treatment is monitored, and prices paid by the NHS are adjusted according to whether expected patient benefits are realised over the long term.

In the United States of America, all four drugs are available but the individual's circumstances regarding health care coverage, through a private insurance plan or enrollment in a Medicare plan, vary enormously. An individual's health care coverage dictates the types of prescription medications available, and the actual cost of treatment for the individual. Each of the pharmaceutical companies offers a program designed to help people apply for and use all the state and federal programs for which they are eligible. Pharmaceutical companies also offer some assistance to those who are uninsured or under-insured, through patient assistance programs (National MS Society, 2006).

Avonex, Betaferon and Copaxone are the three available medications to PwMS living in New Zealand. In addition to having access to just three of the available drugs, the New Zealand government's Pharmaceutical Management Agency (PHARMAC) offers only a small number of PwMS fitting strict eligibility criteria, fully subsidised treatment (NZ Pharmaceutical Schedule, August 2006). This means that the vast majority of people living with MS in New Zealand must pay up to NZ\$1202.00 per month in order to access treatment.

While availability of each medication can differ across countries, all four medications have been tested in large, multicentre, double blind, placebo-controlled clinical trials in people

with RRMS (Burks et al., 2002; Goodin et al., 2002). Disease modifying therapies have been found to reduce the severity of the symptoms, the number of exacerbations by approximately one third, and the progression of the disease (Goodin et al.,2002). All but glatiramer acetate have been tested in similar clinical trials in people with SPMS, and have been found to have a positive effect on slowing the disease progression (Burks et al., 2002; Goodin et al., 2002).

All disease modifying therapies are injection based. Of the beta interferons, Avonex is an intramuscular medication given once a week. Rebif is a medication administered subcutaneously three times per week, and Betaferon (also administered subcutaneously) is given every second day. Side effects of the beta interferons are experienced by approximately 60% of patients and include influenza-like symptoms such as chills, muscle aches, fever and fatigue (Calabresi, 2004). Other side effects can include injection site reactions and depression, but researchers report these are rarely severe, and all side effects usually dissipate with continued therapy (Calabresi, 2004). Copaxone (glatiramer acetate) is administered subcutaneously once a day. Glatiramer acetate is generally well tolerated, and is not associated with influenza-like symptoms, however, immediate post injection reactions can include local inflammation, anxiety, chest tightness and heart palpitations, which resolve very quickly (Calabresi, 2004; Johnson et al., 1995).

As mentioned above, Natalizumab (Tysabri) is a new immunomodulating treatment just emerging onto the world market for use in MS. Tysabri is administered via intravenous infusion on a monthly basis, and is recommended as treatment for people with RRMS experiencing high disease activity despite treatment with beta-interferon, or for those with rapidly evolving severe RRMS (European Medicines Agency, 2006). A two year, phase-III, randomised and placebo controlled trial recently showed Tysabri reducing sustained progression of disability for those with RRMS by 68% over one year, and 42% over two years (Polman et al, 2006). The number of

new or enlarging T2 MRI lesions were reduced by 82%, and gadolinium enhanced MRI lesions were reduced by 92%, over the two year trial (Polman et al, 2006). Side effects of this new medication have been reported as including fatigue, allergic reaction, and hypersensitivity reactions (Phillips et al., 2006; Polman et al., 2006). While Tysabri shows great promise as a new medication for PwMS, and has been approved for use in many countries in 2006/2007, it may be a number of years before the medication is subsidised by the PBS in Australia (or equivalent in other countries) and therefore made affordable to the average person living with MS.

An additional agent, mitoxantrone (Novantrone) has also been approved in the U.S., Europe, and Canada, for the treatment of SPMS, and PRMS and for those with worsening forms of RRMS (Calabresi, 2004; Scott & Figgitt, 2004). Mitoxantrone is a chemotherapeutic agent, that through a phase-III, randomized, placebo-controlled, multicentre trial, was found to reduce the number of MS relapses by 67%, slow disability progression, and reduce MRI measures of disease activity (Hartung et al., 2002). However, due to the cumulative cardiotoxicity, this intravenous chemotherapeutic agent should only be used for two to three years, and acute side effects of the drug can include alopecia and nausea (Calabresi, 2004).

While there appear to be several treatment options for PwMS, access to the medication depends largely on the type of MS an individual is diagnosed with, the country they live in, and the affordability of the medication. Just as MS exhibits unique disease characteristics in each individual, one's response to the disease modifying therapies can also be unique. There is still a lack of agreement among researchers or clinicians as to the most effective treatment to slow the progression of the disease, and so there is a relatively high level of patient choice in which agent to use. However, accumulating evidence indicates that the best time for people with RRMS to begin any of the disease modifying treatments is early in the course of the disease (Burks et al.,

2002; Coyle & Hartung, 2002). Miller (2004), among others, goes further by suggesting that treatment with an immunomodulatory agent should begin following clinically isolated events, therefore before the technical diagnosis of definite MS is made, in order to reduce the risk of the degenerative progression of MS.

2.7.2 Relapse Specific Treatment - Adrenal Corticosteroids

Before a patient is treated for an MS relapse, it is important that infections which may be producing MS relapse-type symptoms are ruled out. Such infections could include a urinary tract infection, sinusitis, or bronchitis. Once a definite diagnosis of an MS relapse is made, treatment for an acute relapse of MS is found in corticosteroids such as methylprednisolone (Calabresi, 2004). Intravenous methylprednisolone is an established adrenal corticosteroid treatment for MS relapses (Then Bergh et al., 2006) and can reduce inflammation of the nervous system, restore the blood brain barrier, and reduce oedema (Calabresi, 2004). Steroids may also improve axonal conditioning thereby shortening the duration of acute relapses (Calabresi, 2004), although the use of corticosteroids has not been shown to improve the recovery response to a relapse, or change the long term course of MS (Milligan, Newcombe & Compston, 1987). Patients are most commonly admitted to hospital to receive steroid treatment intravenously (although there are oral alternatives available). Steroids are generally reserved for relapses that cause the patient to experience acute disability, impairing their ability to do daily tasks, as long term effects of steroids can be serious (Costello & Harris, 2006).

2.7.3 Allied Health Treatments and Symptom Management

During relapses, or during periods of remission, PwMS may benefit from other treatments such as physiotherapy and occupational therapy. In addition, talking to a social worker about

practical issues such as employment concerns, or talking to an MS nurse about immunotherapy issues such as injection site reactions, can also be beneficial. Seeing a psychologist to discuss the impact a diagnosis of MS has had on the patient and their family (among other issues) could also be of benefit. Indeed, a united health care team approach is crucial to the effective management of MS (Calabresi, 2004), with the Consortium of MS Centres recommending that all PwMS have access to care from a multidisciplinary care team with expertise in MS (Costello & Harris, 2006). The International Organization of Multiple Sclerosis Nurses (IOMSN) is an example of a body ensuring the expertise of nurse practitioners working with PwMS across the world. Uccelli, Fraser, Battaglia, Maloni and Wollin (2004) outline the four domains of MS nursing that encompass the competencies necessary for IOMSN MS nurse certification at an international level; clinical practice, advocacy, education, and research. Combined with the expert MS knowledge of health practitioners working with PwMS, there are also a number of medical treatments available to PwMS to enable the targeting of symptom specific problems such as spasticity, fatigue, bladder and bowel dysfunction, pain, and depression, among others (Crayton, Heyman & Rossman, 2004; Halper, 2001). Both Crayton, Heyman and Rossman (2004) and Halper (2001) identified that a multimodal approach to managing MS symptoms, inclusive of effective communication, patient education, occupational and other therapies, and diverse treatment strategies in conjunction with the provision of medication, is critically important to the maintenance of a high quality of life for PwMS.

2.7.4 Complementary or Alternative Therapies

The use of non-traditional therapies such as complementary or alternative therapies is increasing both in the general population and in populations of people with neurological disorders, such as MS (Eisenberg et al., 1998; Stuifbergen & Harrison, 2003). Such therapies

include meditation, biofeedback, hyperbaric oxygen therapy, homeopathy, the use of herbal remedies, acupuncture, bee venom therapy, massage, adherence to a special diet, or the addition of nutritional supplements to the diet (Pucci, Cartechini, Taus & Giuliani, 2004; Stuifbergen & Harrison, 2003). PwMS may initially investigate, or partake in, the use of such therapies due to anecdotal reports of benefit to others (Pucci et al., 2004), but few randomised controlled trials have been conducted to verify the efficacy or safety of complementary therapies such as those listed above (Huntley & Ernst, 2000). One exception is a study by Weeselius et al. (2005) who carried out a randomised study to assess the benefit of bee venom therapy for PwMS. Results showed that while the therapy was well tolerated by participants, the bee venom did not reduce disease activity, fatigue, or disability, and did not improve quality of life.

In a study by Pucci et al. (2004) PwMS reported that they were attracted to using complementary or alternative therapies as recommended by friends, so as to remain open to all possibilities of assistance, and to retain a sense of control. It is uncommon for the practice of complementary or alternative therapies to negatively impact on compliance with conventional medicine; however, treating physicians are often not consulted or informed about the use of complementary or alternative therapies (Pucci et al., 2004). This lack of communication between patient and physician can become a concern if the complementary therapies interact negatively with the prescribed medication. Pucci et al. outline a number of factors that may influence an individual's choice not to discuss alternative treatments with their doctor. First, a PwMS may believe that the conventional practitioner will hold a negative attitude toward non-conventional therapies. Second, a PwMS may perceive that complementary or alternative therapies are completely safe as they do not require a medical prescription. Third, the doctor may be perceived as having an inadequate knowledge of complementary or alternative therapies. Finally, there may not be sufficient time in a medical appointment for the PwMS to discuss complementary or

alternative therapies with their physician (Pucci et al., 2004). Despite many barriers to communication, Stuifbergen and Harrison (2003) warn health professionals that it is not possible to predict who will, and who will not, use a complementary or alternative therapy, and they stress the importance of effective communication with patients about all of their treatment practices (conventional or complementary). Instead of waiting for PwMS to raise the subject, it may be preferable for doctors to ask patients directly if they are using complementary therapies. In this era of evidence based medicine, medical practitioners should ensure that they are also up to date with complementary or alternative therapies and, while remaining clinically cautious, should also keep an open mind in order to assist patients wanting to do everything possible to combat their disease (Pucci, 2004).

2.8 Prognosis

People newly diagnosed with MS may want to know how MS will affect their everyday functioning over time. As the clinical course of MS can be vastly different for each person, one of the greatest difficulties faced by physicians at diagnosis is making a prediction of how quickly, if at all, the disease will progress (Burks et al., 2002). Needless to say, this is also arguably one of the greatest difficulties faced by the PwMS at the time of the diagnosis, as they may be left feeling very uncertain about their future. Burks et al. (2002) state that there are certain prognostic factors to assist in the determination of whether, and/or when, a PwMS will progress from the initial stages of the disease with little or no disability to a stage of more chronic and severe disability.

A large proportion of PwMS (45%) are not severely affected in terms of ability to function on a daily basis (MSIF, 2002). Nonetheless, it has been reported that the majority of people diagnosed with MS will experience increasing progressive deterioration and disability

over time (Devins & Shnek, 2000). Prognostic factors identified in previous research as eliciting poorer outcomes include: older age at onset (50 years+); male gender; an initial exacerbation involving motor symptoms; a short interval between first and second exacerbations and a lack of complete recovery from these relapses; those with PPMS; and those acquiring a moderate level of disability within five years of the diagnosis (Burks et al., 2002; Scott, Schramke, Novero & Chieffe, 2000; Weinshenker et al., 1991). However, recent research has shown no association between gender, symptoms at onset, or age at onset and poorer outcome (Ghezzi et al., 2002; Tremlett & Devonshire, 2006), indicating that further research is required to identify accurate prognostic indicators for MS. Despite likely physical deterioration and increasing disability, most PwMS have a normal life expectancy (MSIF, 2002). As Boeije and Janssens (2004) point out, there is no way, unfortunately or otherwise, to provide people newly diagnosed with MS with an individual prognosis. Thus, PwMS are left with uncertain expectations about their future health from the time of diagnosis.

CHAPTER THREE

THE DIAGNOSING PROCESS AND BEHAVIOUR FOLLOWING DIAGNOSIS

3.1 Overview of the Chapter

The complexities inherent in the disease of MS were addressed in the previous chapter. MS has a curious aetiology and epidemiology that attracts the attention of researchers as they attempt to understand possible causes, and potentially, discover a cure. Physicians and patients confront the often difficult path to diagnosis and the threat, if not the reality, of a number of diverse symptoms. Combined with the assorted range of often unappealing treatment options, and the lack of prognostic information that can be offered to those with MS, people newly diagnosed with MS face an uncertain future.

In this chapter, an overview of the diagnosing process from the point of view of the person being diagnosed is presented, including an examination of the anticipatory uncertainty that comes in the lead up to, and with, a diagnosis of MS. The reported preference of PwMS for early diagnosis is also explored. An examination of post-diagnosis behaviours is then offered, with a focus on information seeking, the recruitment of social support and disclosure of diagnosis, and talking to other PwMS. Some of the post-diagnosis lifestyle changing activities that people newly diagnosed with MS engage in, such as the commencement of medication, exploring complementary therapies, making changes to work hours, modifying the physical environment, and experiencing a change in the level of interest in spirituality and/or religion, are then identified and discussed.

3.2 The Diagnosing Process

It is conceivable that the stress experienced by an individual at the time of being diagnosed with MS may surpass any stress leading up to the event. However, a diagnosis of MS follows an often lengthy diagnosing process whereby many patients experience fear, stress and anxiety (Nicolson & Anderson, 2001). Indeed, research and anecdotal evidence suggests that individuals often express an initial sense of relief when told of their diagnosis of MS, as they often feared 'something worse', such as cancer (Elian & Dean, 1985; Ford & Johnson, 1995). Acceptance of, and adjustment to, a diagnosis of MS varies, and preliminary reactions can range from shock at the diagnosis of a chronic illness, to relief that symptoms are not due to a psychiatric condition or a life threatening illness (Costello & Harris, 2006).

Sullivan et al. (2004) found that those diagnosed with MS during a period of remission exhibited better psychological adjustment than those experiencing an exacerbation, or those with ongoing symptoms of SPMS, at the time of diagnosis. However, individuals without evidence of physical or cognitive impairment at the time of diagnosis may, nevertheless, experience high levels of distress based on their perceptions of future negative consequences of MS (Halligan & Reznikoff, 1985). As MS is a disease of morbidity rather than mortality (Poser, Kurtze, Poser & Schlaf, 1989), the increased level of stress experienced at the time of diagnosis may not abate, as an individual's uncertainty of the potential disability continues (Crigger, 1996). However, Hopman et al. (2000) conducted a longitudinal study of 45 PwMS over four years from the time of diagnosis, and found an improvement in participants' mental health over time, supporting the idea of a psychological adjustment process to the diagnosis of a chronic illness. While the initial shock of a diagnosis may be reduced quickly for some, the continuing uncertainty surrounding the impact MS will have on the individual's life can endure.

During the diagnostic phase, individuals' symptoms become the focus of medical attention, and anticipatory uncertainty and anxiety relating to what they perceive as possible explanations for symptoms, may be experienced (O'Connor, Detsky, Tansey & Kucharczyk, 1994). Indeed, Lopez (2001) argued that uncertainty is one of the most pervasive 'symptoms' of MS from the time before diagnosis, extending to the uncertainty experienced in personal relationships and the uncertainty about an individual's ability to fulfill daily tasks, post-diagnosis. Similarly, Boeije and Janssens (2004) found that individuals' uncertainty about future disease progression continued to be a predominant psychological factor following diagnosis. Although people diagnosed with MS are generally aware that the disease may have major consequences for the life they expected to live (Boeije & Janssens, 2004), it is impossible for the individual to know exactly how MS will impact on their life, as medical practitioners are unable to give an accurate individual prognosis. This lack of prognostic information contributes to the high levels of uncertainty that have been reported in PwMS following diagnosis (Wineman, Schwetz, Goodkin & Rudick, 1996). The uncertainty of how MS will affect the individual's future physical and cognitive functioning can be extremely stressful (McNulty et al., 2004). In 2004, Chalfant, Bryant and Fulcher observed evidence of post traumatic stress disorder in PwMS at an incidence close to that observed in populations suffering potentially life threatening illnesses, such as cancer. Experiencing a diagnosis of MS, and subsequently living with the disease, exposes a PwMS to a variety of stressors related to the uncertainty MS brings. Attempting to incorporate this state of uncertainty into one's life can be daunting, and the psychosocial adaptation to living with MS is a multidimensional and complex process (Antonak & Livneh, 1995).

Most people who receive a diagnosis of MS will have had clinical symptoms for a period of months, or years, prior to consulting a neurologist (O'Connor et al., 1994) and the diagnostic

testing and confirmation of MS can extend for a similar period of time (Eeltink & Duffy, 2004). Following such a lengthy process, the diagnosis of MS is often a life changing event for the person diagnosed and the family members closest to that individual (Cook, 2002). The variable and unpredictable nature of MS can make it a particularly difficult diagnosis to incorporate into an individual's life (Thomas et al., 2003). Indeed, diagnosing physicians of the past would withhold the confirmed diagnosis of MS in order to 'save' their patients from what they deemed to be 'unnecessary stress' (Elian & Dean, 1985). As the confirmatory studies used for diagnosing MS can be invasive, frightening and confronting, O'Connor et al. (1994) examined the effect of diagnostic testing for MS on patient health perceptions and concluded that there was no justification for the delay in giving a diagnosis of MS, even though some physicians continue to believe that delaying diagnosis reduces the emotional burden on patients. The current belief is that a timely diagnosis is more likely to lessen a patient's level of anxiety and psychological distress (Costello & Harris, 2006; Janssens et al., 2004). For example, in a recent study of 1200 PwMS, 91% of people favoured learning of the diagnosis immediately, while the remaining minority suggested a possible preference for delayed delivery (Papathanasopoulos, Nikolakopoulou & Scolding, 2005). Similarly, Janssens et al. (2004) found that 94% of their 95 participants preferred a short diagnostic period (median of one month). Interestingly, Janssens et al. (2004) also highlight the possibility that those presenting after a single exacerbation may need to be informed about the possibility of facing an MS diagnosis in the future due to the ever increasing accessibility to the internet. This ease of internet access may mean that a person diagnosed with optic neuritis will quickly learn about the possibility of a future diagnosis of MS if they conduct research on line (Hickman, Dalton, Miller & Plant, 2002), and may face increased levels of anxiety and worry if the possibility of MS has not been addressed by their physician (Janssens et al., 2004).

Previously, informing an individual of the diagnosis of MS could be considered much more traumatic for the PwMS, as the news today can be tempered somewhat with optimistic information about recent advances in MS treatment and research (Costello & Harris, 2006), although diagnoses made today continue to present the affected individual with ambiguity surrounding their prognosis. Combined with the unpredictable nature of the disease, and the lack of a cure, PwMS face an uncertain future at the time of their diagnosis, and beyond (McNulty, Livneh & Wilson, 2004). Once a diagnosis of MS is made, the PwMS is likely to engage in one, or many, post-diagnosis behaviours in an attempt to cope with, and make sense of, the diagnosis.

3.3 Post-Diagnosis Behaviours and Lifestyle Changing Activities

Those diagnosed with MS face immediate uncertainty about their future physical and cognitive functioning. Health practitioners may attempt to alleviate the concerns and ease the stress of patients by providing information on MS. For example, diagnosing neurologists may arrange a follow up appointment with the patient to answer any questions they may have, or refer a patient to an MS nurse specialist for post diagnosis follow-up (Boeije & Janssens, 2003). Written information may also be provided to the individual at the time of their diagnosis. However, even with the efforts of neurologists, MS nurses and allied health professionals offering people information and support at the time of diagnosis, individuals newly diagnosed with MS often engage in additional behaviours and/or activities that they identify as being of assistance to them in coping with the diagnosis (O'Hara, Cadbury, De Souza & Ide, 2002).

Reynolds and Prior (2003) outlined the strategies used by a sample of women with MS in coping and living with the disease. The strategies used by the women to achieve well-being and satisfaction while living with MS, changed over time. Initially, emotional turmoil and a sense of dislocation and uncertainty accompanied the immediate post-diagnosis period. However,

participants reported that over time, they experimented with different behaviours and lifestyle changes, accepted support, and found positive ways of interpreting the illness experience (Reynolds & Prior, 2003). Indeed, the participants in Reynolds and Prior's study provided information on the strategies they had developed over time for achieving quality of life with MS. Participants were not asked to comment on the activities they engaged in or resources they used during a set period of time, rather they were asked about strategies they had used since diagnosis. To date there has been no research specifically examining the behaviours exhibited by PwMS within the first 12 months following diagnosis. Therefore, an examination of post diagnosis behaviours and lifestyle changing activities within the first 12 months following diagnosis is important in order to increase insight into the activities engaged in by persons newly diagnosed with MS.

It would be impractical to list and discuss all possible behaviours that individuals could exhibit following a diagnosis of MS. A number of post diagnosis behaviours and lifestyle changing activities recently mentioned (over the past ten years) in the MS literature (either comprehensively or sketchily) are considered to be appropriate categories for inclusion in the current study and are detailed below. Recently mentioned post-diagnosis behaviours include information seeking, the disclosure of diagnosis to others, talking to other PwMS, and the seeking of wider social support. Lifestyle changing activities include actions that are taken in an attempt to alleviate symptoms, such as the commencement of medication, actions that improve functioning or enhance quality of life, such as the maintenance of meaningful occupations and roles and modifications to exercise activity or to the physical environment, and engaging in activities to make sense of the disease, such as an increased interest in spirituality/religion (Calabresi, 2004; Reynolds & Prior, 2003; Stuijbergen & Harrison, 2003; Thorne, Paterson & Russell, 2003).

3.3.1 Post-Diagnosis Behaviours

3.3.1.1 Information Seeking

The information needs and information seeking behaviour of PwMS is arguably the most widely studied post-diagnosis behaviour discussed in the MS literature (Baker, 1996, 1997, 1998; Hepworth & Harrison, 2004, Wollin, Dale, Spencer & Walsh, 2000). In 1977, Matson and Brooks surveyed PwMS to determine how they had adjusted to the condition following diagnosis. Based on their findings, they proposed a model of adjustment to MS, whereby the seeking of information played a major role. Matson and Brooks found that immediately following diagnosis, PwMS sought information from medical professionals and others, in an attempt to dispute the diagnosis. When the reality of having MS was realised, individuals then sought a cure, together with additional information about the condition from a variety of sources. More recently, Baker (1998) looked at the information needs of PwMS during, or shortly after, an exacerbation, and concluded that relevant, current, and specific information was needed by PwMS in order for them to retain their independence and to empower them to make informed decisions.

While some individuals will initially attempt to ignore the presence of MS in their lives, others will actively seek out information about MS from the diagnosis or the onset of symptoms (Stittmatter, 2004). Information seeking activity may start in the pre-diagnosis period and continue up to, and beyond, the confirmation of diagnosis (Stewart & Sullivan, 1982). Many PwMS initially request, and are given, general information about the disease from medical professionals. However this often generic information describing the pathology of MS has been reported to be inadequate, as more practical information relevant to living with MS is often requested (Brooks & Matson, 1987; Matson & Brooks, 1977). Honest and realistic information that addresses an individual's specific concerns and needs has been found to be of greater benefit

than broader information about MS (Baker, 1998). Individuals prefer to have an explanation of MS, and its possible impact on their life, provided to them through the use of unambiguous statements, than to be left uninformed and fearful of the possibilities (Elian & Dean, 1985; O'Connor et al., 1994). The amount of information provided to PwMS by their diagnosing physicians, and the relevancy of its content, seems to have improved over time, with medical professionals providing a greater quantity of material, with increasingly more useable information, to PwMS at the time of diagnosis (Hepworth & Harrison, 2004). Previous studies have provided evidence that information leading to a sound knowledge of MS is beneficial to the wellbeing of PwMS as it increases the individual's sense of personal control, as well as leading to a reduction in dependence on government health services (e.g., Somerset, Peters, Sharp & Campbell, 2003).

Based on research into the information needs of PwMS, Hepworth and Harrison (2004) compiled a list of categories of information that should be made available to a PwMS at the time the diagnosis is made. The categories were: general information about MS, drug treatments, symptoms (and their management), the possible course of the disease, information on diet and exercise, and material for the family. Hepworth and Harrison also recommend two further categories of information that should be provided to the individual shortly after diagnosis. First, further information about MS such as results of research trials, complementary therapies, nutritional recommendation, health and fitness advice, and information on emotional changes should be made available at a point shortly following diagnosis. Second, knowledge to help PwMS interact with the world, including information about service providers, support groups, aids and facilities, information about MS and work, how to communicate about MS with family, friends and colleagues, and information about leisure activities, should also be made available at a time shortly after diagnosis. As these categories of information span a wide range of content,

Sullivan et al. (2004) suggest that health professionals should take into account an individual's level of cognitive functioning, as well as education level, when providing information.

As Wollin et al. (2000) identified in their study of the information needs of people newly diagnosed with MS and their families, there exists differences between individuals in the amount of information desired at the time of diagnosis, and the preferred format for the delivery of information. Participants in Wollin et al.'s study stressed the need for individualised information, with many describing a sense of shock upon receiving information about MS, while at the same time expressing a preference for being informed. Ideally, a variety of sources of information, in different delivery formats, should be available to all people newly diagnosed with MS, including research based journal articles, popular press articles, and commentary on personal experiences by PwMS (Hepworth & Harrison, 2004).

In a study on the information needs of PwMS during an acute exacerbation, Baker (1998) found that information was obtained (in descending order of frequency) through the MS Society, health professionals, libraries, support groups, friends and other PwMS. Wollin et al. (2000) found that at the time of diagnosis, PwMS identified MS Societies as a preferred source of information, followed by the neurologist's and general practitioner's consulting offices, and local support groups. Personal contact in one-on-one sessions or group information sessions was preferable to written material as the format for receiving information about MS, although over 50% of PwMS indicated that pamphlets and books were also important sources of information.

Seeking out information on MS is thought to be a necessary part of adjusting to a diagnosis of MS (Matson & Brooks, 1977). There is a plethora of information available to those wanting to learn more about MS with topics ranging from disease pathology, treatments and symptom management, to complementary and alternative therapies, employment issues, and MS related services. Similarly, there is an extensive array of sources of MS related information

ranging from printed material, information sessions, conversations with other PwMS, and the broader media including information available on the internet. It is this latter source of electronic information that is attracting ever increasing interest by the MS community, as the cost of personal computers has steadily decreased (Lorence, Park & Fox, 2006) and the number of computers connected to the internet across the world has steadily increased (Illingworth, 2001). Further to this, Atreja et al. (2005) report that together with the aged, people with disabilities comprise the fastest growing population of internet users. For those seeking information about MS, the internet is able to provide access to current and specific information about the disease, while also providing an electronic avenue of contact to other PwMS across the global community.

3.3.1.1.1 *Finding information via the internet.* The broader media plays a role in the provision of information to people with health concerns, but this information (often reporting new treatments or a ‘cure’ for MS) must be examined with caution, as it can provide ‘spectacular’ news that may be scientifically unreliable, particularly in the case of MS (Pucci, 2003). While this is occasionally evident in television and print media reports regarding ‘breakthroughs’ in MS, there is an overwhelming amount of information accessible via the world wide web, much of which is incorrect, misleading or, at times, dangerous (Bard, 2005). Bard (2005) writes that “MS is a complex disease. It takes more than a few mouse-clicks to keep yourself connected and up to date” (p.62) and instructs her readers (other PwMS) not to substitute the information they find on the internet for professional health care advice, to look for evidence based research from reliable and reputable sites, and to avoid sites that are selling the ‘cure’. Similarly, ‘Lush202’ (below) summarises the upside and downside of PwMS carrying out their own internet based research:

Well, I would say the emergence of the home computer and internet has made research experts out of many people with MS. The upside of this is that we are all much better informed and can go to our doctors' appointments armed with great questions, and not be easily fobbed off. The downside is that we tend at times to frighten ourselves to death and indeed become obsessive; researching and looking for answers, forgetting that we still have a life to live ('Lush202', PwMS, internet posting on Jooly's Joint Message Board, 2003).

The internet has not always been a preferred method of information gathering for people newly diagnosed with MS. Less than ten years ago Wollin et al. (2000) found that in a survey of Australians with MS and their family members, participants did not list the internet as a preferred format for obtaining information on MS. In participant interviews, only one of the seven PwMS interviewed mentioned using the internet as a source of information about MS. However, more recent research such as Brewer (2005), suggests that PwMS are relying more and more on the internet to provide them with information about the disease. Looking more broadly, a report on Americans' internet use in 2005 suggested that 80% of all internet users, or 95 million Americans over 18 years of age, had sought health information in an action oriented and highly purposeful way due to a pressing personal medical issue (Pew Internet & American Life Project, 2005). In the ACNielsen Australian eHealth study (2002) it was reported that 27 percent of internet users, or approximately 1.4 million Australians, not only seek health information online but are more likely to obtain information about their own personal health from the internet than from their doctor. In response to the growing demand by both health professionals and consumers for reliable health information accessible online, MedlinePlus was founded and is an example of an online service providing such information. Launched in 1998, the site attracted over two million

hits from around the world per month in 2000, increasing to over five million hits per month in 2005 (Schloman, 2006). This site, and its rapid growth over five years, provides evidence of the developing need for reliable health information to be made available online.

While the demand for online health information is increasing, the medical debate over online information consumption has been largely negative, with concerns that the internet provides an unregulated source of health information to vulnerable individuals (Lewis, 2006). Conversely, there are many reports from PwMS that having access to the internet as a primary source of information is not only useful, but also empowering (Brewer, 2005). Brewer (2005) examined the relationship between internet use of PwMS and health knowledge and attitude, and found that while the health knowledge among internet users was generally greater than that of non-internet users, those who gained knowledge about MS online tended to be overconfident regarding their level of knowledge. Clinicians are therefore increasingly finding themselves 'upstaged' by their patients who arrive at appointments with volumes of information downloaded from the internet (Coiera, 1996). Due to this increase in the gathering of information on-line by PwMS, Costello and Harris (2006) advise clinicians to supply those newly diagnosed with accurate written materials and reputable resources, as the internet can provide patients with a great deal of information with little quality assurance. Taking it one step further, Schloman (2006) and Pucci (2003) urge health professionals to remain up to date with the online information available to their patients. Schloman (2006) suggests that as informed patients take a greater interest in their own health management, physicians should actually 'refer' patients to specific and reputable web sites.

Just as the seeking of online information regarding MS is increasing, so too is the demand for being able to meet other PwMS using e-technology, rather than face to face or via the telephone. In a small study of people newly diagnosed with MS, Strittmatter (2004) found that

participants who accessed peer support on-line reported a certain amount of anonymity and choice regarding timing of engagement, while still allowing the beneficial effects of communicating with another PwMS to take place. The benefits of face to face, telephone and internet based peer support are discussed below.

3.3.1.2 Talking to Other People with Multiple Sclerosis

Matson and Brooks (1977) identified that as part of the adjustment process, people diagnosed with MS sought out other PwMS, as well as MS related groups and organisations. Indeed, it has been reported that following diagnosis, other PwMS may be sought as an alternate source of information about the disease, and to provide emotional support (Brooks & Matson, 1987; Hepworth & Harrison, 2004). Along with speaking to medical professionals and gathering written information, communicating with other PwMS enables a person newly diagnosed to develop a greater knowledge about the disease (Strittmatter, 2004). Strittmatter (2004) found that meeting another person living with MS to discuss the diagnosis was viewed as a positive encounter by those newly diagnosed. The reasoning behind this interaction being positive is that an individual who has had MS for a longer period can provide the person newly diagnosed with a sympathetic ear, understanding, constructive help and first hand experience regarding living with MS. Hepworth and Harrison (2004) state that enabling access to other PwMS is of great importance for those newly diagnosed, and should be a priority in the work of neurologists, health professionals and MS specialist organisations. As an alternative, or in addition, to more formal introductions, informal peer support can also occur between PwMS who have known each other prior to diagnosis, are relatives, friends, friends of friends, or co-workers. More formalised peer support is often also available through MS societies, hospitals or community health centres, where PwMS are linked up to meet face to face, over the telephone or via the internet (Mohr,

Burke, Beckner & Merluzzi, 2005). To date, there is no research offering an explanation for why some people newly diagnosed with MS seek peer support while others do not. Exploration and understanding of this post diagnosis behaviour would be advantageous considering access to others with MS soon after diagnosis is viewed in a positive light by current literature (e.g., Hepworth & Harrison, 2004).

Formal peer support programs are widely used by MS Societies and other organisations such as hospitals, to offer a source of personal support to PwMS (Messmer Uccelli et al., 2004). Peer support programs are generally administered by PwMS, and while they may not have formal mental health backgrounds, peer support providers have generally undergone some training such as active listening techniques (Mohr et al., 2005). A common goal of peer support programs is to improve the wellbeing and quality of life of participants, with other programs also aiming to improve self-efficacy (Lorig et al., 2001). Despite its popularity, the literature on the benefits of peer support is inconclusive due to differences in study designs and results (Schwartz, 1999). Messmer Uccelli et al. (2004) studied the efficacy of face to face peer support programs that primarily aimed to provide support, and found them to be ineffective in improving participants' depression and quality of life. However the face to face peer support programs that also instruct participants on self-management techniques and goal-setting, in addition to providing support, have shown significant improvements across outcomes such as mood and health related behaviours (Lorig et al., 2001; Von Korff et al., 1998). Similarly, telephone administered peer support programs were not shown to have significant improvements in participants' quality of life or mood (Messmer Uccelli et al., 2004; Schwartz, 1999), until a study by Mohr et al. (2005) showed significant improvements across a broad range of outcomes including quality of life and depression when the program contained an element of self-management. Interestingly, a study of the effects on peer supporters (of telephone peer support provision), showed that those

administering the support showed pronounced improvement in confidence, self-awareness, self-esteem and reduced depression (Schwartz, 1999). Face to face and telephone administered peer support programs can have a wide range of outcomes for participants and providers, including improved quality of life and mood, particularly when the program aims to provide more than basic support alone.

As mentioned above, the world of online peer support for PwMS is rapidly growing. Online peer support provides PwMS with benefits such as anonymity, flexibility regarding opportunities for involvement and timing of peer interaction, and reduced emphasis on mobility as online peer support can be accessed from home (Strittmatter, 2004). An example of a website encouraging PwMS to meet online and to discuss MS related issues is MSWorld.org. A person with MS, Kathleen Wilson, created the website offering chat rooms, message boards, email groups and an online magazine, when she felt a need to talk to others with MS but was hesitant to meet face to face. In a recent interview, Kathleen said “I wasn't ready for face-to-face meetings. I went online looking for support. There were chat rooms but nothing for MS. I decided to make my own and on July 10, 1996, I posted a notice on the Internet for a chat about MS. Six people responded. Now we have 20,000 visits a day.” (King, Kraut & Sullivan, 2006, p.18). Just as MSWorld.org is run in conjunction with the National MS Society of America, there are a number of other websites offering peer discussion run by other MS Societies and pharmaceutical companies around the world, and countless additional independent chat rooms, message boards and email lists accessible for those living with MS. There is no research known to the author at this time examining the provision of online peer support to PwMS.

It is apparent from the number of options available, that talking to other PwMS, whether by phone, internet, or face to face, is considered valuable by those who have been recently diagnosed with this chronic illness. Research into the efficacy of peer support is still in its

infancy, and has yet to look at internet based delivery, or informal peer support provision. Rather, research has focused on telephone and face to face peer support provided within the framework of a formal program. The offering of peer support to those newly diagnosed with MS appears to be increasing as its benefits are being realised by both researchers and clinicians, and the ease of accessibility, through online options as well as face to face and telephone, is escalating.

3.3.1.3 Disclosure of Diagnosis

Matson and Brooks (1977) identified that a substantial component involved in an individual adjusting to a diagnosis of MS, was the disclosure of the diagnosis to others. However, research into the disclosure of an MS diagnosis, including factors such as the timing of disclosure, who PwMS choose to disclose to, and their reasons behind doing so (or not), remains understudied and poorly understood. The overarching benefit of disclosing a diagnosis of MS is that the individual is likely to receive an increase in emotional or practical support from those to whom they disclose (Joachim & Acorn, 2000). However the risks associated with disclosing a diagnosis of MS are many. Such risks include losing control over the information, having difficulty handling the responses of others, and facing rejection and/or stigmatisation (Charmaz, 1991). If an individual chooses not to disclose, there are further risks associated with attempting to hide a condition, such as the threat of being ‘found out’ (Charmaz, 1991).

Those who are showing visible signs of an illness have less choice about disclosure than those whose illness remains entirely invisible (Joachim & Acorn, 2000). For example, the PwMS who experiences motor symptoms apparent to others, may perceive that they have no other choice but to disclose, while the person experiencing solely sensory symptoms may use ‘covering’ to resist disclosing (Goffman, 1963). Covering is an attempt to minimise the effect of

a stigmatised condition, so that others may remain oblivious to its presence (Goffman, 1963). Individuals may choose not to disclose based on the belief that illness is a private matter; they do not want to be the focus of attention; or for reasons of guilt or shame about their condition (Charmaz, 1991). Charmaz suggests that individuals who choose to disclose a chronic illness with invisible symptoms do so in one of two ways: protective disclosing or spontaneous disclosing. Protective disclosing is planned, whereby individuals aim to control how, what, when and to whom they will tell about their condition. Conversely, spontaneous disclosing is more often than not an emotional response to the shock and disbelief that accompanies such a diagnosis. An example of a situation prompting spontaneous disclosing is when an individual diagnosed with MS on their lunch break returns immediately to work to 'blurt' out the diagnosis to their colleagues. The ramifications of such an unplanned outburst may range from increased support from sympathetic colleagues, to isolation, stigmatisation or discrimination within the workplace (Charmaz, 1991).

Another form of disclosure, as identified by Troster (1997), is preventative disclosure. Preventative disclosure is a strategy often used by those with an invisible condition, where symptoms are not under their control. While epilepsy is a perfect example of such a condition, preventative disclosure is also apparent in cases of MS (Joachim & Acorn, 2000). The decision to disclose is based on the degree of perceived risk that others will find out about the condition over time, and individuals can prevent, or reduce, the negative perceptions of the condition by disclosing the diagnosis before others witness visible symptoms (Troster, 1997). There is very little known regarding whether PwMS regret their decision to disclose after the fact, and how they cope with the results of their decision to disclose (Joachim & Acorn, 2000).

There are numerous reasons why PwMS may choose to disclose, or not disclose, their condition to others. The reality is that as MS can combine both visible and invisible symptoms

within a single disease trajectory, it makes the disease unique among chronic conditions and may complicate the matter of disclosure (Joachim & Acorn, 2000). There is no research to the author's knowledge that broadly outlines who people diagnosed with MS choose to disclose to, and when. A more thorough understanding of the issues involved in disclosing a diagnosis of MS to others, and the possible ramifications of disclosure, would assist health professionals working with PwMS to provide guidance about the advisability of disclosure.

3.3.2 Lifestyle Changing Activities

People with MS can exhibit a wide range of post-diagnosis behaviour. Information seeking, talking to others with MS, and disclosing the diagnosis, as described above, are among these. Making lifestyle changes in an attempt to alleviate and/or prevent symptoms, improve functioning and enhance quality of life, or to make sense of the disease, also has a place in a study of post-diagnosis behaviour. Lifestyle changing activities following a diagnosis of MS include, but are not limited to, the taking of disease modifying agents (immunotherapies), the seeking out of complementary or alternative therapies, a change in work hours, and a changed level of interest in spirituality/religion (Calabresi, 2004; Reynolds & Prior, 2003; Stuijbergen & Harrison, 2003; Thorne, Paterson & Russell, 2003). Each of these behaviours is considered below.

3.3.2.1 Medication

As discussed in Chapter 2, the availability of medication to slow the progression of MS is largely dependent on the subgroup of MS an individual is diagnosed with, and the country they live in. If in a position to access immunotherapy, the decision for a PwMS to start medication can be daunting for several reasons. First, all immunotherapies are administered via injection,

usually self administered (subcutaneously in the case of Betaferon, Copaxone, and Rebif, or intramuscularly for Avonex), while Mitoxantrone, together with the newly approved Tysabri, must be administered by health care professionals (usually in a hospital setting). Second, accumulating evidence indicates that the best time to begin any of the disease modifying treatment is early in the course of RRMS (Burks et al., 2002; Coyle & Hartung, 2002), or once a clinically isolated event has occurred (even before the technical diagnosis of definite MS is made), in order to reduce the risk of the degenerative progression of MS (Miller, 2004). Third, higher and more frequent doses of the interferon drugs have been shown in recent head to head trials to be more effective in treating RRMS than lower, less frequent doses (Burks et al., 2002). Lastly, there still remains some controversy surrounding the value of immunotherapies in the treatment of MS (Filippini et al., 2003). For most people diagnosed with MS, deciding whether or not to begin immunotherapy, and which one to choose if any, is far from a straight forward decision. The method of administering the medication together with the perceived urgency around when to start and the often overwhelming information linked to the medication can prove daunting for some. Additionally, the commencement of treatment may be perceived by the PwMS and family members as confirmation of an altered future; an acknowledgement of the reality of living with a chronic and unpredictable condition (Kalb, 2007).

The method of administering the immunotherapies, the dosing quantities, and the debate on the effectiveness of the medication, combined with the potential impact self-administered injections may have on a person's lifestyle, often promotes a shared role between the PwMS and the medical professional in the decision making. Unlike many other diseases, in the case of MS there is usually some discussion between the physician and the patient regarding if and when to start medication, and the choice of medication (Heesen et al., 2004). There is no set procedure for neurologists to determine treatment for each individual, although examining clinical

symptoms together with MRI results to determine if a patient's condition is worsening and if treatment is warranted will assist practitioner, and thereby patient, to make a decision as to whether to start immunotherapy (Burks et al., 2002). If immunotherapy is to begin, a patient's lifestyle may also be taken into account when deciding between the medications available for MS. Some people with RRMS, for example, may prefer to take a lower dose injection once a week rather than experience the inconvenience of an injection every day or every second day, due to lifestyle factors or a fear of injections (Burks et al., 2002). Indeed, there is some evidence that suggests PwMS have an increased risk of discontinuing immunotherapy if unable to self-inject due to injection anxiety (Mohr et al., 2001). On the contrary, some people with SPMS (if they do not suffer from needle-related anxiety or phobia) may be less concerned with convenience and more concerned with the potential increased efficacy of a more frequently administered drug, as there is more disability associated with SPMS (Burks et al., 2002). Individuals suspected of having a benign course of MS, or those who are in a period of remission at the time of diagnosis, can face an additional element of difficulty in their decision, as they may not see the need to start immunotherapy given a lack of symptoms, an absence of disability and the possible unwanted side effects of the treatment.

Physicians' increasing preference for early treatment may mean that PwMS are prompted to begin the immunotherapy medication very shortly after diagnosis (Burks et al., 2002). In order to be involved in the choice of medication, people newly diagnosed with MS may try to process the scientific literature regarding immunotherapies. For some, this may be a difficult task at such a stressful time. However, some PwMS may find that reading the literature, being involved in the decision, and commencing immunotherapy shortly after diagnosis, gives them back an sense of personal control over the disease; a knowledge that they are doing all they can to reduce, and potentially minimise, the effects of MS (Jelinek, 2005).

3.3.2.2 Complementary or Alternative Therapies

Many aspects of successfully dealing with the diagnosis of MS, and making a decision about medication, fall outside the medical model (Wassem & Dudley, 2003). It is not surprising then that people newly diagnosed with MS often seek out complementary therapies or make lifestyle changes in addition to, or rather than, the commencement of immunomodulating therapy (Pucci et al., 2004). Schwarz and Leweling (2005) refer to PwMS turning to complementary therapies for assistance as ‘almost inevitable’, due to the course of MS often worsening despite medical measures taken.

PwMS often report using one or more complementary or alternative therapies in combination with immunotherapies or medication prescribed by their doctor, as discussed in Chapter 2 (Schwartz et al., 1999). Indeed, the majority of PwMS will undertake a variety of complementary therapies (Schwarz & Leweling, 2005). In a recent study on the frequency of complementary and alternative therapy use by PwMS, Apel, Greim, Konig and Zettl (2006), found that over 67% ($n=171$) of participants reported using one or more complementary or alternative therapy, with an average of 2.7 different therapies. Those participants experiencing a more severe course of MS, and those who had had MS for a longer duration, were more likely to engage in complementary therapies. Hence, PwMS may embrace complementary or alternative therapies more enthusiastically as the disease progresses and if conventional medicine is viewed as ineffective. Exhibiting similar lifestyle changing activities to those with chronic illnesses such as Parkinson’s disease and epilepsy, PwMS are likely to take up any opportunity for disease improvement (Apel et al., 2006). In an attempt to slow further progression, those with chronic degenerative disease may engage in complementary or alternative therapies in the absence of adequate studies verifying the effectiveness of the treatment, and/or in the absence of noticeable personal efficacy (Apel et al., 2006).

While there is a lack of literature (in comparison to other chronic conditions) on complementary and alternative therapies used by PwMS, current research indicates that the most popular complementary therapies employed by PwMS include; adherence to a specific ‘MS diet’; the addition of vitamin supplements to the diet; and an increase in exercise or engaging in a specific exercise suited to the MS symptoms experienced (Apel et al., 2006; Pucci et al., 2004; Schwarz et al., 1999). These three lifestyle changing activities and commonly used complementary or alternative therapies, are described below.

3.3.2.2.1 *Diet.* Eating healthy foods is generally recognised by PwMS as an important factor in their ability to feel well and to postpone disease progression (Thorne, Paterson & Russell, 2003). In Australia, adherence to a special diet is a complementary therapy increasingly embraced by PwMS (Jelinek, 2005). One such diet that holds specific interest for Australians with MS is the ‘Jelinek’ diet. Created by an Australian professor of emergency medicine living with MS himself, the ‘Jelinek’ diet has roots in the USA based ‘Swank’ diet. Both popular diets focus on eliminating saturated fats, increasing omega 3 (fish) oils and increasing Vitamin D intake through sun exposure (Jelinek, 2005). While benefits from any particular diet in MS have not yet been proven, adherence to an MS-specific diet may be seen to have three main beneficial effects for PwMS (Schwarz & Leweling, 2005). First, there are claims that a diet low in saturated fat and high in Omega 3 oils and Vitamin D may have a preventative effect on MS disease progression (Jelinek, 2005). Second, combined with exercise and healthy lifestyle choices, following such a diet may contribute to ensuring the body is as healthy as possible to cope with the occurrence of an MS exacerbation. Third, adherence to a low fat diet will reduce the likelihood of other health complications for the person living with MS, such as obesity.

PwMS across many countries are increasingly looking to adapt or modify their diets in accordance with the literature, as a way of taking some personal control in the management of their disease (Jelinek, 2005). Indeed, people newly diagnosed may adopt an MS specific diet if it offers them hope for recovery, or reduced progression of the disease. Moreover, a complicated or time consuming diet may actually provide a sense of control and initiative, limiting the feeling of being helplessly exposed to an incurable and mysterious disease (Schwarz & Leweling, 2005). However, while these MS specific diets can be viewed by some as empowering, others may view them as negatively constricting their lifestyle, with adherence to a diet regime difficult. Zielinski (2006) states “For me, adherence to my injections has been the easiest part of managing my MS. What is really hard for me is adherence to the more internal or subtle issues: physical therapy and diet” (p.49). Together with the difficulties of adhering to a restrictive diet, the lack of evidence based knowledge regarding the benefits of diet on MS may make an attempt to change dietary habits difficult for those newly diagnosed.

3.3.2.2.2 *Addition of vitamin supplements.* Hewson et al. (1984) found that two thirds of PwMS made changes to their diet following diagnosis. Not all changes involved a substitution of one type of food for another, or the strict adherence to a particular diet regime. Rather, some PwMS merely added vitamin supplements to their pre-MS diet. Currently, there seems to be a trend in the addition of fish oil (omega-3 fatty acids), evening primrose oil (rich in omega-6 fatty acids), linseed oil, and Vitamin D to the diet (among others), usually in the form of capsules taken orally with food (Jelinek, 2005). While there is not enough data to date to recommend vitamin supplementation specifically for use in the treatment of MS, such additions to the diet are generally not discouraged, as when used in appropriate dosages they can be beneficial for general health (Schwarz & Leweling, 2005). Antioxidants, such as vitamins C and E are also viewed by

some as being of benefit to PwMS, although recent research shows the potential therapeutic effects of antioxidants as limited and conflicting (Carlson & Rose, 2006; Yadav, Marracci & Lovera, 2005). Apel et al. (2006) found that although PwMS rated vitamin, mineral and other supplements as only moderately effective, they were widely used despite being the most expensive of the complementary or alternative therapies reported. The most commonly reported, most effective and least expensive therapy is exercise (Apel et al., 2006), described below.

3.3.2.2.3 *Exercise*. Exercise is often referred to as a complementary therapy for PwMS, however, many would agree that regular strength and cardiovascular exercise should be looked upon as an essential part of a healthy lifestyle for all, not just those with a chronic condition. In previous years, health professionals would advise PwMS to avoid exercise, warning that it would increase fatigue levels (Surakka et al., 2004). However, such recommendations of abstinence from exercise can promote muscle deconditioning and a lower level of overall fitness (Mostert & Kesselring, 2002), detrimental to general health. Research over the past two decades has shown the opposite effect whereby aerobic and strength exercise actually reduces, not increases, fatigue levels in PwMS (Petajan & White, 1999). Further to this, the more recent approach of advising PwMS to engage in exercise is seeing not only reduction in fatigue, but enhanced muscle performance as well as improvement in quality of life, mood, self-efficacy, and self-esteem in these PwMS (Mostert & Kesselring, 2002; Navipour et al., 2006; Petajan & White, 1999; Sutherland & Andersen, 2001). As Chamberlayne (2006, p.35) states, “deep water jogging has increased my physical stamina, enabling me to stand erect longer and walk further with the use of my walker. I have more energy and sleep solidly. The stress in my life is reduced”.

A study by Sutherland and Andersen (2001) identified that PwMS experiencing mild to moderate levels of disability benefit more from exercising than those experiencing severe levels

of disability. Such a finding suggests that increasing exercise shortly after a diagnosis of MS and retaining a regular exercise regime, is of greater benefit than trying to incorporate exercise into an individual's lifestyle after the disease has progressed to a severe level of disability. PwMS participating in physical exercise believe that if they maximise their overall health, strength and fitness, their MS symptoms may be better controlled (Reynolds & Prior, 2003).

As a lifestyle changing activity following diagnosis, exercise offers PwMS not only improved physical health, but also potential for improvement in factors affecting quality of life (Petajan & White, 1999; Reynolds & Prior, 2003). People newly diagnosed with MS may be directed by physicians to maintain or increase the amount of exercise in their lifestyle, or they may take it upon themselves to become as physically healthy as possible, perceiving that a healthy body would be better able to combat disease progression.

3.3.2.3 Change in Work Hours

MS is frequently diagnosed during the most productive years of an individual's life, when relationships and adult life in the community are consolidating, and career exploration and development occurs (Metz, 2003; Nodder et al., 2000; Van Denend, 2006). Hence, the diagnosis of MS can have an enormous impact on employment related issues, and an individual's ability to fulfill expected life roles. Together with its impact on self image, MS may result in profound biographical disruption (Bury, 1982). An individual with MS may face significant factors affecting their ability to work include spastic paresis of the legs, coordination difficulties, cognitive dysfunction, and fatigue (Ford & Johnson, 1995). Although faced with the possibility of such hurdles, PwMS who remain employed following diagnosis are less likely to perceive themselves as severely impaired, and have a greater sense of autonomy, than those not employed (Brooks & Matson, 1982). Not surprisingly, people with chronic diseases who are unemployed

report a lower quality of life than those who are employed (Feagan et al., 2005; Johnson et al., 2004). As engagement in a meaningful occupation plays a key role in achieving a high quality of life and a positive self image, self identity can be threatened if poor health results in early retirement from work (Reynolds & Prior, 2003).

While making life altering decisions is not generally advised during periods of crisis, PwMS may make important decisions immediately following diagnosis, such as reducing work hours or leaving the workforce altogether, due to a fear of what the future may bring if they have another relapse, or if their level of disability increases (Strittmatter, 2004). However, once a person is unemployed due to disability, difficulties often surface in attempting to regain employment (Allaire et al., 2005; Habeck, 1999; Sirvastava & Chamberlain, 2005). In addition, due to perceived risks to the employer, the greatest obstacles to re-employment, or commencing employment, appear to be faced by people with progressive illness or whose level of disability varies, such as those with MS (Robinson, 2000). This underscores the importance of resisting the urge to reduce work hours, or change employment, at the time of diagnosis. Recent literature highlights both the advantages of employment and the potentially damaging consequences of disability-related unemployment for employees, employers, and society as a whole (e.g., Allaire, Niu & LaValley, 2005; Habeck, 1999).

Drawing on data from the Australian Multiple Sclerosis Longitudinal Study (AMSLS), the recent Access Economics Report (2005) indicates that of the more than 16,000 people in Australia who have MS, 87% are of working age. While it is suggested within the report that PwMS tend to be in higher skilled jobs than the general population, almost half had left paid employment due to MS and another third felt their current employment was at risk (Simmons et al., 2004). Consistent with overseas evidence regarding early loss of employment (e.g., O'Day, 1998), the AMSLS data indicate that 80% of PwMS change their employment status within 10

years of diagnosis, often in their 30s or 40s, with inadequate retirement savings, risks of social isolation, and disadvantages in re-entering the workforce (Access Economics, 2005). Due to the association of unemployment with loss of income and impaired quality of life, the impact of joblessness on PwMS and their families is profound (Metz, 2003).

Reducing hours of employment, or attempting to change careers to something better suited to living with the symptoms of MS, has its risks. While there are multiple and complex factors often making employment difficult for those with MS, people newly diagnosed with MS may be prone to reducing their work hours or seeking a change in employment, as a reaction to the shock of diagnosis and a fear of what the future holds. These changes may not be necessary at the time, but may be motivated by a fear of the unknown. For many PwMS, the line between employment and unemployment may be a fragile one (Johnson et al., 2004), and changes made to employment, as a lifestyle changing activity immediately following diagnosis, is a critical issue for PwMS, their families, and the health professionals working with them.

3.3.2.4 Modifications to Physical Environment

PwMS may experience restrictions in mobility and difficulty with everyday functions. A wide range of factors including physical, psychological, environmental and economic issues may contribute to these difficulties (Freeman, 2001). When an individual with MS experiences difficulty with everyday functioning over a period of time, modifications to their physical environment may be considered so that they are able to manage the activities of daily living. The employment of non-medical resources, such as a walking stick or wheelchair, or making modifications to the home or car, may be included in post diagnosis activities for those who experience an increased level of disability at the time of diagnosis, or indeed, at any time during the disease progression (Kobelt et al., 2006). Other modifications include changes to bathrooms,

the widening of doorways, installing ramps and railings, or the procurement of wheelchairs, hoists, special beds, mattresses, cushions, and other aids (de Judicibus & McCabe, 2005). Making such modifications to the physical environment may prolong independence, and postpone early institutionalisation of individuals living with MS (Aronson, Cleghorn & Goldenberg, 1996). However, modifying the physical environment is often not easy, as there are a number of potential obstacles in the way of a PwMS receiving the correct equipment, or home modifications needed (Frames, 1994).

One such obstacle to modifying the physical environment appropriately is the cost (Frames, 1994). Obtaining equipment or making modifications to a home or vehicle is, for the most part, very expensive (Kobelt & Pugliatti, 2005). Figures representing the cost of equipment and modifications are often missing from the literature on estimates of overall financial burden on individuals with MS, as cost of equipment/modifications (together with formal and informal care, and loss of earnings) are often not included within the definition of personal health care costs (Whetten-Goldstein, Sloan, Goldstein & Kulas, 1998). Whetten-Goldstein et al. (1998) estimated the annual cost of modifications to the physical environment to be approximately \$US1100 per individual with MS. Private health insurance, government healthcare schemes, or government needs-based funding (determined by level of disability) is generally needed to decrease the cost to the consumer (Kobelt et al., 2006). However, a study by Freeman and Thompson (2000) found that modifications to the home environment are only moderately related to level of disability for PwMS living in the UK, raising questions about equitable allocation of resources within the community. Similarly, a study carried out in Denmark indicated inequality of grant administration for equipment and home modifications in the case of people living with MS (Christensen & Clausen, 1997). A recent Australian study highlighted that the progressive nature of MS often means that by the time funding is granted for specific items of equipment, the

individual's requirements may have changed (de Judicibus & McCabe, 2005). The costs associated with making modifications to the physical environment are generally high and can make the acquisition of appropriate equipment, at the time it is needed, difficult.

A second obstacle to obtaining appropriate equipment or receiving appropriate home modifications is that a PwMS may make inappropriate changes to the physical environment without seeking advice (Frames, 1994). Appropriate changes require individual assessment and intervention, often from a variety of different perspectives using a coordinated, goal-oriented, multi-disciplinary approach (Freeman, 2001). Ideally, a health professional working as part of a team with expertise in aids and equipment, such as an occupational therapist or physiotherapist, would then recommend the equipment or modifications from a long term perspective, rather than prescribing a 'quick fix' (Freeman, 2001). This may seem excessive for the PwMS who 'knows' they only need a walking stick for example, but as there are several options available to improve mobility issues, it is imperative that the equipment chosen best matches the individual's needs. The process of using a multidisciplinary team assessment and intervention for each individual with MS is often not utilised due to expense, waiting lists, and PwMS deeming the process unnecessary.

In order to instigate or agree to modifications to the physical environment, the person with MS must allow time to grieve the losses associated with any current, and possibly future, limitations imposed by the disease. Therefore, a third barrier to PwMS making modifications is the attitudes people with MS themselves have about their disease, and about using equipment. It can be very difficult for a PwMS to admit (to themselves as well as others) to needing the assistance of equipment such as a walking stick or wheelchair. Indeed, many PwMS resist using aids that will improve their mobility, for fear of becoming dependent on them (Kalb, 2000). Wheelchair dependence has been perceived by able bodied PwMS as being equal to loss of

independence (Boeije & Janssens, 2004). Indeed, the acceptance of an initial mobility aid can instigate concerns of a continual decline in mobility (the 'beginning of the end'), losing independence, becoming a burden on caregivers, and the future possibility of having to move into a nursing home (Finlayson, 2004; Finlayson & van Denend, 2003). Combined with such fears, PwMS may also be hesitant to use equipment, being realistically apprehensive of a change in other's perceptions of them, their social role, and their activity levels (Kalb, 2000; Neri & Kroll, 2003).

While there can be barriers to making modifications to the physical environment, some PwMS take the approach that using aids and equipment and making modifications to the home when needed, assists them in continuing to lead a full life with MS, and such changes may even give them more control over the disease. In a study by Finlayson and van Denend (2003) PwMS expressed both the importance of trying to remain in control of their independence, and the devastation incurred by increased disability and the need for aids. When a loss of mobility occurred, participants underwent a period of mourning their losses, before taking action. Taking action, in accepting equipment or home/vehicle modifications, re-empowered these participants as they felt an increased sense of personal control in effectively managing their MS (Finlayson & van Denend, 2003).

Making modifications to the physical environment, whether in the form of utilising aids and equipment, or having modifications made to the home or vehicle, is not an easy process for most PwMS. Many barriers such as expense of equipment, inappropriate choice of modification, and negative perceptions tied to use of equipment by PwMS, can interfere with appropriate modifications to the physical environment at the time it is needed. While making modifications can be a rewarding and beneficial post diagnosis activity for PwMS who view such alterations as a way of retaining control over their MS, this is not the case for all PwMS. If the individual

views modifications as a loss of independence, rather than a way of retaining independence, this post diagnosis activity may not be engaged in at the time it would be of most benefit.

3.3.2.5 Change in Level of Interest in Spirituality/Religion

When Brooks and Matson (1982) asked PwMS what helped them cope with the illness, religion was the second most frequent response (the first being ‘accepting it’). While not as visible as making home modifications, a change in the level of interest in religion or spirituality may also occur as a post MS diagnosis activity. For many, spirituality refers to an individual’s attempt to find meaning in life, which can include a sense of involvement with the transcendent outside institutional boundaries, whereas religion tends to refer to aspects of belief and behaviour, including spirituality, grounded in a religious community or tradition (Williams & Sternthal, 2007). An increased interest in religion, or even religious conversion, has been reported as common in people after receiving catastrophic news, such as the diagnosis of a chronic illness (Langgartner, Langgartner & Drlicek, 2005). While it is also conceivable that an MS diagnosis may result in a loss of faith in a higher power or God, the research into spirituality and MS has focused predominantly on the presence of an interest in spirituality/religion (e.g., Makros & McCabe, 2003; Russell, White & White, 2006), rather than a change in level of interest in spirituality/religion following diagnosis. As there is growing recognition among health professionals of the important role played by the various dimensions of spirituality and religiosity in coping with stressful life events, including the diagnosis of chronic conditions (Kilpatrick & McCullough, 1999; Underwood-Gordon, Peters, Bijur & Fuhrer, 1997), exploring a change in level of interest in spirituality/religion following a diagnosis of MS would be useful.

Over the past 25 years, spirituality and religiosity have been found to be positively correlated with perceived quality of life (Brooks & Matson, 1982; Micello, 1988), self-esteem (Paloutzian & Ellison, 1982), and hope (Foote, Piazza, Holcombe, Paul & Daffin, 1991), and inversely correlated with anxiety (Kaczoroski, 1989) in both healthy and chronically ill populations. When examining populations living with specific health concerns, spirituality and religiosity have been linked to greater overall mental health and positive wellbeing in individuals diagnosed with various forms of cancer (Ell, Mantell, Hamovitch, & Nishimoto, 1989); higher quality of life in women with breast and gynecological cancers (Colton, et al., 1999; Gioiella, Berkman, & Robinson, 1998); higher levels of well being in those with spinal cord injury (Decker & Schulz, 1985); less psychosocial distress after recovery from cardiac surgery (Ai, Dunkle, Peterson, & Bolling, 1998); and hardiness in individuals diagnosed with AIDS (Carson & Green, 1992). Spiritual well-being and/or religiosity have also been shown to be important variables in the adaptation to a chronic illness (Hilton, 1988; Michello, 1988), including MS (Crigger, 1996).

Incorporating spirituality into an individual's life can result in the addition of a constructive force, particularly when attempting to tackle the uncertainty a diagnosis of MS can bring (McNulty, Livneh & Wilson, 2004). McNulty et al. (2004) suggest that spiritual well-being can act both as a mediator between the uncertainty that the diagnosis brings and successful adaptation to a diagnosis of MS, and as a predictor of positive psychosocial adjustment to a diagnosis of MS. Exploring gender differences and spirituality, Bussing, Matthiessen and Ostermann (2005) found that women with MS engaged in activities related to spiritual well-being more often than men with MS. In a study on uncertainty in women with MS, Crigger (1996) found that relationships with other human beings, together with a belief in a higher power or God, were the two greatest strengths identified by women with MS in dealing with the disease.

While there is a growing body of research indicating that religion and spirituality are associated with better psychological health in MS, the findings of Makros and McCabe (2003) stand out as an exception, suggesting that higher levels of religiosity and spirituality among PwMS was positively related to depression and anxiety, and negatively related to quality of life and psychological well being. While the direction of effect may remain unclear, an individual may exhibit a change in their level of interest in spirituality or religion following a diagnosis of MS; a factor that may contribute to overall health and wellbeing.

A diagnosis of MS can take many months or years to make due to the complexity of the disease and the often rigorous diagnosing process. Previous research into various aspects of adaptation to diagnosis have typically involved participants recruited from an MS Society registry, and have focused on one geographical location. Most studies have incorporated data collection techniques involving a pen and paper questionnaire, and have targeted those people with RRMS. While the majority of previous research sample sizes have been small (adding to the reduction of generalisability), previous research findings have prompted important future research questions. Generally, PwMS indicate a preference for a timely diagnosis; to be informed as soon as the physicians are able. In attempts to reduce the anticipatory uncertainty that comes in the lead up to, and with, a diagnosis of MS, post-diagnosis behaviours such as information seeking, the recruitment of social support and disclosure of diagnosis, and talking to other PwMS are often exhibited. Engaging in lifestyle changing activities such as taking medication, exploring complementary therapies, changing work hours, making modifications to the physical environment, or experiencing a changed interest in spirituality, is not uncommon following a diagnosis of MS. For many people newly diagnosed, employing one or more of these post diagnosis activities can provide ways of alleviating symptoms and improving quality of life,

as well as coping with the uncertainty of the disease. It is therefore important to explore the occurrence of such post diagnosis behaviours and activities of people newly diagnosed with MS.

CHAPTER FOUR

ADAPTATION TO DIAGNOSIS IN THE FIRST TWELVE MONTHS

4.1 Overview of the Chapter

Engaging in post diagnosis behaviours and lifestyle changing activities, as explored in the previous chapter, is not uncommon following a diagnosis of MS and may impact on an individual's health and quality of life when attempting to adapt to a diagnosis of MS. For individuals diagnosed with MS, responding to the psychological and physical stresses of being diagnosed with a condition of unknown cause, and no cure, can be challenging (Koopman & Schweitzer, 1999). There is little known about how people cope with a diagnosis of MS (Pakenham, 2005; Sullivan, Mikail & Weinshenker, 1997) and the factors that may assist, or hinder, adaptation to MS in the first 12 months following diagnosis. It is likely however, that the successful adaptation to MS in the first 12 months following diagnosis is multilayered.

In this chapter, a discussion of why it is important to isolate the first 12 months following diagnosis is presented. Factors that may assist in the adaptation to diagnosis during this time period are then identified before a brief overview of coping is given, with a focus placed on a number of coping resources relevant to adaptation to a diagnosis of MS including social support, optimism/positive attitude, and eagerness to take control following diagnosis. Finally, a number of factors that may hinder adaptation to diagnosis for people newly diagnosed with MS are then acknowledged before two (denial and avoidance, and the unhelpful attitudes of others) are explored in more detail.

4.2 Why Examine the First 12 Months Following Diagnosis?

Studies on psychological wellbeing and quality of life in PwMS have predominantly been conducted among individuals at advanced stages of disease (Janssens et al., 2003). Indeed, the vast majority of studies regarding adaptation to MS are conducted many years after diagnosis. For example, Pakenham and Stewart (1997) in their study on the role of coping in adjustment to MS, studied PwMS who reported an average interval of 16 years since diagnosis. Similarly, McNulty, Livneh and Wilson (2004) examined psychosocial adaptation in individuals with MS by surveying those who had an average illness duration of 10.9 years. While such studies provide important information about adaptation and adjustment to MS some time after diagnosis, it has been suggested that the stresses associated with the onset of a chronic illness may differ in significant ways from the day to day stresses of living with a long standing chronic condition (Lyons, Sullivan, Ritvo, & Coyne, 1995; Shontz, 1975). This suggests the importance of exploring the period of time immediately following the onset of illness or the diagnosis of MS.

The 12 months following diagnosis may constitute the period where key strategies, resources, or patterns of behaviour are established by the individual diagnosed with MS to ensure successful coping. While it is likely that many behaviours will be sustained for a duration of more than one year, it is important to invite PwMS to report on their experience of the initial 12 month period to enable a better picture of the psychosocial factors that they identify as being of assistance, or hindrance, to their own adaptation early in the disease process.

While the first 12 months may be identified as an important stage in adaptation to diagnosis, the existing research into psychosocial adaptation to MS either examines individuals' entire period of illness up until the time of the participation in a study (which often accounts for many years), or excludes the first 12 months from examination (e.g., McNulty, Livneh & Wilson, 2004). However, this time period is of critical importance as PwMS can be acutely aware of the

uncertainty linked to disease progression, and the prospect of potential serious disability (Lyons et al., 1995). In addition, the uncertainty about unexplained symptoms that had evoked anxiety and distress before the diagnosis may continue into the immediate period thereafter (Janssens et al., 2003). Hence, in appreciation of the likely differences between people who have lived with MS for many years and people who are newly diagnosed with MS, a separate course of study focusing on the first 12 months following diagnosis is warranted.

Research focusing on the first 12 months following an MS diagnosis is extremely limited. Recognising the lack of research conducted in the earlier phases of the disease, Janssens et al. (2003) recruited people recently diagnosed with MS and their partners in a study of the impact of the disease on quality of life and psychological outcomes. Their participants with MS had been diagnosed within 24 months of participating in the study, with an average of eight months since diagnosis. It was found that both PwMS and their partners experience substantial emotional effects of the disease shortly after diagnosis, including higher levels of anxiety and distress when compared with controls (Janssens et al., 2003). While previous studies have shown that psychological well-being and quality of life are reduced in people with advanced stages of MS, Janssens et al. demonstrate that MS can also have a major impact on the quality of mental health in those recently diagnosed. These findings validate the importance of examining the period immediately following diagnosis, and the necessity of exploring the post diagnosis behaviours and activities that PwMS identify as being of assistance or hindrance to their adaptation to diagnosis.

There are three main research options available to those wanting to study the first 12 months following a diagnosis of MS. These are prospective, retrospective and concurrent research methods. Henry et al. (1994) suggest that prospective longitudinal studies offer the most promising method for accurately linking events and behaviors across time. However, prospective

studies examining behaviours following diagnosis and factors that may assist or hinder adaptation to MS present a number of challenges to researchers. The length of time needed to conduct a longitudinal study, as well as the expense of such research, are among the main challenges. An additional challenge may be the difficulty inherent in recruiting participants at the exact time of diagnosis. In the absence of longitudinal prospective studies, researchers often turn to retrospective studies and ask people to talk or write about their past experiences (Robins, 1988). For studies examining the first 12 months of a chronic illness, retrospective research methods are favoured over strictly concurrent research designs which would demand only participants who had been diagnosed within the previous 12 months (Galassi, Frierson & Sharer, 1981). It would not be ideal for researchers to recruit only those who had been diagnosed within the previous 12 months for two key reasons. First, anecdotal evidence suggests that a large number of individuals diagnosed within 12 months may not want to be involved in research so soon after their diagnosis (personal communication, Dr. E. McDonald, Medical Director, MS Society of Victoria, 2002), so targeting only these individuals would heighten the risk of low participant numbers. Second, studies into the factors that people found of assistance, or hindrance, during the first year following diagnosis may require a longer time for reflection (personal communication, Ms. S. Diffey, Social Worker & Program Coordinator, MS Society of Victoria, 2002). Therefore, a retrospective study design utilising a self-report questionnaire could be considered favourable when wanting to examine participants' perspectives of the first 12 months following diagnosis.

When examining the first 12 months following diagnosis, the use of materials involving self-report measures are a good choice for researchers. Self-report measures can include questionnaire or interview, with questionnaires able to cover a broader sample of participants and interviews able to cover the subject of interest in more depth. Questionnaires also have the advantage of being applicable across countries within a limited time frame. The use of self-

report measures within retrospective studies is growing, and is receiving increasing recognition as a valid source of data (Kardum & Daskijevic, 2001). Historically, the data compiled from other more traditional sources, such as observed behavior, historical information, population norms, formal testing, and clinical assessments was considered more reliable than self-reported data (Kardum & Daskijevic, 2001). However, research over the last two decades has shown that the use of self-report measures to record behavioural activity and psychological information can ensure even greater validity than the traditional methods of data collection (e.g., Burisch, 1984; Korchin & Schulberg, 1981; Lanyon, 1984; Osberg & Shrauger, 1986; 1990). For example Osberg and Shrauger (1986) found that individuals' assessments of their own past behaviours were more accurate than relying on less individuating information, such as population norms. Similarly, Korchin and Schulberg (1981) suggest that self-report measures allow greater emphasis to be placed on the participant's own views of their character, problems and situation than the reliance on external measures such as objective tests and behavioural observations, allows.

Although gathering increasing respect as a research tool, the use of self-report measures should not be regarded as a recent development in psychological research, with Allport (1942) noting its value over 60 years ago: "If we want to know how people feel: what they experience and what they remember, what their emotions and motives are like, and the reasons for acting as they do - why not ask them" (p.37). The use of self-report measures when conducting retrospective research on the first 12 months following diagnosis of MS may be considered a valid methodological approach to such research.

4.3 Factors Involved in Adaptation to Diagnosis

Some PwMS seem better able to adapt to the diagnosis than others (Pakenham, 1999), and the reasons for this are undoubtedly complex. A review of the literature provides an enormous array of factors that may assist or hinder the successful adaptation to a diagnosis. Medical or physical factors that may contribute to the successful adaptation to the diagnosis may include extent of MRI lesions, muscle weakness, and level of disability (Mitchell, Benito-Leon, Gonzalez & Rivera-Navarro, 2005), while neuropsychiatric factors may include cognitive impairment and fatigue (Mitchell et al., 2005). Although several studies have shown a significant relationship between physical symptoms and adaptation to MS (Rudick et al., 1992; Zeldow & Pavlou, 1984), physical symptoms alone do not explain differences in post-diagnosis psychological functioning (McIvor et al., 1984; Walsh & Walsh, 1987). It is therefore important to look beyond the physical realm when identifying factors that may contribute to successful psychological adjustment to a diagnosis of MS.

A review of the psychological literature surrounding the diagnosis of a chronic condition also provides a multitude of factors that may assist or hinder the successful adaptation to a diagnosis. Psychosocial factors include, but are not limited to: coping (Lazarus & Folkman, 1984; McCabe, 2005; Pakenham, 1999; Sullivan, Mikail & Weinshenker, 1997), personality variables (Papuc & Pawlowska, 2005), self-esteem (McCabe, 2005; Walsh & Walsh, 1987), positivity and optimism (Barnwell & Kavanagh, 1997), perceived uncertainty (McNulty, Livneh & Wilson, 2004; Wineman, 1990) and self-efficacy or perceived support (Mitchell, Benito-Leon, Gonzalez & Rivera-Navarro, 2005; Pakenham, 1999; Wineman, 1990). While all psychosocial factors may play a part in successful adaptation to diagnosis, the variation in adjustment of individuals to a diagnosis of MS is broad and cannot be adequately accounted for by psychosocial, medical, or neuropsychiatric factors in isolation (Pakenham, 1999; VanderPlate,

1984). However, there is value in exploring and understanding each factor before incorporation of multiple factors into a workable and useful model is possible.

Indeed, Pakenham (1999) suggested that while a number of variables have been identified as possible predictors of adjustment to MS, the integration of all into a workable and coherent model is difficult. Instead, models relevant to single psychosocial variables have been offered within the literature, and can be applied to the study of adaptation to a diagnosis of MS. For the purposes of the current study, the stress and coping model proposed by Lazarus and Folkman (1984) and subsequent research into coping and MS will be explored in brief, before an examination of specific coping resources available to people newly diagnosed with MS is undertaken. This focus on coping resources, rather than coping strategies, or indeed other psychosocial variables and factors involved in the adaptation to diagnosis, is important for the primary reason that an individual's coping resources can potentially be modified or enhanced by health professionals following a diagnosis of MS. Therefore such examination and recognition of the resources that PwMS identify as being helpful (or indeed, hindering) to their coping over the first 12 months following diagnosis may assist health professionals in their work with those newly diagnosed.

4.4 Coping - A Brief Summary

The complexity of the coping domain of research is reflected in the diversity of existing approaches to both the conceptualisation and assessment of coping (Billings & Moos, 1984). The literature on coping is vast, often complex, and is unable to be covered in full here. However, a broad understanding of the coping literature, including knowledge of coping strategies and appraisal of stress, is of value before taking a focused look at the coping resources available to those following a diagnosis of MS.

Within the field of adjustment to chronic illness, the cognitive stress and coping theory of Lazarus and Folkman (1984) is one of the dominant paradigms (Pakenham, 2001; Steptoe, 1991). Coping is typically conceptualised as a conscious response or reaction to stressful or negative events (Folkman & Lazarus, 1984; McCrae, 1984), and is often described in terms of the strategies that individuals use to minimise the negative impact of life stressors on their psychological well-being (Coyne, Aldwin, & Lazarus, 1981; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). Much of the coping literature asserts that coping comprises three main elements, rather than coping strategies alone (Parker & Endler, 1992). These three components are: the coping strategies used to manage a stressful situation; the subjective appraisal of the stressful situation (Lazarus & Folkman, 1984; Wineman, Durand & Steiner, 1994), and the personal or coping resources available to the individual during the period of stress (Shnek et al., 1995; Stuifbergen & Rogers, 1997; Wasseem, 1992). These three main elements of coping are described below.

4.4.1. Coping Strategies

Parker and Endler (1992) assert that if there is any consensus in the vast coping literature, it is in regard to the distinction between the two basic coping strategies; problem-focused and emotion-focused coping strategies. In general, the coping literature defines problem-focused coping strategies as those that refer to a task orientation (e.g., strategies directed at managing the source of stress), while emotion-focused coping strategies refer to a person orientation (e.g., strategies directed at managing emotional reactions to stressful situations) (Parker & Endler, 1992; Sullivan, Mikail & Weinshenker, 1997). Billings and Moos (1984) give examples of both coping strategies in their coping assessment measure, with items indicating problem-focused coping including ‘talk with friend about the problem’ and ‘made a plan of action and followed it’.

Items indicating emotion-focused coping include: 'took it out on other people when I felt angry or depressed' and 'tried to see the positive side of the situation' (Billings & Moos, 1984). The findings of research assessing both the general population and those with chronic illness, have suggested that the use of emotion-focused coping strategies are associated with higher levels of distress (Billings & Moos, 1981; 1984; Bombardier, D'Amico, & Jordan, 1990; Coyne, Aldwin & Lazarus, 1981; Holahan & Moos, 1987; Revenson & Felton, 1989; Rosenstiel & Keefe, 1983; Sullivan & D'Eon, 1990; Thompson, Gil, Abrams & Phillips, 1992), while the use of problem-focused coping strategies are associated with lower levels of distress (Keefe et al., 1987; Lazarus, 1993; Revenson & Felton, 1989; Sullivan et al., 1997).

In line with these results, Pakenham, Stewart and Rogers (1997) found that individuals employing problem-focused coping demonstrated better adjustment to a diagnosis of MS than those using emotion-focused coping strategies. However, it must be noted that not all research into MS agrees with the two broad categories of coping strategies, with some researchers suggesting that each category contains subtypes of coping strategies not necessarily correlated with one another (Arnett et al., 2002; Carver, Scheier & Weintraub, 1989). When looking specifically at emotion-focused coping strategies, and subtypes of such, both cross-sectional (Eklund & MacDonald, 1991; Mohr et al., 1997; O'Brien, 1993) and longitudinal (Aikens, Fischer, Namey & Rudick, 1997; Pakenham, 1999) studies on MS have found that passive avoidant emotion-focused coping strategies (e.g., wishful thinking, self-blame and avoidance) are related to poorer outcome, while approach oriented emotion-focused coping strategies (e.g., acceptance) are linked with better adjustment to living with MS (Brooks & Matson, 1982). Although not looked upon as favourably as problem-focused coping, emotion-focused coping is not necessarily related to poorer adjustment in MS (Mohr, Goodkin, Gatto, & Van der Wende,

1997), and may indeed include coping strategies useful to those diagnosed with a chronic condition.

People with MS may use both problem-focused and emotion focused strategies when dealing with a disease related stressful event (Jean, Paul & Beatty, 1999). It has been documented however, that PwMS are more likely to use emotion-focused coping strategies than problem-focused coping (Livneh & Antonak, 1997; Mohr & Cox, 2001). This use of emotion focused coping may be the result of PwMS having few options for altering the course of their disease (Livneh & Antonak, 1997). Pakenham (2001) suggests that the effects of different coping strategies will vary between individuals according to MS-related illness and psychosocial factors. A review of the coping literature demonstrates that it is too simplistic to label one coping strategy as necessarily better than another, and that both emotion and problem focused strategies need to be considered when looking at successful adaptation to a diagnosis of MS.

4.4.2 Coping Appraisal

Coping appraisal is defined by Lazarus and Folkman (1984) as a cognitive evaluative process reflecting an individual's subjective interpretation of a stressful event. Events are appraised in terms of their potential threat to the individual, the challenge faced by the individual in managing the threat, and the possible control the individual has over the threat (Lazarus & Folkman, 1984). Adaptation to MS is likely to be negatively influenced if, through appraisal of the diagnosis, MS is viewed as threatening, uncontrollable and/or a potential threat to self-identity (Pakenham, 1999). Pakenham (1999) suggests that such an appraisal of MS is likely to generate stress that may exceed the coping resources available to the individual. Few studies have examined the relationship between the subjective appraisal of stressors associated with a diagnosis of MS and adjustment to the condition. However, an individual's appraisal of MS as

'highly threatening' has been found to be related to higher levels of distress in two studies (Pakenham et al., 1997; Wineman, Durand & Steiner, 1994). Similarly, the appraisal of MS as 'creating high levels of illness uncertainty' has also been found to be related to higher levels of distress (Wineman, Durand & Steiner, 1994). As a diagnosis of MS can be appraised as stressful or highly threatening, and can be a contributor to high levels of distress or illness uncertainty within individuals diagnosed with MS, it is important to examine the types of resources PwMS report as being of assistance (or hindrance) to their coping with the diagnosis.

4.4.3 Coping Resources

Contemporary research on stress and coping has evolved from placing an emphasis on individuals' deficits and vulnerabilities, to placing increasing emphasis on individuals' adaptive strengths, resources, and capacity for resilience and personal growth in the face of challenge (Holahan & Moos, 1991; Holahan, Moos, Holahan & Cronkite, 1999). Considered to be relatively stable characteristics of an individual's environment, coping resources refer to what is available to individuals as a response to their appraisal of the stressor (Moos & Billings, 1982). In attempts to explain the relationship between the three coping variables (appraisal, strategies, and resources) and adjustment to chronic illness, two alternative models have been proposed (Pakenham, 1999). In the main effects model, an individual's subjective appraisal of stressors, their coping resources, and coping strategies, all have direct and independent effects on adaptation (Aldwin & Revenson, 1987; Cohen & Wills, 1985). Alternatively, in the stress buffering model, an individual's coping resources and coping strategies work together to buffer against the negative consequences of what is appraised by the individual as a low to moderate stressor (Finney, Mitchell, Cronkite, & Moos, 1984). Coping resources serve to promote the use

of adaptive coping strategies, whereas a lack of coping resources may instead foster the use of other less adaptive coping strategies (Lazarus & Folkman, 1984).

On examination of the literature regarding the coping resources available to individuals during stressful periods, the most frequently mentioned resources include an individual's use of social support (Billings & Moos, 1984; Pakenham, 1999), eagerness to take control of certain aspects of the disease (Armstrong-Stassen & Cameron, 2003; Sullivan et al., 1997), and the use of positive thinking or optimism (Sullivan et al., 1997). Such resources provide valuable assistance in coping with stress both by moderating the link between stress and potential psychopathology, and by directly or indirectly influencing the level of distress (Cozzarelli, 1993). These key coping resources, which may be involved in assisting an individual to adapt successfully to a diagnosis of MS, will be explored below. These three areas of interest have also been selected for examination as they are representative of themes that have been identified by PwMS in their own words in previous qualitative studies (Mohr et al., 1999; Russell, White & White, 2006; Sullivan et al., 1997).

4.4.3.1 Social Support

Weinert (1987) suggests that interpersonal relationships are a key factor in promoting good physical and emotional health. Supportive social relationships have also been found to be beneficial for those experiencing ill health or a decline in physical functioning (Mishel & Braden, 1987). Within the stress and coping paradigm, social support factors (e.g., informal social networks and relationships with partners and family members) are identified as resources for managing stress and maintaining health (Billings & Moos, 1984). As PwMS have numerous social support needs at diagnosis as well as throughout the course of the illness (Kraft, Freal, &

Coryell, 1986), the use of social support as a coping resource has received the most attention in the MS literature on coping resources (Pakenham, 1999).

There is support for both the main and buffering effects models of social support (Aldwin & Revenson, 1987; Cohen & Wills, 1985). Pakenham (1999) suggests that there is mounting evidence to indicate that the size of an individual's social network has a direct relationship with the psychological well-being of PwMS, whereas the quality or supportiveness of that network may have a mediating effect, by working to buffer the harmful effects of stress on well-being (Cohen & Wills, 1985). Consistent with research into other chronic illnesses, it has been shown that a greater amount of social support is related to better adjustment to MS over time (Long & Miller, 1991; Wineman, 1990). While current research may provide ample evidence of the benefits of social support as a coping resource for people living with MS for many years, the identification of social support as being of assistance when PwMS are attempting to cope with the diagnosis in the first 12 months, has not yet been reported.

4.4.3.2 Optimism/Positive Attitude

In simple terms, optimism reflects an expectation that good things will happen (Chang, 2001). Fournier, de Ridder and Bensing (1999) depicted optimism as having a multidimensional structure encompassing three components; positive outcome expectancies, positive efficacy expectancies and unrealistic positive thinking. Conceptualised by Lazarus and Folkman (1984) as a coping resource, optimism is thought to precede and influence the use of coping strategies, which in turn mediates the response to a stressful or negative event. When reviewing health related research, optimism has been shown to have a positive effect on the adaptation to acute medical stressors such as early breast cancer surgery (Carver et al., 1993) and coronary bypass surgery (Fitzgerald et al., 1993; Scheier et al., 1989). Following such surgeries, those with higher

levels of optimism showed an improved sense of well-being and a reduced number of reported physical symptoms than those with lower levels of optimism (Carver et al., 1993; Fitzgerald et al., 1993; Scheier et al., 1989).

A growing number of studies have also demonstrated that optimism plays a significant role in adaptation to chronic disease (Fournier, de Ridder & Bensing, 1999; Pakenham, 1999). For example, people with rheumatoid arthritis (Brenner, Melamed, & Panush, 1994), Parkinson's disease (Shifren, 1996) and breast cancer (Carver et al., 1993; Epping-Jordan et al., 1999) who show high levels of optimism have reported better psychosocial and physical functioning. The studies of women with breast cancer by Carver et al. (1993) and Epping-Jordan et al. (1999) highlight optimism as having both direct and indirect positive effects upon well being.

It has been suggested that being optimistic may be of special benefit to PwMS (Barnwell & Kavanagh, 1997; de Ridder, Schreurs & Bensing, 2000; Fournier et al., 2003). Barnwell and Kavanagh (1997) found that optimism acted as a positive predictor of psychological adjustment to MS, and a number of studies have found optimism to be negatively related to depression in MS (Buelow, 1991; Fournier et al., 1999; Gold-Spink et al., 2000; de Ridder et al., 1999; Shnek et al., 1995). Indeed, Gold-Spink et al. (2000) found a strong negative association between optimism and depression for PwMS, together with a negative association between levels of optimism and illness uncertainty. Fournier et al. (1999) found that while there were no associations found between optimism and physical health or impaired mobility, optimism was negatively associated with depression. Not surprisingly, Gold-Spink et al. (2000) suggest that these findings may be due to the tendency of optimists to think positively and expect favourable outcomes.

Optimism as a coping resource is believed to positively influence an individual's ability to handle the potential stress created by a diagnosis of a chronic illness (Lazarus & Folkman, 1984; Moos & Schaefer, 1982). Indeed, cognitive adaptation theory purports that individuals may not

only try to remain positive, but may search for meaning in the experience, and engage in self-enhancement, or find ways of feeling good about oneself (Taylor, 1983; Taylor, Kemeny & Reed, 2000). In attempting to adapt to the diagnosis, PwMS may endeavor to identify the benefits inherent in facing such a challenge. Whether through maintaining a positive attitude, or being able to find benefits of the experience despite the diagnosis, PwMS may be able to reduce the stress associated with such a diagnosis. Park and Folkman (1997) proposed that in stressful situations where the individual has little to no control, such as dealing with a diagnosis of MS, the negative effects of the stress caused by diagnosis may be buffered by the individual's personal outlook on the situation. Having a positive attitude, or displaying optimism following diagnosis, is a coping resource that may assist PwMS in the first 12 months to adapt to a diagnosis, but it has not yet been thoroughly explored.

4.4.3.3 Taking Control

For many, the onset of a serious illness brings with it cause to reflect upon the 'story' or meaning of one's life, seek answers to existential questions, prioritise values and goals, and take control of personal matters, in the face of a diagnosis that could not be controlled (Candib, 2004; McAdams, 1993; Miller, 1997; Russell, White & White, 2006). The concept of taking control over personal matters, together with concepts such as self mastery and self-esteem, is related to the construct of self-efficacy (Airle, Baker, Smith & Young, 2001). According to Bandura's social cognitive theory, self-efficacy refers to an individual's belief in their ability to overcome specific challenges (Bandura, 1989) such as a diagnosis of MS. While closely related, the concepts of self-efficacy and taking control differ in that self-efficacy refers specifically to an individual's *belief* in their ability to overcome specific challenges, and taking control refers to the *actions* taken by an individual to overcome the specific challenges.

MacLeod and MacLeod (1998) found that people with the degenerative disorder of MS were found to have lower levels of self-efficacy than those with a chronic but stable disorder such as spinal cord injury. This may be because the opportunities for individuals to take control over current or future events in the case of MS appear less clear cut due to the unpredictable nature of the disease (MacLeod & MacLeod, 1998). PwMS may also be conflicted by attempts to balance their need to take control over their lives, with the need to collaborate with, and take direction from, their health professionals on the ongoing and possibly changing treatment of their disease (Reid, 1984). The absence of definitive directions on treatment of MS by medical professionals may also contribute to the uncertainty and lack of control experienced by a person newly diagnosed with MS. It must be noted here that Rothbaum, Weisz and Snyder (1982) suggest that surrendering control of certain aspects of disease management (such as therapy decisions) to powerful others can be adaptive, and may assist individuals to cope in situations where few opportunities for personal control are available, such as dealing with a diagnosis of MS. Nevertheless, there are certain areas where people with chronic illnesses may attempt to take control over a number of disease related issues, contributing to their successful adaptation to the diagnosis (MacLeod & MacLeod, 1998).

In the case of MS, opportunities to take control on matters that may assist adaptation to diagnosis include: obtaining information and knowledge of the disease, disclosing the diagnosis to others, making practical changes to facilitate effective symptom management, changing diet and/or exercise regimes, and prioritising time for self (Jelinek, 2005). As a coping resource, taking control is associated with increased psychosocial well-being in PwMS independent of the type of MS, severity and extent of the disease process, physical disability, and fatigue (Airle, Baker, Smith & Young, 2001; Devins et al., 1993). The identification of an individual's

eagerness to take control of matters that may assist adaptation to diagnosis in the first 12 months, has not yet been reported.

4.5 Factors that Hinder the Adaptation to Diagnosis

Coping resources, such as social support, optimism, and taking control of disease related matters, lie within the enormous array of factors that may assist successful adaptation to a diagnosis of MS. There exists a similar enormity of factors hypothesised to hinder adaptation to a diagnosis of MS, as some PwMS do not adapt as well as others (Pakenham, 1999). It is of equal importance to identify the factors that may hinder, as well as those that may assist, in an attempt to prevent or reduce the maladaptive effect they may have on an individual's coping. As mentioned previously, factors such as physical symptoms, level of disability, cognitive impairment, and fatigue may work to either assist or hinder an individual's successful adaptation to diagnosis. However, only considering medical variables does not explain differences in post diagnosis psychological functioning, whether positive or negative (McIvor et al., 1984; Rudick et al., 1992; Walsh & Walsh, 1987; Zeldow & Pavlou, 1984). When identifying factors that may hinder successful adaptation to a diagnosis of MS, psychological and social variables must also be explored (Pakenham, 1999; VanderPlate, 1984). Such variables, including coping strategies, may hinder adaptation to diagnosis and have been mentioned above in the discussion on factors that may influence adaptation. For the purposes of the current study, two factors that may hinder the successful adaptation to a diagnosis of MS will be explored below. First, denial or avoidance of disease is examined, as denial can be considered a maladaptive coping strategy (Mikail & Weinshenker, 1997; O'Carroll et al., 2001). A second factor that may hinder the successful adaptation to diagnosis is then explored. This is an individual's perceived lack of understanding from others following diagnosis, or others' unhelpful attitudes. As in the case of coping

resources that can assist adaptation, an individual's perception of others' lack of understanding of their diagnosis can also potentially be modified or reduced by health professionals following a diagnosis of MS. Therefore an increased understanding of denial and avoidance, and the perceptions of the lack of understanding of others, as being hindrances to successful adaptation over the first 12 months following diagnosis, may assist health professionals in their work with those newly diagnosed.

4.5.1 Denial and Avoidance

Historically, an individual's denial of an illness, or their avoidance of disease-related information or changes, has been viewed by the literature as a maladaptive construct that holds up healthy adjustment to a diagnosis of a chronic illness (Greer, 1974; Kortte & Wegener, 2004; Mikail & Weinschenker, 1997; O'Carroll et al., 2001). However, within the coping literature denial has, at times, been viewed as somewhat of an adaptive and useful strategy to cope with a diagnosis of a chronic illness (Shontz, 1975). Shontz (1975) considered that denial of disease can prevent the individual from becoming overwhelmed with the stress of illness onset and the threat of disability in the days following the diagnosis. In this way, denial may be seen to function as a regulating mechanism allowing for the gradual management of a perceived threat (Horowitz, 1976; Roth & Cohen, 1986; Shontz, 1975; Sullivan et al., 1997).

In the early stages following a diagnosis of MS, denial could provide the individual with the necessary time to assimilate threatening information about illness and disability, consider alternatives for coping, and adapt to the situation at hand (Kortte & Wegener, 2004; Sullivan et al., 1997). Indeed, Sullivan et al. (1997) found that both avoidance and denial strategies were associated with reduced likelihood of depression immediately following a diagnosis of MS. A form of denial known in the literature as 'reinterpreting the medical condition' (Kortte &

Wegner, 2004) is where individuals reinterpret or reframe the meaning of an illness related event in an attempt to reduce the personal threat to their health. An example of this is 'I will walk again so I need to work really hard in rehab to make that happen'. It is this reinterpretation form of denial that is often associated with optimism and more positive outcomes, providing support to the notion that denial of illness can, in some instances, be of assistance to adaptation to illness (Kortte & Wegener, 2004; Lazarus & Folkman, 1984; Levine et al., 1987; Prigatano & Klonoff, 1998; Suls & Fletcher, 1985). However, attributing denial strategies with positive and healthy long term outcomes, contrasts with the more widely held belief that avoidance and denial are maladaptive methods of dealing with stress (e.g., Kortte & Wegener, 2004; Lazarus & Folkman, 1984; 1986). Although consideration must be given to the type of denial being presented, avoidance and denial strategies are not helpful to an individual's coping if such strategies impede activities that promote general wellbeing.

A discussion of denial within the context of illness must encapsulate behaviours that range from complete denial that a medical condition exists, to selective denial of, or resistance to, the implications of the condition for daily functioning (Kortte & Wegener, 2004; Prigatano, 1988). Recognised as a multidimensional construct, Kortte and Wegener (2004) identified two subgroups of denial: complete and partial. Complete denial of an illness is shown by an individual asserting a belief that no serious medical problem exists, or that complete recovery is imminent (Kortte & Wegener, 2004). An example is 'I do not have multiple sclerosis... the doctors are wrong'. In the case of the second subgroup, partial denial of an illness is exhibited by an individual indicating a deliberate reluctance to acknowledge the impact that an illness may have on daily life, even though there is expressed knowledge and acceptance of the presence of the medical condition (Kortte & Wegener, 2004; Prigatano & Klonoff, 1998). 'I know I have MS, but it won't affect my lifestyle' is an example of partial denial as exhibited by an individual

with MS. Kortte and Wegener (2004) consider that the term avoidance is used to describe “verbalizations, behaviors, and coping strategies aimed at downplaying, negating, or showing resistance to recognizing the impact of the medical condition” (p.195). An example of avoidance is ‘I do not need to seek out information/tell people about MS because it is not going to affect me’. Both complete and partial denial of illness, as well as avoidance as outlined above, are generally viewed throughout the literature as negative or maladaptive constructs that keep healthy adjustment from occurring across the illness process (e.g., Greer, 1974; Kortte & Wegener, 2004; Mikail & Weinshenker, 1997; O’Carroll et al., 2001).

Sullivan et al. (1997) suggested that denial can move from being an assistance, to a hindrance to adaptation if it compromises illness prevention or health promoting behaviours (e.g., positive lifestyle changes such as compliance with medication or dietary changes), interferes with adaptive behaviour (e.g., refusing equipment or home modifications to manage change in mobility), or contributes to an increase in the frequency or intensity of intrusive thoughts (Mullen & Suls, 1982; Roth & Cohen, 1986; Suls & Fletcher, 1985). Although denial may serve a psychologically protective function for the first few days or weeks immediately after diagnosis, it may also impede adaptation and participation in rehabilitation activities in the longer term (Kortte & Wegener, 2004; Mikail & Weinshenker, 1997). An individual’s acknowledgement of the presence of denial in the first 12 months following diagnosis has not yet been explored within the MS literature.

4.5.2 Unhelpful Attitudes of Others/Perceived Lack of Understanding of Others

While family members, friends, colleagues and health professionals are able to assist an individual with MS to cope by providing support following diagnosis, they also have the capability of acting as a hindrance to the coping efforts of the PwMS (Baker, 1998). The

unhelpful attitudes of others include dismissive, judgmental or negative attitudes that become apparent through comments or actions directed at or about the PwMS. An individual's perceived lack of understanding from others is a different yet related construct to the actual unhelpful attitudes of others. An individual with MS may perceive that a family member, friend, or colleague lacks an empathetic understanding of MS, symptoms or other disease related factors. This perception, whether accurate or misguided, can be detrimental to the PwMS who is looking for a supportive social environment when attempting to adapt to the diagnosis of MS. While the unhelpful attitudes of others may not be easily changed by the PwMS, an individual's perception of, or response to, others' attitudes may be altered. With the assistance of psychologists or other health professionals, individuals with MS may be able to engage in therapies such as cognitive behavioural therapy, to reframe the perception they hold of others' attitudes, or their own responses to these perceived attitudes. Examples of others' unhelpful attitudes (which may be real or perceived), and their impact on PwMS shortly after diagnosis, are explored below under the subheadings of family/friends/colleagues, and health professionals.

4.5.2.1 Family/Friends/Colleagues

A friend or family member's denial of, or failure to acknowledge, the presence of MS can become an external barrier to the PwMS seeking information, disclosing diagnosis or, in some cases, accepting treatment (Baker, 1998). In a qualitative study on managing the stigma associated with having MS in social networks, Grytten and Maseide (2005) found that PwMS experience a sense of feeling more ill than they would usually if they perceive that those in their social networks are ignoring them because of their diagnosis, or are overemphasising the presence of MS. PwMS may perceive that they are being judged in interpersonal encounters, and

may find it more difficult to cope or adapt to their diagnosis if they are also attempting to counteract stigmatising experiences in social relationships (Grytten & Maseide, 2006).

When looking at interpersonal relationships in the workplace, people with chronic illness are often concerned about disclosing their illness to their employer or colleagues because they are worried about co-workers responding negatively to them. In addition, anxiety about being subjected to potential acts of discrimination based on information disclosed about an illness may also be cause for concern. Harden, Kossoy, Vera and Nikolov (2004) looked at reactions to epilepsy, MS, and depression, in an attempt to determine the characteristics of epilepsy that produce avoidant behaviour in the workplace. While participants did not report high levels of worry about the possible unpredictable behaviour of PwMS or depression (a concern that was reported for people with epilepsy), MS was perceived as having a greater effect on job performance than depression or epilepsy (Harden et al., 2004). Harden et al. (2004) propose that the visibility of an illness, or perceived physical disability, may lead coworkers to believe that a chronic condition such as MS will have a negative impact on job performance. Further, Harden et al. found only 40-50% of participants felt comfortable talking about the illness with their co-worker, working on a project together, sharing an office, or eating lunch together, regardless of whether their coworker had MS, epilepsy or depression (Harden et al., 2004). This clearly indicates that PwMS (as well as those with epilepsy and depression) face the potential for encountering unhelpful attitudes in the workplace. This fear of stigma, or an individual's perceived lack of understanding from others, may produce ongoing concern about how open and honest they can be with coworkers, and how confident they can be in their appropriate career progression. The unhelpful attitudes of family, friends and colleagues, and the barriers to disclosure, honesty and support that may result, may hinder an individual's successful adaptation to diagnosis.

4.5.2.2 Health Professionals

In reviewing the available literature, it is not surprising that health professionals' use of empathy and a caring, positive attitude has been found to be of assistance to PwMS (Hainsworth, 1993). Similarly, when health professionals convey a pessimistic attitude about the disease prognosis in their communication with a person with a chronic condition, a sense of hopelessness about the situation may be developed by the individual being treated (Carter, McKenna, MacLeod & Green, 1998).

Carter et al. (1998) investigated the differences between health professionals' responses to PwMS and people with motor neuron disease (MND). Health professionals involved in the study had lower confidence levels in their ability to care for those with MND and higher confidence levels in their ability to care for those with MS. This discrepancy in confidence level was partly due to the health professionals' feeling that they had more to offer PwMS while reporting a reduced ability to convey hope to people with MND, contributing to their increased levels of negativity toward this population of patients. However, while Carter et al. (1998) found that health professionals generally demonstrated more positive attitudes towards those with MS than to those with MND, conveying hope to PwMS was also reported as difficult. There were a number of reasons given for why health professionals found it difficult to convey hope to PwMS. These reasons included the unpredictability inherent in the course of MS and the incurable nature of the disease. Health professionals also identified that PwMS experiencing progressive disability, changes in cognition, and problems adjusting to their diagnosis, were more difficult to cope with than PwMS not experiencing such things (Carter et al., 1998).

Working with PwMS may present a number of challenges for health professionals. These challenges may negatively affect health professionals' attitudes toward PwMS which may, in

turn, have a negative effect on an individual's satisfaction with their health professional. Counte, Bieliauskas, and Pavlou (1983) reported that psychosocial adjustment to MS is largely influenced by an individual's satisfaction with their physician. If health professionals engage in poor communication skills or display a negative or unhelpful attitude when working with a PwMS, the health professional-patient relationship may be adversely affected (Counte et al., 1983). Just as a health professional's empathetic and caring attitude can assist in an individual's adaptation to MS, the negative attitudes of health professionals working with PwMS can act as a hindrance to adaptation (Carter et al., 1998).

There are a number of factors that may serve to hinder, or assist, an individual's adaptation to a diagnosis of MS in the 12 months following diagnosis. Coping resources, such as social support, optimism, and taking control are among the factors that may assist adaptation, while an individual's denial of an illness and the unhelpful attitudes of others (perceived or real) may hinder adaptation. All psychosocial factors discussed in this chapter, whether potential hindrances or assistants to adaptation, have the ability to be modified, enhanced, or reduced, with the assistance of health professionals such as psychologists.

4.6 The Difficulty in Assessing Adaptation Following a Diagnosis

The bulk of previous research on adaptation to a chronic illness has required participants to complete a battery of self-report standardised instruments with a focus on psychosocial variables such as coping strategies (Antonak & Livneh, 1995; Bensing, Schreurs & De Ridder, 2002; Hulsman, McNulty, Livneh & Wilson, 2004; Wineman, 1990). However, reliance on checklist measures to assess coping, or other variables, has been the target of pointed criticism (Stone, Greenberg, Kennedy-Moor, & Newman, 1991; Sullivan & D'Eon, 1990; Sullivan et al., 1997; Tunks & Bellissimo, 1988). For example, Stone et al. (1991) argued that many of the

items included in standardised measures of coping are not applicable to many of the stresses that individuals experience. It has also been argued that checklist coping scales frequently contain items that are confounded with symptoms of depression thus rendering observed relations between coping and depression difficult to interpret (Stanton, Danoff-Burg, Cameron, & Ellis, 1994; Sullivan & D'Eon, 1990). While recognising that the use of psychological measures and standardised instruments is very important, and definitely has a place in research on adaptation in MS, the currently available instruments have a clear focus on coping strategies and little examination of coping resources. Such instruments also lack inquiry into participants' own subjective experiences and the resources they identify as being of assistance when attempting to cope with a diagnosis of MS. An examination of what participants themselves identify as coping resources, or what was of assistance, or a hindrance, to their coping following diagnosis would provide an important addition to the MS literature.

CHAPTER FIVE

KEY DEMOGRAPHIC VARIABLES

AND JUSTIFICATION FOR CURRENT STUDY

5.1 Overview of the Chapter

A number of psychosocial factors that may play a role in adaptation to MS in the first 12 months following diagnosis were discussed in the previous chapter. These included three factors identified as being of assistance to adaptation, and two factors that may be considered hindrances to adaptation. All five factors were linked by their potential to be modified with the assistance of health professionals such as psychologists.

In this chapter, three factors that are unable to be modified by health professionals are examined. These are the key demographic factors of gender, country of birth and type of MS. While these cannot be changed, such factors may influence adaptation or engagement in post-diagnosis behaviour and lifestyle changing activities following a diagnosis of MS. Thus, an understanding of these factors may assist health professionals in the appropriate targeting of services and support. This chapter also outlines the justification for the current study, and includes a rationale for combining qualitative and quantitative methodologies, and for using an online questionnaire. Finally the importance of the current study for health psychologists and health professionals is explained, before the research aims are presented.

5.2 Key Demographic Factors that May Affect Adaptation to Diagnosis

There have been many demographic factors described and compared in previous research on medical, psychological or social variables relevant to the field of MS. For example, an

individual's age, gender, birthplace, marital status, employment status, type of MS, and level of disease severity (measured by the Expanded Disability Status Scale, or EDSS) (Kurtzke, 1983), have all been investigated across studies ranging from neurological research to epidemiological exploration (e.g., Burks et al., 2002; Dyment, Sadnovich & Ebers, 1997). While demographic variables cannot be modified by psychologists or other health professionals, an understanding of whether such factors impact on an individual's adaptation to a diagnosis to MS, and the role they may play in post-diagnosis behaviour and lifestyle changing activities is warranted. This exploration is justified as an understanding of the demographic variables associated with MS can assist in the accurate targeting and provision of services to people with MS. When exploring post-diagnosis behaviour and lifestyle changing activities, three key demographic factors are apparent. These are gender, country of birth, and type of MS. The rationale behind choosing each for examination in the current study is described below.

5.2.1 Gender

There is a clear gender discrepancy in the prevalence of MS, with two to three times more women diagnosed with MS than men (Eeltink & Duffy, 2004). This gender divide not only has implications for epidemiological research and studies into the cause and treatment of MS, but it may also have implications for research examining post-diagnosis behaviour, and the provision of information and services targeted toward the MS population. While there are conflicting reports in the literature with regard to gender differences in adjustment to chronic illness, there are a number of well known gender differences that may be considered relevant to a study of behaviour following a diagnosis of MS.

One such gender difference may be that women and men experience different emotional responses when presented with similar situations, with women reporting more intense emotional

experiences than men (Vrana & Rollock, 2002). Hopman et al. (2000) argued that while women experience the greatest emotional impact at the time of their diagnosis of MS, men experience a greater level of emotional deterioration than women over time, in line with disease progression. This difference may contribute to variations in behaviour exhibited by men and women in the first 12 months following diagnosis, and indeed, over the course of their MS.

A second gender difference may be found between men's and women's identified level of social support. Social support is known to affect health and health outcomes in the general population as well as in those with MS (Billings & Moos, 1984; Mishel & Braden, 1987), and women may be more likely to have stronger and wider social support networks than men (Dalgard et al., 2006), at the time of diagnosis. Differences may also exist in men's and women's likelihood to seek social support, or additional social support, following diagnosis (Norberg, Lindblad & Boman, 2006).

The distinct life issues that may be experienced by men and women at the time of diagnosis may constitute a third gender difference relevant to a study on behaviour following a diagnosis of MS. As MS is usually diagnosed between the ages of 20 and 40 years of age (Calabresi, 2004), different life issues may exist for men and women at the time of diagnosis. In 2003, 30-34 year old women in Australia had the highest fertility rate, followed by the 25-29 year old age group (Australian Bureau of Statistics, 2005). Fertility rates are likely to influence employment status among these age groups, as women of these age groups may be more likely to be working in the home as full time parents at the time of diagnosis, while more men may be in full time paid employment. This possible discrepancy in employment situation and other life issues between the genders may impact the post-diagnosis behaviour of men and women differently.

Looking very specifically at MS, there are also gender differences observed between the different subgroups of the disease. While there are more females than males in the general MS population with a ratio of approximately 3:1 (Orton et al., 2006), there are more males diagnosed with primary progressive MS than females, with a ratio of 1.3:1 (Dujmovic et al., 2004). The gender difference apparent in the subgroups of MS calls for a close examination of the potential confounding effect these factors may have on post-diagnosis behaviour.

5.2.2 Country of Birth

Country of birth is another demographic variable that may play a role in an individual's engagement in post-diagnosis behaviour and lifestyle changing activities following a diagnosis of MS. It is clear that there are a number of factors associated with an individual's country of birth that may affect their likelihood of being diagnosed with MS, as the prevalence of MS is greater in some countries than others. A large Caucasian population will affect a country's prevalence of MS as MS affects more Caucasians, or people of European origin, than any other racial group (Williamson, 2006). A country's geographical zone, as described by Kurtzke (2000), will also affect the prevalence of MS with countries such as Canada, northern USA, south eastern Australia, New Zealand, and most countries in Europe considered to be within a high frequency geographical zone for MS. While migration from one country to another before the age of 15 years may change the risk of developing MS (Gale & Martyn, 1995; Kurtzke, 2005), data on international migration only exist for a small number of countries (United Nations Department of Economic and Social Affairs/Population Division, 2004) and it can be assumed that the majority of people do not immigrate from their country of birth. Therefore looking at country of birth as a demographic variable of interest is appropriate given the impact geographic zones and ethnicity have on MS population numbers.

Combined with the differences between countries in the likelihood of being diagnosed with MS, there may also be differences between countries in the post-diagnosis behaviour of those diagnosed with MS. There are two main reasons why country of birth may affect an individual's post diagnosis behaviour. First, the health services available to people with MS across the world differ enormously in cost and accessibility (Burks et al., 2002). The availability of diagnostic equipment, medication and psychosocial services for people with MS may differ dramatically depending on the birth country of the person with MS. Second, cultural differences may affect any number of post-diagnosis behaviours including an individual's level of comfort in disclosing the diagnosis to family, friends and employers, their choice to take medication, and their ability to seek up to date information about MS. While a number of demographic variables related to geography could be of interest in a study of behaviour following diagnosis, such as country of residence at time of diagnosis or country of residence at time of study participation, the variable of country of birth is the variable that encompasses the likelihood of developing MS as well as the differences in culture and service provision.

5.2.3 Type of MS

As discussed in chapter 2, the exact number of subgroups contained within the definition of MS remains somewhat contentious. The five subgroups or types of MS that will be discussed in this thesis are Benign, Relapsing Remitting, Primary Progressive, Secondary Progressive, and Progressive Relapsing. There can be marked differences between these types of MS on a number of levels. First, each type of MS can exhibit different rates of disease progression. For example, people with Benign MS have a low relapse rate with good recovery from disability between relapses (Burks et al., 2002). On the other hand, people with Primary Progressive MS experience a progressive loss of functioning from the disease outset (Burks et al., 2002). Such apparent

differences between types of MS may lead to differences in the psychological impact a diagnosis of a particular type of MS can have on the individual, and therefore the behaviours exhibited by people with different subgroups of MS, in the first 12 months following diagnosis.

Just as disease progression can vary between types of MS, the experience of symptoms and visibility of illness may also vary across the subgroups. The types of treatment offered will differ depending on the type of MS diagnosed, as well as the individual's ability to access medication. The differences between the types of MS, which may determine disease progression, visibility of illness and accessibility to medication, may contribute to differences in post-diagnosis behaviour. As mentioned above, gender and type of MS are confounding factors, with apparent gender differences identified between the types of MS with males more likely to be diagnosed with Primary Progressive MS than females. The gender differences between the types of MS may also contribute to differences in post-diagnosis behaviour.

Demographic variables such as gender, country of birth, and type of MS cannot be altered or modified by an individual with MS working with a psychologist or other health professional. Nevertheless, such variables and their relationship with behaviours and lifestyle changing activities following a diagnosis of MS require understanding so that the targeting and provision of services to people with MS can be carried out as effectively as possible.

5.3 Justification for Current Study

In earlier chapters, MS and common behaviours that can be exhibited leading up to and following a diagnosis of MS, were described. It was evident from extensive literature searches that very little previous research had been directed toward a) examining the experiences of people prior to, or at the time of, a diagnosis of MS; and b) exploring the behaviour of people with MS in the first 12 months following diagnosis. This is despite post diagnosis behaviour, particularly

in the form of information seeking, informational needs, and the need for social support years after the diagnosis, having been examined in several studies (Baker, 1996; Gulick, 1994; Hepworth & Harrison, 2004; Janssens et al, 2003; Matson & Brooks, 1977; Stewart & Sullivan, 1982; Wollin et al., 2000). A broadening of post-diagnosis behaviour research is now required to look at other areas that may also be critical to adaptation in the first 12 months following diagnosis.

In the current research, the 12 months following diagnosis was specifically examined, as this time period is an important stage for the person diagnosed with MS (Janssens et al., 2003). Straight after diagnosis a person with MS usually begins to build their knowledge of the disease through available information and their own experiences of MS, shape their thoughts about how the disease may impact on their lives (e.g., physically, interpersonally, and financially), and build relationships with health professionals and community members (Koopman, Benbow & Vandervoort, 2006). People newly diagnosed with MS may begin to develop important patterns of behaviour and strategies for adaptation to diagnosis and management of MS symptoms. While these experiences will necessarily extend past the initial 12 months following diagnosis, and a person with MS may build on their knowledge of the disease, continue to form relationships with health professionals and incorporate MS into their lives, the first 12 months is of particular interest given that this time period may demonstrate how the individual will continue to approach living with and managing MS in later years. Just as positive and adaptive strategies may be established in this time period, maladaptive approaches to dealing with the disease may also be formed. It is likely that the first year following diagnosis will include meetings with generalist and MS specific health professionals where positive and productive working relationships can be developed. Thus, the first 12 months following diagnosis is both a crucial time for those with MS, and a period that has been neglected by previous research (Janssens et al., 2003).

A better understanding of people's experiences, behaviours, thoughts and feelings during this first 12 months following diagnosis is vital for health professionals working with those newly diagnosed. The importance of this study for health psychologists and other health professionals is discussed later in this chapter.

5.3.1 Rationale for Combining Qualitative and Quantitative Methodology

Some researchers (e.g., Patton, 1980; Reinharz, 1992) suggest that a multiple methodological approach, combining both qualitative and quantitative data, is suited to research undertaken in poorly understood areas as it contributes layers of information to a wider understanding of the topic. Asking people with MS to share their thoughts about the post-diagnosis behaviour and lifestyle changing activities they engaged in during the first 12 months following diagnosis is a new area of study. Therefore, both quantitative and qualitative data was sought in the current research because of the desire to more fully understand people's experiences prior to, and their behaviour following, a diagnosis of MS. Qualitative data were collected in the form of written answers to open-ended questions.

Psychologists, amongst other scientists and researchers, may hold the view that the only valid research is quantitative and empirical (Banister et al., 1994). This emphasis on the superiority of quantitative research may reflect a desire to prevent researcher interpretation and bias (Banister et al., 1994), while maintaining distance and objectivity. Indeed, qualitative analysis may be seen as subjective and therefore unreliable (Dey, 1993). Patton (1990) refutes this with the counterclaim that distance does not guarantee objectivity, and Dey (1993) suggests that the use of numeric data analysis is not sufficient to prevent bias.

Dey (1993) also suggests that qualitative approaches are less favoured by many researchers as they necessitate the time-consuming process of immersion in, and familiarity with,

the data. However, researchers are increasingly faced with the dilemma that the often reductionist techniques of quantitative analysis fail to provide sufficient context for research results to be meaningful in a 'real world' context (Banister et al., 1994). On the other hand, qualitative data enables a more thorough investigation into the construct under review. This is especially important if, as in the current research, the underlying dimensions of the construct have not been fully explored or reported in the literature. Consequently, qualitative research may go some way toward providing structure and explanation, rather than pure description.

A combination of qualitative and quantitative methodologies is useful when researching an area for which there is little previous research, or for which there is no theoretical framework (Cohen & Manion, 1994; Reinharz, 1992), such as the exploration of behaviour following a diagnosis of MS. The amalgamation of both data collection techniques enables a more thorough and richer exploration of not only what people diagnosed with MS did following diagnosis, but also their thoughts on reasons behind their behaviour, or choice of activities. This helps to explore the factors that were important to participants during the first 12 months following diagnosis. There now appears to be a trend toward informing patients, and empowering people diagnosed with a chronic illness to take an active role in the management of their illness, but this means that there is an accompanying need to carefully explore the behaviours following a diagnosis of MS, and the reasons behind them.

5.3.2 Rationale for Using an On-line Questionnaire

The number of computers connected to the internet world wide has steadily increased since its inception some 30 years ago, as government, corporate and personal use has intensified (Illingworth, 2001). While young people comprise the largest group of users, people with disabilities and the elderly are currently the two fastest growing populations of internet users

(Atreja et al., 2005). The internet is now an excellent tool for inexpensive and efficient communication with individuals who are geographically distant or are unable to travel easily. Communication via the internet crosses time and space barriers, allowing people to choose a place and time suitable to them, to respond to an electronic query, or to a research request. It also provides a safe and convenient environment to a range of people living around the world, including those with disabilities, to participate in research.

The cost of an email or web based survey is estimated at between 5% and 20% of a paper survey (Sheehan, 2001). This is because the cost of an internet based survey decreases significantly as the sample size increases. Web-based surveys are “easy for respondents to complete, typically by selecting responses from predefined lists or entering text in boxes and then simply clicking a ‘submit’ button when finished” (Mann & Stewart, 2000, p.70). Combined with the benefits of being safe, convenient, and easy for participants, conducting research via the internet allows easy handling of data for the researcher as it does not require the transcription of participant responses as the text is already provided.

The NUA internet survey in September 2002 found that a total of 605.6 million people worldwide were online. However, access to the internet is unevenly distributed across the world’s population: Africa – 6.31 million, Asia/Pacific – 187.24 million, Europe – 190.91 million, Middle East – 5.12 million, Canada and US – 182.67 million, and Latin America – 33.35 million. Combined with the uneven spread of internet users across the world, there are other challenges facing those wanting to conduct research online. These include computer literacy and recruitment of research participants. Not everyone feels comfortable with this ‘new’ form of communication, and therefore such a sample may be unrepresentative. There are a number of factors influencing an individual’s use of the internet. In Australia for example, gender, age, and having access to the internet, are amongst the issues faced, with more men than women and more

young people than old people using the internet (Australian Bureau of Statistics, 2000). It must be noted however, that with rapid change in the reliance on technology over recent years, online user information from the early part of this decade should be considered only a guide to identifying the internet users of today.

There are recognisable limitations to conducting research online. It has been argued that “whilst the internet and www does offer new and exciting prospects for sociological research, in many aspects the methodological issues which it raises are by and large not new. The key issue that any survey research conducted via the internet will have to contend with, as with non-internet based surveys, is that of sampling bias” (Coomber, 1997, p.1). Conducting research online often presents researchers with similar challenges to those of more traditional research methods. Including a qualitative component into research adds another dimension to a quantitative study conducted offline or online, and as Mann and Stewart (2000) noted, “...there has been little systematic analysis of how the internet might be incorporated into qualitative research practices” (p.4). The literature on the internet as a data gathering tool is limited, particularly regarding qualitative research; however the use of the internet as a medium for questionnaire based research offers exciting new possibilities in terms of accessing a geographically diverse, and sizable, population. The use of a self-report online questionnaire in the present study was chosen after careful consideration of the issues associated with online research, both positive and negative.

In order to avoid some of the weaknesses and limitations of earlier studies into the behaviour following a diagnosis of MS, the design of the present study involved the utilisation of a web based questionnaire; a relatively new method of participant recruitment. Generally, previous psychosocial research into MS has drawn participants from (a) the registration lists of

MS Societies only; or (b) a single geographic location. A web based questionnaire was employed to address these two methodological limitations of previous research.

First, as registration with the MS Society is among the behaviours examined in this research, it would have been inappropriate to gather participants through the use of MS Society databases. Miles (1979) compared disease and social factors in PwMS who did and did not join a local MS Society, and found that those who registered with an MS Society led more restricted lives, participating in fewer community activities than those who did not join. While Miles' findings may or may not remain applicable two and a half decades later, a restricted sample comprising only those who had registered with an MS Society was not desired. Other differences between those who register with an MS Society in the first 12 months following diagnosis and those who do not could include information seeking behaviour and willingness to disclose the diagnosis to others. Accessing people with MS via a web based questionnaire prevented the sample being comprised solely of those who had already registered with an MS Society, a commonality of previous research. While the questionnaire was linked to the MS Australia website (the overarching body of MS Societies in Australia), an individual does not have to be registered with an MS Society to access the site, and indeed PwMS, researchers, clinicians, and members of the general public both in Australia, and across the world, may access the MS Australia website when looking for online information about the disease.

To address the second limitation of previous research (recruiting participants from a single geographic location) a sample of participants was sought from multiple and diverse geographic locations. To do this, it was thought that a web based survey would enable the participation of a sufficiently large sample of PwMS from across Australia and internationally. To the author's knowledge, there has been no research to date that has examined pre-diagnosis experience, or behaviour following diagnosis, of people with MS across a number of countries.

Those diagnosed with MS may face similar uncertainties and questions about their future; however, being born in one country rather than another, may affect an individual's experience leading up to, and actions following, a diagnosis of MS.

To determine an approximate number of participants likely to volunteer for this study, and to gain an idea of the countries participants may access the questionnaire from, statistics outlining how many visits the MS Australia website had each day in the three months leading up to the research being linked to the website, and the countries those visits came from, were examined. It was found that an average of 38,678 visits to the website was made by different individuals each month (approximately 1290 visits per day) (personal communication with Hyma Vulpala, Webmaster, MS Australia, 2003). Of these visits, approximately 52% were made from Australia. Eighteen percent of visits were made from the United States of America, 14% were made from New Zealand, 10% were made from Japan, 3% were made from the United Kingdom, 1% was made from Canada, and the remaining 1% was made from a combination of other countries, the largest contributors being Germany, Sweden, France and China. Participants from more than one geographical location were sought for this research in order to conduct cross country comparisons of experience leading up to, and behaviour following, a diagnosis of MS. Based on the information provided by the Webmaster at the MS Society, it was expected that by linking the questionnaire to the MS Australia website, a sample would be drawn from across at least five countries; Australia, the USA, New Zealand, Japan and the UK. Providing the study attracted sufficient numbers of participants, this would allow cross country comparisons to be made.

5.3.2.1 Online Participant Recruitment

Criteria for participation in the study were that participants were adults (aged above 18 years) diagnosed with MS. Participants' self-reports of their age and diagnosis of MS were

reviewed against these criteria before inclusion in the study. Other than the formal link advertised on the MS Australia website, (detailed in section 4.6 of this chapter) there was no advertising carried out to attract participants. It is acknowledged that a sample bias may be present in this research as participants self selected to be involved by accessing the questionnaire on-line. Participants would have had to have internet access, and be searching for information about MS, in order to see the invitation to be involved in the study. These factors should be taken in account when considering the results of this study.

5.3.3 The Importance of the Current Study for Health Psychologists/Health Professionals

The American Psychological Association (APA, 1997) described health psychology as a specialist field advancing the prevention, treatment and rehabilitation of illness and disability within the community, as well as working to improve the health care system on a broad scale. When looking specifically at MS, the discipline has much to offer regarding the reduction of disability, management of disease and symptoms, rehabilitation following an exacerbation of MS, and treatment of the complex psychological issues that may result from the diagnosis of an incurable chronic condition. Further, research performed within a health psychology framework has the potential to assist PwMS to remain healthy, manage the disease, and live well with MS. “This specialty [health psychology] is dedicated to the development of knowledge regarding the interface between behaviour and health” (APA, 1997, p.4). The current study contributes to an increased understanding of MS within this framework of health psychology, with PwMS invited to give their own perceptions of their behaviour following diagnosis.

Within the field of health psychology, health psychologists work from a biopsychosocial perspective, often evaluating and assessing the biological, psychological and socio-environmental factors relevant to the health issues presented by an individual client (Taylor, 1995). When

working in a clinical role, health psychologists will work with clients to identify the health concerns involved, before implementing empirically supported treatment practices, health promotion strategies, and/or prevention interventions (APA, 2007). The clients' perspective on the issues presented, the factors at play, and the treatment options, are valued highly by health psychologists who may take the view that they work *in conjunction with* the client to achieve the desired outcome. Therefore, the notion that health psychologists can gain much from the client perspective in order to work most productively in their clinical work shaped the current research by placing an emphasis on the perspectives of PwMS.

It is of particular importance to examine the perspectives of PwMS regarding coping following diagnosis. The current study is placed within the theoretical framework of coping, with a focus on the coping resources that may be identified by PwMS as being available to them within the 12 months following diagnosis. Health psychologists, and other health professionals working with those newly diagnosed with MS, may be able to assist PwMS to identify the coping resources available to them. Indeed, further to the identification of resources, health psychologists are then able to assist PwMS to modify, enhance or optimise such resources when attempting to adapt to the diagnosis of MS.

While demographic variables such as gender, country of birth, and type of MS can not be altered by a psychologist or health professional working with a person with MS, there are a number of factors that may contribute to successful adaptation to diagnosis (described in Section 4.3). These factors can be identified by health professionals and explored in conjunction with the person with MS. The coping resources available to a person with MS are often able to be identified by the PwMS themselves, before being discussed with a health professional to ensure that appropriate utilisation of such resources occur. Similarly, factors that may hinder adaptation to diagnosis can be examined by the person with MS and the health professional working

together, to limit the maladaptive effects of such factors. Once recognised and acknowledged, the person with MS will have a better chance of enhancing the resources that will assist them, while limiting or reducing the effects of the factors that may hinder their coping.

Shortly after the diagnosis, health psychologists can play an important role in ensuring the PwMS and their partner/family are provided with appropriate psychological support (Janssens et al., 2003). The reality of an uncertain future, possible decreased mobility and future difficulties with daily living tasks, can lead people with MS to become psychologically vulnerable at the time of diagnosis (Prilleltensky & Prilleltensky, 2003). Psychologists can assist people newly diagnosed to identify resources, develop new and ongoing coping skills, to rebuild self-confidence and to take an active role in effectively managing the disease (Strittmatter, 2004). The emotional challenges inherent in adapting to a diagnosis of MS, together with practical issues such as disclosure to others and employment concerns, can be discussed and effectively managed with the assistance of health professionals such as psychologists (Strittmatter, 2004). The current research is of utmost importance as it provides a step toward recognising and exploring some of the coping resources and factors that may assist or hinder adaptation as identified by people with MS. Potentially, such factors can then be modified or enhanced by psychologists following a diagnosis of MS, to ensure an individual is in the best psychologically supported position to constructively adapt to the diagnosis of MS.

5.4 Research Aims

Few explicit hypotheses were formulated for the current study given the exploratory nature of the research. Thus, general aims were developed with a focus on extending the body of knowledge in the area of study. The overall aims were two-fold. First, given the paucity of background information regarding the pre-diagnosis experience of MS, a broad aim was to add to

the body of knowledge about the MS related experiences prior to, or at the time of, an individual being diagnosed with MS. This included an exploration of the possible relationships between the three key demographic variables of gender, country of birth and type of MS, and MS related experiences pre-diagnosis.

The second aim was to identify and further clarify the post-diagnosis behaviours and lifestyle changing activities exhibited by individuals in the first 12 months following a diagnosis of MS, as recalled by participants. This also included an exploration of the possible relationships between the three key demographic variables of gender, country of birth and type of MS, and post-diagnosis behaviours and lifestyle changing activities. In addition, specific post diagnosis behaviours such as discussing the diagnosis with another PwMS, disclosure of diagnosis to others, and lifestyle changing activities, were described through participants' responses to a number of open ended questions.

CHAPTER SIX

METHOD

6.1 Participants

Four hundred and seventeen people accessed the on-line questionnaire. Of these, one hundred and twenty-two incomplete questionnaires were excluded from analysis as insufficient data (generally only demographic information, partial or complete) was provided. In total, 295 usable questionnaires were completed. The participants included 243 females and 52 males. It was to be expected that there would be more female participants than male, as epidemiological evidence (Eeltink & Duffy, 2004; Mohr & Cox, 2001) has demonstrated that there is a greater incidence of MS in females than in males by a rate of approximately two to one. More recently, Orton et al. (2006) have demonstrated that the female to male sex ratio by year of birth in Canada has been increasing for at least 50 years and now exceeds 3.2:1. In the present study, the ratio of female to male participants was approximately four to one, slightly higher than the Orton et al. study outlining the prevalence of MS by gender.

The age range of participants was between 20 and 67 years, with a mean age of 40.81 years ($SD = 10.45$ years, $median = 41.00$ years). Female participants' age ranged between 20 and 67 years, with a mean age of 41.00 years ($SD = 10.90$ years, $median = 41.00$ years). Male participants' ages ranged between 25 and 64 years, with a mean age of 41.62 years ($SD = 9.84$ years, $median = 43.00$ years). A t-test showed no significant difference on age of participants and gender.

The average time between diagnosis and participation in the current study was 3.67 years ($SD = 4.42$ years, $median = 2.00$ year). Female participants' average time since diagnosis was

3.61 years ($SD = 4.33$ years, $median = 2.00$). Male participants' average time since diagnosis was 3.98 years ($SD = 4.80$ years, $median = 3.00$). A t-test showed no significant difference between males and females in time since diagnosis.

When examining the country of birth of participants, the sample was grouped into six categories (displayed in Table 1 below). The majority of the participants were born in Australia (45.4%), 16.9% were born in the U.S.A, 13.9% in the U.K, 11.5% in New Zealand, 6.1% in Canada and 6.1% were born across 13 countries grouped together as 'Other'. A detailed description of the countries comprising the 'Other' category can be found in Appendix A.

Table 1

Participants' Country of Birth

Country of Birth	Participants		
	Total	Male	Female
Australia	134	20	114
United States of America	50	5	45
United Kingdom	41	8	33
New Zealand	34	7	27
Canada	18	3	15
Other	18	9	9
Total	295	52	243

While participant numbers were relatively small in the 'Canada' ($n=18$) and 'Other' ($n=18$) groups, they were considered sufficient given the statistical techniques employed (Tabachnick & Fidell, 1996). The countries represented in this study, and the proportion of participants from each country, was expected following the brief given to the researcher by the MS Society on the numbers of people, and their geographical location, accessing the internet site; with one

exception. The researcher expected approximately 10% of participants to be born in Japan (given the statistics outlined in the brief), but instead received no questionnaires from PwMS born in Japan. This could be due to an oversight on the part of the researcher, as while the MS Australia website can be accessed in Japanese, the questionnaire could only be accessed in English. It is assumed that the lack of expected Japanese participants thereby increased the resultant proportion of participants from New Zealand and Canada.

Chi-square tests were performed to investigate whether gender associations existed in groups of participants based on country of birth. There was a significant association found between gender and country of birth $\chi^2(5,1) = 15.98, p < .01$. The ratio of female to male participants was within an expected range for four of the countries; New Zealand (3.9:1), U.K (4:1), Canada (5:1), Australia (5.7:1). Participants from the USA comprised a much higher ratio of females to males (9:1), and participants from the category combining many countries ('Other') comprised an equal ratio of females to males (1:1).

Participants were asked what type of MS they had been diagnosed with. They were given the following five options to select from: Relapsing Remitting MS (RRMS), Primary Progressive MS (PPMS), Secondary Progressive MS (SPMS), Progressive Relapsing MS (PRMS), and Benign MS. As only one participant reported being diagnosed with Progressive Relapsing MS, they were included in the Secondary Progressive MS group, as this is the most closely related category based on possible exacerbation frequency and access to immunotherapy medication (personal communication, Dr. E. McDonald, Medical Director, MS Society of Victoria, 2004). See Table 2 (below) for a description of participant numbers as a function of type of MS. Participants' self reports regarding the type of MS they were diagnosed with showed that over three quarters of participants ($n=227, 77.0\%$) had been diagnosed with RRMS, while less than ten

percent ($n=21$, 7.1%) reported that they ‘didn’t know/were unsure/were not told’ of their type of MS at diagnosis.

Table 2

Number and Percentage of Participants as a Function of Type of MS

Type of MS	Participants					
	Female		Male		Total	
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
Relapsing Remitting	192	79.0	35	67.3	227	77.0
Primary Progressive	14	5.8	9	17.3	23	7.8
Don’t know/unsure/wasn’t told	16	6.6	5	9.6	21	7.1
Secondary Progressive	11	4.5	3	5.8	14	4.7
Benign	10	4.1	0	0.0	10	3.4
Total	243	100	52	100	295	100

Participants in the current study broadly reflected the wider prevalence of different subgroups of MS as reported in the literature (Burks et al., 2002; Hawkins & McDonnell, 1999; Mohr & Cox, 2001), with two notable exceptions. Firstly, while the literature suggests 10-15% of PwMS have PPMS, only 7.8% of the current participants reported being diagnosed with PPMS. This could be due to the fact that neurologists are hesitant to label PPMS at the time of an MS diagnosis, for fear of alarming the patient with what could be incorrectly perceived as the ‘worst case’ scenario (Burks et al., 2002). They may instead give a broad diagnosis of ‘MS’, which could partly explain the 7.1% of participants who were unsure of their type of MS at the time of diagnosis. Secondly, Weinshenker (1995) and Burks et al. (2002) discuss SPMS as a type of MS that approximately 50% of people diagnosed with RRMS ‘transition’ to within ten years following

diagnosis. While 4.7% of participants in the current study reported being diagnosed with SPMS, this figure seems unusually high as it is not a type of MS usually given at the time of diagnosis (but rather later in the disease process) (Poser, 1992).

Chi-square tests were performed to investigate whether participants' self reports of the type of MS they were diagnosed with, was associated with their gender or country of birth. There was a significant association found between gender and type of MS $\chi^2(4,1) = 10.92, p < .05$. A greater proportion of females reported their type of MS as RRMS, than males. Similarly, a greater proportion of females reported having Benign MS than males (no male reported Benign MS as the type of MS they were diagnosed with). Conversely, a higher proportion of males reported their type of MS as PPMS, than females. This was not surprising as previous research has shown a higher male to female ratio in PPMS than that observed in other sub groups of MS (Dujmovic et al., 2004). There was no significant association found between participants' type of MS and country of birth.

6.2 Materials

6.5.1 Questionnaire Development

An extensive literature review was conducted to determine the subsections of the questionnaire. These subsections were based on the evident gaps in research on people's MS related experiences before a diagnosis of MS, and similarly, on people's MS related behaviour in the 12 months following diagnosis. Therefore, the four subsections of the questionnaire are: demographic information at the time of participation in the study, demographic information at the time of diagnosis, experience pre-diagnosis, and behaviour in the first 12 months following diagnosis. Preliminary questionnaire items for each subsection were drafted by the researcher following the literature review. These included all of the items included in the demographic

information at the time of participation in the study subsection, and all of the core questions in the remaining subsections, apart from the question regarding hospital stays before diagnosis, which was added following consultation with members of the MS community (as outlined below). In the qualitative component of the questionnaire, open ended questions were drafted to encourage participants to expand on their (a) experience of meeting another PwMS, (b) reasons behind disclosing their diagnosis of MS to others, and (c) actions post diagnosis that they believe assisted or hindered their ability to cope with the diagnosis. Options for closed questions were also drafted by the researcher at this point, however additions to answer options were also added following MS community consultation.

Consultation with two groups of people involved in the MS community, either personally or professionally, was then arranged to gain insight into the specific questions that would be deemed relevant to the questionnaire subsections. The first group comprised PwMS ($n=3$) who offered broad suggestions about the types of experiences they had before diagnosis and the MS related behaviour they engaged in immediately following diagnosis. The group identified all of the broad categories included in the draft questionnaire, and also raised an additional example of pre-diagnosis experience that was not included in the draft questionnaire. Number of hospital stays before or at the time of diagnosis was indicated by this group as an important pre-diagnosis experience, and therefore an item addressing this experience was included in the final questionnaire.

The second group of people involved in the MS community comprised four health professionals (a physiotherapist, social worker, occupational therapist and nurse) and two information and support workers/librarians, working with PwMS at the MS Society of Victoria. They were asked to look over the draft questions and suggest additional answer options to closed questions if they thought appropriate. For example, the group were given a question regarding

information seeking behaviour; 'In the first 12 months following diagnosis, did you do any of the following?' with the following answer options: Ask a medical professional for further information about MS; contact the MS Society for information; access information about MS from the internet; and register with the MS Society. The group identified that an additional answer option of 'access information about MS from a library' should also be offered to participants. This option was therefore included in the final questionnaire. The input into the questionnaire given by both PwMS and the professionals working with them was particularly valuable in the construction of the closed question response options, and suggestions made by both groups were included in the final questionnaire. The questionnaire was re-drafted following this consultation with members of the MS community.

The online questionnaire was constructed with the knowledge that a link would be made available to it on the MS Australia website (www.msaustralia.com.au). The questionnaire was only accessible to participants on-line, through the researcher's use of the program Surveyor (Object Planet Inc., <http://www.objectplanet.com>). Surveyor enables production and publication of online surveys and questionnaires on the Internet using a regular web browser. Swinburne University of Technology (as a licensed holder) held the questionnaire on its server, allowing access to participants through internet browsers such as Netscape.

The questionnaire format and length was designed with simplicity in mind for two reasons. First, due to the nature of the computer package used to format the questionnaire, a short questionnaire using a combination of closed and open ended questions was desired. Second, as the level of English comprehension of potential respondents could not be ascertained before the questionnaire was linked to the website; the questionnaire had to be suitable for participants with diverse English language skills, as well as educational levels. Third, as the questionnaire would be accessed solely through a link to the MS Australia website, it needed to

be brief and easy to navigate, to ensure on-line participants' attention. If it was not brief and easy to interact with, the concern was that participants could get bored or frustrated, and exit the questionnaire before completing all items.

6.5.2 Pilot Study

A small ($n=5$ participants) pilot study was conducted in order to determine if the questions were phrased clearly and to verify whether the multi-choice answer categories were sufficient to capture the full range of possible responses. A paper copy of the questions was administered to five PwMS living in Melbourne, Australia, accessed through the MS Society of Victoria. Pilot study respondents comprised four females and one male. Two of the female respondents had RRMS, and two female respondents had SPMS. The male respondent had PPMS. The pilot study respondents provided information that led to modifications of the multi-choice options available for two questions. First, 'Attending an information session/conference' was added to the options available for the question regarding information seeking behaviour, as four of the five participants included this as an example of additional information seeking activities they had engaged in. Second, three pilot study respondents stated that they had taken vitamin supplements following diagnosis, regardless of whether they had changed the food in their diet. Thus, the option of 'Addition of Vitamin Supplements to the Diet' was added to the question regarding lifestyle changes, to distinguish taking supplementary vitamins from a general 'Change in diet'. These changes are reflected in the description of the questionnaire presented in the next section. No other adjustments were made.

6.5.3 Questionnaire

The questionnaire consisted of 25 items, and was spread over eight web pages. A list of the questionnaire items is in Appendix B. Participants could review the responses they had made on each page before progressing to the next page of questions by clicking a 'next' button. There was a mixture of both closed answer and open ended questions included in the questionnaire. Closed answer questions displayed a selection of possible responses for the participant to choose from. For example, participants had the option of selecting 'male' or 'female' (by clicking a button assigned to either response) when asked to give details of gender. Similarly, when asked their marital status at the time of diagnosis, participants were offered the categories of 'single', 'long term relationship', 'married/living with partner', 'separated/divorced' or 'widowed', and could select the option that best described them. Participants were allowed only one response per question unless otherwise advised, and most questions included the option of 'other' and sufficient space to provide further details by typing them in. For example, question 21 was 'In the first 12 months following diagnosis, did you tell anyone about your diagnosis? If yes, who? Please select all that apply'. Nine options were presented (such as 'Partner/Husband/Wife' and 'Employer') and participants had the option of selecting as many as were appropriate. A tenth option of 'Other: Please Specify' was also presented. This inclusion allowed participants to enter information of others they had disclosed their diagnosis to. The next question gives an example of the open ended questions included in the questionnaire: 'Why did you choose to tell these people about your diagnosis of MS? Please give as much detail as possible'. A box was then available to participants to answer the question by typing in as much detail as they wished.

As mentioned above (in Section 6.5.3), the questionnaire content was divided into four sections; (a) demographic information at the time of participation in the study; (b) demographic information at the time of diagnosis; (c) experience pre-diagnosis; and (d) behaviour in the first

12 months following diagnosis. The questions were aimed at obtaining a broad overview of participants' MS related experiences prior to, or at the time of, diagnosis, and their behaviour within the initial 12 months following diagnosis. Questionnaire items are detailed below.

6.5.3.1 Demographic Information at the Time of Participation in the Study

The first part of the questionnaire consisted of items to ascertain elements of participants' demographic information at the time of completing the questionnaire. First, participants were asked their age (in years). Participants were then asked their gender, and were given the options of male or female to select from. Next, participants were asked to state their country of birth by typing in their response. Finally, participants were asked to name the type of MS they had been diagnosed with, and were given the following six options to select from: Relapsing Remitting, Primary Progressive, Secondary Progressive, Progressive Relapsing, Benign, and 'unsure/do not know/was not told'.

6.5.3.2 Demographic Information at the Time of Diagnosis

In the second part of the questionnaire, participants were asked several questions relating to their personal situation at the time they were diagnosed with MS. Participants were asked to state their age (in years) at diagnosis. Next, participants were asked an open ended question about their occupation at diagnosis. Work status at the time of diagnosis was reported by participants selecting one of the following options: Unemployed, employed part time, employed and student, employed full time, student solely, home duties solely, and retired. Marital status was also recorded by participants selecting one of the following options: Single, long term relationship, married/living with partner, separated/divorced, or widowed. Next, participants were asked to enter the number of dependent children they had at the time of diagnosis. Finally,

participants were asked to select an option to describe the level of education reached at the time of their diagnosis. The options given were: Primary, partial secondary, secondary, trade qualification, partial tertiary, university graduate, and university post graduate.

6.5.3.3 MS Related Experience Prior to, or at the Time of, Diagnosis

The third section of the questionnaire included questions regarding participants' MS related experiences prior to, or at the time of, their diagnosis. Two questions regarding MS symptoms were asked of participants. Arguably, MS symptoms can be grouped into eight categories (Calabresi, 2004; Hickey, 2003; Mohr & Dick, 1998; O'Hara, Cadbury, De Souza & Ide, 2002; Weinshenker et al., 1991). The eight categories of symptoms used in the current study were: *Sensory* symptoms such as- pain, burning, pins and needles, or reduced sensation (numbness) in any area of the body; *visual* symptoms such as- optic neuritis, diplopia (double vision), ocular pain, or spots in field of vision; *motor* symptoms such as- limb ataxia, spasticity, or symptoms that affected the participant's ability to use various muscles (acute or insidious); *cerebeller* symptoms such as- vertigo, nausea, or impairment of balance; *fatigue* such as- extreme tiredness, lethargy or lassitude; *cognitive* symptoms such as- changes in memory, concentration, thinking, problem solving, and emotional disturbances; *bladder/bowel* symptoms such as- constipation or incontinence; *sexual* symptoms such as- erectile dysfunction, or inability to orgasm.

Participants were asked to identify their first symptom(s) of MS. From the eight categories of symptoms described above, a list of the eleven most common MS symptoms as cited in the literature (Calabresi, 2004; Hickey, 2003; Mohr & Dick, 1998; O'Hara, Cadbury, De Souza & Ide, 2002; Weinshenker et al., 1991) were offered, along with the option of 'other: please specify'. The list of symptoms included: Fatigue, numbness, spasticity, pain, paralysis,

tremors, visual difficulties, bladder/bowel difficulties, communication difficulties, balance difficulties, and concentration difficulties. Participants could select as many options as they identified as their first symptom(s). A second question relating to MS symptoms was also asked, this time relating to the symptom(s) they experienced at the time of diagnosis. Participants were provided with the same list of symptoms and the option of 'other: please specify' and were asked to select all that applied. An additional option of 'no symptoms' was also offered thereby creating an additional category of *no symptoms* when categorising participants' responses to this question.

Next, participants were asked how old they were (in years) when they experienced their first symptom(s) of MS. They were also asked to provide the number of exacerbations that they had before a diagnosis of MS was given. To conclude this section of the questionnaire relating to MS experience prior to, or at the time of, diagnosis, participants were asked if they suspected they had MS before the diagnosis was given, and if they were admitted to a hospital, due to MS symptoms, before or at the time of the diagnosis. Participants were asked to answer each of these questions by selecting the option 'yes' or 'no'.

6.5.3.4 Behaviour in the First Twelve Months Following Diagnosis

The final section of the questionnaire comprised questions relating to participants' behaviour in the first 12 months following the diagnosis of MS. First, participants were asked about their information seeking behaviour in the first 12 months following diagnosis. Six information seeking behaviours were presented, and participants were asked to select all that applied. These were: Ask a medical professional for further information about MS, contact the MS Society for information, access information about MS from the internet, access information about MS from a library, and attend an information session or conference on MS. A follow up

question of: 'Did you find out information about MS in any other way? If so, how?' allowed participants to provide further relevant information on their information seeking behaviour in the first 12 months following diagnosis. Participants were then asked if they registered with their local MS Society within the first 12 months of diagnosis.

Next, participants were asked whether they had discussed their diagnosis with someone else who had MS in the first 12 months following diagnosis. They were also prompted, by way of an open question, to explain how they knew that person.

Subsequently, participants were asked to identify who they told about their diagnosis of MS in the first 12 months following diagnosis. Participants were given ten options and were asked to select all that applied. The options were: Partner/husband/wife, mother, father, sibling, children, counsellor/psychologist, close friends, workplace colleagues, employer, and other (please specify). This question was followed by an open ended question 'Why did you choose to tell those people in the first 12 months following your diagnosis?'

Participants were asked whether they had changed their lifestyle due to MS in the first 12 months following their diagnosis. Participants were given the choice of nine categories and were asked to select all that applied. Categories were chosen through identification of lifestyle changes in previous research, and in consultation with members of the MS community (as described in Section 4.5.1). These were: Change in diet, addition of vitamin supplements to diet, decreased exercise, increased exercise, change of career/work, reduction in work hours, started immunotherapy, increased interest in religion/spirituality, decreased interest in religion/spirituality. Participants were then asked to identify any other lifestyle changes (not listed above) that they made in the first 12 months following their diagnosis of MS.

In the final question, participants were asked to identify anything that they found assisted or hindered them in coping with the diagnosis of MS in the first 12 months following diagnosis.

Participants' subjective evaluation of what they thought assisted or hindered them in coping with the diagnosis was sought.

6.6 Procedure

Permission was obtained from the Swinburne University of Technology Research Ethics Committee to conduct the research. In addition, MS Australia then approved the linking of the questionnaire to the MS Australia website. Paper copies of the questionnaire were not made and distributed to participants; rather participants accessed and completed the questionnaire on-line. A link to the questionnaire was included on the homepage of the MS Australia website. It read:

Behaviour Following a Diagnosis of Multiple Sclerosis

What did you do following your diagnosis of MS? Did you seek out information on MS? Did you tell your friends and family? Did you increase or decrease your work hours?

[Click here](#) to participate in a study on behaviour following diagnosis of MS.

After selecting the link on the MS Australia website, participants then viewed the Plain Language Statement (an explanatory statement of the research), before progressing to the questionnaire. A copy of the Plain Language Statement can be seen in Appendix C. The Plain Language Statement informed prospective participants that they were free to withdraw from the study at anytime. Prospective participants were informed that their completion of the on-line questionnaire implied consent. The questionnaire was accessible through the link on the MS Australia website from the 5th of September 2003 to the 28th of February 2004.

Once participants had completed the questionnaire, a window with the following message appeared:

Behaviour Following a Diagnosis of Multiple Sclerosis

Your completed questionnaire has been submitted. Thank you for taking the time to help us carry out this important MS research. Simply close this window to return to the MS Australia web site.

In order to try and prevent participants submitting the questionnaire multiple times, the on-line questionnaire could not be accessed from the same computer more than once. If a participant attempted to complete the questionnaire after already submitting a finished questionnaire, a window would pop up with the message 'Error: You can not respond to this survey more than once'.

CHAPTER SEVEN

RESULTS

7.1 Overview of the Chapter

In Chapter Six the method of the present study was described, including an outline of the participants, materials and procedure used. The results of this study are reported in this chapter. A description of how the data is presented is described in the first section of the chapter. Then, an exploration of participants' demographic information at the *time of their diagnosis of multiple sclerosis* is offered. Age, education level, occupation, work status, marital status, and number of dependent children at time of diagnosis are described. The potential associations between such variables at the time of diagnosis and participants' gender, country of birth and the type of MS are examined. Within this section the first research aim of the study is addressed: To add to the body of knowledge about MS related experiences prior to, or at the time of, an individual being diagnosed with MS.

The first research aim of this study is again addressed in the second section of this chapter as the MS related experiences of participants *before or at the time of their diagnosis of multiple sclerosis* are reported. Age at first symptom, initial symptoms, symptoms at time of diagnosis, number of exacerbations before diagnosis, hospital admission due to MS before or at the time of diagnosis, and suspicion of MS before diagnosis was made, are described. Once again, the potential differences between such variables prior to, or at the time of, diagnosis and participants' gender, country of birth and the type of MS diagnosed are examined.

In the third section of this chapter, the post-diagnosis behaviour of participants *within the first 12 months of their diagnosis of multiple sclerosis* is reported. Information seeking activities,

discussion of diagnosis with another PwMS, disclosure of diagnosis to others, and lifestyle changes made following the diagnosis are described. The potential associations between such variables within the first 12 months of diagnosis and participants' gender, country of birth and the type of MS diagnosed are examined. The second research aim of the study is addressed in this section: To identify and further clarify the information seeking, social and health related behaviours exhibited by individuals within the first 12 months following a diagnosis of MS.

7.2 Presentation of the Data

To examine relationships between participants' key demographic variables, demographic variables at the time of diagnosis, experience prior to, or at the time of, diagnosis, and behaviour following diagnosis, independent sample t-tests, chi-square analyses, and ANOVAs were conducted. Statistical analyses were performed using the SPSS 14.0 for Windows statistical package (SPSS Inc, 2005). Results of such analyses are presented in tables and in text. Qualitative data is also presented in this chapter. In order to describe the qualitative results, a thematic based analysis (Byrne, 2001) of participant responses was undertaken. Thematic analysis focuses on identifiable themes and patterns of behaviour (Aronson, 1994). Qualitative data analysis included the following processes. The researcher read the transcripts several times in order to identify themes. These themes were then provided to an independent reviewer, together with 50% of the qualitative data. The independent reviewer showed 100% agreement with the preliminary themes as identified by the researcher. Given the high level of agreement, further discussion was had between the researcher and independent reviewer, to clarify the suitability of themes. Subsequently, categories were clarified and sub-categories were created and refined, and text segments were assigned to categories and sub-categories. Some text segments were assigned to more than one category (as outlined below). Throughout this chapter,

the qualitative data are presented in a descriptive way and illustrated with verbatim quotes gathered from the questionnaires, resulting in a particularly extensive section on the findings of participant behaviour following a diagnosis of MS. This format was chosen for three reasons, a) to present the data in its full richness, b) to capture a true representation of the reality of the person diagnosed with MS, and c) to acknowledge that the participants are the experts and authorities on their own experience. Beside each quote included in the results section is a participant number, which refers to the identification number assigned to each individual's questionnaire by the Surveyor computer program. Within each quote, key words are highlighted to indicate relevance to the theme described. Complete records of the qualitative responses given by participants are available to other researchers from the author upon request. The way in which the themes are ordered, labelled and presented reflects the researcher's interpretation of the data. The data are further interpreted and related to the literature in Chapter 8.

7.3 Demographics at Diagnosis

The first research aim is addressed in this section: To add to the body of knowledge about MS related experiences prior to, or at the time of, an individual being diagnosed with MS. An outline of participants' demographic information at the *time of their diagnosis of multiple sclerosis* is provided. The following variables were examined: Age, education level, occupation, work status, marital status, and number of dependent children. Examinations of possible gender associations with each of the above were undertaken, as too were examinations of possible associations based on country of birth, and type of MS.

7.3.1 Age at Diagnosis

The sample of 295 participants comprised 243 females with a mean age at diagnosis of 37.13 ($SD = 10.23$) years and 52 males with a mean age at diagnosis of 37.63 ($SD = 10.14$) years. A t-test showed no significant difference between males and females in age at diagnosis. Similarly, a one-way ANOVA showed no significant difference between participants' country of birth and their age at diagnosis. The potential differences in age at diagnosis as a function of type of MS diagnosed was also investigated using a one way ANOVA and a significant difference was found, $F(4,290) = 5.301, p < .01$. A post-hoc Tukey's HSD test revealed a significantly greater age at diagnosis for participants with PPMS in comparison to age at diagnosis for participants with RRMS, and in comparison to the group that were unsure/did not know/were not told of their type of MS at the time of diagnosis (see Table 3 for means and standard deviations).

Table 3

Age at Diagnosis as a Function of Type of MS

Type of MS	Mean Age at Diagnosis	Standard Deviation	Sample Size
Relapsing Remitting	36.64	9.93	227
Primary Progressive	44.43	10.01	23
Secondary Progressive	41.86	11.17	14
Benign	34.40	11.14	10
Unsure/do not know/ was not told	32.57	8.85	21

7.3.2 Education Level at Time of Diagnosis

At the time of diagnosis, 43.7% of participants had completed a university degree or university post graduate degree. A Chi-square test was performed to investigate whether education level at time of diagnosis was associated with gender. Education level and gender were found to be significantly related $\chi^2(5) = 16.92, p < .05$. An association was found between the highest level of education completed and gender (See Table 4).

Table 4

Education Level at Time of Diagnosis

Highest Education Level Attained	Female		Male	
	<i>n</i>	Percent	<i>n</i>	Percent
Primary/Partial Secondary	16	6.6	0	0.0
Secondary	56	23.0	10	19.2
Trade Qualification	19	7.8	11	21.2
Partial Tertiary	46	18.9	8	15.4
University Graduate	60	24.7	19	36.5
University Post Graduate	46	18.9	4	7.7

A greater proportion of females than males reported their highest level of education completed at the time of diagnosis as Primary/Partial Secondary or Secondary, while a greater proportion of males reported completing a Trade Qualification or University Graduate Qualification. However, when looking at the number of participants who had attained a University Post Graduate qualification at the time of diagnosis, there were a greater proportion of females indicating that they had completed this higher level of education.

Education level and country of birth were also found to be significantly related $\chi^2(25) = 54.21$ $p < .01$. An association was found between the highest level of education completed and country of birth. Table 5 gives numbers and percentages of participants from each country according to the highest level of education completed at the time of diagnosis.

Table 5

Education Level at Time of Diagnosis as a Function of Country of Birth

Highest Education Level Attained	Country of Birth											
	Australia		U.S.A		U.K		N.Z		Canada		Other	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Primary/Partial Secondary	10	7.5	5	10.0	0	0.0	1	2.9	0	0.0	0	0.0
Secondary	35	26.1	6	12.0	9	22.0	9	26.5	6	33.3	1	5.6
Trade Qualification	8	6.0	4	8.0	9	22.0	4	11.8	3	16.7	2	11.1
Partial Tertiary	33	24.6	2	4.0	9	22.0	6	17.6	1	5.6	3	16.7
University Graduate	22	16.4	20	40.0	12	29.3	11	32.4	5	27.8	9	50.0
University Post Graduate	26	19.4	13	26.0	2	4.9	3	8.8	3	16.7	3	16.7
Total	134	100	50	100	41	100	34	100	18	100	18	100

A greater proportion of participants born in Australia and the U.S.A reported Primary/Partial Secondary as the highest education level attained. A greater proportion of participants born in the U.K had completed a trade qualification. A lesser proportion of participants from the U.S.A and Canada reported having completed a partial tertiary qualification at the time of their diagnosis. A greater proportion (two thirds) of those participants born in the U.S.A or 'Other' had completed either a degree or a post graduate degree at the time of their

diagnosis, while a smaller proportion of participants born in the U.K or N.Z had completed university post graduate qualifications than those born in the U.S.A, Australia, Canada or 'Other'. There was no significant association found between education level at time of diagnosis, and type of MS.

7.3.3 Occupation and Work Status at Time of Diagnosis

Participants were asked to state their occupation at the time of their diagnosis. The ranked classification system for occupation developed by the Australian National University (ANU) (Broom, Duncan-Jones & Jones, 1977) was adopted to classify participants into an occupational category. The ANU ranked scale is based on the skills and training required by each occupation (rather than a socio-economic consideration) and provides researchers with six categories. A seventh category, 'home duties/student', was also added given the number of respondents identifying their occupation as such. Almost 50% of participants held occupations at a managerial or professional level. Eighty-seven percent of participants were in paid employment (full or part time) at the time of diagnosis. See Table 6 for a break down of participants' occupations and work status at time of diagnosis, by gender.

Chi-square tests were performed to investigate whether occupation or work status were associated with gender. An association was found between occupation and gender $\chi^2(6) = 13.67$, $p < .05$. A greater proportion of females reported their occupation as unskilled/unemployed /retired, semi-skilled or home duties/student, than males. A higher proportion of males reported their occupation as trade, office, manager, or professional. An association was also found between work status and gender $\chi^2(5) = 20.82$, $p < .01$, where a greater proportion of males reported working full time, or being retired/unemployed, than females. Conversely, a greater

proportion of females reported being employed part time, both employed and a student, a student solely, or performing home duties solely, than males.

Table 6

Occupation and Work Status at Time of Diagnosis

	Female		Male	
	<i>n</i>	Percent	<i>n</i>	Percent
Occupation				
Unskilled/retired/unemployed	8	3.3	0	0.0
Semi-skilled	41	16.9	1	1.9
Trade	12	4.9	5	9.6
Office (para-professional)	28	11.5	8	15.4
Manager	32	13.2	11	21.2
Professional	82	33.7	21	40.4
Home Duties/Student	40	16.5	6	11.5
Work Status				
Unemployed/retired	4	1.6	4	7.7
Employed Part Time	51	21.0	3	5.8
Employed and Student	24	9.9	3	5.8
Employed Full Time	134	55.1	41	78.8
Student Solely	11	4.5	1	1.9
Home Duties Solely	19	7.8	0	0

Chi-square tests were also performed to investigate whether occupation or work status were associated with country of birth. There was no significant relationship between occupation and country of birth, or work status and country of birth. Chi-square tests also showed no significant relationship between occupation and type of MS, or work status and type of MS.

7.3.4 Marital Status and Number of Dependent Children at Time of Diagnosis

Marital status and number of dependent children at the time of diagnosis was recorded. Almost three quarters (71.5%) of participants were either married, living with their partner, or in a long term relationship, at the time of their diagnosis. Twenty percent of participants were single, and less than nine percent (8.4%) were separated/divorced or widowed. Chi-square tests showed no significant relationship between marital status at diagnosis and gender, country of birth, or type of MS.

Over half of the participants (58.3%) had no dependent children at the time of their diagnosis, while 13.6% had one child, and almost twenty percent (19.3%) had two children at the time of diagnosis. Less than nine percent (8.8%) had three or more dependent children at the time of diagnosis. A t-test showed no significant difference between number of children at diagnosis and gender. One-way ANOVAs showed no significant differences between the number of dependent children at diagnosis and country of birth or type of MS diagnosed.

7.4 Experience Prior to, or at the Time of, Diagnosis

The first research aim: To add to the body of knowledge about MS related experiences prior to an individual being diagnosed with MS, is again addressed in this section, as participants' MS related experiences *before or at the time of their diagnosis* are presented. The following variables were examined; age at first symptom, initial symptoms, symptoms at time of diagnosis, number of exacerbations before diagnosis, hospital admission due to MS before or at the time of diagnosis, and suspicion of MS before diagnosis was made. Examinations of possible gender differences on each of the above were undertaken, as too were examinations of possible differences based on country of birth, and type of MS.

7.4.1 Age at First Symptom

Female participants reported experiencing their first symptom of MS at a mean age of 31.98 ($SD = 9.78$) years, while males experienced their first symptom at a mean age of 33.17 ($SD = 10.77$). A t-test showed no significant difference between males and females in their age at first symptom. In addition, a one way ANOVA showed no significant difference in age at first symptom as a function of participants' country of birth.

A one way ANOVA was also used to investigate the possible differences in age at first symptom with regard to type of MS diagnosed. A significant difference was found between the age at first symptom for type of MS, $F(4,290) = 5.254, p < .01$. A post-hoc Tukey's HSD test revealed a significantly greater age at first symptom of PPMS in comparison to age at first symptom of RRMS, age at first symptom of unsure/didn't know/were not told of their type of MS, and age at first symptom of Benign MS (See Table 7 for means and standard deviations).

Table 7

Age at First Symptom as a Function of Type of MS

Type of MS	Mean Age at 1 st Symptom	Standard Deviation	Sample Size
Relapsing Remitting	31.79	9.69	227
Primary Progressive	39.57	10.50	23
Secondary Progressive	35.43	11.06	14
Benign	26.90	8.32	10
Unsure/do not know/ was not told	28.71	8.02	21

7.4.2 Initial Symptoms and Symptoms at Time of Diagnosis

Participants were asked to report their first symptom/s of MS, and the symptom/s they were experiencing at the time of their diagnosis. Forty-nine percent of participants reported experiencing only one initial symptom of MS, while 45% of participants reported two or three initial symptoms of MS. The remaining 6% of participants reported experiencing four or more initial symptoms of MS. As the initial presenting symptom, sensory symptoms such as numbness, heat sensitivity or pain were reported by almost two thirds of participants. Just over a third of participants reported visual symptoms, such as optic neuritis, as their first symptom, or one of their initial symptoms, of MS. The lowest reported initial symptom of MS was sexual dysfunction, reported by three percent of participants.

At the time of diagnosis just over a third of participants (35%) reported experiencing one or two symptoms, while the majority (62%) reported experiencing three or more symptoms at this time. Eight participants (3%) reported having no symptoms at all at the time they were diagnosed.

Chi-square tests were performed to investigate whether initial symptoms or symptoms at time of diagnosis were associated with gender (See Table 8). There were only two significant associations found between symptoms and gender. The first association was found between sensory symptoms as an initial symptom and gender $\chi^2 (1) = 4.44, p < .05$, where a greater proportion of females reported experiencing sensory symptoms as an initial symptom of MS, than males. A second association was found between cognitive symptoms at time of diagnosis and gender $\chi^2 (1) = 3.99, p < .05$. A greater proportion of females reported experiencing cognitive symptoms at the time of diagnosis, than males.

Table 8

Frequency of Reported Initial Symptoms and Symptoms at Time of Diagnosis

	Female		Male	
	<i>n</i>	Percent	<i>n</i>	Percent
Initial Symptoms				
Sensory	155	64	25	46
Visual	88	36	23	44
Motor	66	27	18	35
Cerebeller	58	24	13	25
Fatigue	43	18	5	10
Cognition	19	8	3	6
Bladder/Bowel	13	5	0	0
Sexual	1	0.4	1	2
Symptoms at Time of Diagnosis				
Sensory	182	75	35	67
Visual	98	40	27	52
Motor	94	39	18	35
Cerebeller	118	49	27	52
Fatigue	151	62	28	54
Cognition	81	33	10	19
Bladder/Bowel	65	27	8	15
Sexual	0	0	0	0
No Symptoms	7	3	1	2

Chi-square tests were performed to investigate whether initial symptoms or symptoms at time of diagnosis were associated with country of birth. There were no significant associations between participants' initial symptoms of MS and country of birth. However, there was a significant association found between one symptom at the time of diagnosis, and country of birth. This association was between cognitive symptoms at the time of diagnosis and country of birth $\chi^2 (5) = 12.01, p < .05$. A greater proportion of people from Australia, the U.S.A, Canada and Other (30-40%), reported experiencing cognitive symptoms at the time of diagnosis, than those from the U.K and New Zealand (10-20%).

Chi-square tests were also performed to investigate whether initial symptoms or symptoms at time of diagnosis were associated with type of MS (See Table 9).

There were only two significant associations found between participants' initial symptoms of MS, and their type of MS, and only one significant association found between participants' symptoms at the time of diagnosis and their type of MS. An association was found between sensory symptoms as an initial symptom and type of MS $\chi^2 (4) = 11.59, p < .05$. A greater proportion of participants with types of MS other than primary progressive MS, reported experiencing sensory symptoms as an initial symptom of MS. An association was also found between motor symptoms as an initial symptom and type of MS $\chi^2 (4) = 11.61, p < .05$. A greater proportion of people with primary progressive MS reported experiencing motor symptoms as an initial symptom of MS, than those with other types of MS. An association was also found between sensory symptoms at the time of diagnosis and type of MS $\chi^2 (4) = 10.12, p < .05$. A greater proportion of people with RRMS, SPMS, and those that did not know/were not sure/were not told what type of MS they had, reported experiencing sensory symptoms at the time of diagnosis, than those with other types of MS.

Table 9

Frequency of Reported Initial Symptoms and Symptoms at Time of Diagnosis (TOD) as a Function of Type of MS

	Type of MS									
	RR (n=227)		PP (n =23)		SP (n =14)		Benign (n =10)		Don't know (n =21)	
	n	%	n	%	n	%	n	%	n	%
Initial Symptoms										
Sensory	144	63	8	35	7	50	9	90	12	57
Visual	86	38	9	39	4	29	3	30	9	43
Motor	60	26	13	57	5	36	1	10	5	24
Cerebeller	46	20	9	39	4	29	3	30	9	43
Fatigue	39	17	3	13	4	29	1	10	1	5
Cognition	16	7	3	13	1	7	0	0	2	10
Bladder/Bowel	9	4	0	0	2	14	0	0	2	10
Sexual	1	0.4	0	0	0	0	0	0	1	5
Symptoms at TOD										
Sensory	172	76	12	52	13	93	6	60	14	67
Visual	94	41	13	57	5	36	5	50	8	38
Motor	81	36	14	61	8	57	2	20	7	33
Cerebeller	106	47	18	78	7	50	4	40	10	48
Fatigue	140	62	15	65	7	50	6	60	11	52
Cognition	69	30	8	35	4	29	4	40	6	29
Bladder/Bowel	55	24	5	22	6	43	0	0	7	33
Sexual	0	0	0	0	0	0	0	0	0	0
No Symptoms	6	3	1	4	0	0	0	0	0	0

7.4.3 Number of Exacerbations before Diagnosis

Participants were asked to report the number of exacerbations they experienced before a diagnosis of MS was made. Responses were grouped into one of four categories; one exacerbation before diagnosis ($n=70$, 23.7%); two exacerbations before diagnosis ($n=69$, 23.4%); three or more exacerbations before diagnosis ($n=70$, 23.7%); and not sure of the number of exacerbations before diagnosis ($n=86$, 29.2%). As almost a quarter of participants reported experiencing only one exacerbation before a diagnosis of MS was made, and the current diagnostic criteria, as of 2001, require the occurrence of two exacerbations before a diagnosis of RRMS is made (McDonald et al, 2001), the relationship between number of exacerbations and years since diagnosis was explored. A one way ANOVA was performed to investigate the possible differences in number of exacerbations before diagnosis with regard to number of years since diagnosis. There was no significant association found between the number of exacerbations reported before diagnosis, and the number of years since diagnosis.

Chi-square tests were then performed to investigate whether number of exacerbations before diagnosis was associated with gender or country of birth. There was no significant relationship found between number of exacerbations before diagnosis and gender, or number of exacerbations before diagnosis and country of birth. A Chi-square test was also performed to investigate whether number of exacerbations before diagnosis was associated with type of MS (See Table 10). An association was found between number of exacerbations before diagnosis and type of MS $\chi^2(12) = 31.38, p < .01$. A greater proportion of those with Benign MS and those who were unsure of the type of MS they had, reported only one exacerbation before diagnosis, than those with other types of MS. A greater proportion of those with PPMS and SPMS were not sure of the number of exacerbations they had before diagnosis.

Table 10

Frequency of Reported Number of Exacerbations before Diagnosis as a Function of Type of MS

# Exacerbations before Diagnosis	Type of MS									
	RR		PP		SP		Benign		Don't know	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
1	51	23	4	18	2	14	5	50	8	38
2	62	27	1	4	2	14	1	10	3	14
3+	60	26	3	13	4	29	1	10	2	10
Not Sure	54	24	15	65	6	43	3	30	8	38
Total	227	100	23	100	14	100	10	100	21	100

7.4.4 Admission to Hospital due to MS Symptoms before, or at time of, Diagnosis

Forty percent of participants ($n=117$) were admitted to hospital due to their MS symptoms before, or at the time of, diagnosis. The remaining 60% reported that they had not been admitted to hospital due to MS symptoms before, or at the time of, diagnosis. Chi-square tests showed no association of admission to hospital due to MS symptoms before or at the time of diagnosis, with gender or country of birth or type of MS.

7.4.5 Suspicion of MS before Diagnosis was Made

Forty percent of participants ($n=117$) suspected that they had MS before the diagnosis was made. A chi-square test was performed to investigate whether suspicion of MS before diagnosis was made was associated with gender. An association was found between suspicion of MS and gender $\chi^2(1) = 5.67, p < .05$. A greater proportion of females (42.8%) reported suspicion

of MS before a diagnosis was made, than males (25.0%). Further chi-square tests showed no association between suspicion of MS and participants' country of birth, or between participants' type of MS.

As the number of participants reporting admission to hospital before or at the time of diagnosis ($n=117$) equalled the number of participants reporting suspicion of MS before a diagnosis was made ($n=117$), a check for association between the two groups of participants was conducted. A Chi-square test showed no association between the forty percent of participants who were admitted to hospital due to MS symptoms at or before the time of diagnosis, and the forty percent of participants who suspected MS before the diagnosis was made.

7.5 Post-Diagnosis Behaviour

The second research aim: To identify and further clarify the information seeking, social and health related behaviours exhibited by individuals within the first 12 months following a diagnosis of MS, is addressed in this third section as post-diagnosis behaviour of participants *within the first 12 months of their diagnosis of multiple sclerosis* is outlined. The following variables were examined; information seeking, discussion of diagnosis with another PwMS, disclosure of diagnosis to others, and lifestyle changing activities made following the diagnosis. Examinations of possible gender associations with each of the above were undertaken. As too were examinations of possible associations based on country of birth, and type of MS.

7.5.1 Information Seeking

Most participants (91%) reported engaging in more than one activity to seek out further information about MS in the first 12 months following diagnosis. Over half (54%) reported engaging in four or more different activities to seek out information on MS. Accessing

information via the internet (81%) and speaking to a medical professional for further information about MS (80%) were the two most reported activities. While 71% of participants reported contact with an MS Society, only 62% registered as clients with the MS Society in their state/country. A third of participants (34%) accessed information about MS from a library, and a quarter (26%) attended an information session or conference to learn more about MS in the first 12 months following diagnosis. Three participants (1%) reported no information seeking activities.

Chi-square tests were performed to investigate whether information seeking activities were associated with gender. There were no associations found between information seeking activities and gender, however, there was an association found between engaging in *no* information seeking activities, and gender $\chi^2 (1) = 5.02, p < .05$. A greater proportion of males (3.8%, $n=2$), reported engaging in no information seeking activities, than females (0.4%, $n=1$). However, this result must be viewed with caution due to small sample sizes.

Results of chi-square tests also indicated that there was no association between information seeking activities within 12 months of diagnosis and country of birth. Chi-square tests were also performed to investigate whether information seeking activities following diagnosis were associated with type of MS (See Table 11). An association was found between accessing the internet as an information seeking activity and type of MS $\chi^2 (4) = 10.40, p < .05$. A smaller proportion of participants with Benign MS (50%) reported accessing the internet as one of their information seeking activities in the 12 months following diagnosis, than participants with other types of MS (>50%). As internet use has increased over recent years (Illingworth, 2001), it was important to investigate whether there was a significant difference between years since diagnosis and type of MS (See Table 12).

Table 11

Frequency of Reported Information Seeking Activity as a Function of Type of MS

Information Seeking Activity	Type of MS									
	RR (N=227)		PP (N=23)		SP (N=14)		Benign (N=10)		Don't know (N=21)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Internet	190	84	18	78	9	64	5	50	18	86
Medical Professional	186	82	18	78	12	86	7	70	12	57
Contact MS Society	166	73	15	65	11	79	6	60	11	52
Register MS Society	146	64	13	57	10	71	6	60	9	43
Library	77	34	5	22	5	36	5	50	9	43
Information Session	57	25	7	30	7	50	3	30	3	14
No Activity	2	1	0	0	0	0	0	0	1	5

Table 12

Years since Diagnosis as a Function of Type of MS

Type of MS	Mean Years since Diagnosis	Standard Deviation	Sample Size
Relapsing Remitting	3.68	4.49	227
Primary Progressive	2.74	2.70	23
Secondary Progressive	4.36	3.43	14
Benign	4.70	3.50	10
Unsure/do not know/ was not told	3.67	6.02	21

A one-way ANOVA found no significant relationship between number of years since diagnosis and type of MS. As internet use is reported to be an information seeking tool for younger people (Atreja et al., 2005), it was also important to investigate whether there was a significant difference between participants' age at diagnosis and the type of MS diagnosed, and participants' age at diagnosis and accessing the internet as an information seeking activity. As was reported in Section 7.3.1, although a significantly greater age at diagnosis was found of participants with PPMS in comparison to those with RRMS, and those who were unsure/didn't know/were not told of their type of MS (See Table 3 for means and standard deviations), a t-test showed no significant difference between participants' age at diagnosis and whether accessing the internet was used as an information seeking activity.

7.5.2 Discussion of Diagnosis with Another Person with Multiple Sclerosis

Two hundred and seventy-two participants responded to this question. One hundred and twenty participants (44%) did not speak to another PwMS in the first 12 months following diagnosis, while 152 participants (56%) discussed their diagnosis with another PwMS. Participants who reported speaking to another PwMS in the 12 months following diagnosis also gave details as to how they contacted that person (See Table 13).

Chi-square tests were performed to investigate whether discussion of an MS diagnosis with another PwMS, and the avenue used for contact with that person, was associated with gender, country of birth or type of MS. There were no associations found.

Table 13

Discussion of MS Diagnosis with Another Person with MS

Avenue for Contact with Another PwMS	Sample Size	Percent
MS Society/Support Group	43	15.8
Friend/Acquaintance	42	15.4
Internet	26	9.6
Relative	20	7.4
Work	14	5.1
Other	7	2.6
No Contact with another PwMS	120	44.1
Total	272	100

7.5.3 Discussion of Diagnosis with Another Person with MS - Qualitative Data

One hundred and ninety-two (70.6%) of the 272 participants who responded to the question on discussing the diagnosis with another PwMS, added a comment on how they viewed the interaction or why they did not discuss the diagnosis with another PwMS. Qualitative responses were analysed with a view to developing themes or categories concerning participants' comments on meeting another PwMS in the first 12 months following diagnosis. Three broad categories emerged: 'neutral interaction', 'positive interaction', and 'negative interaction'. These first three categories were prominently and consistently reflected in the data, and each participant's response was coded into one of these three mutually exclusive themes. Two additional themes were also identified from reading the data. These fourth and fifth themes were

not mutually exclusive from the first three categories (or each other), but rather additional areas of interest deemed worthy of examination and reporting. The fourth theme was identified as ‘meeting online’. The fifth theme was identified as ‘reasons given for not meeting another PwMS in first 12 months’. A description and examples of each of these themes follow. Within the following section, participant numbers refer to the coding of participants’ questionnaires. Key words relevant to each theme are highlighted.

7.5.3.1. Neutral Interaction

Sixty nine percent of participants who spoke to someone else with MS in the first 12 months following their diagnosis ($n=105$) reported the contact in a neutral manner. For example: **“Yes, through the MS Society local branch”** (Participant 17154).

7.5.3.2 Positive Interaction

Twenty-four percent of participants who spoke to someone else with MS in the first 12 months following their diagnosis ($n=36$) reported a positive experience upon meeting another PwMS. For example, Participant 17938 valued the experience of giving information to, and receiving information from, someone who understood what it was like to live with the symptoms and the social ramifications of the illness:

Yes, was introduced to a lady with MS by a mutual friend. **We spoke about how MS was affecting us both at the time, what each was doing as far as treatment was concerned and the ways of dealing with well intentioned people’s advice.** It was good to speak to someone who knew what you meant when you were tired all the time. (Participant 17938)

This participant reported satisfaction in being able to share her specific experiences with someone who was able to relate to them. From the physical effects of MS, to the trials in communicating with others about the disease, this participant felt very positive about discussing varied MS related topics with another PwMS.

Participant 17075 reported meeting a positive PwMS at a local support group, within the first 12 months following her diagnosis. She described positive interactions with other PwMS, gaining additional information and support (above and beyond that offered by health professionals):

She was a **POSITIVE lady who inspired me** to take control of the disease. I joined the local swimming MS group and **found comfort in their stories and tips and hints that the doctors weren't able to offer. Surrounding myself with positive people was the best thing I could do.** (Participant 17075)

Together with other participants who described positive experiences upon meeting another PwMS, this participant clearly indicates being inspired by PwMS who demonstrated a positive approach to their MS.

These participants' first experience of another PwMS was described in positive terms. While some found meeting another PwMS inspiring, some simply reported the satisfaction in sharing personal information with another who had lived with similar symptoms, or had faced similar situations.

7.5.3.3 Negative Interaction

It may often be assumed by caring health professionals, relatives and friends of someone newly diagnosed with MS, that meeting another PwMS will be a necessarily positive experience for the person newly diagnosed. However, seven percent ($n=11$) of participants in the current study who spoke to someone else with MS in the first 12 months following their diagnosis viewed the interaction negatively. For example, Participant 18311 did not seek out the interaction himself but a friend with MS, who had not disclosed to him previously, sought him out when she learnt of his diagnosis:

A friend who found out approached me and told me she also has MS. We spoke about it a few times but she was **too negative with everything. Don't do this and don't do that and you shouldn't be working now that you've got MS...**

(Participant 18311)

This participant conveyed a frustration at the negative attitude put forward by his friend with MS about his future with the disease, as well as her own.

Participants also recalled situations where they felt a sense of despair at the level of MS-related disability they saw in those they met, combined with the implications verbally expressed about their future health. For example, Participant 18188 describes being initially terrified, and later depressed, upon meeting others with MS:

Went to one support group and met some people with **very progressive MS**. That was **terrifying**, especially because they wanted to know my symptoms and then

all said ‘Oh, yes. **We remember when we had only those symptoms**’. **Got very depressed and never went back.** (Participant 18188)

While the people in the support group may have believed they were being empathetic speaking of their common symptoms at diagnosis, the participant did not find comfort in the implied progression of her disease course. Instead, she found this interaction with other PwMS a terrifying, depressing and negative experience.

These participants’ first experience of another PwMS was described in negative terms. Participants found the interaction scary, alarming, confronting and off-putting. Some comments related to the negative impression made by another PwMS on the participant, if the other person’s physical ability was obviously affected. However, the pessimistic attitudes of other PwMS equally contributed to participants’ viewing this interaction as negative.

7.5.3.4 Meeting Online

An interesting (although not mutually exclusive) theme to emerge from the data was that a noteworthy number of participants consciously chose to meet other PwMS online or via email, rather than face to face or via the telephone. Seven percent ($n=10$) of participants who discussed their diagnosis with another PwMS did so over the internet. For example, Participant 17180 commented that he had met other PwMS exclusively “**...through the internet...** (the people with MS I met were) **very helpful and informative.**” Participant 17148 first met another PwMS nine months after her diagnosis, via email correspondence:

Nine months after I was diagnosed, I had a relapse and was given a three day course of steroid treatment... I was very scared and really needed to talk to somebody who knew what I was going through. My husband's co-worker's wife's friend had been diagnosed with MS five years before and had received the same steroid treatment a number of times, so... **we got in touch with each other by email and she was a great help to me answering my many questions.**

(Participant 17148)

This participant asserted that her situation had become frightening as she relapsed, prompting her to make contact with someone who had personal knowledge of MS. She portrayed her newly formed email relationship as of great benefit.

Some participants who met other PwMS on line reported a sense of security and safety. For example, Participant 19543 described feeling more at ease communicating with other PwMS through emails:

Yes, but not in person as it was, and still is, hard to come to terms with, but through emails. I joined Mc2 [an online community based in Victoria, Australia] and spoke to people in my situation... I still want to meet others that are closer to my age group and see how they are coping, but it (meeting face to face) is hard because then **I'd have to be more open physically** if you know what I mean. **Through the net it's great - I don't really know people, they don't know me.**

(Participant 19543)

As she was engaged in relationships with other PwMS through email alone, the participant did not feel as emotionally exposed as she considered she would have if meeting them physically.

The participants, who described meeting other PwMS on-line or via email, conveyed a sense of satisfaction at forming meaningful relationships with those who could offer valuable advice and support, without having to make themselves entirely vulnerable in a face to face relationship.

7.5.3.5 Motivation for Not Meeting Another PwMS in First Twelve Months Following Diagnosis

The fifth and final theme identified for consideration was the reasons given by participants for not meeting another PwMS in the first 12 months following diagnosis. Of the 120 participants who did not speak to another PwMS in the first 12 months following diagnosis, 40 (33%) volunteered reasons as to why they had not done so. Only a few participants stated that they had not spoken to another PwMS because their diagnosis occurred recently. For example: **“Not yet. I have been diagnosed less than 2 months”** (Participant 22780). Not having the opportunity to meet another PwMS in the first 12 months following diagnosis was given as the reason by 17 (14.2%) participants. For example: **“No. I don't know anyone”** (Participant 23577), and

I did not know of any one else in my area who had MS or I'm sure that I would have been in contact. **My doctor couldn't even tell me if there was an MS support group in my area.** (Participant 17335).

However, the remaining participants who provided a reason for not meeting another PwMS ($n=23$, 19%) indicated that while the opportunity was there, they consciously choose not to discuss their diagnosis with another PwMS because they were not ready to do so:

No, although it was suggested to me on two occasions with offers of contact details. I was **scared of what I would find out, I imagined these people as having a greater level of disability than me** (where I considered myself as having no disability at all), although I had been reassured that they were not disabled. (Participant 17114)

This participant described her fear of the visible disability she may have been presented with, in spite of reassurances from others. She reported actively avoiding meeting PwMS, for fear of being confronted by a disability level greater than her own.

Participant 17117 did not discuss her diagnosis with her sister, who also had MS, as she thought it would be too confronting:

My sister was diagnosed with ms probably 2 years before me. **When I was diagnosed I did not talk to her about MS because it was too close and it upset me. It saddened me to hear of her experiences and also scared me.** (Participant 17117)

While this participant had every opportunity to discuss her diagnosis with another PwMS, she felt uneasy doing so as she was aware of her sister's experiences with MS and found them scary and upsetting.

There were three distinct reasons given for participants not discussing their diagnosis with another PwMS in the 12 months following diagnosis. The first two involved a lack of time since diagnosis or a lack of opportunity to meet another PwMS. The third reason was formed from participants' conscious decision not to seek contact with another PwMS for fear that discussing their diagnosis, or even sighting another PwMS, would be too confronting or distressing.

7.5.3.6 Quantitative Analyses of Qualitative Themes

Chi-square tests were performed to investigate whether participant response to meeting another PwMS in the 12 months following diagnosis was associated with gender, country of birth or type of MS. An association was found between viewing the interaction as positive, and gender $\chi^2(1) = 4.17, p < .05$. A greater proportion of female participants (15.2%) reported the interaction with another PwMS as positive, than males (4.2%). An association was also found between not wanting to meet another PwMS in the first 12 months following diagnosis, and gender $\chi^2(1) = 4.17, p < .05$. A greater proportion of male participants (16.7%) reported not wanting to meet another PwMS as their reason for not discussing their diagnosis with another PwMS, than female participants (4.2%). No other associations were found between responses to interaction with another PwMS (or reasons for no interaction), and gender.

One association was found between not wanting to meet another PwMS in the first 12 months following diagnosis, and type of MS $\chi^2(4) = 10.42, p < .05$. A greater proportion of

participants who ‘did not know/were not told/were unsure’ of their type of MS (25.0%) reported not wanting to meet another PwMS as their reason for not discussing their diagnosis with another PwMS, than participants with RRMS (5.8%), Benign MS (11.1%), PPMS (13.6%), and SPMS (14.3%). No other associations were found between responses to interaction with another PwMS (or reasons for no interaction), and type of MS. There were no associations found between responses to interaction with another PwMS (or reasons for no interaction), and country of birth.

Chi-square tests were also performed to investigate whether participant interaction with another PwMS in the 12 months following diagnosis via the internet was associated with gender, country of birth or type of MS. There were no associations found.

7.5.4 Disclosure of Diagnosis

Participants were asked to list with whom they discussed their diagnosis of MS in the first 12 months following diagnosis. It was expected that partners, children, friends, psychologists/counsellors, employers and workplace colleagues may be among those listed. Complementary therapists, gym instructors, allied health professionals and religious ministers were examples of ‘others’ some participants reported disclosing to. In reporting the results, marital status, number of dependent children and work status were controlled for as required. For example, when looking at the percentage of people who disclosed their diagnosis to their dependent children in the first 12 months following diagnosis, only those participants who identified as having dependent children at the time of diagnosis were examined. These participants comprised the ‘valid’ number and were then used to find the ‘valid percentage’ of participants who disclosed their diagnosis of MS to their children. Two hundred and eighty five participants responded to this question. The results are displayed in Table 14.

Table 14

Disclosure of Diagnosis in First 12 Months

Diagnosis Disclosed to	<i>n</i>	Valid <i>n</i> *	Valid Percent ^
Partner/Husband/Wife	208	208	100
Family member/s	267	285	93.7
Close Friends	222	285	90.5
Children	95	120	79.2
Boyfriend/Girlfriend if 'Single'	19	24	79.1
Employer	157	246	63.8
Workplace Colleagues	142	246	57.7
Counsellor/Psychologist	55	285	19.3
Other	39	285	13.7
No one	2	285	0.7

*Valid *n* = the total number of participants who could have disclosed to the individual/s listed in each category

^Valid Percent = valid percentage of participants who disclosed to the individual/s listed in each category

One hundred percent of participants who were married, living with their partner, or in long term relationships (*n*=208) disclosed the diagnosis of MS to their partner. Just over a third of those who identified as 'single' (*n*=19) also reported disclosing their diagnosis to their partner (presumably short term boyfriend/girlfriend). Seventy-nine percent of participants with dependent children (*n*=95) told their children of the diagnosis. Of those participants in paid employment, 58% (*n*=142) disclosed their diagnosis of MS to workplace colleagues, while 64% (*n*=157) discussed their MS with their employer within the first 12 months of diagnosis. Two participants did not disclose their diagnosis of MS to anyone within the first 12 months following diagnosis.

Chi-square tests were performed to investigate whether disclosure of diagnosis to certain people was associated with gender, country of birth or type of MS. As mentioned above, marital status, number of dependent children and work status were controlled for as required. For example, a test of association between gender and disclosure of diagnosis to employer was only carried out on the sample of participants who reported their work status at the time of diagnosis as employed ('employed full time', 'employed part time', or 'employed and student').

An association was found between disclosing the diagnosis to dependent children and gender, if participants had one child $\chi^2(1) = 10.85, p < .01$. A greater proportion of females with one child (80.6%) disclosed their diagnosis to the dependant child than males with one child (22.2%). No other associations were found between whom participants disclosed to, and gender. An association was found between disclosing the diagnosis to workplace colleagues and the country of birth of participants, if participants were working full time $\chi^2(5) = 12.83, p < .05$. A greater proportion of participants working full time from the U.S.A (74.3%), Australia (63.9%), and New Zealand (55.0%) disclosed their diagnosis to workplace colleagues than participants from Canada (44.4%), the U.K. (36.4%), and Other (33.3%). No other associations were found between who participants disclosed to, and participants' country of birth. No associations were found between whom participants disclosed their diagnosis to, and participants' type of MS.

7.5.5 Disclosure of Diagnosis – Qualitative Data

Once participants had identified who they had disclosed their diagnosis of MS to in the first 12 months following diagnosis, they were asked to explain why they had disclosed their diagnosis. Two hundred and eighty two participants responded to this question. Qualitative responses were analysed with a view to developing themes concerning participants' reasons for disclosure of diagnosis to others. Three broad themes emerged: 'Perceived lack of control', 'To

gain emotional support’, and ‘Why wouldn’t you tell everyone?’. Each participant’s response was coded into only one of these three themes. An additional theme of ‘I regret disclosing’ was also found, and while not describing a reason for disclosure, it will be presented here as a theme that has come from this data, as it is important to acknowledge and describe what participants have learnt from their experiences, whether good or bad. This fourth theme was not mutually exclusive as some participants described the reasons behind disclosure, before going on to explain why they regretted doing so.

A description and examples of each of these themes follow. Key words relevant to each theme are highlighted, and participant numbers refer to the coding of participants’ questionnaires.

7.5.5.1 Perceived Lack of Control

One hundred and twenty two participants (43.3%) reported that they had no choice but to disclose their diagnosis of MS to others. A diagnosis of MS is often made after weeks, months or years of symptoms, numerous appointments with doctors and neurologists, and much speculation about what could be wrong (Eeltink & Duffy, 2004). During the pre-diagnosis period, people experiencing MS symptoms may tell friends, family members or employers/colleagues of their symptoms for emotional support. For example:

While I was having symptoms of my numb hand I told everyone so they could help me and when I went for my MRI scan and lumber puncture I also told them without realising I would have MS. (Participant 17138)

Participants often shared their symptoms with others pre-diagnosis, without forethought to whether or not they would want to share the eventual diagnosis. Recognising that certain

individuals in their lives knew something was wrong, a number of participants felt compelled to explain the cause of symptoms once known, thereby perceiving a lack of control over their choice to disclose. Participant 17147 expressed a sense of obligation to her employer to be forthcoming with the diagnosis because of her use of sick leave leading up to the diagnosis:

Because I had been ill for a long period of time prior to my diagnosis, and I had missed 40 days of work in an eight month period, I felt obligated to tell my employer of my diagnosis once it was made. (Participant 17147)

Perceived lack of control over disclosure of diagnosis was also demonstrated by those participants who reported feeling obligated to tell employers of the diagnosis if they believed MS was having a negative impact on their ability to do the job they were employed to do. For example:

I told my employer because I felt I couldn't cope with teaching the children anymore **and felt I should resign for the sake of the children so they could have a teacher who could give them 100%** not just the tired teacher who could no longer play the piano and often seemed not to have the energy to help them as I wanted to. (Participant 17005)

For others, it was the presence of obvious physical symptoms that led some participants to report that they had no choice but to disclose. Participant 17202 reported a lack of control over the decision to disclose her diagnosis to others due to her obvious lack of mobility:

Shortly after I was diagnosed **I totally lost the ability to walk. Showing up in an electric scooter tends to bring questions. I had no choice.** (Participant 17202)

Similarly, Participant 18102 perceived that he had to disclose, given his equipment needs, and need for physical assistance. He reported having no other option:

I... **needed assistance** to be driven to work and very soon thereafter **I had to use a walker. This then meant hiding the truth was not a realistic option for me.** (Participant 18102)

Participants also recalled situations where they perceived a lack of control around their choice to disclose, when their MS symptoms could be misconstrued as being caused by something else. It was felt that some MS symptoms could be embarrassing if not understood. For example:

I wanted people to understand that my abilities and capabilities would depend on what sort of a day I was having. For example, **I was tired of people assuming I was drunk in the middle of the day just because I couldn't walk straight.** (Participant 16933)

Participants did not want others falsely concluding that they were mentally ill, drunk or lazy (typical explanations given to the invisible symptoms of MS) when they were in fact experiencing pain, vertigo, or fatigue. Participant 17114 indicated that she perceived there to be

no choice as to whether or not to share the diagnosis, given the assumptions her colleagues would make if she did not disclose the medical reason for her fatigue:

I was experiencing fatigue. **I wanted people to know that I had a serious illness** and that this was affecting my mood and ability to carry out my usual work, **that I wasn't lazy or depressed.** (Participant 17114)

Similarly, Participant 17335 felt that colleagues, friends and family thought she was creating excuses so as to get out of work or social gatherings:

I had been having all sorts of problems off and on for years like days when I couldn't walk or pain so bad that I couldn't go to work. I felt that **people thought that I was making up all sorts of excuses for not being able to attend work or go to different social events**, so in some ways I felt **by telling people that I had at last found out a name for what was causing me all these problems** my friends, family and work friends **would understand that I was not making things up.** (Participant 17335)

This participant also hinted at experiencing a small amount of relief when able to name the cause of her socially restrictive symptoms. A diagnosis of MS brought much relief to some participants who, together with others in their life, thought that pre-diagnosis symptoms may have meant something perceived as life threatening, such as cancer. Participant 17012 recounted the reasons for telling her family. She felt she had an obligation to tell her family the 'answer' (diagnosis) to allay misguided assumptions of previous symptoms:

I had to tell my family about my diagnosis, as **it provided them with an answer** to why I was always having headaches, loss of movement, and the hearing loss. In hindsight **I think that I saw the diagnosis as a relief, as I was beginning to suspect that I had a brain tumour!** (Participant 17012)

The threat of an alternative diagnosis of cancer was reported by a number of participants as the reason they felt obligated to disclose the diagnosis of MS to family, friends and colleagues. Participant 16548 described telling her family and colleagues of health problems and tests she was going through:

Everyone knew I was going to see the neurologist after my MRI & they all asked what the result was. **Family were very concerned as I had lost my mother & brother both to cancer** within 12mths of each other & then I started to be unwell within the same 12mths. **So everyone was waiting the results.** (Participant 16548)

This participant may not necessarily have wanted to disclose her diagnosis of MS, but felt she had little choice given her family's concerns that her symptoms were caused by cancer.

A perceived lack of control was also identified in participants' responses when it was reported that it would have been more stressful to hide the diagnosis than to disclose it. These participants reported that the decision to disclose had been made for them, given their living situation or circumstance. For example:

Given the fact that **my treatment would require me to take a daily injection, I didn't think I had a much of a choice when it came to telling my immediate family.** I did keep it a secret from most of my close friends and my not so immediate family. (Participant 17182)

Participant 22808, below, would have felt extra pressure having to 'hide' her diagnosis, particularly when she had identified possible ways of others finding out. She expressed fear around others learning of her diagnosis without her telling them herself:

To take the pressure off. **The MS diagnosis was pressure enough without having to go around hiding the diagnosis** from significant people in my life. A colleague's husband was practicing neurology next door to my own neurologist. **I feared being found out so best the news came from me.** (Participant 22808)

Being 'found out' was of particular concern for those participants who reported living in rural areas or 'tight knit' communities. Such participants perceived a clear lack of control over their decision to disclose the diagnosis to others in their community. For example:

Had no choice but to be honest about what was happening. I became ill on a Friday, was hospitalised on Sunday, and transferred to a larger hospital as **we live in a rural area... It was impossible for me to keep my diagnosis to myself in these circumstances.** (Participant 17595)

In some cases, the decision to disclose was not only perceived by participants as out of their control, but the decision was literally made for them, as others informed participants' friends, family, acquaintances or colleagues of their diagnosis of MS. For example:

At work, **I chose to speak with the Chief Social Worker to warn him that I may need to take time off for medical reasons...** In turn, he asked permission to confidentially advise the Director of Allied Health and I was comfortable with that notion. **Sadly, the DOAH decided to make a public announcement about my diagnosis** at the next Allied Health Managers meeting and soon, **it became public knowledge**. This all happened during the 1st month after diagnosis. **I then quickly advised my family and friends as in country areas, news travels fast.** (Participant 17134)

This participant described her rural setting as a contributing factor to the decision to disclose her diagnosis to her friends and family members quickly. Similarly, Participant 17176 reported living in a small town and having little choice but to disclose, given false rumours of terminal disease:

I live in a small town. I taught school and never missed. All of a sudden I missed and was in the hospital. **The diagnosis almost made it to Nashville before I returned from the hospital.** As part of my job I had to drive a mini-bus to shuttle students from other schools to where I taught as coordinator of the gifted program. **Rumours were out that I had a terminal disease.** I had to be honest

with my elementary-aged students to **assure them that I was neither dying nor contagious.** (Participant 17176)

The primary reason for disclosure in the first 12 months following diagnosis was that participants perceived a lack of control over the decision. This lack of control took a variety of forms depending on the participants' situation. Some participants had told others about symptoms pre-diagnosis and felt compelled to explain the diagnosis once known. Others felt that their obvious physical symptoms or equipment left them with little choice but to disclose. A number of participants wanted to allay misguided assumptions about their symptoms, and felt they could only do that by disclosing. Finally, a group of participants reported that while finding it more stressful to hide the diagnosis, they perceived they had no choice but to disclose their diagnosis of MS to others. In the face of the uncertainty that a diagnosis of MS brings, these participants perceived a lack of control, not only over the course of the disease, but also over their choice to disclose the diagnosis of MS to others.

7.5.5.2 To Gain Emotional Support

The second theme identified as the reason given by participants for their disclosure of the MS diagnosis to others in the first 12 months following diagnosis, was in order to gain emotional support. One hundred and two participants (36%) reported that they disclosed their diagnosis to gain emotional support. Participants reported a need to be able to talk about the diagnosis, and their fears for the future, with those who they could trust to provide them with the level of emotional support they needed. These participants felt that the natural thing to do in a situation such as receiving a diagnosis of a chronic illness was to talk about it. For example, Participant 17165 thought that the family members she shared her diagnosis with could help her: "**My world**

was crashing in around me & these people were the ones that I thought could assist me”. Conversely, Participant 19248 was concerned that she would upset her family members with talk of her diagnosis. She commented that she sought professional assistance to gain the emotional support she needed:

I saw a counsellor at the SA (South Australia) MS Society. It was someone I could talk to about my diagnosis and feelings without feeling guilty. I did not want to upset my family/husband by crying and being depressed all the time.
(Participant 19248)

Participants expressed the belief that they trusted the people they chose to disclose the diagnosis to, and felt comfortable that these people would respond to their personal information with care and understanding. Participants cited disclosing their diagnosis as a means to increase the provision of support, not only to themselves, but to their immediate family members also. For example:

I knew my family would rally behind me. At the time of diagnosis I was hospitalised and neither I nor my doctor knew to what extent the attack would have on my capabilities in the future so felt **it was important to prepare for the need for support of family and friends, not just for me, but particularly for my family.** (Participant 16967)

Some participants believed that close family members would be just as affected by the diagnosis of MS as they were. This belief meant that family members were often provided with

the same level of information as the person newly diagnosed. Participant 23527 concluded that she wanted her family to be informed and comfortable with her diagnosis. She understood that she would receive the support that she desired from her family when needed, if they had a full understanding of MS:

My family had a right to know. I didn't want them to find out accidentally, and also **if support is ever needed they have a prior understanding of the disease.** I also wanted to be able to answer any questions they had, backed up by as much information as I had learnt from my own research. **I felt the more info they had, the more comfortable they would feel. I didn't want ignorance to be a worry to them or me,** and I didn't want them to label or blame themselves.
(Participant 23527)

As lack of knowledge is not conducive to support, Participant 17652 identified that she would not be offered support if her significant others did not have an knowledge of the disease and her experience with it: **“I knew that I would need support and people could not offer support, understanding or patience if they did not know what was going on”.** Participant 17098 recognised that without clear communication about the disease following her disclosure, she would not receive the support she needed both in her home and work life:

I felt that **one of the ways I was going to deal with this diagnosis was through the love and caring of family and friends.** Since I had no visible symptoms, **the only way anyone I cared about would know was through my communication.** I also knew that I had to find a way to manage my fatigue in the workplace; **my**

employer and colleagues have been very supportive in helping me get a daily rest period during my lunch hour. I lie down for about twenty minutes and sometimes fall asleep. My co-workers are very solicitous that I get this time and protect me from interruptions. **I have never missed a day of work because of MS and I feel that is because I work in such a caring environment.**

(Participant 17098)

The second most common reason given by participants as to why they disclosed the diagnosis was to gain emotional support. Participants sought this support mainly from family and friends, but some also described informing employers and colleagues about their diagnosis with a view to gaining both practical and emotional support. A small number of participants also reported seeking professional support from psychologists or counsellors. Trusting the people they disclosed to and providing them with adequate information about MS, was regarded highly by these participants, along with the use of clear communication.

7.5.5.3 Why Wouldn't You Tell Everyone?

The third theme identified as the response given by participants following their disclosure of the MS diagnosis to others, was a sense of 'why wouldn't you tell everyone?' When asked why they disclosed their diagnosis of MS to others, 58 participants (20.6%) gave a response that indicated they did not consider doing anything but disclose their diagnosis. Upon being diagnosed with MS, some participants felt an overwhelming urge to tell all of their family, friends, acquaintances, and colleagues. These participants did not want to hide their diagnosis, but expressed the desire to be honest with themselves as well as with those around them, and felt that disclosure to others assisted them to deal with their diagnosis, and move on. For example:

I thought that I may as well tell everyone about it - so that I could get on with my life. I thought **‘what is the point in keeping this huge ‘time bomb’ a secret?’** It was hard for me to deal with, but it was made easier when I told people. **I prefer to be honest about the MS** to myself and my friends & family around me. (Participant 18581)

Participant 18311 was keen to demonstrate to his family, work and social groups that a diagnosis of MS was nothing to conceal, and that it would not define him:

It's something that I didn't want to hide. If I did hide it, I would have felt like it was something that had a grasp on me. **There is nothing wrong with having MS.** Like someone once told me **‘I have MS, MS does not have me’...** **Keeping things inside of you I think makes you feel worse.** (Participant 18311)

This participant stated very clearly that he felt no need to be embarrassed about his newly diagnosed condition. He believed that keeping the diagnosis to himself would have made him feel worse about his situation. Similarly, Participant 17871 did not want to hide the diagnosis of MS and explained that receiving the actual diagnosis better equipped her to incorporate the management of MS symptoms into her lifestyle. She reported that telling others about her diagnosis felt like the natural thing to do:

To me, **the diagnosis of MS is a ticket to managing my condition better** because I now have information to enable me to manage it appropriately. And, I

have the chance to lessen the frequency and severity of attacks by taking Interferon. **Telling people about this seems normal and natural. Why would I hide it?** (Participant 17871)

A sense of responsibility to educate was another reason given for telling 'everyone' about the diagnosis. While family, friends and work colleagues were to be given up-to-date information on the disease, participants suggested that there was also a need for increased knowledge of MS in the wider community. It was felt that greater community knowledge of MS would benefit all, not just the PwMS providing the information. Participant 18194 reported a desire to challenge the misconceptions held in the community about MS:

...I feel that through detailing my experiences, **I can change the 'face of MS' in a lot of people's minds.** I can, through educating others, help **alleviate the fears** and also **reduce the myths associated with MS** and other disabling diseases. **Knowledge IS power, and not only for those with the disease but for those we encounter as well!** (Participant 18194)

This participant reported wanting to assist people with MS and other diseases, through educating the community. Participants' responses described an advantage to have as many people as possible correctly informed about the disease, in an attempt to de-mystify MS.

Some participants, who chose to disclose their diagnosis widely, did so in order to give others a positive example of MS. Participant 17098 reflected that the first thought of someone with MS is not necessarily the reality:

I really don't conceal my disease if a situation comes up where I might reveal it, because **I feel it helps people to know, since this is such a common disease, that you aren't necessarily going to be disabled immediately.** That is what you imagine when you are first diagnosed and **it is very important for people to have living examples that counteract that message.** (Participant 17098)

A positive example of a PwMS was thought to be lacking in the wider community perception of what having MS means. Participants wanted the notion that 'a diagnosis of MS only happens to other people' to be dispelled, and they wanted to break the clichés associated with how a chronic illness or disability can affect those living with it.

These participants wanted to tell the people in their lives, and those in their communities, about their diagnosis of MS. They wanted to be honest, and some reported the act of disclosure as being of assistance to their coping. Combined with the desire to educate and increase awareness of MS, these participants asked the question: 'why wouldn't you tell everyone?'

7.5.5.4 I Regret Disclosing

The fourth theme relevant to a discussion on disclosure of diagnosis (although not mutually exclusive to the three themes already examined) came from participants' comments regarding their regret at disclosing their diagnosis. Fifteen participants (5.3%) indicated that they regretted their disclosure of the diagnosis to others. These participants had disclosed to others in the first 12 months following diagnosis but, on reflection, stated that they regretted doing so and if they had their time again they would be more selective in who they told, if anyone at all.

Participant 19510 suggested that the negative reactions she received from telling three family members stopped her from telling anyone else:

The reactions of those I told put me off telling others i.e. they have all cried a lot and expected the worst possible outcome - **they don't believe me when I tell them I'm optimistic that things will improve... Even doctors expect the worst as a rule.** Participant 19510.

Some participants, who willingly shared the diagnosis with others initially to gain emotional support, reported regretting the decision based on the responses they received to their disclosure. Participant 18528 recounted receiving pity, and thereby regretting her decision to share the diagnosis with certain individuals:

It finally gave an answer to why I looked OK but was actually feeling so unwell. **I thought it would take some pressure off if I shared it with friends and family. Some people I still wish I had never told. I don't like pity.** My husband of 23 years has since left, he doesn't handle illness well. Participant 18528.

Instead of receiving support following disclosure as was expected, some participants were told stories of PwMS much worse off than them, which made the newly diagnosed PwMS feel very uncomfortable. This experience was also often shared by significant others. Participant 18897 gave a powerful example of his partner disclosing the diagnosis to a work colleague, only to receive potentially damaging feedback:

I found that **people don't always react with open support**. On one occasion when my fiancé was at work, she became upset about my recent diagnosis and asked if she could leave, when asked why, **she explained the situation and the response was that she had better find another partner because MS turns people into vegetables**. That comment did more damage to my relationship than I could ever do. **Therefore from that point onwards both my partner and I do not talk about MS to anyone anymore**. (Participant 18897)

This experience clearly shaped the participant's attitude, and the attitude of his fiancé, toward sharing the diagnosis with others in the future.

Conversely, some participants were told stories of PwMS much better off than them, which they found depressing rather than supportive. For example:

I was encouraged by partner and counsellor to discuss with all the other people that I ticked in the above list. In some ways they had to know but **if I had to do it again I wouldn't tell them... It became really tiresome and depressing that they were supposed to be acting as my support but kept telling me stories about other cases of MS where the person did not have a particularly severe course of the disease** eg 'Susan's grandmother had MS and she was fine'... I now get asked 'so when are the injections going to cure you?' mind you I have explained the basics of immunotherapy many times. **It felt like I had to be like an MS information seminar each time I told the story**. (Participant 22584)

Participant 22584, above, explained that she regretted disclosing her diagnosis so widely. While those she told may have thought they were supporting her by sharing 'positive' stories of other PwMS, this participant clearly perceived these stories as unhelpful. She continued her response to indicate that she was tired of providing information to others, often repeatedly.

Some participants reported regretting disclosing the diagnosis to their employers specifically. While they thought their employer would be supportive and understanding, these participants were shocked at their lack of empathy after hearing of the diagnosis. For example:

My work colleagues & employer had to find out, because I was so distressed at the time, and I didn't want to lie about what was happening. That was probably the only mistake I made, since people definitely treated me differently at work - I felt that they thought I often 'copped out' of working overtime hours. I have since changed employers and have chosen not to tell them about the MS. I don't suffer any obvious symptoms, and I enjoy the fact that people treat me as 'normal'. I now keep MS away from work. (Participant 18581)

This participant expressed her regret at disclosing her diagnosis of MS to work colleagues and her employer, and explained how that experience shaped her behaviour in the next workplace.

Confidentiality issues arose for some participants following disclosure as they struggled to keep control over those that knew. Participant 21691 perceived that she had no choice but to

disclose her diagnosis of MS to her friends, but later regretted doing so as the information was not treated as confidential:

The only reason I told my close friends is that they knew I had the weakness in my right leg & was trying to find out what it was caused from & that I had an appointment with neurologist. Otherwise I would never have told them. I wish I had told them I just had a pinched nerve or something like that as they were told not to tell anyone & some of them have told close family which has distressed me very much. (Participant 21691)

Similarly, Participant 22584 described losing control of her private health information when she wrongly assumed that others would keep the matter confidential:

I also assumed that people would keep it as a private matter but they didn't which made me feel less control and caused lots of conflict with my siblings who told many people. (Participant 22584)

A disclosure of MS cannot be taken back. Once the diagnosis of MS had been disclosed to certain individuals, these participants reported wishing that they had kept the diagnosis of MS to themselves. Reasons for regretting the disclosure included negative responses from others, hearing stories of other PwMS that made participants feel uncomfortable, and a reduction in the confidentiality of personal health information.

7.5.5.5 Quantitative Analyses of Qualitative Data

Chi-square tests were performed to investigate whether reason for disclosure in the 12 months following diagnosis was associated with gender, country of birth or type of MS. No associations were found. Similarly, there were no associations found between a participant regretting the disclosure of their diagnosis and gender, country of birth or type of MS.

7.5.6 Lifestyle Changing Activities

Participants were asked to list any lifestyle changing activities they participated in within the first 12 months following diagnosis. Two hundred and seventy five participants responded to this question. When reporting the results, participants' work status was controlled for as required. For example, when looking at the percentage of participants who reported a reduction in work hours, only those participants who identified as employed at the time of diagnosis ('employed full time', 'employed part time', or 'employed and student') ($n=237$) were examined.

Most participants (76%) reported engaging in two or more lifestyle changing activities in the first 12 months following diagnosis. Roughly half (52%) reported engaging in three to six lifestyle changing activities following diagnosis. The commencement of taking vitamin supplements was the most reported lifestyle changing activity ($n=142$, 51.6%), followed by a change in diet ($n=125$, 45.5%), and then the commencement of immunotherapy ($n=106$, 38.5%). Ninety-eight participants (35.6%) increased the amount of exercise they engaged in, while 67 participants (24.4%) decreased their level of exercise following diagnosis. Twenty percent of participants ($n=53$) reported an increased interest in spirituality following diagnosis, while nine participants (3.3%) reported a decrease in interest. Thirty percent of participants ($n=71$) who identified as employed at the time of diagnosis reduced their work hours in the 12 months

following diagnosis, and 20 percent ($n=46$) experienced a change of work/career. Twelve participants (4%) reported no lifestyle changing activity following diagnosis.

Chi-square analyses were performed to investigate whether any of these lifestyle changing activities were associated with gender. Only one association was found. An association was found between an increased interest in spirituality and gender $\chi^2 (1) = 6.92, p<.01$. A greater proportion of females (22.2% of females, $n=50$), reported an increased interest in spirituality, than males (6.0% of males, $n=3$).

Results of chi-square tests indicated only one association between lifestyle changing activities and country of birth. An association was found between the commencement of immunotherapy and country of birth $\chi^2 (5) = 23.28, p<.01$. See Table 15 for participant commencement of immunotherapy as a function of country of birth.

Table 15

The Commencement of Immunotherapy as a Function of Country of Birth

Commencement of Immunotherapy	Country of Birth											
	Australia		U.S.A		U.K		N.Z		Canada		Other	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes	55	44.0	27	56.3	7	18.4	4	12.9	6	35.3	7	43.8
No	70	56.0	21	43.7	31	81.6	27	87.1	11	64.7	9	56.2
Total	125	100	48	100	38	100	31	100	17	100	16	100

A greater proportion of participants born in Australia, the U.S.A , Canada and ‘Other’ reported commencing immunotherapy within the first 12 months following diagnosis, than in the U.K or New Zealand. Less than twenty percent of participants from the U.K and New Zealand commenced immunotherapy treatment in this time.

Chi-square analyses were also performed to investigate whether lifestyle changing activities following diagnosis were associated with type of MS. Two associations were found. An association was found between the commencement of immunotherapy and type of MS $\chi^2(4) = 26.48, p < .01$. A greater proportion of participants diagnosed with RRMS ($n=98, 46.2\%$ of participants with RRMS) reported commencing immunotherapy within the first 12 months following diagnosis, than participants with PPMS ($n=5, 22.7\%$ of participants with PPMS) or SPMS ($n=3, 23.1\%$ of participants with SPMS), Benign MS ($n=0, 0\%$) and those that did not know their type of MS ($n=0, 0\%$). A second association was found between a reduction in work hours and type of MS, if the participant was working full time $\chi^2(4) = 15.91, p < .01$. See Table 17 for participant reduction in work hours as a function of type of MS. A greater proportion of participants with SPMS and participants who did not know/were not told/were unsure of their type of MS, reported a reduction in their work hours than those with RRMS, PPMS or Benign MS.

Table 16

Reduction in Work Hours as a Function of Type of MS

Reduction in Work Hours (if working full time)	Type of MS									
	RR		PP		SP		Benign		Don't know	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes	33	26.2	4	33.3	7	87.5	1	16.7	6	50.0
No	93	73.8	8	66.7	1	12.5	5	83.3	6	50.0
Total	126	100	12	100	8	100	6	100	12	100

7.5.7 Post-Diagnosis Behaviour – Qualitative Data

Participants were asked to provide a comment on anything that they thought assisted or hindered them in coping with the diagnosis of MS in the first 12 months following diagnosis. Two hundred and fifty three participants (85.8% of total sample) responded to this question. Of these, 226 participants (89.3% of respondents to this question) made a comment regarding what they found to be of *assistance* in their coping with the diagnosis. Seventy-seven participants (30.4% of respondents to this question) commented on what they thought was a *hindrance* to their coping with the diagnosis of MS. Qualitative responses were analysed with a view to developing themes concerning factors that assisted participants in coping with the diagnosis, and themes concerning factors that hindered participants in coping with the diagnosis. Four broad themes emerged in regard to factors that participants perceived as being of assistance: ‘Maintaining a positive attitude’, ‘Making practical changes’, ‘Changing health behaviours’, and ‘Information seeking and sharing’. Four broad themes emerged in regard to factors that participants perceived as a hindrance to their coping with the diagnosis: ‘Dealing with the attitudes of others’, ‘Attempting to maintain a pre-MS lifestyle’, ‘Information overload’, and ‘Negative examples of other PwMS’. The two main categories of themes were not mutually exclusive as some participants described both factors that assisted and factors that hindered their coping with the diagnosis of MS in the first 12 months following diagnosis.

A description and examples of each of these themes follow. Participant numbers refer to the coding of participants’ questionnaires, and key words relevant to each theme are highlighted.

7.5.7.1 Factors that Assisted Participants to Cope with Diagnosis

Two hundred and twenty-six (89.3%) participants provided a comment on what they perceived as being of assistance to them in the first 12 months following diagnosis. An

additional twenty-seven (2.8%) participants indicated that nothing had assisted them to cope with the diagnosis of MS in the first 12 months. These participants either wrote 'n/a' or 'no' as a response to the question, or indicated that there had not been enough time since diagnosis to offer comment, for example: **“I only found out 4 weeks ago so it is early days for me”** (Participant 19947). Some participants did not provide comment as they reported no change to their lives in the first 12 months following diagnosis, for example: **“Not in the first twelve months... Any action I have taken regarding my MS has been at a time later than the first twelve months”** (Participant 21393).

The comments offered by the 226 participants on what they found to be of assistance to them following diagnosis were categorised into four themes: 'Maintaining a positive attitude', 'Making practical changes', 'Changing health behaviours', and 'Information seeking and sharing'. These are described in the following four sections.

7.5.7.1.1 Maintaining a positive attitude. Maintaining a positive attitude was the most frequently identified theme in participants' comments on what assisted them to cope with the MS diagnosis in the first 12 months following diagnosis. Seventy-six participants (33.6% of participants who provided a comment on what they perceived as being of assistance) reported that they found maintaining a positive attitude was the primary thing that assisted them to cope with the diagnosis. For example:

A positive attitude without a doubt was the greatest assistance in accepting, understanding and coping with such a life change. I was often accused of not

accepting because I was too positive, but I believe I did accept very early and just ploughed ahead. (Participant 16967)

This participant received feedback from others that his positive attitude was indicative of his inability to accept the diagnosis. However he was adamant that this was not the case, and that his ability to remain positive truly assisted him. Similarly, Participant 18194 was viewed by others as being in denial. However, she demonstrated her positive attitude toward her situation by describing MS as a 'gift':

I chose to see MS as a 'gift' in my life and not a 'sentence'. I realized that I might not have the time to do all of the things that I'd hoped to do in my life and so **I started checking off the things on my personal 'life list'.** I'd always wanted to learn to pilot an aircraft and so I started flight lessons, fought the FAA for the 'right to fly' and passed my certification. I also began sky-diving (another life dream). **Some people saw it as a form of denial but I found it a source of strength** - to prove to myself that I was a capable and strong individual. (Participant 18194)

Viewing MS as a 'gift' assisted this participant to prioritise what life goals and aspirations she wanted to fulfil. She found that the diagnosis encouraged her to reach these goals, possibly earlier in her life, than if she had not been diagnosed with MS and clearly perceived this positive approach to be of assistance. Participant 19974 also had a positive attitude toward the diagnosis as she saw it as an opportunity to appreciate life more fully:

I believe that I am an extremely emotionally strong person so I was able to make the decision that **this disease is going to make me a more interesting person, and I will be able to have a greater appreciation for life. I have realised that the important thing is to remember to remain positive otherwise things will turn to ‘crap’.** (Participant 19974)

This participant made a conscious decision to view MS as a positive addition to her life, not only because it assists her to appreciate life, but also because she perceived that viewing it any other way would lead to negative outcomes. Maintaining a positive attitude toward living with MS was important for these participants, indeed this positivity seemed to carry through to other aspects of their lives as well. For example:

The only thing I have changed I guess, is my attitude to life – I appreciate it much more, don’t take things for granted like I used to and I don’t get upset about the little things anymore. (Participant 17117)

This participant reported a broader attitude change following diagnosis, as she re-evaluated the importance of the events, big and small, in her life. Participant 22855 extended on this theme and explained why his positive attitude led to an increased appreciation for everything:

I think I just realised that anything can happen in life and you never know what’s around the corner. Make the most of every day and as I said, focus on what you can, not on what you can’t. When I was in rehab learning to walk again,

I realised that it's the little things we take for granted... like walking for instance... It's given me a new lease on life - I know that sounds clichéd. I have another saying – 'I woke up breathing this morning, so I guess I have another chance' !!! (Participant 22855)

Other participants were also keen to impart sayings or adages that reflected their positive attitude towards life with MS. Many participants made reference to 'not knowing what tomorrow will bring' or 'not knowing what is around the corner'. Another example came from Participant 18528:

My favourite saying is **'never put off 'til tomorrow what you can do today because if you can do it today and you like it you can do it again tomorrow'**. **I changed my job to something I enjoyed, with less stress. I stopped worrying about small things.** I try to focus on each moment today instead of dwelling on what may happen tomorrow. (Participant 18528)

This participant touched on the reoccurring themes of prioritising and stress reduction that were mentioned by a number of participants who identified maintaining a positive attitude as their primary assistance following the diagnosis. Similarly, Participant 17360 responded with:

I also tried to put into perspective the more important aspects of my life, i.e. relationships with family and friends as opposed to my material objectives. I have different views on my life since the diagnosis. **I try not to be angered or**

aggravated by unimportant incidents. I try to appreciate aspects of me and my life that previously were in my opinion unsatisfactory. (Participant 17360)

Some participants expressed their positive attitude by comparing themselves to others they perceived as worse off: **“I realized that everybody has something wrong with them. Some people have worse things than MS. I can sit around and wallow in self pity or I can do something about it.”** (Participant 17091) This participant made a clear decision that a negative or self pitying attitude would not assist her in dealing with the diagnosis. Similarly, Participant 17128 responded by identifying those she perceived as facing a worse situation than hers. She reported gaining a sense of perspective on her situation, and even went as far as suggesting she should be thankful for her diagnosis:

I had been dealt a blow and life seemed more precious so I intended to make the most of it.... **The whole thing made me realise that there are many more people out there who are far worse off than me. People dying of cancer, people dying in third world countries and all sorts so for me to feel sorry for myself is selfish** - I am alive and well, I only have mild relapse/remitting MS and **I should be thankful!** I started living my life. (Participant 17128)

For some participants, maintaining a positive attitude was intricately linked to their belief in God. Together with comments on the importance of maintaining a positive attitude, some participants indicated that prayer, belief in God, religiosity, or an increased interest in spirituality, was of imperative assistance following diagnosis:

Prayer and more prayer! NO ONE GETS AWAY SCOT-FREE! Every one of us has something to deal with. **My positive attitude and reaching out to others that were in more need really helped.** (Participant 17204)

Participant 17105 reported a previous commitment to religion, and an increased interest in spirituality following her diagnosis. She responded with a comment on the importance of maintaining a positive attitude, and her increased interest in spirituality and the healing power of the mind:

As a follower of religion/spirituality - I am even more interested in the healing power of the mind... I believe in being positive and focussing on the now. I will not let the disease 'beat' me. I am enjoying my life, watching what I eat and letting my body tell me when to rest. **It is imperative not to focus on the negative side of the disease.** (Participant 17105)

Maintaining a positive attitude assisted these participants to cope with the diagnosis of MS. While participants expressed their positive attitude following diagnosis in a number of ways, all indicated strength and a confidence in themselves to continue living well with MS.

7.5.7.1.2 Making practical changes. Making practical changes was the second most frequently identified theme in participants' comments on what assisted them to cope with the diagnosis. Fifty-six participants (24.8% of participants who provided a comment on what they perceived as being of assistance) reported making practical changes as the primary thing that assisted them to cope. Participants reported making practical changes in four different ways.

Modifications to the physical environment to better manage MS symptoms, prioritising tasks and time for self, learning to say 'no' while learning to accept help, and seeking psychological counselling, were the four areas identified in participants' comments as making practical changes to cope with the diagnosis. While the mechanical installation of air conditioning can be viewed as quite different from the emotional learning to say 'no', all responses included an element of adopting new strategies and making practical changes to live well with MS.

Modifications to the physical environment were practical changes identified by participants as factors that assisted them to cope with the diagnosis of MS. Examples of modifications included installing air conditioning, acquiring a house cleaner or gardener, renovating the house, or buying an automatic car. Participants commented on practical changes they had made to render their physical environment more comfortable: **“I installed air conditioning and bought a very comfy chair”** (Participant 17989). Similarly Participant 16869 reported making a number of practical changes to her surroundings to ensure her independence:

Yes, we are about to move to a smaller house which will require less time and effort in looking after it. Also air-conditioning is being installed as the heat affects my energy levels. I purchased a motorised scooter which gives me extra independence, such as going to the shopping centre by myself and going out with my husband when he takes the dog for a walk. (Participant 16869)

Participants reported a change in their priorities following the experience of an MS diagnosis. Making practical changes included consciously prioritising and planning time for themselves. Participant 18686 reported an increase in her time management following diagnosis, together with a reduction in work hours:

...I did more time management and set limits with the activities that I did. **I seemed to plan my week a lot better**, so I had time to rest in the afternoon. **I changed to part time work and made time for exercise on my days off.**

(Participant 18686)

This participant indicated that she had to make a conscious decision to make time for herself so as to exercise. Some participants reported that saying ‘no’ to external requests was a practical change that came into effect following the diagnosis. Participant 17178 explained that while necessary, making the change to putting herself first was not an easy transition:

I realised that I had to make myself first. **I always did for others no matter what. I always put someone else’s needs before mine. I have learned that with MS, there are times you have to say no.** I don’t push myself to the extreme limits anymore, **I try and make time for myself without feeling guilty about it. It has taken me sometime to realise that it isn’t easy. I just know that I have to make myself #1.** (Participant 17178)

In addition to learning to say ‘no’, participants reported an increase in their need to ask for and accept help from others. For example:

...I learned to accept help from people, even strangers, because I found people were very considerate and liked opening heavy doors etc. I did say when I could do things for myself perfectly well, because I need to keep active and as

independent as possible. So **it was a balance between accepting help and doing my own thing...** (Participant 18893)

This participant summed up her response by mentioning her need for a balance between accepting help and retaining her independence. Other participants reported making the practical change of finding a balance, and listening to their body, as the factor that assisted them most following diagnosis. For example:

In the past 10 months, I have tried to listen to my own body and my own heart, and take things at my own pace. I make allowances for times that I might not be feeling as energetic as I used to be. For example, **I now plan my week to ensure that I am not out every night, yet also to ensure that I am not at home every night either. I am finding balance between rest and play....** this has certainly had a positive effect on my state of mind and stamina. (Participant 18713)

Some participants pursued the support of a psychologist or counsellor following their diagnosis of MS. These participants viewed seeing a psychologist/counsellor as a practical change to their lifestyle that assisted them to cope with the diagnosis. For example:

Shortly after diagnosis I saw a counsellor to help keep me honest in the grieving process. We met on a weekly basis. I found it enormously helpful. I expressed my grief. I journaled about the losses I felt most deeply. (Participant 17253)

This participant linked her experience of dealing with the diagnosis of MS with grieving. She reported using strategies suggested to her by the counsellor, such as journaling, as extremely helpful in her coping with the diagnosis. Participant 22584 sought out a psychologist who specialised in adjusting to disability, who was able to offer her assistance:

Going to a psychologist was useful and gave me ideas of how to cope. I asked her what she would do if she became blind (or couldn't see with optic neuritis) and she said that she would find out what blind people do and see what options are available. It has always stuck in my mind and is so simple but now I find that it underpins everything I do... **the psychologist... really assisted me to find a new way of living with a new body.** (Participant 22584)

This participant reported her feelings of dissatisfaction with life at the time of diagnosis. A psychologist was able to give her the strategies needed at that time to make practical changes to increase her willingness and ability to live with MS.

These participants reported making practical changes as the factor that assisted most in coping with the diagnosis of MS. All practical changes raised included an element of adopting new strategies. Participants either incorporated changes to their physical environment, or changes to their priorities. Prioritising time for themselves, or learning to say 'no', also extended to seeking psychological support for some.

7.5.7.1.3 *Changing health behaviours.* Changing health behaviours was reported by a fifth of participants as the factor that assisted them most to cope with the diagnosis. Forty-seven participants (20.8% of participants who provided a comment on what they perceived as being of assistance) reported that they found changing their health behaviours the primary factor that assisted them to cope with the diagnosis. These participants gave examples of their changes in health behaviours as increasing exercise, decreasing alcohol and caffeine intake and giving up smoking. For example: **“Slowed my alcohol intake (no liquor/little wine/2 beers-a-day max).”** (Participant 17198), and **“Gave up smoking. Decided to get fit. Thought about starting yoga.”** (Participant 19464). As these participants reported, a greater focus was often placed on staying well and remaining strong once diagnosed with MS. Participants looked to reduce the behaviours they considered unhealthy, and enhance the healthy behaviours that they were already engaged in pre-diagnosis:

I am trying to exercise more frequently and increase my fitness for many reasons, to feel healthier in general. Have a much more positive attitude towards life. **Want to keep my body in good strong shape in case I do become disabled either temporarily or permanently later on.** (Participant 19974)

Some participants experienced a change in activity due to restrictions placed on them by their MS symptoms, and were able to find different activities that offered them similar outcomes. For example:

I had to change the forms of exercise I engaged in. I was a life long athlete and avid runner at the time of my diagnosis... **My foot drop made it impossible to**

work out strenuously this way. So I began going to a gym and using non weight bearing exercise - cycling, stair master and rowing machine - to maintain my physical activity. I discovered that I could get a similar work out although I couldn't run. (Participant 17153)

As well as maintaining a high level of general health, many participants introduced MS specific health behaviours into their lifestyles in the first 12 months following diagnosis. The commencement of immunotherapy medication is an example of such behaviour. Together with immunotherapy, participants also mentioned the addition of prescription medications for MS symptom management, such as baclofen, methylprednisolone, and antidepressants. For example: **“I took ditropan, baclofen, and amantadine as well as i.v. solumedrol”** (Participant 17209).

However, along with conventional medicines, complementary and alternative medicines (CAM) clearly played a role in shaping the health behaviour decisions of participants in the first 12 months following diagnosis. The CAM therapies reported by participants included: yoga and tai chi to improve balance and decrease pain; reiki to reduce bladder dysfunction; and evening primrose oil, vitamins, exposure to sunlight and a low saturated fat diet in an attempt to reduce severity of symptoms and to aid in the prevention of disease progression.

I am following a low saturated fat diet whenever I can (which is extremely difficult!), taking vitamin D supplements, and doing tai chi. I also go to the solarium once or twice a week and get out in the sun as much as I can (in Melbourne!). (Participant 19974)

This participant reported the difficulty she encountered when trying to adhere to the CAM's described; however, she also showed enthusiasm in her response, and an eagerness for trying all CAMs that may be of benefit. In a more extreme example, one participant reported investigating CAM therapies with a view to finding 'the cure':

Searching, searching, searching for the cure, mostly in CAM therapy, massage, reflexology, Bowen, yoga, Feldenkreis methods, Kneip/bathing legs - changing hot and cold water or walking in hot and cold water - felt good... Yoga stretches the best way to start each day. Meditation 15 min/day.
(Participant 16539)

Most participants however, investigated CAM with the view to use them in conjunction with conventional medicines for assistance with symptom management or to slow the progression of the disease. A number of participants felt that by enlisting a combination of both conventional medicines and CAM, they were doing all they could to help themselves, leading to an increased sense of control over their MS. For example:

I started immunotherapy almost immediately and also read G. Jelinek's book on managing multiple sclerosis. I changed my diet, as per the recommendations and started taking vitamins & supplements. At the time I was also coming off a course of methyl prednisolone which made me feel extremely shaky. **I started seeing an acupuncturist hoping this would help alleviate the pain behind my eye which flared up again after I came off the**

methyl prednisolone. This made me feel like I was doing something to prevent the disease. (Participant 17569)

Some participants ($n=2$) expressed their desire to avoid conventional medications altogether. They described CAM as their preferred and only treatment, and had strong views on the perceived negative effects of immunotherapy. Participant 17098 gave a detailed explanation of her reasons for actively avoiding conventional medications, and her choice of CAM therapies:

I embarked on a quest to get information about naturopathic avenues that would help me. **I was determined to avoid Copaxone and the interferons because of side-effects; the pressure I perceived coming from the drug companies to take these expensive, invasive drugs; the fact that their success rate isn't that good; the cost; and some good advice from my G.P. that it was my decision. So, I get a combination of acupressure, reflexology, and reiki every other week; I get an intravenous Meyer's cocktail of vitamins and minerals every other week; and under the direction of my naturopath I use alpha lipoic acid.**

I also take the naps I mentioned above. (Participant 17098)

Similarly, Participant 20733 reported that she chose to ignore conventional medication, while instead following a strict MS-specific diet:

I took control of my treatments, and choose medical treatments I desired while ignoring others (eg beta-interferon) which I felt would dramatically change my lifestyle choices. I made optimistic choices about the future based on

a live for the moment attitude, which I believe has been highly influential in my complete remission of symptoms... **I have changed my diet to include more Omega 3 fatty acids found in fish etc. and was on a very strict diet recommended by Coping With MS book**, but have become lazy with it due to lack of symptoms. (Participant 20733)

A point raised by this participant among others, was that the strict diet could be difficult to adhere to generally, and particularly if the symptoms of MS were minor or non-existent.

These participants reported changing health behaviours as the factor that assisted most in coping with the diagnosis of MS. There was a wide variety of changed health behaviours reported. Changes incorporated decreasing unhealthy behaviours (such as smoking and drinking alcohol) and increasing healthy behaviours (such as exercise and healthy eating). Commencing MS specific health behaviours (such as commencement of immunotherapy) and CAM therapies were also reported by participants. All participants inferred that they made changes to their health behaviours post diagnosis to stay well and remain strong while living with MS.

7.5.7.1.4 Information seeking and sharing. Information seeking and sharing was reported by the final 20.8% of participants ($n=47$) as the primary factor that assisted them to cope with the diagnosis. Engaging in information seeking activities immediately following the diagnosis and throughout the first 12 months post diagnosis was common amongst these participants. Participants reported searching for information on MS from a variety of sources. These included traditional written sources of information such as books, peer-reviewed journals and MS Society

publications. Other sources included web based material, other PwMS, and medical professionals. For example:

I read as much as possible about MS from the library, MS society and the internet. I felt that knowing all about the disease, the good and the scary aspects of it, gave me a feeling of some control over the disease. For me it was the ‘knowledge is power’ concept. (Participant 17080)

This participant reported gaining a sense of control over his MS by learning as much as possible about the disease, even if that included information that was anxiety provoking. Some participants told of their desire to read anything they could ‘get their hands on’; in an attempt to learn all they could about MS and ways to manage symptoms. Participants reported that by accessing up to date information on MS, they felt more empowered, even in the face of the disease’s unpredictability:

All I did was try to educate myself with as much information as I could and now I try to keep up to date with new studies... I feel for me it helps to be informed. I know some people can’t handle that, but to understand as much as possible of this disease is to empower yourself especially since MS is so unpredictable. (Participant 21940)

Participants also placed a strong emphasis on being able to gain information about MS (additional to that received at diagnosis) from their health professionals. Neurologists and general

practitioners were most frequently mentioned as valuable sources of information. Participant 19248 reported great benefit in gaining information and support from an MS nurse counsellor:

Talking with the MS Nurse Counsellor, GP and Neurologist really helped me a lot. Especially the first, talking to someone who has experience with MS sufferers. **Knows about the treatments and outcomes and who genuinely understands.** You can talk in confidence and not feel guilty. (Participant 19248)

Participants did not always find their immediate information needs satisfied by their diagnosing physician. Some participants reported obtaining a second opinion before changing doctors to someone they felt better able to satisfy their information needs and support requirements. For example:

Getting a second opinion was the best thing I ever did. I asked around and found another neurologist who is just lovely, so I'm sticking with her. My GP has also been lovely. She phones from time to time to see how I'm going. **She was aware of the problems I was having with the specialist and happily referred me to the new one.** (Participant 23527)

Similarly, Participant 16784 did not feel comfortable with the diagnosing neurologist. She explained that the second neurologist was able to have a discussion with her about her MS, and explain everything to her satisfaction:

I changed neurologists as I didn't feel comfortable with my initial one. He was very clinical and didn't take the time to discuss things with me. As soon as he diagnosed MS he seemed to want to palm me off onto the local MS Society. When I changed neurologists the second one spent so much time explaining everything thoroughly and I felt so much better about it all.

(Participant 16784)

Some participants reported seeking information from, and sharing information with, other PwMS as the most important factor in their coping with the diagnosis. Together with reading written information on MS, participants found additional benefit in the empathy, understanding and support gained from those living with similar symptoms and the uncertainty that MS brings. For example:

Reading info and attending seminars have been valuable. It helps to be well informed. **Knowing others with MS is enormously helpful - they understand how you feel about living with the unpredictable, and know how unsettling the various symptoms can be.** Discussing these things with friends and family is more difficult (can sense their worry or discomfort). **With others with MS, it's just friends chatting.** (Participant 17484)

Face to face contact with others with MS provided information about the disease and symptoms, and a valuable source of emotional support. However, some participants reported accessing other PwMS, and hence information and support, through the less traditional avenue of

internet chat rooms. Participant 16977 reported receiving a lack of information from her medical professionals, instead receiving valuable information and support from a website:

I jointed a website called 'Jooly's Joint MS Webpals' and I truly believe that without that I would have become depressed as there is such a lack of information from the medical profession. I gained and still gain a great deal of support from this site as I find talking with people who share the condition is good as they are the only ones who really understand it. (Participant 16977)

Participant 21718 reported emphatically that the most useful factor in her ability to cope with the diagnosis was joining an online support group. She identified that in spite of the restrictions placed on her by her MS symptoms, technology enabled her to access the information and support she required:

Best thing was joining the online support group. They are always there and if the fatigue or heat makes it impossible to get out I know that I always have my mates right there at the tip of my fingers. Thank God for technology!
(Participant 21718)

These participants reported information seeking and sharing as the factor that assisted them most in coping with the diagnosis of MS. A common theme that emerged from these responses was the belief that knowledge is power. Written information and information published on the internet was sought, along with information gathered in discussions with health professionals and other PwMS.

7.5.7.2 Factors that Hindered Participants' Coping with the Diagnosis

Just under a third of participants ($n=77$) provided a comment on what they viewed as a hindrance to their coping in the first 12 months following diagnosis. The comments offered by the 77 participants on what they found to be a hindrance following diagnosis were categorised into four themes: 'Dealing with the attitudes of others', 'Attempting to maintain a pre-MS lifestyle', 'Information overload', and 'Negative examples of other PwMS'.

7.5.7.2.1 Dealing with the attitudes of others. Dealing with the attitudes of others was the most frequently identified theme in participants' comments regarding what hindered their coping with the diagnosis. Twenty-eight participants (36.4% of participants who provided a comment on what they perceived as being a hindrance) reported that they found other people's attitudes toward the diagnosis as the primary hindrance. The majority of these participants identified the negative or dismissive attitudes of health professionals, primarily neurologists, to be the greatest hindrance in their ability to cope with the diagnosis. For example:

I found the medical community not very helpful at all. My GP is no help and I had a hard time finding a neurologist. Basically they said 'yes you have MS now go home and we will call you in six months'. **I had been going to my family doctor for three years telling him there was something wrong. Only when I lost the vision in my eye and saw an ophthalmologist at Emergency did I get anyone to understand there was a problem.** (Participant 22032)

This participant reported a lack of assistance and support by the health professionals she had seen, as they dismissed her view that something was wrong. Likewise, Participant 19118 reported that her symptoms were credited by health professionals as stress-induced:

I found the health professionals 'dismissive'. I heard a lot of comments about 'somatic' problems and 'have you been stressed or anxious lately?' You feel like a hypochondriac and therefore reluctant to go back to health professionals. As a nurse I felt insulted by the way I felt that I was treated. I no longer share my experiences/symptoms with them as there's no treatment or cure so why subject myself to the humiliation!?!... I was left feeling alone, humiliated, inconsequential and paranoid. (Participant 19118)

As a nurse, this participant felt insulted by the way she was treated by other health professionals during the diagnosis process. She described the negative impact others' comments had on her sense of self, and her resultant reluctance toward seeking further assistance from health professionals.

Another example was given by Participant 23527, who described the insensitive manner in which her neurologist approached the diagnosis. While she did not feel completely comfortable discussing the diagnosis with him, she was also unable to contact him with her questions:

...the careless way my neurologist 'told' me I possibly had MS. No bedside manner at all and he seemed to assume I already knew of my diagnosis. I

could never contact him for results of tests or any questions I had.

(Participant 23527)

Participant 17211 also described an uncomfortable relationship with her doctor. She portrayed him as acting in a condescending and intimidating way throughout the period of her diagnosis:

...before my diagnosis I told my doctor that I had done some research and I was very concerned about multiple sclerosis. He told me, 'That is why people like you shouldn't research into things they don't understand'. Foolishly, I did not change doctors until months after diagnosis... I have switched doctors before because of a condescending attitude... Doctors can be very intimidating. I have carried a lot of anger. Anger with my doctor for not believing in my symptoms, anger with myself for not being more assertive. I know the anger is counter-productive, but I still harbour a lot. (Participant 17211)

This doctor's inappropriate behaviour and attitude toward this participant made her angry. While his behaviour alone could have had a negative effect on the doctor-patient relationship, the participant went on to report that she was also angry with herself following her unassertive response to the situation. She gave the impression that the energy she used on feeling angry about her doctor's dismissive attitude toward her, could have been better spent on coping with the diagnosis. A health professional's inability to empathise and provide a certain level of support, led these participants to feel that their response to the diagnosis was affected in a negative way. For example:

My neurologist's blunt 'You have MS'... He claims to treat hundreds of MS patients a year, yet had no clue the three little words would upset me. I believe wholeheartedly the way you are given the news about a serious illness can make a huge difference in the response. At least initially, I was ready to give it all up and not continue. I think over time that reaction dissipates. **It would have been better for me to have some empathy and know that the person holding your future in his hands cares. I have since found another neurologist and have a chiropractor who has been very supportive.** He believes that whatever helps the patient and doesn't hurt the patient is good medicine. (Participant 18180)

Health professionals' attitudes were identified by the participants above to be the key factor in hindering their ability to cope as well as possible with the diagnosis of MS. However, it was not only the attitudes of health professionals that left participants feeling less able to cope with the diagnosis. The attitudes and comments of family members also played a role in hindering some participants in their ability to cope. For example **"I wished I hadn't told my family and my partner. I found that because I look alright that they did not take me seriously"** (Participant 23892), and **"...unhelpful and hurtful comments from my mother and sister on my diagnosis, i.e. save up bits of poison for when it gets too much, and sell your house as you won't get a wheelchair in there"** (Participant 20045). Participant 22046 described her distress following her family's response to her diagnosis. She did not feel able to express her emotions truthfully as she was encouraged to remain positive:

I became very distressed... with people always saying "keep positive" as if that will make it go away. I feel that I'm not allowed to be angry and yet people always comment on how upsetting the MS is for my parents and sisters. I don't understand why they are allowed to be sad, upset and yet I'm not? I have stopped reading articles on people with MS - because they all seem to have very supporting families and seem to accept the MS. My sister compared the MS to her ongoing weight loss problem. For me - the MS Society has been my saviour; they really listen without devaluing my feelings. (Participant 22046)

This participant indicated that her family was unable to provide the support she desired. She felt that her experience and feelings had been devalued by the comparison made by her sister. Extending past the family, participants also commented on the reactions of friends and relative strangers that hindered their ability to cope with the diagnosis. For example:

The thing that hindered me in the first few weeks was telling people of my diagnosis when I should have realised that they were the sort of people who would say helpful things like 'oh I know someone who has MS and they are in a wheelchair' but I have learnt from that now. (Participant 17138)

Others reported on those in their community who wanted to offer ill-informed or irrelevant advice. Participant 19510 developed a new skill in order to cope with such advice:

I have also developed the skill to politely thank people for their advice and then ignore it rather than get angry that they are advising on matters they have no idea about. (Participant 19510)

Unsuccessfully managing or being negatively affected by the attitudes of others was identified by these participants as the key factor that hindered their successful coping with a diagnosis of MS. Participants found negative, dismissive or condescending attitudes of health professionals upsetting or aggravating. Similarly, the uncaring or insensitive attitudes of family members and friends were found to be distressing and hurtful.

7.5.7.2.2 Attempting to maintain a pre-MS lifestyle. Attempting to maintain a pre-MS diagnosis lifestyle was the second most frequently identified theme in participants' comments on what hindered their coping with the diagnosis. Nineteen participants (24.7% of participants who provided a comment on what they perceived as being a hindrance) reported their attempts to maintain their pre-diagnosis lifestyle as the primary factor that hindered them in coping with the diagnosis in the first 12 months. Participant 22478 explained that she had to keep her diagnosis a secret in order to maintain her pre-diagnosis lifestyle: **"...keeping it secret which I did for many years, and pretending to be well when I wasn't, was stressful"**. Similarly, Participant 21878 reflected that her stress in dealing with the diagnosis increased when she **"...regretfully did not make any changes when I should have regarding my working hours and job responsibility"**.

With the benefit of hindsight, Participant 17062 also noted that trying to keep up with the rate at which her work and social life had once operated, had a negative impact on her ability to adjust and cope with the diagnosis:

...in retrospect I believe that I should have made more changes at that time in the area of work and social life, and should not have tried to maintain the

very busy life I had prior to diagnosis... It was difficult to adjust to a slower pace (I still do not think I have managed it!). (Participant 17062)

Some participants reported being in 'denial' as they struggled to cope with the diagnosis while attempting to maintain the same fast-paced lifestyle that they lived prior to the diagnosis. Participant 18205 reported that he **"Tried to tell everyone, including myself, that I was OK when I really wasn't coping"**. Participant 17153 stated: **"I tried to overcome the disease by working out strenuously to feed my denial. I ended up in a bike accident where I broke my kneecap. Then I was forced to come to grips with my diagnosis..."**. In the same way:

Denial probably made it harder for me at first. I refused initially to accept the need to slow down and had the attitude that I could 'push' through it. All that did was make me feel worse physically. (Participant 21718)

Some participants reflected that, looking back at their behaviour, they should not have acted as secretively about their diagnosis in the first 12 months, as they had come to recognise this approach as a hindrance to their eventual acceptance of the diagnosis. For example: **"I kept much of it a secret and looking back I wished I had told everyone as it happened"** (Participant 17182), and:

A major learning for me was that **my reluctance to speak openly with employers and friends about my illness hindered greatly my acceptance and ability to cope with my illness. If I had been encouraged by my doctor to be more forthcoming about my diagnosis I think the initial 12 months would**

have been significantly easier. I left the job I was in at the time and at my next place of employment I was much more upfront which has made dealing with my illness a lot easier. (Participant 17808)

This participant commented on her belief that if her doctor had encouraged her to disclose her diagnosis at the time, she would have acted differently. She also suggested that this alternate behaviour would have made the first 12 months following diagnosis easier to cope with. Similarly, Participant 17132 reported a sense of regret at not being more honest with others about her diagnosis. She reported keeping the diagnosis to herself for fear of others viewing her differently. She reflected that she would have achieved a better outcome for herself and her friends if she had have disclosed the diagnosis at the time:

I did not tell anyone else about the diagnosis as I thought everyone would imagine I would soon be in a wheelchair. I think it would have been better if I had told people about MS at the time when I had no visible symptoms. I only told people when I felt it was unavoidable and my closest friend was rather hurt that I had kept it to myself. (Participant 17132)

Attempting to maintain a pre-diagnosis lifestyle, whether in regard to a fast paced life or keeping the diagnosis from family, friends and colleagues, was identified by these participants as the key factor that hindered their successful coping with a diagnosis of MS. Participants identified that attempting to maintain the fast paced lifestyle they led before the diagnosis had a negative impact on their ability to adjust to the diagnosis, both emotionally and physically. Those participants who attempted to hide their diagnosis from others reported increased levels of stress, and regret at not disclosing earlier.

7.5.7.2.3 *Information overload.* Information overload was reported by a fifth of participants as the factor that hindered them most in coping with the diagnosis. Sixteen participants (20.8% of participants who provided a comment on what they perceived as being a hindrance) reported that they found being presented with an overload of information on MS to be the primary factor that hindered them in coping with the diagnosis. For example: **“My first reaction was to gain as much information as I could and I would have to say that had a devastating effect on me”** (Participant 17191). While almost all participants (99%) actively sought out information about MS from at least one source, some provided comment that finding a balance between an appropriate amount and too much was difficult:

I read everything I could on MS, I think mostly this helped, but sometimes it was scary to read about ALL the possible symptoms of MS, even though I knew I'd probably never have most of them. It's really hard to find a balance between staying informed and focusing too much on MS. (Participant 16822)

Similarly, Participant 19907 found that the information she obtained was not only confronting, but was offered to her at a pace greater than she would have preferred. She highlighted in her response a need for the recognition of the different informational needs of people newly diagnosed with MS:

I was not ready to read or be confronted with the severeness of MS and need to accept this gradually. Some people want to know everything they can about the disease and read and talk to people. I am not one of them. I went on one website that depressed the hell out of me and I definitely wouldn't recommend

doing that to a newly diagnosed person... I think everyone is different in how they process the info of being newly diagnosed and a person should be given options for getting more information but at their own pace. (Participant 19907)

This participant also considered the information she had found on the internet as 'depressing'. Information sought on the internet was seen by some as a hindrance to their coping with the diagnosis when examples of worse case scenarios were accessed: **“Reading erratically on the internet simply scared me. The more I read on various sites, the more I thought I would end up blind, crippled and incontinent”** (Participant 19464), and **“I think it is very important not to read everything available on the internet because most of the time, they pose the ‘worst case scenario’ and it is very distressing and unnecessary!”** (Participant 19343). Some participants reported burying themselves with information, and not being able to process it effectively to benefit them in a real way:

I knew I wasn't dealing with my condition in the most effective way. I was in the early stages of my MS and I buried myself with information I could get hold of from the internet or from literature given to me. There was so much to wade in and I felt they were just sitting in my brain and not helping me in preparing to cope with the symptoms and their impact on my life in general.
(Participant 18366)

Accessing and appraising an overload of information about MS and its possible symptoms and disease course, was identified by these participants as the key factor that hindered their successful coping with a diagnosis of MS. While almost all participants sought information

from a variety of sources, each participant may have had different, and individual, informational needs with regard to content, style and volume.

7.5.7.2.4 Negative examples of other PwMS. Witnessing negative examples of other PwMS was reported by the final 18.2% ($n=14$) of participants who provided a comment on what they perceived as being a hindrance, as the primary hindrance to their coping with the diagnosis. Participants reported being introduced to, or making contact with other PwMS in a variety of ways. These included meeting through family or friends, being introduced by way of attending support groups or education sessions, or making contact with other PwMS on line. While many participants reported very positive experiences upon meeting others with MS (as outlined in previous sections of this chapter), some participants reported experiences that they felt hindered their coping with the diagnosis. For example:

I joined an MS support group, but was so unnerved by seeing the condition of some of the members that I only went 2 times and didn't return for over a year. Instead of being helpful, even though the members were very kind and accepting, I felt traumatized by the group. (Participant 17085)

Some participants did not report negative experiences relating to the physical appearance of other PwMS, but the attitudes conveyed. For example: **“I found them (support groups) full of negativity. The people attending were full of feeling sorry for themselves”** (Participant 21888). Likewise,

I think I was most hindered by support groups that wanted me to succumb to the idea that with diagnosis came disability - even though that was not my

reality. I chose not to associate with groups that wanted me to sign up for handicapped parking stickers and apply for disability benefits - I didn't need those and yet **all too soon others wanted me to basically sign away my life to MS. That just wasn't me.** (Participant 18194)

This participant quickly recognised that her involvement in such a support group would have hindered her ability to cope with the diagnosis of MS, and therefore removed herself from what she perceived to be a negative environment. Participant 17165 did not make as quick a decision, and instead attended a number of sessions of a support group that she did not perceive as helpful:

There was one individual with MS who on the insistence of my mother, kept phoning me & inviting me to MS support group meetings. **The majority of individuals in the group had poor self-esteem & projected it. After every meeting, I would come home & cry because I felt hopeless & helpless but I thought that's how everyone with MS behaves and yet I didn't want to be that way.** I still remember the negativity after 19 years & I don't want anyone else to ever have to go through that. **That definitely added to my depression.** I've found that positive but realistic people should be made available during this crucial time. (Participant 17165)

This participant suggested that her negative experience with a support group increased her sense of having a lack of control over the disease and may have contributed to her depression.

Participant 17012 reported contacting an MS Society support group for assistance following her diagnosis, only to find that she would be the one providing support:

When I rang the number, a woman answered who then proceeded to tell me about her illness. I found myself doing a ‘telephone counselling’ session with her! I was not in a position to provide support to someone else, so I made the decision that I would keep away from any groups. (Participant 17012)

While not directly coming into contact with another PwMS, some participants reported finding the published stories of PwMS very difficult to cope with. These participants suggested that reading stories perceived as negative examples of the situations of PwMS, hindered their coping with the diagnosis. For example:

I found that Mag Scene Magazine only hindered me because all it seemed to be about was horror stories. Either a focus on bladder problems, heat sensitivity, fatigue etc. & talk about catheters, enemas etc. **All these things you don't want to know about when you are first diagnosed.** Also the stories about people seem to be that they were diagnosed 2yrs or 10 yrs ago but now they are in a wheelchair but they spend their time ‘productively’ on a computer or reading, knitting etc... **It would do people a lot more good not to hear these stories & unlike me they would not go down hill within weeks of being diagnosed & I still do every time I read them.** (Participant 17686)

Participant 21691 also reported feeling poorer after reading stories of PwMS who she perceived as worse off than her. She described her disappointment when unable to find positive stories of PwMS who had improved since diagnosis:

...I found the magazine & brochures sent to me by the MS Society only made me feel more despair, especially the magazine as it always had stories about people that thought how great it was to use a computer, or sail etc. & they were all in wheelchairs. Never any stories about people that maybe had taken some vitamin or used some exercise machine & had felt that they had really improved, also they had advertisements for continence aids etc. which made me feel so much worse. I don't think all these brochures should just be sent to you when you register as some of the symptoms you don't even have yet... Some people may be able to cope but for those of us that can't it makes matters so much worse. (Participant 21691)

This participant made the point that while others may have found assistance in the extensive literature sent out by the MS Society, she found it overwhelming and a hindrance to her ability to cope. Similarly, Participant 19464 reported searching through information on the MS Society's website, only to feel deflated and upset about the negative possibilities for her future, as told in others' stories:

I know that MS organisations, like all charities, have to use exaggeration to get people interested, and to solicit donations, but **it's not much fun for the newly diagnosed patient to scroll through the list of disastrous probabilities and**

awful stories of others with MS, with no word that many MS patients live quite normally for a long time. (Participant 19464)

Finally, Participant 18462 reported that a PwMS is most vulnerable when newly diagnosed, and the stories and suggestions of others have a significant impact on the reader. He described a diet that he saw as unrealistic and that may have had a negative impact on what he perceived as important to his quality of life:

I read people's stories and tried their suggestions. Tried a few really strict diet ideas; Swank. That nearly tipped me into a depression, as I thought my life was over. Not only do I have MS I also cannot EVER eat a donut. Now I look to positive and realistic ideas and stories for inspiration. **I think that you are at your most vulnerable when 1st diagnosed and need a bit of protection.**
(Participant 18462)

Experiencing negative examples of other PwMS was identified by these participants as the key factor that hindered their successful coping with a diagnosis of MS. A negative example of MS was experienced by these participants in a variety of ways; either through a personal meeting, meeting online, or reading about another's experience of MS through written media.

7.5.7.3 Quantitative Analyses of Qualitative Themes

Chi-square tests were performed to investigate whether factors that assisted participants to cope with the diagnosis were associated with gender, country of birth or type of MS. No associations were found. Similarly, there were no associations found between the factors that hindered participants to cope with the diagnosis and gender, country of birth or type of MS.

CHAPTER EIGHT

DISCUSSION

8.1 Overview of the Chapter

In this chapter the findings of the current study are discussed, summarised and integrated. First, the results taken from the sample as a whole are discussed in terms of: a) the demographic information of participants *at the time of diagnosis*; b) the MS related experience of participants prior to, or at the time of, diagnosis; and c) the post-diagnosis behaviours and lifestyle changing activities engaged in by participants in the first 12 months following diagnosis. Second, the findings specific to the key demographic factors of participants' gender, country of birth, and type of MS, are then discussed. Third, the qualitative findings relevant to participants' behaviour following diagnosis are explored and considered. Examined in four sections, the qualitative findings comprise the discussion of diagnosis with another PwMS; the disclosure of diagnosis to others; and the factors that participants' identified as assisting or hindering their coping with the diagnosis in the first 12 months. The implications of all research results are then explored in reference to the theoretical framework of health psychology, and the practical application of the findings for those working with people newly diagnosed with MS. Limitations of the current research are then considered before future research directions are suggested. Finally, conclusions that may be drawn from this thesis are presented.

8.2 Findings Reflected by the Sample as a Whole

The overall findings of the current research, based on the results of the sample as a whole, can be divided into three main aspects: a) demographic information *at the time of diagnosis*; b)

MS related experiences prior to, or at the time of, diagnosis; and c) post-diagnosis behaviours and lifestyle changing activities. First, the findings relevant to each of the three aspects are outlined and discussed in reference to the results reflected by the sample as a whole. Then the findings specific to the key demographic variables of gender, country of birth and type of MS are explored. It should be noted that, as multiple statistical tests were carried out, statistically significant results need to be interpreted with caution.

8.2.1 Demographic Information at Time of Diagnosis

The demographic information of participants at the time of diagnosis was sought to provide a glimpse of participants' existence at the time the diagnosis of MS intruded into their lives. At the time of diagnosis, the average age of participants in the current research was just over 37 years. With diagnosis of MS usually occurring between the ages of 20 and 40 years (Calabresi, 2004), the average age at diagnosis of the current sample might be considered somewhat higher than usual, but nevertheless within the expected range. At the time of diagnosis, almost three quarters of participants were married, living with their partner, or in a long term relationship, and almost half of the sample had at least one child. As the diagnosis of MS is often made in the years of relationship forming and early family commitments, the moment of diagnosis can be a life changing event for the person diagnosed and the family members closest to that individual (Cook, 2002). These family members will include partners and children as is evident by the current sample.

Together with the forming and consolidating of relationships, completing education and the development of career opportunities may also be taking place at the time of a diagnosis of MS (Metz, 2003; Nodder et al., 2000; Van Denend, 2006). The level of education reached by the current participants at the time of their diagnosis was higher than that which would be expected

within the general Australian population, based on figures from the Australian Bureau of Statistics (ABS, 2006). Almost half of the current sample had completed a university or post-graduate degree at the time of their diagnosis, while only a fifth of the general Australian population report completing that level of education (ABS, 2006). As may be expected when such a large proportion of the sample reported completing tertiary education, a smaller proportion reported their highest level of education as a trade, secondary school or a partial secondary school qualification than that which is found within the general Australian population. It must be noted however, that Australian participants comprised just under half of the current sample, making the generalisability of ABS statistics difficult to apply to the sample as a whole. It may be that the general populations of other country groups demonstrate different statistics regarding education levels completed, and occupation and work status, as discussed below.

At the time of diagnosis, the majority of participants were in either full or part time paid employment, with half of the current sample holding occupations at a managerial or professional level. Therefore the current sample's occupation and work status characteristics also differ from that which would be expected within the general Australian population (ABS, 1998), as a greater proportion of the current sample held higher level occupations and were in paid employment than the general population. It is possible that the methodological approach used in this research biased the sample in terms of the level of education reached, occupation and employment status, as participants self-selected to be involved, and the questionnaire was available only on-line. Thus, PwMS who have access to the internet would have been more likely to respond, and it is possible that those who are educated and employed are more likely to have access to the internet as connection can be expensive and is often made available through work.

8.2.2 MS Related Experience Prior to, or at the Time of, Diagnosis

As MS has the ability to affect every PwMS differently, the MS related experiences of individuals in the current research prior to, or at the time of, their diagnoses, were diverse. Less than half of the current sample reported experiencing only one symptom during their first exacerbation of MS (prior to diagnosis), while a similar number experienced two or three symptoms during their first exacerbation. This variability in the number of symptoms experienced in a single exacerbation of MS is acknowledged as one of the many complexities of MS, as is the range of symptoms that may be experienced (Costello & Harris, 2006; Paty, 2000). During their first exacerbation, two thirds of the sample reported experiencing sensory symptoms such as numbness or heat sensitivity, while over a third of the sample experienced visual symptoms, such as optic neuritis, as one of their initial symptoms. This prevalence of sensory and/or visual symptoms at the onset of MS is in line with previous findings outlining the symptoms experienced initially by PwMS (Paty, 2000). As expected, cognitive dysfunction, sexual dysfunction, and bladder/bowel management issues as initial symptoms of MS were not reported widely by the current sample. This underreporting may be because participants did not associate such symptoms having anything to do with MS and therefore did not feel compelled to report them, or because the symptoms were not identified at the time. Another reason for the non reporting of the above symptoms worthy of consideration may be that these symptoms were not experienced by participants at this time; a possibility in line with the general perception that these symptoms do not usually occur until later in the disease course. An exploration of the initial number and types of symptoms experienced by participants in this sample, demonstrates that an exacerbation of MS can combine any number of a range of differing symptoms, and is unique for each person. Thus, health professionals need a broad knowledge of symptoms, and an understanding that experiences of MS vary widely between individuals.

The current sample reported that the actual diagnosis of MS was made, on average, three to four years following the onset of the illness. A length of delay between the experience of initial symptoms and diagnosis is common amongst PwMS (Levin et al., 2003; O'Connor et al., 1994) and the current result may even be considered on the shorter side. These results may reflect the expected decrease in delay from symptom onset to diagnosis due to the recent introduction of the McDonald diagnostic criteria (McDonald et al., 2001) and the availability of imaging technology aiding the timely diagnosis of MS (Marrie et al., 2005).

When looking more specifically at the current sample at the time of diagnosis, almost two thirds of the sample reported experiencing three or more symptoms at the time they were diagnosed. The current sample reported sensory, visual, motor and balance difficulties, and fatigue as symptoms occurring at the time of diagnosis, as is usual (Calabresi, 2004). While Costello and Harris (2003) indicate that 70-90% of PwMS experience fatigue, a lesser proportion of the current participants were expected to report this symptom. This was because Costello and Harris discuss the prevalence of fatigue over the course of the illness, rather than at the exact time of diagnosis. So, as expected, fewer than two thirds of the current sample listed fatigue as a symptom experienced at the time of diagnosis. Interestingly, a greater percentage of the current sample indicated the presence of cognitive dysfunction and bladder/bowel management issues at the time of diagnosis, than at the time of illness onset. One reason for this may be that the contact with health professionals at the time of diagnosis led to an increased awareness of the link between such symptoms and MS.

It may be considered surprising that almost 10% of the current sample were not experiencing any symptoms when they were diagnosed with MS. This lack of symptoms at diagnosis could be due to a period of remission occurring between the time of diagnostic testing and the delivery of the diagnosis. While PwMS diagnosed during a period of remission are rarely

acknowledged in previous studies, a lack of symptoms at diagnosis may impact on an individual's level of emotional distress, psychological adjustment, and behaviour following diagnosis (Halligan & Reznikoff, 1985; Sullivan et al., 2004). This minority group of PwMS, and their experiences prior to, and following, diagnosis should be explored further in future research.

One quarter of the current sample reported experiencing two exacerbations before a diagnosis of MS was made. Another quarter of the sample reported experiencing three or more exacerbations before diagnosis. This frequency of exacerbations before diagnosis was expected given the current use of the McDonald Criteria for diagnosing MS, where establishing the presence of lesions in the CNS that are objectively disseminated in both time and in space, may be assisted by the occurrence of at least two exacerbations (McDonald et al., 2001). However, as mentioned in the previous chapter, it was not expected that a quarter of the sample would report only one exacerbation before diagnosis. While it may be thought that those participants received their diagnosis before the McDonald Criteria came into effect (calling for the occurrence of two exacerbations before a diagnosis of MS could be made), this was found not to be so. Rather, it could be that these participants were told of the possibility of MS following their first exacerbation, and in retrospect, regard that as their time of diagnosis. Or, participants recalled the exacerbation that led them to see the doctor, or impacted on their quality of life, as their first exacerbation when they may have experienced other 'smaller' exacerbations earlier. Further research into what PwMS regard as an exacerbation, and the correlation with the medical definition of an exacerbation, would be of benefit. The final quarter of the sample was unsure of the number of exacerbations they had before a diagnosis was made, which was related to the type of MS participants reported having, and will be considered in section 8.4.3.2.

Forty percent of the current sample were admitted to hospital due to their MS symptoms before, or at the time of, their diagnosis. Interestingly, 40% of participants also reported suspecting they had MS before the diagnosis was made. While it could be hypothesised that those admitted to hospital may be more likely to suspect MS, there was no relationship found between these two groups. This lack of relationship was surprising as it was thought that those who had been admitted to hospital may have either experienced greater contact with a larger number of health professionals; or assessed the situation as more serious, than if not admitted to hospital. Either of these occurrences may have led to earlier information seeking to investigate possibilities for the cause of the symptoms, which may have in turn, led to a greater suspicion of MS before diagnosis. While prospective research into pre-diagnosis suspicion of MS may be difficult to conduct, a better understanding of whether individuals suspect MS pre-diagnosis, and the experiences that may have led them to suspect it, would be of interest.

On examination of the current participants' experiences of MS prior to, and at the time of, diagnosis, it is reasonable to assert that the current sample is representative of the wider MS population. However, when examining the findings reflected by the sample as a whole in terms of their demographic information at the time of diagnosis, the current sample cannot be labeled as representative of the wider general population for two main reasons. First, the sample reported completing higher levels of education and being more often employed, than members of the general Australian population. In addition, the current sample may not be representative of the general population, because the sample was drawn from the wider global community and cannot be compared solely to the norms of the Australian population. The largest proportion of participants were from Australia (hence the comparison with Australia), but extrapolating these comparisons to a world wide sample would be assuming each country reflected the demographic composition of Australia. If actual comparisons taking into account the diverse demographic

statistics of each country involved in the study were possible, then the sample may be found to more closely represent the wider general community.

8.2.3 Post-Diagnosis Behaviours and Lifestyle Changing Activities

The seeking out of information about MS during the first 12 months following diagnosis was amongst the most widely reported post-diagnosis behaviours. Over half of the current sample engaged in four or more information seeking activities in the first 12 months following diagnosis and 99% reported engaging in at least one. Only one percent of the sample, or three male participants, reported participating in no information seeking activities in the first 12 months following diagnosis, and will be discussed in relation to gender differences in information seeking, in Section 8.4.1.3.

The most popular information seeking activities were accessing information via the internet, followed by speaking to a medical professional for further information about MS. Participants also sought information by contacting their local MS Society, visiting a library, and/or attending an information session or conference about MS. The current sample favoured seeking information about MS on-line above all other information seeking activities regardless of participants' age at diagnosis or years since diagnosis. This result indicates a trend congruent with Brewer's (2005) findings that PwMS are relying more and more on the internet to provide them with information about the disease. The high percentage of participants seeking further information about MS from health professionals is also in line with previous research (Baker, 1998), as is seeking information from the MS Society (Hepworth & Harrison, 2004). Conversely, only one third of the current sample accessed information about MS from a library; a noticeably smaller proportion when compared to previous studies of information seeking in MS (e.g., Baker, 1998; Wollin et al., 2000). This decrease in the reliance on public libraries for

information could be due to the rapidly growing use of the internet to access information about the disease by PwMS (Brewer, 2005).

The overwhelming majority of participants engaging in information seeking activities within the first year may indicate a desire for immediate information about MS following diagnosis. Such a finding should re-emphasise the suggestions of previous researchers, as to the value and importance of accurate, appropriate, and timely information provision by the diagnosing health professionals (e.g., Baker, 1998; Hepworth & Harrison, 2004).

Less than two thirds of the sample registered with their local MS Society in the first 12 months following diagnosis, despite over 70% contacting the MS Society for information in the same period. This is an interesting finding considering it can be assumed that MS Societies around the world would be aiming to register as many PwMS as possible, and may be disappointed that people newly diagnosed with MS are requesting information from their service, while not wishing to register as a client. There may be many reasons for this discrepancy. Perhaps some people newly diagnosed with MS view registering with a charity, or disability related organisation, as confronting and conflicting with their self-image. Alternatively, the MS Society may be viewed by some as an information resource only, and therefore the benefits of registering as a client and being able to access other offered services, may not be apparent within the first 12 months following diagnosis. Similarly, some people newly diagnosed with MS who are experiencing no symptoms, or symptoms that are not impacting upon their quality of life, may regard themselves as having no need to be a member of an MS specific organisation. Further research into this discrepancy, and the reasons given by people newly diagnosed with MS who do/do not choose to register with the MS Society, would be of value to MS Societies in their planning of services and advertising of benefits of registration to those newly diagnosed with MS.

More than half of the present sample discussed their diagnosis of MS with another PwMS in the first 12 months following diagnosis. This is in keeping with the work of Brooks and Matson (1987) and Hepworth and Harrison (2004) who report that PwMS are often sought out by people newly diagnosed as a source of information about the disease and as a source of emotional support. Indeed, Hepworth and Harrison (2004) suggested that neurologists, health professionals and MS specialist organisations should prioritise the meeting of those newly diagnosed, with other PwMS. Although a slim majority of the current sample met with another PwMS in the 12 months following diagnosis, it is unlikely that such meetings are a top priority of health professionals and MS related organisations, as a larger number of the current sample would have been expected if this were the case. PwMS meeting one another following diagnosis is certainly an area worthy of further research, for although the literature on the benefits of peer support remains inconclusive (Schwartz, 1999), peer support programs are becoming more commonplace and some research has shown significant improvements in participants' quality of life, confidence, self-awareness and self-esteem, and reductions in depression following peer support (e.g., Mohr et al., 2005; Schwartz, 1999). Most participants who chose to discuss their diagnosis with another PwMS met that person through the MS Society or a support group, or contacted a pre-existing friend or acquaintance known to have MS. Interestingly, almost a fifth of those who discussed their diagnosis did so with another PwMS that they met online. This finding may reflect the benefits of accessing peer support online, which include flexibility regarding opportunities for involvement and the timing of peer interaction, anonymity, and a reduced emphasis on mobility. The benefits of online interaction between PwMS were originally outlined by Strittmatter (2004), and seem to be validated by the current research as is discussed when examining relevant qualitative findings in Section 8.5.1.3.

When looking more broadly at disclosure of diagnosis, the current sample disclosed to a wide range of family, friends, colleagues and health professionals. All participants who identified as being in a relationship disclosed their diagnosis to their partner within the first 12 months following diagnosis. This may indicate that PwMS look to partners for emotional and/or practical support shortly after the diagnosis is made, or that they feel that they have no choice but to disclose to their partners. Reasons for disclosure will be discussed in full when examining qualitative findings in Section 8.5.2.

It was found that within the current sample, not all participants with children disclosed to them. The reasons for this are unknown, although the age of children could have contributed to participants' decision whether or not to disclose to their children. It is highly likely that participants with young children may not have disclosed to them in the first 12 months following diagnosis on consideration that they would be too young to understand. Or, it may be that some PwMS consider the diagnosis too complex to reveal to children, or want to protect them from the diagnosis. Both findings highlight a need for organisations such as the MS Society to produce, and make accessible at a time very shortly after diagnosis, information that would assist PwMS in disclosing the diagnosis to partners and children, if they so choose. Similarly, diagnosing physicians need to be aware that disclosing the diagnosis to family members is highly likely, and PwMS may benefit in discussing this with health professionals.

A higher percentage of the sample disclosed to their employers than to their colleagues in the first 12 months following diagnosis, indicating the possibility that disclosure in the workplace may have been more often about alerting management to the diagnosis, than for reasons of collegial support. Participants may have engaged in preventative disclosure in the first 12 months following diagnosis, voluntarily telling their employers so as to avoid being 'found out' if symptoms were, or were to become, obvious (Troster, 1997). However, it may be that some

participants disclosed their diagnosis to their employers spontaneously as a result of the shock or disbelief following diagnosis (Charmaz, 1991). The ramifications of such an unplanned disclosure, whether to employers or colleagues, could be problematic for those wanting to avoid stigmatisation or discrimination within the workplace. While PwMS who show visible signs of symptoms have less choice regarding disclosure (Joachim & Acorn, 2000), those who are able to 'cover' their symptoms may resist telling their colleagues for a longer period of time, thereby minimising the possible negative effects of others knowing about their diagnosis of MS in the workplace (Goffman, 1963). The culture of the workplace may have also impacted the current participants' decisions to disclose the diagnosis of MS to employers and/or colleagues. An organisation's privacy policy, and its practical application, may have led some PwMS to feel confident in their decision to disclose to some in the workplace, and not others. Further study into the specific reasons behind disclosure of MS to employers and colleagues and the potential differences between these groups is warranted.

Looking at the current sample's disclosure to friends, 10% chose not to disclose their diagnosis to close friends within the first 12 months, while two participants did not disclose their diagnosis of MS to anyone within that time period. These findings may be because a minority of participants viewed the potential risks of disclosing the diagnosis, such as losing control over the information or facing rejection or stigmatisation (Charmaz, 1991), as more likely than the possibility of receiving emotional support upon disclosure to friends (Joachim & Acorn, 2000), and were therefore not willing to take the risk of disclosure. It is also possible that some participants did not identify having any friends at the time of their diagnosis with whom they wished to share the diagnosis of MS.

One fifth of the sample disclosed their diagnosis to a psychologist or counsellor within the first 12 months following diagnosis. As there have been no previous studies to the author's

knowledge examining the seeking of counselling following a diagnosis of MS, it is unknown whether this proportion was to be expected. It may be viewed as a small percentage of the sample, considering the diagnosis of MS can be deemed a major life event for most, with the ability to dramatically change an individual's opinion of their expectations for the future. Further education into what health psychologists can offer individuals in the general community may see a gradual increase in the acceptance of psychological services for those diagnosed with a chronic condition such as MS. Reduced costs of psychological services through the provision of a government rebate, such as those seen in Australia since 2006, may also contribute to an increase in psychological services provided to PwMS who demonstrate a psychological condition such as depression or anxiety (Australian Psychological Society, 2006). Such schemes may promote the affordable use of psychologists to those newly diagnosed with MS and their diagnosing physicians.

As there is no research to the author's knowledge that broadly outlines who people diagnosed with MS choose to disclose to, and when, the current findings are a valuable start to understanding who people newly diagnosed with MS initially share the diagnosis with, and the potential issues involved in their decision to disclose (or not). An in-depth discussion of participants' reported reasons for disclosing the diagnosis to others, together with some participants' reflections on regretting disclosure, will be presented in section 8.5.2.

Almost all participants in the current sample reported participating in some lifestyle changing activity, or activities, within the first 12 months following diagnosis. Indeed, half of the sample participated in between three and six different lifestyle changing behaviours in the 12 months following diagnosis, with very few participants reported no lifestyle changing activity following their diagnosis of MS. The embracing of changes to lifestyle in the first 12 months following diagnosis may indicate a willingness, or desire, to actively take steps to live well with

the disease, to live in a healthy manner despite the disease, and/or to prevent disease progression if possible. While it is unknown whether the current sample continued to carry these lifestyle changes through the following years, the enthusiasm for change, or taking control of aspects of life that could impact their experience of living with MS soon after diagnosis, is evident.

The number of participants who had made lifestyle changes in relation to diet or vitamin intake, the two most common lifestyle changing activities engaged in by the current sample, was not surprising given recent studies on the frequency of complementary and alternative therapy use by PwMS (e.g., Apel et al., 2006). In accordance with Pucci et al.'s (2004) findings, it was evident that the current sample had sought out complementary therapies, in addition to, or in preference to, the commencement of conventional medical treatment. This preference for dietary and vitamin supplement changes, rather than the commencement of immunotherapy, may be a reflection of the make up of the sample, as the sample included both PwMS who would have been eligible to commence immunotherapy, and those who would not. Alternatively, it may be a reflection of the sample's concerns regarding immunotherapy and its perceived negative impact on lifestyle, combined with the increasing availability and awareness of alternative or complementary therapies.

The findings regarding both medical and complementary therapies are of utmost importance to the medical professionals working with those newly diagnosed with MS. An understanding of the complexities involved in the decision to begin immunotherapy is needed by health professionals so that they can adequately discuss any concerns held by the PwMS about treatment, and provide appropriate information. Similarly, possible reluctance felt by some PwMS about telling their treating physician about complementary therapies (Pucci et al., 2004) must be addressed in order to maintain a healthy relationship between health professional and client.

8.3 Findings Specific to the Key Demographic Variables

Three key demographic variables were chosen for more detailed examination in the current study. While demographic variables cannot be modified by health professionals, an increased understanding of such variables, their potential impact on an individual's adaptation to a diagnosis to MS, and the role they may play in post-diagnosis behaviour and lifestyle changing activities is valid. A more thorough understanding of demographic variables and their relationship with post-diagnosis behaviours may assist health professionals and MS specific agencies to accurately target and provide appropriate services to PwMS. The findings specific to the key demographic variables of gender, country of birth, and type of MS, are discussed below.

8.3.1 Gender

8.3.1.1 Gender and Demographic Information at the Time of Diagnosis

When examining the results of the current study, three demographic differences at the time of diagnosis were apparent between the males and females in the sample. These differences were in the areas of level of education, occupation, and work status at the time of diagnosis. Males were more likely to have completed a trade certificate or University degree than females, were more likely to be working full time, and were also more likely to be working within a trade, office, managerial or professional occupation at the time of diagnosis. In contrast, the females who had completed a degree were more likely to have also finished University post-graduate studies by the time they were diagnosed with MS than the males in the sample. Female participants were more likely to be working part time, working and studying, or solely performing home duties, than males at the time of diagnosis. While such findings are in line with general Australian population statistics, the inter-country nature of this research needs to be considered when interpreting these results.

8.3.1.2 Gender and MS Related Experience Prior to, or at the Time of, Diagnosis

While there was no difference in male and female participants' age when they experienced their first MS symptom, a greater proportion of females reported initially experiencing sensory and cognitive symptoms, than males. There could be many reasons for these findings. First, it may be that the men and women in the sample actually experienced, and therefore reported, different symptoms. However, the disparity may instead be due to a gender difference in the reporting of symptoms, with a greater proportion of women reporting invisible symptoms, such as cognitive dysfunction and sensory symptoms, than men. Just as women are more likely to visit the doctor (Berzel, Heller & Zucchini, 2006), they may be more likely to report symptoms, even if the symptoms are invisible, not interfering with their quality of life, or ability to manage daily tasks. As there are no previous studies to the author's knowledge showing significant differences between the symptoms experienced by males and females during the course of MS, future examination of MS symptom reporting inclinations and differences between the genders may be helpful to explain this finding.

There were no significant differences found between the genders with regard to number of exacerbations or admissions to hospital prior to diagnosis. However, women were more likely than men to suspect MS before the diagnosis was made. One reason for this finding may be that women might be more open than men about their unexplainable symptoms with friends, family, and health professionals. Open discussion about unusual symptoms may lead others to make comment that, for example, their 'aunty' had experienced similar symptoms before being diagnosed with MS. Such a remark would obviously get the PwMS thinking about the possibility of experiencing a similar diagnosis once all testing had been complete. However, this is merely speculation, and a more thorough examination of the reasons given for suspicion of MS before a

diagnosis is made would be beneficial, in order to insure appropriate and timely information about MS is provided to those facing diagnosis.

8.3.1.3 Gender, Post-Diagnosis Behaviours and Lifestyle Changing Activities

The male and female participants in the current sample took part in similar numbers of information seeking activities and sought information via similar avenues during the 12 months following diagnosis. The only exception to this was that a greater proportion of males reported engaging in no information seeking activities than females. This may be because these male participants were more likely to spend a longer time (over 12 months) considering their options for coping, before seeking out information about MS. Or, the failure of these males to seek further information about the disease in the first year after diagnosis could be viewed as a way of denying the diagnosis by avoiding having to recognise the possible impact MS may have on the future (Kortte & Wegener, 2004). However, as the sample for comparison on this matter was very small, this finding should be considered with caution.

Contrary to previous research suggesting that women may seek more social support than men following a diagnosis of MS (Norberg et al., 2006), the current sample showed no gender differences with regard to who they disclosed their diagnosis to, or whether they discussed their diagnosis with another PwMS. However, where Strittmatter (2004) found that people with MS, regardless of gender, viewed meeting another PwMS as a positive experience, a greater proportion of the current female participants viewed the interaction as positive, than the male participants. Also, a greater proportion of males reported their reason for not discussing their diagnosis with another PwMS as 'not wanting to' than females, who were more inclined to say that they did not have the opportunity to meet another PwMS. It must be noted that the findings relevant to participants' perceptions of the interaction with another PwMS, or why they did not

disclose the diagnosis to another PwMS, should be considered with caution as participants were not specifically asked to comment on either situation. Participant responses, in relation to meeting another PwMS, will be explored in Section 8.5.1 of the discussion of qualitative findings.

The vast majority of the current sample participated in a diverse range of lifestyle changing activities from dietary changes to changes of career in the 12 months following diagnosis. Only one significant association was found between lifestyle change and gender, with a greater proportion of female participants reporting an increase in their interest in spirituality than males. This association is in line with Bussing et al.'s (2005) finding that women with MS engaged in activities related to spiritual well-being more often than men with MS, and Crigger's (1996) observation that a belief in a higher power, or God, was identified by women with MS as one of the greatest strengths in dealing with the disease. While diagnosing physicians attend mostly to the physical needs of their patients, and allied health professionals such as psychologists play a role in attending to the emotional and psychological needs of PwMS, the spiritual needs of those diagnosed with MS could also be taken into account. As indicated by the current research, a heightened focus on the spiritual needs of those newly diagnosed may be of particular importance for women. The information and recommendations provided to PwMS about lifestyle changing activities following diagnosis should be the same regardless of gender, however, any information given on spirituality may be particularly appreciated by women, and this area should not be neglected by health professionals when assessing the various needs of those newly diagnosed.

8.3.2 Country of Birth

8.3.2.1 Country of Birth and Demographic Information at the Time of Diagnosis

When examining participants' demographic information at the time of their diagnosis, only one significant association was found with regard to country of birth. This association was regarding participants' education at the time of their diagnosis. The highest level of education completed by participants' differed depending on their country of birth. This is likely to be a reflection of the societal and cultural differences between countries. Each country may place a slightly different value on education which would, in turn, have an impact on the level of education needed in order to work in a particular occupation. Similarly, the workings of each education system across countries could be different in regard to accessibility and cost. However, despite the existence of associations within the sample regarding country of birth and highest level of education reached, there were no significant associations found between occupation or work status and country of birth. This needs to be taken into consideration when examining the results.

8.3.2.2 Country of Birth and MS Related Experience Prior to, or at the Time of, Diagnosis

Looking broadly at the results of the current study, country of birth did not appear to affect participants' experiences prior to, or at the time of, their diagnosis of MS. There was no difference in participants' age at first symptom, nor was there an association between the initial symptoms of MS, and the country of birth of participants. However, looking more specifically at the symptoms experienced at the time of diagnosis, there was an association found regarding cognitive dysfunction and country of birth. A lesser proportion of those born in the United Kingdom and New Zealand reported experiencing cognitive symptoms at diagnosis, than those born in other countries. It is unlikely that participants from different countries would have

experienced different medical symptoms, however, it is plausible that participant knowledge, and therefore reporting, of cognitive dysfunction could be disparate. As cognitive dysfunction in MS has only recently gained widespread recognition by researchers and clinicians (personal communication, Dr. E. McDonald, Medical Director, MS Society of Victoria, 2005), it is plausible that health professionals in various countries have taken different lengths of time to incorporate this symptom into their MS assessments, or into the information they provide to PwMS. The likely differences between countries' assessments of symptoms, or information provision to PwMS about cognitive dysfunction, may be the reason for the variation seen in the current sample regarding the reporting of cognitive dysfunction as a symptom at diagnosis.

8.3.2.3 Country of Birth, Post-Diagnosis Behaviours and Lifestyle Changing Activities

Participants from all countries involved in the current research sought information through similar avenues, and took part in a similar amount of information seeking activities during the 12 months following diagnosis. Participants' country of birth did not affect whether or not they spoke to another PwMS following their diagnosis, how they came into contact with that person, or whether they viewed the interaction as positive, negative or neutral. In addition, the reasons given by some participants for not meeting another PwMS in the first 12 months following diagnosis were not associated with participants' country of birth. Based on these findings, it seems apparent that the majority of people newly diagnosed with MS, regardless of where they were born, desire to meet another PwMS soon after diagnosis. This ostensible universal need to discuss MS related experiences with someone else who has MS indicates that more research is required to explore the ways in which PwMS connect with one another to share experiences. Indeed, further research into how MS organisations or practitioners can work with

PwMS to secure a positive interaction between parties for those newly diagnosed, would be beneficial.

When looking at the other people participants disclosed their diagnosis to, there was a significant association found between disclosing the diagnosis to workplace colleagues, and participants' country of birth. A greater proportion of participants working full time from the U.S.A., Australia and New Zealand, disclosed their diagnosis to workplace colleagues, than participants working full time from Canada, the U.K, and other countries. Without expert knowledge in disability discrimination law across these countries, one reason for this finding may be that those participants from Canada and the U.K. may be more hesitant to reveal their diagnosis to colleagues for fear of discrimination or negative ramifications to their employment status. The impact of a change to employment, taking into consideration possible loss of income and impaired quality of life, can be immense for a PwMS and their family (Metz, 2003), and it is possible that those participants born in Canada and the U.K. are more acutely aware of these employment related issues if discrimination laws are markedly different from other country groups. However, this suggestion must be viewed as conjecture given the current author's lack of knowledge of international work place laws. A further exploration of employment related issues in MS, and the differences observed across countries, could be of use to those working within the disability discrimination field of law or human resources.

The number and types of lifestyle changing activities engaged in during the first 12 months following diagnosis did not differ across country groups in the current sample, apart from one notable exception. A lesser proportion of participants from the U.K and New Zealand reported commencing immunotherapy in the first 12 months following diagnosis, than participants from the other country groupings. This finding is not surprising, as fully or partially subsidised immunotherapeutic treatment is only available to a small number of PwMS fitting

strict eligibility criteria in both countries (NZ Pharmaceutical Schedule, 2006; UK Department of Health, 2005). For example, it is estimated that only 12-15% of the PwMS population in the United Kingdom receive subsidised MS immunotherapy treatment (UK Department of Health, 2005). Disparity in accessibility to immunotherapy highlights one of the very practical differences faced by PwMS from different countries. Despite this difference specific to conventional treatment, the findings relevant to other behaviours following diagnosis and lifestyle changing activities show many similarities observed across the countries of the current study. These consistencies indicate that the current findings may be applicable to PwMS living in countries other than Australia.

8.3.3 Type of MS

8.3.3.1 Type of MS and Demographic Information at the Time of Diagnosis

The types of MS as identified and discussed in the current study were Benign, Relapsing Remitting (RRMS), Primary Progressive (PPMS), Secondary Progressive (including Progressive Relapsing) (SPMS) and a fifth group formed by participant responses indicating that they were unsure or were not told of their type of MS at the time of diagnosis. When looking specifically at these five different subgroups of MS when exploring relationships with other variables, the only significant finding relevant to the demographic information of participants at the time of diagnosis, was the age of participants when diagnosed. In accordance with previous research (McDonnell & Hawkins, 1998; Noseworthy et al., 1983) indicating that PPMS is usually diagnosed later in life, those with PPMS in the current sample were older at the time of diagnosis than both those with RRMS and those who were unsure of the type of MS they had been diagnosed with.

8.3.3.2 Type of MS and MS Related Experience Prior to, or at the Time of, Diagnosis

There were a number of differences noted between the five types of MS in relation to participants' experiences prior to, or at the time of, their diagnosis. Not surprisingly, participants with PPMS were found to differ from other groups in some of their MS related experiences, such as age at diagnosis and symptoms encountered. This may, in part, be due to the absence of exacerbations or relapses, with no periods of remission, evident at the start of a course of PPMS (Lublin & Reingold, 1996). As people diagnosed with PPMS experience clinical differences from other types of MS, such as continual worsening of symptoms and a progressive loss of functioning from the disease outset (Burks et al., 2002), differences could be expected in the types of symptoms reported by the different subgroups of MS and in the number of exacerbations or lack thereof, reported before diagnosis. Therefore, the findings of the current study, in relation to differences between the types of MS, reflect those reported in the literature.

In accordance with the findings discussed above regarding age at diagnosis, participants with PPMS were significantly older when they experienced their first symptom of MS, than those with RRMS, Benign MS, or those who were unsure of the type of MS they were diagnosed with. When examining the types of symptoms reported at the onset of the disease, a greater proportion of participants with all types of MS other than PPMS reported experiencing sensory symptoms, while a greater proportion of those with PPMS reported experiencing motor symptoms as an initial symptom of MS. At the time of diagnosis, a lesser proportion of participants with PPMS experienced sensory symptoms than those with RRMS, SPMS and those who were unsure about their subtype of MS. These findings are in line with previous research identifying PPMS as different in many respects to the other subgroups of MS (e.g., Olerup et al., 1989).

A greater proportion of participants who reported being diagnosed with PPMS or SPMS indicated that they were unsure of the number of exacerbations they had experienced before

being diagnosed with MS. This finding stands to reason considering those with PPMS demonstrate an absence of exacerbations, as do those who have transitioned from RRMS to SPMS. Interestingly, there was also a significant association found between those with Benign MS and those who were unsure of their type of MS, and experiencing only one exacerbation before diagnosis. This finding makes sense for those who report having Benign MS, as they could be expected to experience a low relapse rate (Burks et al., 2002).

It must be noted here that it was not expected that as many participants would identify as being *diagnosed* with Benign MS, as were found in the current study. Benign MS is considered most controversial when used to describe a type of MS, let alone when used as a diagnostic label (Lublin & Reingold, 1996). Indeed, most clinicians and researchers would agree that an individual can be given this label only after 15 years of living with MS and experiencing very little disability (Burks et al., 2002; Lublin & Reingold, 1996). The reasons for this higher than expected reporting of Benign MS in the current study may include diagnosing physicians wanting to buffer the ‘bad news’ of diagnosis, with some hope that the course of MS will be mild. It is possible that health professionals use the term ‘benign’, believing that this will aid an individual’s adaptation to the diagnosis of MS. However, whether this treatment of people newly diagnosed with MS by their physicians is part of a caring approach, or is in fact unethical conduct, is questionable. Alternatively, individuals who report being diagnosed with MS may have, in fact, been diagnosed with the broad term of ‘MS’ and added the term ‘benign’ after learning about the different subgroups and determining that Benign MS matched their course, or desired course, of MS. Similarly, the reported number of people *diagnosed* with SPMS was higher than expected considering the widely held view that people originally diagnosed with RRMS transition to SPMS within 10 years of diagnosis (Burks, 2002; Weinshenker, 1995). It can be assumed that SPMS would rarely be the first diagnosis of MS made given the usual experience of RRMS first.

It may be that participants in the current sample identified themselves as having SPMS, as that was the type of MS they identified as having at the time of completing the questionnaire, rather than at the original time of diagnosis. If this is the case, the methodological issue of participant recall, and how questionnaires are designed, when completing retrospective research must be considered.

8.3.3.3 Type of MS, Post-Diagnosis Behaviours and Lifestyle Changing Activities

While participants with all types of MS were involved in a similar number of information seeking activities following diagnosis, a smaller proportion of those with Benign MS accessed information about the disease on-line, than those with others types of MS. This was an interesting result as the two factors thought to have an effect on an individual's internet use following diagnosis (years since diagnosis and age at diagnosis), were found to be unrelated to Benign MS. First, it was thought that the number of years since diagnosis may affect information seeking online, as the internet has become a more popular tool for accessing information in more recent years (Brewer, 2005). However, there was no relationship between type of MS and number of years since diagnosis. Second, it was thought that an older age at diagnosis could affect the seeking of information online as the internet has tended to be a research tool for younger people (Atreja et al., 2005). Once again, there was no significant relationship between those diagnosed with Benign MS and age at diagnosis. Therefore, age at diagnosis and time since diagnosis can not explain why those with Benign MS were less likely to access information about MS online. Rather, it may be that those who identify as being told they had Benign MS at the time of their diagnosis were less likely to actively seek information about MS in the first year following diagnosis, as they may have felt no urgent need to investigate symptoms they were not experiencing. Indeed, they may have held the belief that MS would not

affect them in the same way it would affect those with other types of MS. Perhaps participants with Benign MS felt as though they had been given enough 'basic' information from the health professionals, given their lack of symptoms, and so did not need to seek additional information from the internet in the first 12 months following diagnosis. However, this reason for a difference between types of MS is speculation, and further research into why people with Benign MS did not seek additional information via an easily accessible medium such as the internet, is worthy of further investigation.

Looking at the results related to type of MS and disclosure of diagnosis, there was a significant association found between type of MS and the reason given for not meeting another PwMS following diagnosis. It was found that a greater proportion of those who were unsure of their type of MS did not want to meet another PwMS, than those with identified types of MS. Perhaps the diagnosing physicians of the participants in this group were reluctant to give a particular label of MS to their patients at the time of diagnosis. This may have stopped these participants from identifying with a particular group of PwMS and were therefore less interested in meeting someone else with MS. Such a finding may highlight the need for health professionals to ensure clear communication at the time of diagnosis on the type of MS, if known at that time. Knowing the type of MS an individual is diagnosed with may assist in their gathering of accurate and applicable information. However, as the number of participants in this 'unsure' type of MS group was low, such findings should be viewed with caution.

There were two interesting findings regarding participants' type of MS and the types of lifestyle changing activities they engaged in during the first 12 months following diagnosis. First, a greater proportion of people with RRMS reported commencing immunotherapy in the first 12 months than those with other types of MS. This finding was expected given the widespread recognition of immunotherapy as an effective treatment for RRMS, particularly in the

early course of the disease (Burks et al., 2002; Coyle & Hartung, 2002). Also recognised for its positive effects on slowing the disease progression of SPMS (Burks et al., 2002; Goodin et al., 2002), it could be thought strange that those identifying as being diagnosed with SPMS were not similarly making a change to incorporating immunotherapy into their lifestyle within the first 12 months following diagnosis. However, as a diagnosis of SPMS is usually made following a period of RRMS, as discussed above, a prudent perspective of these results is required.

The second finding related to type of MS and lifestyle changing activity is that a greater proportion of those with SPMS and those who were unsure of their type of MS, reported a reduction in work hours in the first 12 months following diagnosis, than those with other types of MS. Those with SPMS may have experienced an increase in level of disability over the first 12 months following diagnosis, or may have experienced exacerbations that did not result in full recovery to their baseline functioning, thus making it more difficult for them to continue working at the same capacity that they were before diagnosis. Once again, the need for clear communication from health professionals regarding the type of MS, if known at the time of diagnosis, is apparent in this example, as those unsure of their diagnosis also reported a reduction in work hours in the first 12 months following diagnosis. Considering the difficulties that may be faced by an individual attempting to regain employment following a reduction in hours or resignation from a position due to disability (Allaire et al., 2005; Habeck, 1999; Sirvastava & Chamberlain, 2005), these findings regarding changes to work hours are of great importance. Health professionals and MS related organisations must be aware of the statistics regarding employment and MS (as found in the AMSLS Access Economics Reports, 2005), and address the issues surrounding changes in employment with PwMS at risk of a reduction to their work hours. Doing so may assist in the prevention of PwMS making unnecessary, and possibly permanent,

negative changes to their work identity, economic situation, and sense of autonomy (Brooks & Matson, 1982; Reynolds & Prior, 2003).

8.4 Qualitative Findings

Seeking qualitative in addition to quantitative data in emerging areas of research, or areas that are poorly understood, may result in a wider understanding of the topic as multiple layers of information are gathered (Patton, 1980; Reinharz, 1992). The qualitative aspects of the current study were included to enhance the applicability of the current research findings, and to place the experiences of people newly diagnosed with MS in a meaningful 'real world' context (Banister et al., 1994). To the author's knowledge, asking PwMS to share their thoughts about specific aspects of post-diagnosis behaviour and lifestyle changing activities undertaken in the first 12 months following diagnosis has not previously been explored.

For a number of reasons it is of utmost importance to hear from PwMS themselves when conducting research into their behaviour following diagnosis. For example, the increasing trend for those with chronic illnesses to take an active role in the management of their condition should prompt researchers to discover more about what PwMS identify as being of benefit to their own coping with MS. Similarly, a greater understanding of the motivations behind action in the first 12 months following diagnosis may assist health professionals to further empower and support people newly diagnosed with MS. Further, asking PwMS to comment on such topics may lend a richness to research results, thereby providing an increased insight to the health professionals working with PwMS. In the current research, open ended questions encouraged participants to expand on the discussion of diagnosis with another PwMS; the disclosure of diagnosis to others; and factors post-diagnosis that they believe assisted or hindered their ability to cope with the diagnosis. The findings of the qualitative data relevant to these points will be discussed below.

8.4.1 Discussion of Diagnosis with Another Person with MS

Participants were asked if they had discussed their MS diagnosis with another PwMS in the first 12 months, and if so, how they knew that person. Almost three quarters of the sample gave a response to this open ended question, and while answers included basic information about how they knew or met the other PwMS, three themes relevant to the participants' perception of the interaction as neutral, positive, or negative, were also identified. This variation in the perception of meeting another PwMS was in contrast to Strittmatter's (2004) suggestion that meeting another PwMS is only viewed as positive by those newly diagnosed, and will be discussed below. An additional two themes were also identified with regard to the discussion of the diagnosis with another PwMS. Firstly, a proportion of the current sample identified that they had participated in online interaction with another PwMS, and secondly, some participants identified their reasons for not meeting another PwMS in the first 12 months following diagnosis.

8.4.1.1 Positive Interaction with a Person with MS

The benefits of information sharing and being able to communicate with someone who has similar first hand knowledge of MS related experiences, contributed to some participants viewing the interaction with another PwMS as positive. This is concordant with previous research suggesting that other PwMS can provide an alternate source of information about the disease to conventional sources such as health professionals, as well as providing emotional support to those newly diagnosed (Brooks & Matson, 1987; Hepworth & Harrison, 2004). Meeting another PwMS who had been diagnosed for longer and who demonstrated a positive approach to living with MS, was seen as inspirational by some of the current participants. Drawing inspiration from other PwMS soon after diagnosis, as distinct from having a positive encounter with another PwMS, has not been covered in previous research addressing the needs of

people newly diagnosed with MS. Despite this, there are programs already offered by MS Societies (such as the MS Ambassador Program in Australia) who recruit inspirational speakers who have MS to share their stories with those newly diagnosed in efforts to educate their listeners about MS, as well as to motivate them to live their lives to the fullest, in spite of having MS (Shaw, 2001).

Having a positive encounter with another PwMS shortly after diagnosis may provide an opportunity to share information with someone who has had similar experiences, and the meeting may even allay some fears about the disease. In contrast, being inspired by someone with MS shortly after diagnosis may have lasting beneficial effects for someone newly diagnosed as their expectations for their abilities in the future may be significantly enhanced. Further research into the differences between ‘positive’ and ‘inspirational’ interactions with other PwMS shortly after diagnosis, if any, would assist MS Societies and programs such as the MS Ambassador Program, to organise the most beneficial interactions with other PwMS for those newly diagnosed.

8.4.1.2 Negative Interaction with a Person with MS

Although previous research may have suggested as such, it would be too simplistic to think that all meetings with another PwMS would be positive for those newly diagnosed. Indeed, some participants in the current study viewed their interaction with another PwMS in the first 12 months following diagnosis as negative. With popular perception implying that meeting another PwMS is a necessarily positive experience for those newly diagnosed, this finding is of particular interest. Almost a tenth of the current sample viewed their interaction with another PwMS as negative. Participants’ perceptions of a negative encounter were largely formed by the pessimistic attitudes about living with the disease held by the other PwMS encountered by those newly diagnosed. Similarly, those who came into contact with another PwMS living with a high

level of MS-related disability, combined with pessimism toward the newly diagnosed person's future, also resulted in the interaction being viewed as negative. Interestingly, it was not the level of disability on its own that made the newly diagnosed person view the interaction as negative; rather it was the pessimistic attitudes of the other PwMS, regardless of level of disability. This finding may contradict the general perception that seeing PwMS in wheelchairs is going to scare or cause distress to those people newly diagnosed with MS. It may be that level of visible disability has less of a negative impact on those newly diagnosed than once thought, and this research area would certainly be worthy of future consideration.

It is a widely held belief that people newly diagnosed with MS benefit from speaking to another person who has lived with the disease for longer. Indeed, the increase in peer support programs available through MS Societies or MS clinics around the world vouch for this (Messmer Uccelli et al., 2004). Through numerous research publications, formalised peer support programs are showing beneficial effects in many areas of the health and well-being of PwMS (e.g., Lorig et al., 2001; Von Korff et al., 1998). Similar research into the effects of informal interaction with PwMS has not yet been done, and it may be this informal, and not necessarily positive, interaction that is reflected by some of the current sample. Just because someone has been diagnosed with MS does not mean that they will be naturally able to provide support, encouragement or inspiration to someone newly diagnosed. Health professionals in particular, together with well-intentioned family members and friends, may wish to assess the attitude and capabilities of a PwMS before they recommend them to someone who has experienced a recent diagnosis of MS. It should not be assumed, just because an individual has MS, that they are equipped to support another person whose sole similarity may be the diagnosis. It also appears that those with higher levels of disability do not need to be 'hidden' from those newly diagnosed, if they have a positive attitude toward others with MS.

8.4.1.3 Online Interaction with Another Person with MS

Another theme evident through the responses from participants regarding how they met another PwMS was online communication, with almost a tenth of those who discussed their diagnosis with another PwMS, meeting online. A sense of perceived security, anonymity, and safety was observed in the responses of these participants, in line with Strittmatter's (2004) views on the benefits of online support for PwMS. Also, participants conveyed a feeling of self-preservation through meeting other PwMS online, as they did not feel as vulnerable as they perceived they may have been in a face to face peer support setting. This hesitation from some PwMS around meeting other PwMS face to face, has been reported in previous literature (e.g., King, Kraut & Sullivan, 2006), although there has been no research to date examining the internet as an alternative delivery method for informal, or formalised, peer support. As the internet is a rapidly growing communication device with many websites and chat rooms dedicated solely to the support of PwMS (Brewer, 2005), an increased interest in such research is expected.

This alternate way to meet another PwMS opens numerous opportunities for those PwMS living in isolated or rural communities, or those PwMS with mobility issues, who want to meet another PwMS following diagnosis. The added benefits of anonymity and flexibility in the timing of peer interaction may also make the online communication option for peer support appealing to others newly diagnosed. MS Societies around the world who have not yet tapped into the provision of appropriate online peer support may wish to do so as its popularity seems to be increasing rapidly. Being able to link into pre-existing online groups set up by MS Societies in other countries, if possible, would reduce both time and monetary costs for those MS Societies not offering online peer support already.

8.4.1.4 Reasons Given for Not Meeting Another Person with MS

Of those who did not discuss their diagnosis with another PwMS in the first 12 months following diagnosis, one third volunteered an explanation. There were two main reasons given for not meeting another PwMS in the first 12 months following diagnosis. These were not having the opportunity, and consciously choosing not to meet another PwMS. While not everyone diagnosed with MS will necessarily have the opportunity to meet another PwMS, this situation could be considered the exception in most western countries. Through the various information seeking activities engaged in by those newly diagnosed, it could be assumed that a health professional or the MS Society would suggest contact with another PwMS, or a person newly diagnosed would come across the opportunity of online support when searching for information on the internet (if accessible). This was demonstrated by the current sample, as only a few reported not having the opportunity to meet another PwMS.

The second reason given for not meeting another PwMS in the 12 months following diagnosis, was because participants did not want to as they did not feel ready, or able, to do so. The thought of having contact with another PwMS, particularly someone with a greater level of disability than themselves, made these participants feel scared, uneasy or upset. The discussion of their own diagnosis with another PwMS seemed too confronting for these participants. This finding demonstrates the importance of allowing and enabling those newly diagnosed with MS to take their time in considering options around engaging in MS related activities following diagnosis. While some can find the discussion of their diagnosis with another PwMS a positive experience, or even inspirational, there are a minority of people newly diagnosed with MS who may not benefit from, or who may not be ready for, a meeting with another PwMS. Therefore, health professionals should be aware that meeting another PwMS may benefit some but not all, and should not push those newly diagnosed into this activity. Apart from the range of positive

and negative attitudes of other PwMS, the reasons behind people's interpretations of interaction with other PwMS should be explored further, to refine the provision of peer support services to PwMS in the first 12 months following diagnosis.

8.4.2 Disclosure of Diagnosis

After participants listed with whom they discussed their diagnosis of MS in the first 12 months following diagnosis, they were asked to explain why they had disclosed their diagnosis. Almost the entire sample responded to this open ended question, and from the extensive answers given, three broad themes were identified concerning reasons for disclosure of diagnosis to others. Participants in the current sample reported that they disclosed their diagnosis because of a perceived lack of control; to gain emotional support; or for reasons that were summarised into the theme of 'Why wouldn't you tell everyone?' Interestingly, another theme emerged from the data, and was labeled 'I regret disclosing'. The substance of all four themes will be discussed below.

8.4.2.1 Perceived Lack of Control

Joachim and Acorn (2000) suggested that the main benefit of disclosing a diagnosis of MS is the increase in emotional support received by the person diagnosed. If emotional support is reported as the main benefit of disclosure, then it could be expected that the main reason given for disclosure of diagnosis would be to gain this emotional support. However, the majority of participants in the current study did not identify this as their primary reason for disclosing their diagnosis. Instead, the largest proportion of participants in the current study indicated that they disclosed the diagnosis of MS in the following 12 months because they felt a lack of control over their choice to do so. Therefore, the perception that people newly diagnosed with MS make a conscious decision, or choose to disclose their diagnosis to others, is challenged by this finding.

Taking control of certain aspects of life following a diagnosis of MS is a coping resource, and may assist individuals in their adaptation to disease (Armstrong-Stassen & Cameron, 2003; Moos & Billings, 1982; Russell, White & White, 2006). Jelinek (2005) discussed the importance of those newly diagnosed taking control over matters such as information seeking, diet and exercise, and disclosure, following a diagnosis of MS. According to Jelinek, taking control may be an important coping resource for those newly diagnosed. However, many participants in the current study did not perceive that this resource was available to them with regard to their disclosure of the diagnosis. They instead suggested that the control was taken away from them as they felt compelled or obligated to reveal the diagnosis for one of a number of reasons, as will be discussed below. While taking control may assist in the adaptation to diagnosis, there are few opportunities for individuals to exert control over MS related events due to the unpredictability of the disease (MacLeod & MacLeod, 1998). Therefore, maintaining the integrity of the choices available to PwMS around disclosure of diagnosis may be considered of utmost importance to the adaptation process.

The perceived lack of control over disclosure reported by participants took a variety of forms depending on the individual's situation. Some participants made a choice to tell others about the symptoms they were experiencing, or their visits to the doctor, in the pre-diagnosis stage. These participants explained that their choice to disclose symptoms or medical appointments before the diagnosis then left them with little or no choice about disclosing the eventual diagnosis. They felt compelled to explain the diagnosis to those they had already told of the 'unexplainable' symptoms or unusual diagnostic tests. While this was often the case with friends and family, it was also relevant for some who had told employers of their MS-related experience pre-diagnosis, with a sense of obligation to disclose the diagnosis to employers present in some participants' comments. Such findings demonstrate that the actions of PwMS before

diagnosis can have an enormous impact on the choices available to them following diagnosis. Their subsequent control over certain aspects of disease related experience may be perceived as diminished, thereby potentially reducing the coping strategies available to them when attempting to adapt once the diagnosis of MS has been made.

The displaying of obvious MS related symptoms, for example lack of mobility, equipment use, or reliance on others for physical assistance, led some participants to perceive a lack of control over their disclosure of diagnosis. These participants reported that they had no choice but to disclose as their physical changes were so obvious to those around them. Similarly, some participants reported having to disclose their diagnosis for fear that their symptoms would be misconstrued as being caused by something else. These participants did not want others to think that symptoms were caused by something that they perceived as 'worse' than MS, such as drunkenness, laziness, or mental illness, or something 'more serious' such as cancer. Disclosing the diagnosis was perceived by these participants as the only option in order to avoid others making inaccurate assumptions, and possibly negative judgements. It is these perceptions of what others would think of obvious MS symptoms, and the perceptions of the disclosure choices available, that could be addressed by health psychologists to assist PwMS in exploring their options for disclosure.

A perceived lack of control was also identified in participants' responses when it was reported that it would have been more stressful to hide the diagnosis than to disclose it. Hiding the diagnosis from others would have meant an increase in emotional pressure on top of that felt by the diagnosis of MS itself, and the threat of 'being found out' was so great that disclosure for these participants was not viewed as something they had control over. In some extreme cases, the decision to disclose was not only perceived by participants as out of their control, but was literally made for them, as others informed participants' friends, family, acquaintances or colleagues of

their diagnosis of MS. This was particularly evident for participants who identified as living in rural or small communities.

The perception that all, or even the majority, of those diagnosed with MS have control over disclosure is contested by the current qualitative findings. These findings flag the importance of appropriate discussion between health professionals, in particular health psychologists, and PwMS at, or indeed before, the time of diagnosis. The reality is that PwMS may not be able to access taking control of disclosure as a coping resource when attempting to adapt to the diagnosis without some professional support. Individuals' reasons for disclosure of pre-diagnosis experiences, or the diagnosis of MS itself, could be discussed with health psychologists and the consequences of disclosing, or not disclosing, examined so as to assist the PwMS to make informed and real (rather than perceived) choices about disclosing.

Taking control is one of the coping resources available to PwMS which may contribute to their coping with the diagnosis. Coping can be viewed as a conscious response or reaction to a negative or stressful event (Folkman & Lazarus, 1984; McCrae, 1984) and includes the three components of: Coping strategies used to manage a stressful situation; the subjective appraisal of the situation (Lazarus & Folkman, 1984; Wineman, Durand & Steiner, 1994); and the personal or coping resources available to the individual during the period of stress (Shnek et al., 1995; Stuifbergen & Rogers, 1997; Wassem, 1992). While taking control of certain aspects of MS, such as the disclosure of diagnosis, can be viewed as one small part of the much larger coping picture, it may be a crucial element of successful adaptation for some. Perceiving a loss of ability to take control over one of the few controllable aspects of MS, may enhance, rather than reduce, the stress associated with a diagnosis of MS. This may in turn have a negative effect on the individual diagnosed with MS, and on their adaptation to diagnosis. It is for these reasons that health

professionals working with PwMS should be aware of the importance of feeling in control, and the role they can play in assisting PwMS to remain in control of their disclosure of the diagnosis.

8.4.2.2 To Gain Emotional Support

In the current study, the second most frequently reported reason for disclosure in the first 12 months following diagnosis was in order to gain emotional support. As mentioned above, this reason for disclosure was expected given that an increase in emotional support is considered the main benefit of disclosure (Joachim & Acorn, 2000). These participants reported choosing to disclose the diagnosis to others in order to talk about their MS related experiences and to gain the emotional support needed to cope. Some participants highlighted the importance of being able to trust those that they spoke to about the diagnosis with their feelings about MS and their fears for the future. These social supports were most often identified as family, friends, and counsellors. However, employers were also mentioned by some which was interesting given employers are not typically identified as sources of emotional support. Disclosing the diagnosis to others was also reported as a way of securing emotional support for family members as well as for the PwMS themselves. These participants expressed the importance of family members having a clear understanding of MS through the provision of accurate information, and having access to emotional support if needed.

Social support has received the most attention in the MS literature on coping resources available throughout the disease course (Pakenham, 1999). Indeed, the emotional support offered through interpersonal social relationships is identified as one of the key coping resources available to PwMS, promoting both physical and emotional health (Weinert, 1987). Social support factors, including an individual's social network and relationships with family and

friends, are resources for managing stress and maintaining health (Billings & Moos, 1984); resources that could be considered critical at the time of diagnosis.

About one fifth of the current sample disclosed their diagnosis to a counsellor or psychologist, and did so because they did not want to ‘burden’ family members with their need for emotional support, or they wanted professional support to assist in the adaptation to diagnosis. Even though all comments about speaking to a counsellor reflected a positive experience, there appears to be room for an increase in the number of people seeking counselling following a diagnosis of MS. For although 20% of the current sample could not be considered a low number accessing professional support, health psychologists could provide highly beneficial emotional support services to a greater number of people in the first 12 months following diagnosis. The reasons given by people newly diagnosed for not accessing professional psychological support would be worthy of further exploration. It may be that the vast majority of people newly diagnosed with MS are unaware of the emotional support that can be provided by a psychologist or counsellor at the time of diagnosis. It could be advantageous for diagnosing physicians to recommend health psychologists with expertise in the field of chronic illness to those newly diagnosed, so that PwMS, and their family members, have the option of accessing appropriate emotional support without feeling a sense of burdening their family or friends, or in the case that their family and friends cannot provide the emotional support they require.

8.4.2.3 Why Wouldn't You Tell Everyone?

Participants in the current study were asked why they disclosed their diagnosis of MS to others in the first 12 months. Following a perceived lack of control, and disclosure to gain emotional support, the third most identified theme in the qualitative data was a sense of ‘why wouldn't you tell everyone?’ Indeed, approximately one fifth of the current sample did not offer

a specific reason for disclosure, rather they suggested that they did not consider doing anything but disclose, and in most cases, disclosed widely to family, friends, acquaintances, and colleagues. Disclosing the diagnosis of MS to others in the first 12 months was the 'natural' thing for these participants to do.

These participants gave a number of explanations for why they believed disclosure of diagnosis was a natural action for them. These participants felt that MS was not going to define them, so they did not see a need to hide the diagnosis or be embarrassed about explaining the cause of their symptoms to others. Some participants insinuated that disclosing the diagnosis to others was a part of their coping strategy. Maybe this was the case because telling others made the diagnosis seem 'real' to the PwMS. Or perhaps disclosing the diagnosis allowed discussion of MS related issues with a social support network. These participants also wanted to provide information about MS to the people in their lives, and disclosing their own diagnosis of MS was the first step in informing their friends, family and colleagues. In addition, there was a strong sense of wanting to use the disclosure of their own diagnosis to educate the wider community about MS, and in some cases, to provide members of the general community with a positive example of a PwMS, thought to be lacking in the general community. There was an indication that clichés or inaccurate information about MS should be fought against, and that those willing to disclose their diagnosis could make a beneficial difference to all PwMS.

The participants in the current study who reported a sense of 'why wouldn't you tell everyone' about the diagnosis of MS, did not appear to subscribe to the reasons listed by Charmaz (1991) for withholding disclosure, such as viewing the illness as a private matter, not wanting to attract attention, or holding feelings of guilt or shame about their condition. Instead, they may have seen the disclosure of their diagnosis as an opportunity to take control over a certain aspect of the disease. Their resultant embracing of disclosing the diagnosis to numerous

others may have thereby contributed to their adaptation to diagnosis (MacLeod & MacLeod, 1998). It may be that these participants did not necessarily identify the stigma or negative connotations attached to the diagnosis of MS, thereby making 'disclosure to all' an easier decision given they may not have thought through the possible negative ramifications of disclosure (Grytten & Maseide, 2006). Alternatively, the stigma may have been acknowledged, but together with an eagerness to fight against the negative connotations of the label of MS. Or, the stigma attached to MS in the past may have waned, allowing people diagnosed with MS more recently to feel greater freedom in their disclosure of the diagnosis.

8.4.2.4 I Regret Disclosing

Participants in the current study were not asked specifically if they regretted disclosing their diagnosis in the first 12 months following diagnosis. However, it was interesting that when asked for reasons as to why they disclosed, over five percent of participants volunteered a reason as to why they *regretted* disclosing the diagnosis of MS (following their reporting of a reason for disclosure in the initial instance). Joachim and Acorn (2000) suggest that there is little known about how PwMS cope with their decision to disclose their diagnosis to others and whether some PwMS regret their decision to disclose, thus the current research provides an important contribution to the field.

These participants stated that they had regretted telling others of the diagnosis and if they could live the experience again, they would be more selective about who they told, if anyone at all. This was often the case for those who received unexpected responses from others. While the person newly diagnosed may have expected emotional support and understanding, they reported receiving pity, or expectations for the worst case scenario. Some participants reported that others, upon hearing of the diagnosis, would offer stories about other PwMS who were

experiencing high levels of disability or distress. These stories were not well received by these participants, as they were not perceived as helpful. Conversely, some participants also commented on regretting telling others about their diagnosis if they were then offered stories of other PwMS who were experiencing lower levels of disability than themselves, as this may have devalued or diminished their experience of MS. Some participants made specific comment about regretting disclosing to employers or colleagues, as they then perceived a change in attitude toward them following disclosure. Many MS Societies across the world have already recognised the importance of offering information and advice regarding employment concerns for PwMS, including the issue of disclosure to employers (Simmons et al., 2004). These findings highlight the importance of ensuring that information about disclosure of a diagnosis of MS is provided in a timely fashion, ideally before disclosure to employers or colleagues takes place.

Privacy and confidentiality issues were also raised by participants who identified regretting their disclosure of diagnosis. Some participants felt as though they quickly lost control over the information regarding their MS diagnosis as soon as it was disclosed. Others identified that while they believed they had no choice but to disclose at the time for reasons of obligation or compulsion, they later regretted it. These participants inferred that hindsight gave them the ability to see that they did have a choice about disclosure, but at the time they felt powerless. This is an area that health professionals working with those newly diagnosed can address.

This finding, that a number of participants regretted disclosing their diagnosis, is a clear indication that a proportion of all PwMS regret their decision to disclose in the first 12 months following diagnosis. This finding is made all the more interesting considering that participants in the current study were not asked to comment on regret following disclosure, rather, this information was volunteered when participants were asked why they disclosed their diagnosis. It is therefore possible that research specifically targeting the construct of regret following

disclosure, would identify a greater number of PwMS who indicate regret around disclosure than the current study reveals. The initial finding discussed here suggests that health professionals may want to add disclosure of diagnosis, alongside medication options and credible information sources, to their list of issues to discuss with those newly diagnosed. Indeed, as mentioned above, it may be in the individual's best interests to discuss the positives and negatives of disclosure of symptoms and/or diagnosis of MS even before the diagnosis is made.

8.4.3 Factors that Assisted Participants to Cope with Diagnosis

Participants in the current sample were asked to provide a comment on anything that they thought assisted or hindered them in coping with the diagnosis of MS in the first 12 months following diagnosis. Almost all of the participants who responded to this question offered a comment regarding what they found to be of assistance. Participants' comments on what they found to be of assistance to their coping in the first 12 months were grouped into four themes; 'Maintaining a positive attitude', 'Making practical changes', 'Changing health behaviours', and 'Information seeking and sharing'. The findings of all four themes will be discussed below.

8.4.3.1 Maintaining a Positive Attitude

In accordance with the findings of Barnwell and Kavanagh (1997) indicating that optimism acts as a positive predictor of psychological adjustment to MS, maintaining a positive attitude was the most frequently reported source of assistance for the PwMS who participated in the current study, when attempting to cope with the diagnosis of MS. These participants indicated that their positive attitudes assisted them to accept and understand the diagnosis, and to cope with the life changes and expectations that came with a diagnosis of MS in the first 12 months.

The ability to maintain a positive attitude, believed to be invaluable by these participants, was not necessarily accepted by others who labelled these participants as 'in denial' or unable to acknowledge the severity of the diagnosis, based on their preconceived ideas that someone newly diagnosed with MS should not be feeling positive. However, these participants were resolute that their positive attitudes were genuine, healthy and of great assistance to their coping with the diagnosis. A number of participants in the current study went one step further by reporting that they not only had a positive attitude about their diagnosis, but that they also viewed it as a gift, or a positive addition, to their lives. The diagnosis of MS had inspired some of the current participants to have a greater appreciation for life, to assess what was truly important to them, and to find a clarity regarding the life goals they wanted to achieve; reflections often observed in those facing a serious illness as described by McAdams (1993) and Candib (2004), among others.

This finding challenges the simplistic view that those diagnosed with a chronic illness will necessarily respond with a negative outlook on their future. The ways in which individuals respond to a diagnosis of a chronic illness are often complex, and may include an element of positivity about the disease, or even thanks, for the diagnosis (Candib, 2004). Health professionals must be aware of such reactions, and support PwMS in their identifying and utilising of the positive aspects of the diagnosis, if this is the case. It should be noted however, that the retrospective nature of the current research may have prompted participants to report feeling positive in the first 12 months following diagnosis, if they have felt more positive about the diagnosis over the subsequent years. Prospective research into positivity or the maintenance of a positive attitude immediately following diagnosis of MS would be of benefit in order to guide health professionals in their work with PwMS.

The reoccurring themes of assessing what was important and having a new found appreciation for life were frequently highlighted by participants as they reported on the ways in

which they maintained a positive attitude. These participants looked past the negative experience of diagnosis, and searched for and found, meaning in their lives and things they wanted to be thankful for. Some participants compared themselves to others they perceived as being worse off, an activity that gave them perspective, and reinforced their positive attitude. This process of finding positivity or meaning from a negative experience is discussed in the post-traumatic growth literature, and often includes reference to an increase in spirituality (e.g. Tedeschi, Park & Calhoun, 1998).

Brooks and Matson (1982) found that the second most reported response from PwMS regarding what helped them cope with the illness was religion. In the current study, the ability to maintain a positive attitude was perceived by some participants as being fundamentally linked to a belief in God. While the mention of religion or spirituality was not as frequent in the current study as that reported by Brooks and Matson (1982), it must be noted that the participants in Brooks and Matson's study were American, whereas the current study included PwMS from a number of countries. In a recent study examining the religious devotion of the United States and its political allies, Americans were more likely to have an unquestioning belief in God than people from countries including Australia, Britain, Canada, France and Germany (Schaeffer-Duffy, 2005). While it may be that spirituality or religiosity plays a larger role in the lives of Americans, participants in the current study from a range of countries suggested that without the presence of God in their lives maintaining a positive attitude would not have been possible, and it was this positive attitude that they reported as being of greatest assistance to their coping with the diagnosis. Indeed, the current study showed no significant association between identifying spirituality as an important factor in adaptation to diagnosis, and country of birth. The participants who raised the issue of spirituality in conjunction with the belief that maintaining a positive attitude assisted them to cope with the diagnosis were from a range of nationalities.

Optimism and the demonstration of a positive attitude have been shown in previous studies to play a significant role in adaptation to chronic disease (Fournier, de Ridder & Bensing, 1999; Pakenham, 1999). The participants of the current study reported maintaining a positive attitude as the primary factor that assisted them to cope with the diagnosis of MS. These participants used their positive attitude as a coping resource in the first 12 months following diagnosis, which may have influenced their choice and use of coping strategies, and mediated their responses to MS related challenges (Lazarus & Folkman, 1984). It may be that a positive attitude assisted these participants by buffering the negative effects of the stress caused by the diagnosis of MS (Park & Folkman, 1997). Large scale quantitative research into whether the positive attitudes of PwMS mediates or moderates the effects of stress in the first 12 months following a diagnosis would be beneficial, in an effort to further identify and promote effective coping resources to PwMS.

8.4.3.2 Making Practical Changes

The second most frequently reported factor that participants in the current study identified as being of assistance to their coping with the diagnosis of MS was making practical changes. The current study included a number of actions under the broad umbrella of making practical changes, as a quarter of the sample gave a response that included an element of adopting new strategies and/or making practical changes in order to cope with the diagnosis. The theme ‘making practical changes’ as identified in this study, included the tangible changes or modifications to a participant’s physical environment, the organisational changes to the individual’s prioritising of tasks and time for themselves, the practical and emotional changes of learning when to ‘say no’ while simultaneously learning when to accept help, and the seeking of psychological counselling. These examples were all grouped together under the theme of

‘making practical changes’ as they are all indicative of participants’ willingness to make a change to their lives in the belief that it would assist them to cope with the diagnosis.

As was found by Aronson, Cleghorn and Goldenberg (1996), the participants in the current study who made changes to their physical environment, such as modifications to their home or car, expressed doing so to ensure their independence. Making changes to the physical environment may have given these participants reassurance that they could maintain a continued independence, despite the perceived threats of changing levels in ability due to the MS disease course. Taking the proactive steps to make modifications or allowances for current symptom management, or possible future disability, was perceived to have resulted in a sense of control over the disease. These participants may have felt that working with, rather than fighting against, the disease assisted their coping with the diagnosis in the 12 months following diagnosis. Making physical changes to the environment so as to facilitate effective symptom management is an example of the coping resource of taking control available to people newly diagnosed (McLeod & McLeod, 1998). It is a widely held belief that PwMS resist making modifications to their physical environment due to a fear of losing their independence, or risking a change to others’ perceptions of them (Finlayson, 2004; Neri & Kroll, 2003). The finding of the current study challenges the narrow view that all PwMS view making modifications as threatening rather than empowering, as it acknowledges the making of practical changes, including changes to the physical environment, as the second most identified factor that assisted the current participants in coping with the diagnosis. In line with the findings of Finlayson and van Denend (2003), the current participants felt empowered with an increased sense of personal control when they took action by modifying their physical environment to better suit their management of symptoms, following the diagnosis of MS.

The other three areas grouped under the broader theme of ‘making practical changes’ may not have been as apparent to the people known to the PwMS, as they are not necessarily visible changes to the physical environment such as the installation of a ramp, or air conditioning. However, they are all related by the participants’ willingness to make practical changes in an area of their lives, in order to better manage the diagnosis of MS. Some participants reported making a change in prioritising what was important for them on a day to day basis, as well as in longer term planning. Scheduling time for themselves following diagnosis, to participate in health promotion activities such as exercise or relaxation, was viewed by these participants as a priority in order to maintain living well with MS. Some participants identified that making the practical change of ensuring time for themselves was of greatest assistance to their adaptation to MS; an area that health psychologists can provide assistance with. In some cases, this meant learning to say no, in conjunction with learning to ask for, and accept, help. A balance had to be found between caring for the mind and body to effectively manage life post-diagnosis, and retaining independence. Some participants identified that this balance was easier to achieve with the assistance of a psychologist or counsellor, and so incorporated counselling sessions into their post-diagnosis lifestyles. Participants’ willingness to make a practical change to their lives, in the form of modifications to physical environment, prioritising tasks, or learning to seek and accept help, was the second most frequently reported factor that current participants identified as being of assistance to their coping with the diagnosis of MS.

8.4.3.3 Changing Health Behaviours

Changing health behaviours was the third most frequently identified theme in the current sample’s responses to what they thought assisted them cope with the diagnosis of MS. Many of these participants reported a reduction in the unhealthy behaviours they engaged in pre-diagnosis,

combined with an enhancement of their pre-existing healthy behaviours. In addition, some participants took on new behaviours that they perceived as beneficial to their health post diagnosis, such as new exercises, or dietary changes. For some, a change in the type of exercise they engaged in following diagnosis was necessitated by MS symptoms impacting on what they were able to do pre-diagnosis.

Maintaining a high level of general health was very important to these participants. This could be explained by the finding of Reynolds and Prior (2003) that PwMS hold the belief that good general strength and fitness will assist in the effective management of MS symptoms, and contribute to a higher overall quality of life; a belief based on medical evidence (Sutherland, 2001). Findings of the current study support this belief of PwMS, indicating that in the first 12 months following diagnosis, some PwMS attempt to maintain or get their body into peak physical condition in order to combat MS symptoms and potential changes in ability. The current participants recognised these changes in health behaviours as an important factor that assisted them to cope with the diagnosis of MS. In accordance with Sutherland and Anderson's (2001) findings that those with mild to moderate levels of disability benefit more from exercising than those experiencing severe levels of disability, the current findings suggest that changing health behaviours incorporating an increase in exercise should be promoted in the first 12 months following diagnosis, as it may not only assist PwMS to increase their general health, but it may also assist them in stress management and coping with the diagnosis.

The theme of changing health behaviours also encompassed participant uptake of conventional and/or complementary therapies. As described in Chapter 3, conventional therapies, such as immunotherapy, can be daunting for the recipient for a number of reasons, and can be difficult to access depending on availability and cost. However, some PwMS may argue that going through the process of deciding to begin immunotherapy, and indeed commencing the

treatment shortly after diagnosis, returns a sense of personal control over the disease. By engaging in conventional medicine, the PwMS may feel that they are actively combating the progression of the disease (Jelinek, 2005). Current participants' reporting of the benefit of complementary therapies was not surprising given the documented increase in interest shown by PwMS in a wide variety of therapies over recent years (e.g., Pucci et al., 2004; Schwarz & Leweling, 2005). As outlined by Apel et al. (2006), PwMS may engage in complementary therapies regardless of research or personal experience verifying the treatments as effective. The current participants may have viewed their engagement in complementary therapies in the first 12 months following diagnosis as opportunity for slowing disease progression.

It is important that health professionals acknowledge the likelihood of PwMS exploring complementary therapy options shortly after their diagnosis. This is of particular importance given that the most popular complementary therapies found in the current study included changes to diet and vitamin supplementation, activities that may interact with conventional medicines. It is therefore highly likely that the issue of possible interaction between dietary supplements and medication may need to be discussed with PwMS soon after diagnosis. As was pointed out by Schwarz and Leweling (2005) the addition of a complex or time consuming diet may provide some PwMS with a sense of control and initiative over the uncontrollable illness. Health professionals may wish to advise PwMS on an appropriate diet, and point them to reputable source of information on this, and other complementary therapies. Engaging in health changing behaviour may be seen as taking control over the aspects of health that can be maintained, in the face of the MS diagnosis which can not be controlled. Those who reported changing health behaviour as the factor that assisted them most found that actively working to stay well and remain strong in the first 12 months following diagnosis helped them to cope with the diagnosis of MS.

8.4.3.4 Information Seeking and Sharing

The fourth most frequently identified theme from participants' responses regarding what they found to be of assistance to their coping with the diagnosis of MS, was information seeking and sharing. These participants relied heavily on a variety of information sources to gain a thorough understanding and knowledge about MS. It was this 'knowledge is power' construct that was identified by some as being of the greatest assistance to their coping with the diagnosis. In some cases, participants indicated that although they had felt a certain level of anxiety upon reviewing details of possible symptoms, worse case scenarios, and high levels of disability, they still felt empowered by the information, and believed it helped them cope in the 12 months following diagnosis.

This theme of information seeking and sharing also encompassed some participants' search for a second opinion, or a neurologist that they perceived suited them better. The participants in the current study identified that they felt better able to cope when they were comfortable with their doctor and confident that the information they needed would be shared with them in a timely and effective manner, as was outlined by Baker (1998). Therefore, PwMS should not be discouraged if they express a desire to seek a second opinion or meet with other physicians, and health professionals should not take offence to this behaviour.

Some participants in the current study also identified the importance of sharing information about MS, with other PwMS in particular. The sense that other PwMS would empathise with how participants were feeling in the first 12 months following diagnosis was of enormous benefit, as they could speak openly about symptoms and the unpredictability of MS while feeling supported and understood. Where written information from health professionals or researchers offers information about certain aspects of MS, a different type of information was also able to be gleaned from another PwMS. PwMS are able to give and receive personal

information about their own experiences of the ramifications of having MS, whether physical, social, or emotional. This source of information added a new layer of understanding about MS for the current participants. Interestingly, many of these participants indicated that the sharing of information with other PwMS had happened online, through support groups, emails or websites. The reliance on the internet as a tool for the gaining and sharing of information as demonstrated by the current participants, is in line with Brewer's (2005) findings regarding the internet as an information source for PwMS. The findings of the current study are also in line with Strittmatter's (2004) study outlining the benefits of PwMS peer interaction via the internet. The ability to access other PwMS in the first 12 months following diagnosis and to share information, whether face to face or online, was identified by many participants as being of assistance to their coping with the diagnosis.

Matson and Brooks (1977) indicated that the seeking out of information on MS is a necessary part of adjusting to a diagnosis. For the most part, it would be safe to say that health professionals working with PwMS today are aware of the importance of information provision at, or soon after, the time of diagnosis. However, the types of information and the sources by which it can be gathered by PwMS, seem to be ever-evolving. Those working with people newly diagnosed with MS may wish to explore all resource options with the individual, including other PwMS and reputable websites; two of the least studied, but rapidly emerging, sources of information for PwMS. It is the importance of meeting and sharing information with other PwMS, and the use of the internet to access information and meet other PwMS, that current participants highlighted in several instances in this research as activities they engaged in, as well as factors that assisted them in the first 12 months following diagnosis.

8.4.4 Factors that Hindered Participants' Coping with Diagnosis

Approximately one third of the participants who responded to the open ended question regarding what they thought assisted or hindered them in coping with the diagnosis of MS in the first 12 months, gave a response regarding a hindrance they identified. When analysed, participants' comments on what they found to be a hindrance to their coping presented four themes: 'Dealing with the attitudes of others', 'Attempting to maintain a pre-MS lifestyle', 'Information overload', and 'Negative examples of other people with MS'. The findings of all four themes will be discussed below.

8.4.4.1 Dealing with the Attitudes of Others

Dealing with the attitudes of others was the most frequently identified theme in participants' comments regarding what hindered their coping with the diagnosis. As suggested by Baker (1998), those who form the social and medical support of PwMS have the capacity to assist in, or hinder, the coping efforts of the individual as they attempt to adapt to the diagnosis. For these participants, members of their social or medical network hindered their ability to cope with the diagnosis by displaying unhelpful attitudes. This theme encompassed participants who reported being negatively affected by the attitudes of others, as well as participants who reported being unable to manage unhelpful attitudes. For some PwMS, these unhelpful attitudes were demonstrated by health professionals, family members, friends, and for some, members of the wider community, or relative strangers. Participants found that experiencing unhelpful attitudes in the first 12 months following diagnosis was upsetting or aggravating. Although a greater number of participants reflected on the negative, dismissive or condescending attitudes of health professionals, the uncaring or insensitive attitudes of family members, friends, and others were also highlighted by a number of these participants.

Concordant with Carter et al.'s (1998) findings that those with a chronic illness develop a sense of hopelessness when their health professionals convey a pessimistic attitude about disease prognosis, the current participants reported feeling less able to cope with the diagnosis of MS if their doctor was dismissive of their concerns, or patronising in their approach. When negative attitudes of health professionals were perceived, participants expressed frustration and disappointment in their physicians, and reported a sense of isolation as they felt they could not rely on their health professionals to provide support. Some participants were so affected by the negativity of their health professionals that they reported these attitudes as being a hindrance to their ability to cope with the diagnosis in the first 12 months. Considering that Counte et al. (1983) found that psychosocial adjustment to MS is largely influenced by an individual's satisfaction with their physician, the current findings are not surprising. It makes sense that the current participants reported the attitudes of their doctors as a hindrance to their coping if the doctors' attitudes were perceived as anything but supportive, helpful and positive. A physician's poor communication skills, which were identified by some of the current participants as being fundamental to their unhelpful attitudes, may have adversely affected the relationship between patient and health professional and left the participant feeling less able to cope with the diagnosis (Counte et al., 1983).

It is unknown why the current participants' physicians were negative, pessimistic, or dismissive when communicating with their patients. It may be related to the health professional's confidence in their ability to care for the person newly diagnosed, or their ability to convey hope to the patient, as discussed by Carter et al. (1998). It may be that they have poor social or communication skills, or that sometimes health professionals forget to put themselves into the shoes of the person they are working with and to focus on the immediate needs of the PwMS, including their emotional needs. Diagnosing someone with MS may become a 'routine' event for

a neurologist, who may fail to realise the enormity of the situation for the individual who may have no previous knowledge of MS.

Baker (1998) suggested that a friend or family member's failure to appropriately acknowledge the diagnosis of MS can become an external barrier for the PwMS in their attempts to seek out information, disclose the diagnosis or seek treatment. The current findings reflect this assertion as some of the current participants reported the unhelpful attitudes of family members, friends and others, as acting as a hindrance to their own coping with the diagnosis of MS. Some participants reported that members of their social network were not only dismissive, but were hurtful in their attempts to bring humour, or normality, to the diagnosis of MS, as the person newly diagnosed looked well. Alternatively, some participants reported being treated as unwell, despite their effective management of MS symptoms. The current participants commented on the stigma connected to PwMS, and the comments they would receive based on the misunderstanding of MS held broadly in the community. This finding is in line with that of Grytten and Maseide (2006) who found that PwMS found it more difficult to cope if they are attempting to counteract stigmatising experiences in their social relationships.

It may be considered surprising that no participants reported specifically on unhelpful attitudes received within the workplace. Given the research by Harden et al. (2004), among others, it may have been expected that some participants would comment on employer or colleagues' attitudes as being of a hindrance to their coping. However, the comments regarding stigma about MS were reported to be made by those in participants' social networks, rather than within the context of employment.

While some PwMS may be able to ignore unhelpful comments, or manage the unhelpful attitudes of others, some PwMS are unable to prevent such attitudes from hindering their ability to cope with the diagnosis. Health psychologists, amongst other health professionals, may be

able to assist people newly diagnosed with MS to better manage the real or perceived attitudes of others when attempting to adapt to the diagnosis. Health psychologists are also able to work with PwMS on developing better communication strategies to ensure effective communication with their health professionals, family members, and friends. Diagnosing physicians may serve their patients well by suggesting an appointment with a health psychologist if communication issues are present.

8.4.4.2 Attempting to Maintain a Pre-MS Lifestyle

Attempting to maintain a pre-MS diagnosis lifestyle was the second most frequently identified theme in participants' comments on what hindered their coping with the diagnosis. These participants attempted to maintain a pre-MS lifestyle by hiding the diagnosis from others, not making changes to their post-diagnosis lifestyle, or attempting to continue with the fast pace of life they were used to before the diagnosis of MS. Participants reported that their coping was hindered because of the added stress that came with such activities. While only a few participants used the word 'denial' in their response regarding what they thought hindered their coping in the first 12 months following diagnosis, all responses categorised under this theme alluded to the presence of avoidance or denial related behaviour in the first 12 months following diagnosis. These participants reflected that attempting to maintain their pre-MS lifestyle was a way of denying or avoiding the diagnosis. It was only with the power of hindsight that they could report this as being of a hindrance to their coping efforts.

Shontz (1975) considered that denial can be an adaptive strategy used to cope with a diagnosis of a chronic illness, as it can prevent the individual from becoming overwhelmed with the stress of illness onset and the threat of disability shortly after diagnosis. Indeed, denial has been viewed as a regulating mechanism, allowing an individual to manage a perceived threat,

such as a diagnosis of MS, gradually (Horowitz, 1976; Roth & Cohen, 1986; Shontz, 1975; Sullivan, Mikail & Weinschenker, 1997). While some of the current participants reported that denial, as seen in their attempts to maintain their pre-MS lifestyle, was not helpful in the first 12 months following diagnosis, this report has been made with the benefit of hindsight. It is possible that at the time, these participants used denial as a strategy to manage the diagnosis as best as they could at the time. This is of particular importance for health professionals working with those newly diagnosed. Health professionals should be aware that denial may serve a psychologically protective function for a short period following diagnosis (Kortte & Wegener, 2004). However, if the presence of denial continues for a longer period of time, it may hinder adaptation to diagnosis through compromising health promotion or illness prevention activities, interfering with adaptive behaviour, or contributing to the frequency or intensity of intrusive thoughts (Mullen & Suls, 1982; Roth & Cohen, 1986; Suls & Fletcher, 1985). Future research into the psychologically protective function of denial, specific to adaptation to MS, and the length of time that may be considered an 'unhealthy period of denial' would be beneficial.

The current finding that some PwMS recognise that they attempted to maintain their pre-MS lifestyle, as a way of partially denying the illness presence in their lives for the first 12 months following diagnosis, is new to the field. Indeed, the current participants were able to discuss their reasons for attempting to maintain their former lifestyle, while concurrently viewing these attempts as being of a hindrance to their coping in that time period. Further research into the attempts by PwMS to maintain their pre-MS lifestyle, and their reasons for doing so, would be of great benefit to the health professionals working with people newly diagnosed.

8.4.4.3 Information Overload

Information overload was the third most frequently identified theme in participants' comments regarding what hindered their coping with the diagnosis. This finding may come as somewhat of a surprise given the ever-increasing emphasis on the importance of providing information to those newly diagnosed with MS, and the popular concept that 'knowledge is power'. It is also in contrast with the information seeking and sharing that some participants identified as being of assistance to their coping with the diagnosis. The participants who identified information overload as a hindrance to their coping reacted to the diagnosis by consuming as much information about MS as possible, before discovering that the volume or type of information was too much for them to cope with. Finding a balance between an appropriately informative amount and too much information was difficult for these participants, who suggested that MS information overload hindered their coping with the diagnosis in the first 12 months.

Previous studies have confirmed the importance of appropriate information provision to those newly diagnosed with MS (e.g., Baker, 1998; Hepworth & Harrison, 2004; Somerset et al., 2003). For example, Somerset et al. (2003) suggested that information leading to a sound knowledge of MS is beneficial to the wellbeing of PwMS as it increases the individual's sense of personal control, as well as leading to a reduction in dependence on government health services. Previous studies have also been conducted into the problems individuals may face if unable to access enough information at the time of diagnosis (e.g., Brooks & Matson, 1987; Matson & Brooks, 1977). It is the potential detrimental effects of information overload that is studied less frequently. Some of the participants in the current study were able to identify that too much information about MS, the potential symptoms and disease course, was unhelpful in their attempts to adapt to the diagnosis. A conversation with a health professional about finding a

balance between enough information, and too much information, would be helpful for those newly diagnosed.

Concordant with the findings of Wollin et al. (2000), participants in the current study also stressed the need for individualised information in terms of content, format and volume, expressing that the informational needs of all PwMS are not the same. The current participants highlighted that wading through copious amounts of generic information did not necessarily assist them in their preparation to cope with MS. Indeed, these participants suggested that too much non-specific information hindered their coping by preventing realistic planning for their individualised situation. Broad information about MS was consumed at a rapid pace by these participants, who reported much of the information as distressing, depressing, and instilling hopelessness at a very early stage following diagnosis.

The information on MS that is accessible on-line by those newly diagnosed was raised by these participants as a specific contributor to their experience of information overload. As Pucci (2003) and Bard (2005) reported, incorrect, misleading, and in some instances, dangerous information about MS can be found on-line, is often scientifically unreliable and frequently promoting spectacular 'cures' for the condition. Some participants expressed fear for their future with MS, following the reading of information they had accessed online. It was perceived that worst case scenarios were often presented online, leaving participants feeling distressed. Some participants reported reaching a conclusion in the first 12 months following diagnosis that they had to limit their information intake as the never ending information on symptoms and negative outcomes of MS were impacting on their ability to cope well with the diagnosis.

Lewis (2006) raised concerns that the internet provides an unregulated source of information to vulnerable individuals. The findings of the current study support this assertion, and suggest that health professionals attempt to tailor information provision to the needs of the

individual. This would include a careful examination of the internet sites available to those newly diagnosed with MS, with recommendations of helpful, useful sites made to PwMS, and possibly warnings about those that may not be of assistance in the first 12 months following diagnosis. This would follow the suggestions of Schloman (2006) and Pucci (2003) regarding health professionals 'referring' patients to specific reputable online sites, to assist in the prevention of information overload, and the accessing of dangerous information. Health professionals may also consider taking the time to talk to PwMS about their own information seeking, and finding a balance between appropriate levels of information uptake, and information overload.

8.4.4.4 Negative Examples of Other People with MS

Witnessing negative examples of other PwMS was the fourth most frequently identified theme in participants' comments regarding what hindered their coping with the diagnosis. This result extends the current finding that while many people newly diagnosed with MS report meeting another PwMS as beneficial and a positive experience, some PwMS do not have that experience, instead viewing the meeting as negative, or a perceived hindrance to their coping with the diagnosis. Participants identified encountering negative examples of other PwMS in two different ways. First, the high level of physical disability of other PwMS was named by some participants as the reason they viewed an example of another PwMS as negative. Second, the negative, hopeless, or helpless attitudes of other PwMS, regardless of visible disability, contributed to some participants viewing negative examples of other PwMS as a hindrance to their coping with the diagnosis. These encounters with other PwMS were not strictly via face to face or even on-line meeting, instead they included published stories about PwMS that focused on disability and did not provide inspiration to the person newly diagnosed with MS.

This finding has implications for both the information seeking aspects of behaviour following diagnosis, and the desire by some people newly diagnosed with MS to contact and discuss their diagnosis with another PwMS. In responding to this question of what hindered coping in the first 12 months, one of the current participants raised the issue that PwMS are at their most vulnerable straight after diagnosis, and may need some protection from the factors that could hinder their ability to cope with the diagnosis. As discussed above, information tailored to the individual may assist in reducing the likelihood of PwMS encountering negative examples of other PwMS in published stories. However, there is often a fine line between what one person finds distressing or uncomfortable, and another finds inspirational. It would be extremely difficult for health professionals to guarantee that information that could assist was being made available to the individual, while information that could hinder was withheld. Similarly, while some people newly diagnosed with MS find discussing the diagnosis with another PwMS of great benefit, others do not. As discussed above, the commonality of being diagnosed with MS does not ensure that one person can provide another with support, encouragement or inspiration. Participants in the current study have reported that this is not necessarily the case, and have instead suggested that a negative example of another PwMS may actually hinder their coping with the diagnosis. Again, health professionals may wish to assess the appropriateness of linking a person newly diagnosed with MS into a support group or situation where they are exposed to others with MS, as while positive encounters can assist in adaptation to diagnosis, negative experiences can hinder.

8.5 Theoretical Implications within a Health Psychology Framework

The opportunity for PwMS to identify what assisted and/or hindered their coping in the first 12 months following diagnosis, was provided for in this research. In their own words,

PwMS explained why they behaved as they did regarding disclosure, speaking to another PwMS, and what they believed helped, or hindered them to cope with the diagnosis. It was these participant responses that often included details of the coping resources they drew upon to aid them in their adaptation to diagnosis. The findings of the current research relevant to coping resources fit within the coping model of Lazarus and Folkman (1984), as participants identified that specific coping resources assisted them in their coping in the first 12 months, whereas a lack of coping resources hindered their coping, or led to unhelpful coping strategies such as attempting to maintain a pre-MS lifestyle without taking into consideration changes that may have occurred as a result of MS symptoms.

Taking control was the most common coping resource and strongest theme identified throughout the findings of the current research relating to what PwMS thought helped them in the first 12 months following diagnosis. While social support and positive thinking were both identified as important coping resources by participants, the dominance of taking control as the leading resource identified by PwMS makes both conceptual and theoretical sense. It is not difficult to recognise the need of many people diagnosed with an incurable, inexplicably caused, and largely uncontrollable disease such as MS, attempting to take control of issues within their power to control, such as information gathering, disclosure, and lifestyle changing activities. While this may not be the case for all people newly diagnosed with MS, it makes conceptual sense that taking control is of utmost importance to many when first diagnosed.

The recognition of taking control as both the dominant theme and the most identified coping resource throughout the current results may be relatively uncommon in studies on coping resources, but it is theoretically sound. Social support is arguably the most commonly cited coping resource available to PwMS, and indeed, also the coping resource that receives the most attention in broader health-related research (Pakenham, 1999). Similarly, optimism or a positive

attitude has also received much attention as a coping resource in the MS related literature (Fournier, de Ridder & Bensing, 2003). The coping resource of taking control is not as common in the literature as social support or optimism, but is closely linked to the concept of self-efficacy as described by Bandura (1989); a construct familiar to MS researchers. Self-efficacy has been shown to be an important variable in relation to adaptation to MS, as described in Chapter 4. An investigation into self-efficacy by examining participants' beliefs in their abilities to overcome the specific challenges of MS, was not included in the current study as the researcher did not want to presuppose the responses of PwMS, but rather sought an exploration of what PwMS thought assisted them, in their own words. However, the notion of PwMS acting in a way to take control over various aspects of life following the diagnosis came through very strongly in the data. Taking control can be seen as an extension of an individual's self-efficacy, with self-efficacy referring to an individual's *belief* in their ability to overcome specific challenges, and taking control referring to the *actions* taken by an individual to overcome the specific challenges. A theoretical implication of the current study's findings could be that when exploring models that predict coping in MS, the variable of taking control should be examined together with social support, optimism and self-efficacy.

Of all the possible hindrances to successful coping and adaptation to a diagnosis of MS, the emphasis within the relevant literature remains on denial and avoidance. There have been mixed findings in the MS literature regarding adaptive coping with regard to the inclusion or exclusion of avoidant coping strategies (e.g., Mohr et al, 1997; Pakenham, 2001). More generally, as is implied in the current study, it has been found that denying the diagnosis of MS or avoiding MS related issues following diagnosis is related to decreased well being (Brooks & Matson, 1982). In the current research, PwMS who reported attempting to deny the presence of the disease during the first 12 months following diagnosis found that doing so acted as a

hindrance to their coping with the diagnosis. Participants described engaging in avoidance behaviour by choosing not to meet another PwMS and by attempting to maintain a pre-diagnosis lifestyle. However, there may be times in the first 12 months following diagnosis that PwMS feel better able to deal with the stress of diagnosis by way of managing emotional responses using avoidant coping strategies such as these. It should also be noted that the current study's retrospective design allowed participants time to reflect on their actions in the first 12 months, which may have led them to conclude that avoiding or denying the diagnosis was unhelpful given the benefit of hindsight, although at the time it may have been a functional coping strategy. The challenge for practitioners working with PwMS is to find the point in time when avoidance turns from a helpful short term strategy, to a hindrance to their longer term coping.

Some participants in the current study reported that a number of positive outcomes also came from their diagnosis of MS. The finding that PwMS may report perceived benefits from their diagnosis experience is consistent with literature regarding cognitive adaptation theory (Taylor, 1983; Taylor et al., 2000). Cognitive adaptation theory purports that, as well as attempting to regain mastery over the event and over life more generally when attempting to adjust to a threatening event, individuals will search for meaning in the experience, and engage in self-enhancement, or find ways of feeling good about oneself (Taylor et al., 2000). PwMS in the current study reported that maintaining a positive attitude during the first 12 months following diagnosis assisted their coping, even though some of their friends or family labeled this positivity as 'being in denial'. For some, this positive attitude extended into a perception that the diagnosis held benefits for the individual, or even that the diagnosis was viewed as a 'gift'. The current research extends the concept that PwMS can draw a greater appreciation for life, find clarity of goals and a new grasp of what is truly important to them, following their diagnosis. Such findings seem concordant with the view of cognitive adaptation theory that people are adaptable,

self-protective and functional in the face of setbacks (Taylor, 1983). Based on the exploratory findings of the current research, future research may benefit by extending Taylor's (1983) cognitive adaptation theory to a population of PwMS.

8.6 Implications of the Current Findings for Health Professionals Working with People Newly Diagnosed with MS

Over recent decades, much has changed in the attitude toward, and the delivery of, health care services for those with a chronic illness. At present, there is an increasing emphasis being placed on the role of self-management in chronic illness, including MS (Gately, Rogers & Sanders, 2007). Self-management programs for those with chronic illnesses emphasise that individuals 'take control' of their disease by setting realistic goals with their health professionals for effective self-management of symptoms and general health, both in the short and long term. Findings of the current study contribute to the notion that there is a great need for PwMS to be able to take control of various aspects of their adaptation to the diagnosis within the first 12 months. For example, the acquisition of information, engaging in positive health behaviours, making practical changes, and disclosing the diagnosis to others are among the areas that PwMS may want to herald some control over. Through engaging PwMS in open communication and training in self-management techniques, the health professionals working with PwMS in the first 12 months following diagnosis may be able to assist PwMS to have some control over life with MS, acknowledged in this study as being important to their adaptation to diagnosis.

While increased and open communication with PwMS and the provision of training in self-management techniques are broad areas that health professionals can apply to their work with those newly diagnosed, the current research also provides more specific implications for health professionals working with PwMS. These will be discussed below and include:

information provision, registration with MS Society, making lifestyle changes, spiritual needs, disclosure of diagnosis, recommendation of peer support, encouraging a positive attitude, and dealing with the attitudes of others.

8.6.1 Information Provision

Information about MS is often provided by health professionals at the time of diagnosis, and/or during subsequent appointments. The current findings support those of Baker (1998) and Hepworth and Harrison (2004) among others, indicating that the health professionals working with people newly diagnosed with MS need to be able to provide timely and accurate information to their patients. Initially, both PwMS and their family members should be provided with information on disease activity and progression (Kalb, 2007), and as Hepworth and Harrison (2004) suggested, information in a variety of forms should be made available. Together with providing facts sheets about MS, research based journal articles and commentary on personal experiences written by other PwMS, health professionals may also want to take some time to view what is available on the web. The current sample favoured seeking information about MS on-line above all other information seeking activities. While a thorough examination of the enormous amount of online information about MS would be unattainable for most individual health professionals, a local MS Society may be able to invest some time in developing, and updating, a guide to reputable sites, as well as providing warning information about the sites offering dangerous or misleading information. As discussed in the 'limitations of current research' section below, the preference for seeking information about MS online may be a reflection on the current sample and the data collection method used in this study. However, as the amount of information about MS available online continues to grow, consumer reliance on the internet as a preferred source of information is worthy of health professionals' attention.

While there exists an enormous amount of information about MS online, a health professional's willingness and ability to tailor information specifically to the individual may assist in the prevention of information overload for people newly diagnosed with MS. If not already taking a leading role in information provision to PwMS directly, MS Societies could lend support to community health professionals as they guide PwMS through the plethora of information available. Health professionals and MS Societies may find benefit in discussing the risks of information overload with PwMS, and may be able to suggest strategies on how to draw the line between appropriate information seeking and gaining the required knowledge about MS, and information overload; a hindrance to coping with the diagnosis as reported by some participants of the current study.

8.6.2 Registration with the MS Society

One of the first ports of call for some people newly diagnosed with MS wanting to acquire information about the disease is the MS Society or a local MS specific organisation. In most instances, MS organisations will provide information about the disease to PwMS, family members, health professionals, and members of the general public. The current research highlighted the disparity in PwMS contacting the MS Society for information, and PwMS registering as clients with the MS Society within the first 12 months following diagnosis. With a lesser number of PwMS registering as clients, as opposed to seeking information from the MS Society, this finding is of value for health professionals and MS Societies alike. MS Societies can be a valuable resource for both health professionals and PwMS, and may provide client services and information resources targeted specifically toward PwMS, and founded on current research. Health professionals working with PwMS cannot be expected to cover every area of need relevant to an individual's life in the first 12 months following diagnosis, or beyond.

Instead, health professionals should be willing to explore what their local MS Society can provide their patients, and guide their patients to make use of the resources available to them. Future research into why some PwMS elect to seek information from the MS Society while simultaneously declining to register as a client of the organisation would be of interest to MS Societies and may assist them in their marketing strategies.

8.6.3 Making Lifestyle Changes

Health professionals working with those newly diagnosed with MS may find that many show an immediate interest in making lifestyle changes and participating in activities that they believe will improve their disease prognosis, or management of symptoms, as was shown in the current study. Such activities include, but are not limited to, the uptake of conventional medicine, the use of complementary therapies, and making other practical changes to their physical environment. In line with the findings of Pucci et al. (2004), the current research demonstrates that complementary therapies are embraced by PwMS following diagnosis. Engaging in complementary therapies may be indicative of the willingness of the person newly diagnosed to take control of aspects of this ‘uncontrollable disease’. As some complementary therapies can be dangerous, health professionals can play a crucial role in pointing PwMS toward safe complementary therapies and the research surrounding the efficacy of such therapies, while warning of the harmful ones. Supporting PwMS to explore alternative therapies or make other practical changes may assist PwMS to feel empowered about certain aspects of managing the disease.

A common lifestyle change for PwMS, particularly those diagnosed with RRMS, is the commencement of conventional medicine or immunotherapy. While this form of treatment may be considered more straightforward to practitioners than complementary therapies, it is equally

important for the health professionals working with PwMS to understand the complexities involved in beginning medical treatment and the reluctance that may be evident in some people newly diagnosed. Health professionals also need to ensure that PwMS feel able to discuss their desire to explore combinations of complementary and conventional therapies. Clear communication between health professionals and PwMS will aid in open and honest discussion, thereby promoting patient confidence in their practitioner, and increased safety for PwMS wanting to combine more than one form of therapy.

In the same way that commencing conventional or complementary therapies can empower PwMS by giving them a sense of control over aspects of managing their MS, making other practical changes to their lives can do the same. Practical changes may include modifications to the physical environment, such as installing air-conditioning to reduce the impact of some MS symptoms, or the adoption of new strategies to cope well with MS. The current study identified that making practical lifestyle changes following diagnosis is reported by PwMS as something that assists them to cope with MS in the early stages of living with the disease. Health professionals can play a key role in teaching PwMS effective coping strategies and introducing ways of making positive practical changes, to ensure the best management and incorporation of MS into their lives.

8.6.4 Spiritual Needs

In the current research it was found that the spiritual needs of PwMS should not be dismissed or ignored by the health professionals working with PwMS at the time of diagnosis. This may be particularly important for women, given that more women in the current study reported an increase in interest in spirituality in the first 12 months following diagnosis, than men. However, health professionals working with PwMS at the time of diagnosis have an

enormity of issues to be aware of, topics of information to consider, and matters to discuss. The spiritual needs of the individual may not be as palpable as their physical or emotional needs at the time of diagnosis or during subsequent medical appointments, and may be best served by programs or discussion groups run by MS Societies. If health professionals are aware of such groups run by the MS Society, they could discuss this option with their clients. Health professionals may wish to reassure those newly diagnosed that questions about spirituality or a change of interest on such matters is typical following a life changing diagnosis, and if more comfortable, PwMS may wish to seek private counsel with a religious or spiritual advisor. Alternatively, a psychologist is also able to discuss such issues with a client, and may be of benefit if the person newly diagnosed with MS wants to discuss a changed level of interest in spirituality. Health professionals need to be aware that spiritual issues may arise following diagnosis and that an open discussion of such may be helpful.

8.6.5 Disclosure of Diagnosis

A further implication of the current research for health professionals working with people newly diagnosed with MS is in regard to an individual's choice to disclose their diagnosis to others. A large number of PwMS in the current research did not feel as though they had a choice about whether or not to disclose, especially those who had already advised others of their symptoms prior to receiving the diagnosis. This finding highlights a possible need for discussion between health professionals and patients about disclosure *prior* to diagnosis. However, such a discussion may not be easy for either party. The individual undergoing tests for inexplicable symptoms may be made more anxious if their doctor advises them against disclosure even before a diagnosis is made. It is also possible that the doctor would feel very uncomfortable discussing the pro's and con's of disclosure with a patient, while still carrying out tests. However, such a

discussion may assist in the prevention of unwise early disclosure made without appropriate thought being given to ramifications of such an action. Disclosure of symptoms or the diagnosis of MS can have negative effects on significant areas of an individual's life, such as their employment situation. If health professionals working with PwMS are aware of the potential detrimental effects of premature disclosure, they may be able to prompt PwMS to consider all options and ramifications to ensure that people newly diagnosed are not disclosing their diagnosis without making the conscious decision to do so.

While a discussion about disclosure is likely to be very difficult prior to diagnosis, a possible approach would be to empower the patient to take control of their health and symptom related information. If possible, health professionals may be able to indicate that erring on the side of caution, before a diagnosis can be made, may make decisions about full disclosure easier down the track.

8.6.6 Recommendation of Peer Support

Peer support is rapidly emerging as a legitimate option in the provision of emotional and social support to PwMS across the world (Messmer Uccelli et al., 2004). While formalised peer support programs can provide beneficial health and well being effects for participants (e.g., Lorig et al., 2001), the current study found that speaking to another PwMS is not always viewed as helpful by people newly diagnosed with MS. This departure from the popular view that peer support is always helpful is noteworthy. In particular, the findings of the current study indicate that the attitude of the other PwMS may be more important to those newly diagnosed, than the presence or absence of physical disability. This is a critical finding, and can assist health professionals (and friends and family of the person newly diagnosed) to assess peer support participants based on their attitude toward living with the illness, and toward those newly

diagnosed, rather than their physical presentation. Not all people newly diagnosed will want to meet another PwMS. However, for those who express an interest in doing so, it is very important that they are matched appropriately with the utmost concern for their wellbeing.

8.6.7 Encouraging a Positive Attitude

The current study identified that PwMS rate maintaining a positive attitude as the factor that most assisted them to cope in the first 12 months following diagnosis. As positive attitudes can be encouraged from the time of diagnosis, diagnosing physicians may want to take care to present the diagnosis in a realistic but positive and hopeful manner. PwMS should be encouraged to use optimism as a valid coping resource, as a positive attitude can play a significant role in the adaptation to chronic disease (e.g., Fournier, de Ridder & Bensing, 1999). This is not to say that health professionals should negate patients' concerns or dismiss negative thoughts or feelings about the diagnosis, but positive attitudes or feelings of hope should not be quashed. Together with encouragement around taking control of manageable aspects of life with this disease, health professionals are also able to support the realistic positive attitudes of PwMS, and the importance of doing so should not be downplayed.

8.6.8 Dealing with the Attitudes of Others

Participants in the current study identified dealing with the attitudes of others as the biggest hindrance to their adaptation to diagnosis. The attitudes that participants found difficult to cope with came from two groups: members of their social network, and members of their medical network. The unhelpful attitudes of others in the social network included dismissive attitudes, comments made based on stigma related to MS, or an inability to appropriately acknowledge the diagnosis of MS.

As participants in the current study described the detrimental impact of others' attitudes, there was also an emphasis on the negative attitudes of members of their medical network. Health professionals working with PwMS may already be aware that their attitudes toward the patient, and the disease, can have a meaningful impact on the person with the illness. In accordance with the findings of Carter et al (1998), participants in the current study also reported feeling less able to cope with the diagnosis of MS if their doctor was dismissive of their concerns, or patronising in their approach.

In the first 12 months following diagnosis and presumably after this initial period as well, PwMS report their own ability to maintain a positive attitude as being of *assistance* to their adaptation to diagnosis (as described in the previous section), and the negative attitudes of others as being a *hindrance* to their adaptation. Health professionals should be able to support and encourage patient positivity, while simultaneously avoiding transmission of negativity or hopelessness. In addition, health psychologists may also be able to work with PwMS to better manage the attitudes of those in their social and medical networks and the impact these attitudes have on their own ability to cope, and in developing better communications strategies to use with their health professionals, family and friends, to combat the negative ramifications of having to deal with unhelpful attitudes. Effective communication strategies and the management of real or perceived attitudes of others may be an area in which health psychologists could take a lead in the education of other health professionals working with those newly diagnosed.

8.7 Critical Evaluation of the Current Research

Along with several strengths, there are several limitations of the current research that must be acknowledged and discussed. Analogous to most psychological research, participants in the current study volunteered to be involved. Indeed, the current participants self-selected to be included in the online research, and thus may have differed from the general population of PwMS in three main ways. First, all participants had to have access to a computer and the internet in order to complete the online questionnaire. While the percentage of PwMS who have access to both a computer and the internet is unknown, the online questionnaire format necessarily excluded from the study those PwMS who do not have such access. This may have contributed to the sample's higher level of education, employment status, and occupation type, when compared to the general Australian population. Although, as the sample was drawn from the global community and compared to Australian population norms, participant difference from the norm is not a certainty. However, the sample's obvious computer access and internet use must be kept in mind when examining the results.

Second, the questionnaire was only accessible through a link posted on the MS Australia website, so participants had to have been searching for MS related information on-line at the time of accessing the study. Although participants were asked to reflect on their first 12 months following diagnosis, the use of an online questionnaire format may have biased participants' responses regarding their online behaviour of the past. In particular, the findings relevant to internet based activities in information seeking behaviour and the prevalence of the online discussion of diagnosis with another PwMS, may have been affected by the sample's salient interest in internet technologies at the time of completing the questionnaire. Considering the growing use of the internet as a source of information, this can be seen as a modern example of a

problem inherent in all retrospective research: reliance on the subjective memory of participants, to be discussed below.

Third, participants in the current study may have self-selected to be involved because of a particularly strong desire to share their thoughts on the first 12 months following diagnosis, or to reflect and make meaning of their post-diagnosis experiences. This desire to participate in research on the post-diagnosis experience may come from particularly memorable events of the first 12 months. Indeed, participants may have experienced particularly positive, or negative, events in the first year. Thus, these participants may not be representative of other PwMS who did not have a particularly meaningful experience, or were not as keen to ruminate, or report, on their experience of the first 12 months following diagnosis. The relatively high levels of education and professional status in the sample may have also contributed to a buffering of the view that the diagnosis of MS is a form of social oppression, or contributed to the individualistic attitude of maintaining control (personal communication, Dr. Frances Reynolds, 2008).

The current research used a retrospective design that involved a self-report measure only. Unlike much research into MS, the current study did not require participants to undergo an assessment of disability such as completion of the EDSS (Kurtzke, 1983), as participants were asked about their experience of symptoms in the 12 months following diagnosis. A limitation of these methodological features is the reliance and dependency on the subjective memory of the participants (Heesen et al, 2003). The retrospective nature of the current research and the reliance on participant memory and interpretation of previous events is demonstrated by the comments of Participant 17167, who emphasises both the weaknesses and strengths of such a design:

Your question asks about 12 months and **when I look back at five years, they all seem to run together as an awkward journey. The first year was tough, but almost didn't seem that tough at the time...** Everything was new and different. **Only now do I start to see the clarity of what was happening and how I did and didn't cope that well.** (Participant 17167)

Participant 17167 highlights the difficulty of having to isolate her experiences within the first 12 months following diagnosis, from her broad experience of MS up until the time of participating in the study. It is this retrospective research approach and reliance on participant memory that may have contributed to the high number of participants in the current study reporting unexpected MS related information, such as a low number of exacerbations prior to diagnosis, or receiving a diagnosis of SPMS or Benign MS, as explained in Section 8.3.3.2. However, Participant 17167 also identifies the benefit of this methodological approach as having time since the first year following diagnosis to gain some clarity on the issues she faced, and the MS related experiences she had in the first 12 months. Therefore, this feature of the current research may be seen as both a limitation and strength of the study, given the participants could use the benefit of hindsight to identify and describe their experiences in the first 12 months following diagnosis.

Another limitation of the current study is its cross-sectional design, as there can be no causality determined between the variables based on the study's findings. However, the current research was primarily exploratory and, with a focus on qualitative data, aimed to extend the body of knowledge in the area of study. A future longitudinal study into post-diagnosis behaviour and lifestyle changing activity within the first 12 months and beyond, would allow

more sophisticated analyses and the possibility of causal connections to be made between factors of interest.

A decline in sample response rate was observed as participants moved through the questionnaire. The current researcher chose not to eliminate all incomplete questionnaires from analysis to avoid this predicament. Rather it was considered that benefit could still be had in analysing the responses that were provided, as the research was exploratory in nature and most questions with diminished response rates provided data for qualitative analysis. In addition, some qualitative findings were drawn from unsolicited comments made by some participants. For example, participants were asked whether they had discussed their diagnosis with another PwMS, and if so, how they knew or met that person. While their perception of that interaction was not required, there was an overwhelming offering of this information by many participants, and it was deemed important to report as such. It is indeed a limitation of the current study that participants were not asked directly to report on their perceptions of the interaction with another PwMS, however, the voluntary offering of such provides strong support for the need for future research addressing the specific area of perception of interaction between PwMS in the first 12 months following diagnosis.

Country of birth was identified by the current study as a potential key demographic factor that may influence adaptation or engagement in post-diagnosis behaviour and lifestyle changing activities following a diagnosis of MS. While there was certain merit to examining this factor as discussed in Section 5.2.2, an alternative that may have been of more relevance to the current study, could have been participants' country of *residence* during the time period of interest. This could have added value to the examination of some results such as a potential explanation for participant immunotherapy uptake in the first 12 months. While there may have been benefit in including country of residence in the study, a strength of the current research is its inclusion of

participants from multiple and diverse geographical locations, rather than a single geographical location as found in the majority of previous research. This use of inter-country comparisons should be considered in future research related to behaviour following diagnosis of MS, as in the current study there have been many consistencies demonstrated by PwMS across countries.

8.8 Future Research Directions

The current study was primarily exploratory in nature, with findings that naturally point to future research directions. Suggestions for further research can be made in regard to MS related experience prior to the diagnosis, at the time of a diagnosis, and in the first 12 months following a MS diagnosis. The results of the current study regarding MS related experiences prior to diagnosis demonstrate a potential area for research on MS exacerbations. Participants were asked to identify the number of MS exacerbations they experienced before diagnosis. As highlighted in the study findings, an unexpectedly large number of participants reported experiencing only one exacerbation before diagnosis. While this could be due to inaccurate recall of participants, future research into what PwMS regard as an exacerbation, and what they will report as an exacerbation when asked in retrospect (or indeed at anytime), is needed. Similarly, the correlation of such findings with the medical definition of an MS exacerbation would be of use to future research requiring participants to report on their experience of MS exacerbations. Likewise, further research into the accuracy of reports of MS symptoms as identified retrospectively by PwMS, may be of use to future research to indicate accuracy and reliability of data.

While Benign MS may not be widely recognised as a type of MS by both researchers and clinicians, it is apparent by the current research findings that PwMS across country groups and genders are identifying as having Benign MS, and report having been diagnosed as such. Further research into whether diagnosing physicians are using the term Benign MS, or whether PwMS

are taking that label on themselves, and the reasons behind the use of the term, would be worthy. It may be that physicians use the term to feel more comfortable diagnosing the disease, or it may be that PwMS adopt the term as it would be their desired course of MS.

Continuing with the line of research into experiences at the time of diagnosis, some of the participants in the current study identified as having no symptoms at the time of diagnosis. This small group of PwMS is rarely identified in research, and further studies into their unique experiences and potentially different behaviour following diagnosis could lead to a broader understanding of the diversity of experience of this disease as demonstrated by PwMS.

Equally understudied are the differences in experiences and behaviour exhibited by those who suspected they had MS before diagnosis. In the current study it was found that women were more likely to suspect they had MS before diagnosis than men, but this finding barely touches on the reasons behind, and the ramifications of, such suspicion. Future research could explore differences in familial occurrence of MS, or general knowledge of MS, and likelihood of suspecting MS prior to diagnosis. Whether PwMS who suspect the diagnosis react differently to those without suspicion would also be a worthy area to study, as it may be that those who suspected MS find it easier (or harder) to cope with the initial phase following diagnosis. If this is the case, diagnosing physicians may be able to have a more detailed discussion with the person who suspected MS at the time of diagnosis about the facts they already know about MS, the myths that they may need to dispel, and the appropriate information they can then provide given the level of pre-existing knowledge. However, it is hoped that such a discussion would take place with all newly diagnosed PwMS.

Withstanding the methodological issues of the current study being conducted on-line, there was a clear indication that participants relied heavily on the internet to seek out information about MS, and to communicate with other PwMS. This rapidly emerging source of information,

and avenue for communication with others around the globe, deserves considerable future research attention. As has already been raised here, the reliance on the internet for reliable, accurate and up to date information, is not without its concerns. Current participants both praised the internet, while simultaneously citing its ability to scare or shock those most vulnerable in the first 12 months following diagnosis. Future research into the preference for online information by people newly diagnosed, and the advantages of seeking and gaining peer support online is necessary, and will surely be a focus of attention in the coming years. With a smaller proportion of the current participants who identified as being diagnosed with Benign MS, as opposed to other types of MS, accessing information about MS online, this may also be an area worthy of future research. As already discussed, there are many reasons why this could be so, and a clearer understanding of the information needs of people with Benign MS would assist practitioners in their attempts to provide suitable sources of information to such individuals.

A suggestion for future research that may hold particular interest for MS Societies is based on the current finding that PwMS seek information from MS Societies, but do not necessarily register as clients in the first 12 months following diagnosis. MS Societies work hard to provide information and support to those newly diagnosed and indeed to PwMS throughout the disease process. As with any not-for-profit organisation that seeks funding based on the number of registered clients, this finding may be of concern. Reasons for seeking information through the MS Society and registering with the organisation shortly after diagnosis, and possibly more importantly, the reasons given for not contacting or registering with the MS Society following diagnosis should be explored thoroughly. Such research would then assist MS Societies to promote their services appropriately both to PwMS and the health professionals that may, or may not, be referring clients to them.

Several areas of interest related to disclosing the diagnosis of MS to others were identified in the current study and could be examined more rigorously in future research. It was somewhat surprising that participants in the current study identified that disclosing the diagnosis to others was more likely as a result of feeling obligated or compelled to do so, rather than for reasons of gaining emotional support. A challenge to this finding may be found in future research conducted into the reasons behind disclosure to close family and friends. In addition, a critical analysis of the timing of disclosure and the reasons given by PwMS behind their decision to disclose to employers and workplace colleagues, and the ramifications of such, would be useful. An in-depth analysis of the differences between countries with regard to work cultures, discrimination laws, and inhabitants' decision to disclose their diagnosis of MS to those at work, would contribute further inter-country data on the topic of MS disclosure and its ramifications for PwMS. Such research may be able to indicate whether disclosure to employers and colleagues is based on discrimination laws alone. In the current research some PwMS regretted disclosing their diagnosis to colleagues, or others, in the first 12 months. As mentioned earlier, the phenomenon of regret following disclosure is a complex one given the many and varied reasons behind disclosure, and the difficulty in educating PwMS about the issues of disclosure before, or at the time, of diagnosis. However, this area is in need of future research as some participants in the current study highlighted the theme of regret in their responses to questions that did not ask specifically about lamenting their disclosure. As disclosure cannot be withdrawn, research specifically targeting the construct of regret following disclosure, may identify a greater number of PwMS who indicate regret around disclosure than previously thought. This would re-emphasise the need for health professional support regarding the discussion of issues around disclosure, potentially prior to diagnosis.

As demonstrated by the current study, PwMS may seek psychological support following diagnosis, but the number doing so could be viewed as quite low considering the potential benefits available. Future research into the perceptions PwMS hold about psychologists, and what they think they could gain from speaking to a psychologist about various issues relevant to adaptation to diagnosis, would be advantageous. Health psychologists in particular have expertise in the area of adaptation to chronic illness, and PwMS could benefit from seeing them. Research into the perceptions held by PwMS about psychological services could assist in the determination of whether it is negative perceptions that prevent PwMS seeking psychological support following diagnosis, or whether it may in fact be that health professionals are not promoting the services of psychologists to PwMS.

Following the results of the current study, a more detailed examination of how PwMS view interactions with other PwMS in the first 12 months following diagnosis, and beyond, would be worthy of further research. Participants in the current study showed a variety of reactions to discussing their diagnosis with other PwMS, and interesting results were seen regarding the influence of physical and observable disability on the interaction. Participants appeared to place more of an emphasis on the attitude of the other PwMS than on the physical ability of that person, when forming their opinion on whether the interaction was positive or negative. The current research only stumbled upon the apparent differences in individuals' perceptions of meeting with other PwMS. Further research could be more specific in addressing the perceptions held by people newly diagnosed with MS toward other PwMS, and the impact of such meetings on adaptation to diagnosis. Such research would further the goal of MS Societies and health professionals in providing positive, empowering and reaffirming experiences of other PwMS to those newly diagnosed.

Finally, there is a need for further research into the importance of taking control as a coping resource for those newly diagnosed with MS. Participants in the current study reported on their desire to be in control, and indeed their ability to take control, across a number of areas of their life relevant to the diagnosis, and more generally. Further research into whether the use of taking control as a coping resource predicts better outcomes in adaptation to an MS diagnosis is warranted. An emphasis on the first 12 months is needed as key strategies, resources, or patterns of behaviour may be established by the individual diagnosed with MS in this time period to ensure successful coping. However the longer term ramifications of PwMS taking control, and their perceptions of how this resource assists, or hinders, their coping is also required. A follow up study employing the use of an in-depth qualitative approach with interviews would be beneficial.

8.9 Conclusion

The central aim of this thesis was to extend the body of knowledge regarding the experience of being diagnosed with MS. The MS related experiences of participants prior to, and at the time of, being diagnosed with MS were explored, before post-diagnosis behaviours and lifestyle changing activities, as recalled by participants, were examined. Specifically, the first 12 months following diagnosis were investigated. These aims were addressed primarily through qualitative means by asking people with MS to comment on their experiences in the 12 months following diagnosis. An exploration of the possible relationships between the key demographic variables of gender, country of birth and type of MS, and pre-diagnosis experience and post-diagnosis behaviour was also undertaken.

A dominant theme running through the findings of the current research was that participants were trying to take control of certain aspects of their lives relevant to MS, while simultaneously trying to adapt to the diagnosis in the first 12 months. Taking control was repeatedly identified as a particularly important coping resource drawn upon by participants to cope with areas such as information seeking, disclosure, and lifestyle changes. While present, the more traditionally and frequently identified coping resources such as social support did not play such a consistent role in the lives of current participants in the first 12 months following diagnosis. This emphasis on the importance of taking control differs from most previous research findings and may be attributed to the study's invitation to participants to indicate their reasons for behaviour and what they identified as being of assistance or hindrance to their coping, rather than the researcher imposing their views and asking participants to respond.

Health psychologists, and indeed health professionals at large, can assist people newly diagnosed with MS to identify what works for them in their attempts to adapt to the diagnosis. By working together to identify and strengthen available coping resources, together with modifying the areas that PwMS identify as hindrances to their coping, health professionals can have a positive effect on the adaptation process for people newly diagnosed with MS. Results from the current study provide health professionals with a number of key directions to promote their assistance of those newly diagnosed with MS.

Not everyone with MS will respond to the diagnosis in the same way. A health professional cannot assume to know how someone newly diagnosed will adapt to the diagnosis. Similarly, a health professional may not be confident of knowing the coping resources available to the individual to assist in adaptation. Reactions to a diagnosis of MS are many and varied, and

the behaviour following diagnosis cannot be predicted. In an unsolicited personal email written to the current author, Sarah³ makes comment on her reaction to being diagnosed with MS:

I have a surreal picture of the disease formed by wikipedia, web pages with worst case scenario stuff about incontinence and sexual dysfunction countered by anecdotal evidence regarding friends of friends who are running marathons at the age of 97 with MS, weird information about fish-eating vegan diets from my mother, MS society webpage information, the ‘don't worry - just take the drugs’ spiel from the neurologist and a DVD from some drug company. I’m not sure that my doctors know how overwhelming it can all be. Do feel fairly positive about it all, but also a little confused about some things. Not quite sure what to do with it all. (Personal Communication with ‘Sarah’, 11.01.07).

Sarah highlights the confusion that anyone newly diagnosed with MS may face. Her exposure to multiple sources of information combined with her contact with health professionals who demonstrated little understanding of the complexities inherent in attempting to adapt to a diagnosis of MS, left Sarah overwhelmed and not sure of what to do next. Recognising the critical importance of the individual perspectives of PwMS toward adaptation to diagnosis is the first step to health professionals being able to competently support and guide people newly diagnosed with MS to feel in control and able to make informed decisions about what to do in the first 12 months following diagnosis.

³ Not her real name. ‘Sarah’ was born in Australia, and is a woman living with Relapsing Remitting MS. Diagnosed at the age of 30 years, Sarah had been diagnosed for 3 weeks at the time of personal communication with the author.

REFERENCES

- Access Economics. (2005). *Acting positively: Strategic implications of the economic costs of multiple sclerosis in Australia*. Report for Multiple Sclerosis Australia, Winter.
- ACNielsen. (2002). *Australian eHealth Study*. Retrieved 14/09/04 from the World Wide Web: <http://au.acnielsen.com/pubs/index.shtml>.
- Ai, A.L., Dunkle, R.E., Peterson, C. & Bolling, S.F. (1998). The role of private prayer in psychological recovery among midlife and aged patients following cardiac surgery. *Gerontologist*, 38, 591-691.
- Aikens, J.E., Fischer, J.S., Namey, M. & Rudick, R.A. (1997). A replicated prospective investigation of life stress, coping, and depressive symptoms in multiple sclerosis. *Journal of Behavioural Medicine*, 20, 433-445.
- Airlie, J., Baker, G.A., Smith, S.J. & Young, C.A. (2001). Measuring the impact of multiple sclerosis on psychosocial functioning: the development of a new self-efficacy scale. *Clinical Rehabilitation*, 15, 259-265.
- Ajamian, P.C. (2004). Does optic neuritis mean MS? *Review of Optometry*, 141(5), 92-93.
- Akesson, E., Oturai, A., Berg, J., Fredrikson, S., Anderson, O., Harbo, H.F., Laaksonen, M., Myhr, K. M., Nyland, H. I., Ryder, L. P., Sandberg-Wollheim, M., Sorensen, P. S., Spurkland, A., Svejgaard, A., Holmans, P., Compston, A., Hillert, J. & Sawcer, S. (2002). A genome-wide screen for linkage in Nordic sib-pairs with multiple sclerosis. *Genes and Immunity*, 3, 279-285.
- Aldwin, C.M. & Revenson, T.A. (1987). Does coping help? A re-examination of the relation between coping and mental health. *Journal of Personality and Social Psychology*, 53, 337-348.

- Allaire, S.H., Niu, J., & LaValley, M.P. (2005). Employment and satisfaction outcomes from a job retention intervention delivered to persons with chronic diseases. *Rehabilitation Counseling Bulletin, 48*, 100-109.
- Allport, G.W. (1942). *The Use of Personal Documents in Psychological Science*. Ann Arbor, MI: Edwards Brothers.
- Alter, M., Yamoor, M. & Harshe, M. (1974). Multiple sclerosis and nutrition. *Archives of Neurology, 31*, 267-272.
- American Psychological Association. (1997). *Archival description of clinical health psychology as a specialty in professional psychology*. Minutes of the Council of Representatives Meeting, August 1997. Washington, DC: American Psychological Association.
- American Psychological Association. (2007). *Tempe Summit Report: Application of the Competency Model to Clinical Health Psychology*. Retrieved 01/09/07 from the World Wide Web: <http://www.health-psych.org/>
- Antonak, R.F. & Livneh, H. (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science and Medicine, 40*, 1099-1108.
- Antonovsky, A., Leibowitz, U., Smith, H.A., Medalie, J.M., Balogh, M. Kats, R., Halpern, L. & Alter, M. (1965). Epidemiologic study of multiple sclerosis in Israel. *Archives of Neurology, 13*, 183-193.
- Apel, A., Greim, B., Konig, N. & Zettl, U.K. (2006). Frequency of current utilisation of complementary and alternative medicine by patients with multiple sclerosis. *Journal of Neurology, 253*, 1331-1336.
- Armstrong-Stassen, M. & Cameron, S.J. (2003). The influence of prior coping resources and constraints on nurses' coping responses to hospital amalgamation in Canada. *International Journal of Stress Management, 10*, 158-172.

- Arnett, P.A., Higginson, C.I., Voss, W.D., Randolph, J.J. & Grandey, A.A. (2002). Relationship between coping, cognitive dysfunction and depression in multiple sclerosis. *The Clinical Neuropsychologist*, 16, 341-355.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1).
- Aronson, K.J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, 48, 74-80.
- Aronson, K.J., Cleghorn, G. & Goldenberg, E. (1996). Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disability Rehabilitation*, 18, 354-361.
- Asselman, P., Chadwick, D.W. & Marsden, D.C. (1975). Visual evoked responses in the diagnosis and management of patients suspected of multiple sclerosis. *Brain*, 98, 261-282.
- Atreja, A., Mehta, N., Miller, D., Moore, S., Nichols, K., Miller, H. & Harris, C.M. (2005). One size does not fit all: Using qualitative methods to inform the development of an internet portal for multiple sclerosis patients. *AMIA Annual Symposium Proceedings*, 16-20.
- Australian Bureau of Statistics (1998). *Employment and unemployment patterns, 1994-1998*. Retrieved 05/06/07 from the World Wide Web: <http://www.abs.gov.au>
- Australian Bureau of Statistics (2000). *Increasing the use of internet and home computers*. Retrieved 20/08/02 from the World Wide Web: <http://www.abs.gov.au>
- Australian Bureau of Statistics. (2005). *Australian Social Trends, 2005: Recent Fertility Trends*. Retrieved 10/05/07 from the World Wide Web: <http://www.abs.gov.au/ausstats/>
- Australian Bureau of Statistics. (2006). *Education and Training Experience, 2005*. Retrieved 05/06/07 from the World Wide Web: <http://www.abs.gov.au/ausstats/>

- Australian Government - Department of Health and Aging. (2006). *Schedule of Pharmaceutical Benefits Scheme*. Retrieved 23/11/06 from the World Wide Web: <http://www9.health.gov.au/pbs>
- Australian Psychological Society. (2006). *Affordable Access to Mental Healthcare is Now a Reality*. Retrieved 18/07/07 from the World Wide Web: http://www.psychology.org.au/news/media_releases/1nov2006/
- Avasarala, J.R., Wall, M.R. & Wolfe, G.M. (2005). A distinctive molecular signature of multiple sclerosis derived from MALDI-TOF/MS and serum proteomic pattern analysis: detection of three biomarkers. *Journal of Molecular Neuroscience*, 25, 119-125.
- Baker, L.M. (1995). A new method for studying patient information needs and information-seeking patterns. *Topics in Health Information Management*, 16(2), 19-28.
- Baker, L.M. (1996). A study of the nature of information needed by women with multiple sclerosis. *Library Information Science Research*, 18, 67-81.
- Baker, L.M. (1997). Preference for physicians as information providers by women with multiple sclerosis: A potential cause for communication problems? *Journal of Documentation*, 53, 251-262.
- Baker, L.M. (1998). Sense making in multiple sclerosis: The information needs of people during an acute exacerbation. *Qualitative Health Research*, 8, 106-120.
- Ban, M., Stewart, G.J., Bennetts, B.H., Heard, R., Simmons, R., Maranian, M., Compston, A. & Sawcer, S. J. (2002). A genome screen for linkage in Australian sibling-pairs with multiple sclerosis. *Genes and Immunity*, 3, 464-469.
- Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, 44, 1175-84.
- Bard, D. (2005). MS on the web: The good and the bad. *Inside MS*, 23(6), 62-64.

- Barnwell, A.M. & Kavanagh, D.J. (1997). Prediction of psychological adjustment to multiple sclerosis. *Social Science and Medicine*, 45, 411-418.
- Beatty, W.W., Blanco, C.R., Wilbanks, S.L., Paul, R.H. & Hames, K.A. (1995). Demographic, clinical, and cognitive characteristics of multiple sclerosis patients who continue to work. *Journal of Neurological Rehabilitation*, 9, 167-173.
- Beatty, W.W., Hames, K.A., Blanco, C.R., Williamson, S.J., Wilbanks, S.L. & Olson, K.A. (1998). Correlates of coping style in patients with multiple sclerosis. *Multiple Sclerosis*, 4, 440-443.
- Bensing, J.M., Schreurs, K.M.G. & De Ridder, D.T.D. (2002). Adaptive tasks in multiple sclerosis: Development of an instrument to identify the focus of patients coping efforts. *Psychology and Health*, 17, 475-488.
- Berzel, A., Heller, G. & Zucchini, W. (2006). Estimating the number of visits to the doctor. *Australian & New Zealand Journal of Statistics*, 48, 213-224.
- Best, S. J., Krueger, B., Hubbard, C. & Smith, A. (2001). An assessment of the generalizability of internet surveys. *Social Science Computer Review*, 19, 131-145.
- Billings, A. & Moos, R.H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine*, 4, 157-189.
- Billings, A. & Moos, R.H. (1984). Coping, stress, and social resources among adults with unipolar depression. *Journal of Personality and Social Psychology*, 46, 877-891.
- Boeije, H.R. & Janssens, A.C.J.W. (2004). 'It might happen or it might not': How patients with multiple sclerosis explain their perception of prognostic risk. *Social Science and Medicine*, 59, 861-868.
- Bombardier, C.H., D'Amico, C. & Jordan, J.S. (1990). The relationship of appraisal and coping to chronic illness adjustment. *Behaviour Research and Therapy*, 28, 297-304.
- Bowker, N. & Tuffin, K. (2004). Using the online medium for discursive research about people with disabilities. *Social Science Computer Review*, 22, 228-241.

- Brenner, G.F., Melamed, B.G. & Panush, R.S. (1994). Optimism and coping as determinants of psychosocial adjustment to rheumatoid arthritis. *Journal of Clinical Psychology in Medical Settings, 1*, 115–134.
- Brewer, N.T. (2005). The impact of internet use on health cognition and health behaviour. In C.P. Haugtvedt, K.A. Machleit, & R.F. Yalch (Eds.), *Online Consumer Psychology: Understanding and Influencing Consumer Behaviour in the Virtual World* (pp.433-354). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.
- Brooks, N.A. & Matson, R.R. (1982). Social-psychological adjustment to multiple sclerosis: A longitudinal study. *Social Science and Medicine, 16*, 2129-2135.
- Broom, L., Duncan-Jones, P. & Jones, F.L. (1975). The social standing of jobs: Scores for all Australian occupations. *Social Science Research, 6*, 211-224.
- Brown, S.J. (2006). The role of vitamin D in multiple sclerosis. *Annals of Pharmacotherapy, 40*, 1158-1161.
- Brown, T. (2003). Internet-based research: Is it a viable strategy for increasing the representation of ethnic minorities in psychological research? *Individual Differences Research, 1*, 218-229.
- Buelow, J.M. (1991). A correlational study of disabilities, stressors and coping methods in victims of multiple sclerosis. *Journal of Neuroscience Nursing, 23*, 247-252.
- Bugeja, M.J., Booth, D., Bennetts, B., Heard, R., Rubio, J. & Stewart, G. (2006). An investigation of polymorphisms in the 17q11.2-12 CC chemokine gene cluster for association with multiple sclerosis in Australians. *BMC Medical Genetics, 7*, 64.
- Buljevac, D., Hop, W.C.J., Reedeker, W., Janssens, A.C.J.W., van der Meché, F.G.A., van Doorn, P.A. & Hintzen, R.Q. (2003). Self reported stressful life events and exacerbations in multiple sclerosis: Prospective study. *British Medical Journal, 327*, 646.
- Burisch, M. (1984). Approaches to personality inventory construction. *American Psychologist, 39*, 214–227.

- Burks, J.S., Arnason, B.G., Coyle, P.K., Ford, C.C., Noronha, A. & Rammohan, K.W. (2002). Issues and practices in multiple sclerosis. *Neurorehabilitation and Neural Repair*, 16(4), 1-14.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.
- Bussing, A., Matthiessen, P.F. & Ostermann, T. (2005). Engagement of patients in religious and spiritual practices: Confirmatory results with the SpREUK-P 1.1 questionnaire as a tool of quality of life research. *Health Quality of Life Outcomes*, 6(3), 53.
- Butler, M.A. & Bennett, T.L. (2003). In search of a conceptualization of multiple sclerosis: A historical perspective. *Neuropsychology Review*, 13, 93-112.
- Butt, Z. & Demaree, H. A. (2004). Assessing depression in patients with multiple sclerosis. *International Journal of MS Care*, 6, 116-122.
- Byrne, M. (2001). Data analysis strategies for qualitative research. *AORN Journal*, 74, 904-905.
- Calabresi, P.A. (2004). Diagnosis and management of multiple sclerosis. *American Family Physician*, 70, 1935-1944.
- Candib, L.M. (2004). Making sense of my thumbs: Coming to terms with chronic illness. *Families, Systems, & Health*, 22, 139-151.
- Carlson, N.G. & Rose, J.W. (2006). Antioxidants in multiple sclerosis: Do they have a role in therapy? *CNS Drugs*, 20, 433-441.
- Carson, V.B. & Green, H. (1992). Spiritual well-being: A predictor of hardiness in patients with acquired immunodeficiency syndrome. *Journal of Professional Nursing*, 8, 209-220.
- Carter, H., McKenna, C., MacLeod, R. & Green, R. (1998). Health professionals' response to multiple sclerosis and motor neuron disease. *Palliative Medicine*, 12, 383-394.

- Carver, C.S., Pozo, C., Harris, S.D., Noriega, V., Scheier, M.F., Robinson, D.S., Ketcham, A.S., Moffat, F.L. & Clark, K.C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, *65*, 375-390.
- Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, *56*, 267-283.
- Cendrowski, W., Wender, M., Dominik, W., Flejsierowica, Z., Owsianowski, M. & Popiel, M. (1969). Epidemiological study of multiple sclerosis in western Poland. *European Neurology*, *2*, 90-108.
- Chalfant, A. M., Bryant, R.A. & Fulcher, G. (2004). Posttraumatic stress disorder following diagnosis of multiple sclerosis. *Journal of Traumatic Stress*, *17*, 423-428.
- Chamberlayne, N. (2006). Come on in, the water's fine! *Inside MS*, *24(4)*, 34-35.
- Chang, E.C. (2001). Introduction: Optimism and pessimism and moving beyond the most fundamental question. In E.C. Chang (Ed.), *Optimism and Pessimism: Implications for Theory, Research and Practice* (pp. 3-12). Washington: American Psychological Association.
- Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Jersey: Rutgers University Press.
- Christensen, O. & Clausen, J. (1997). Social remedial measures for multiple sclerosis patients in Denmark. *Acta Neurologica Scandinavica*, *55*, 394-406.
- Cohen, S. & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*, 310-357.
- Coiera, E. (1996). The internet's challenge to health care provision. *British Medical Journal*, *312*, 3-4.

- Cole, S.R., Beck, R.W., Moke, P.S., Kaufman, D.I. & Tourtellotte, W.W. (1998). The predictive value of CSF oligoclonal banding for MS five years after optic neuritis. *Neurology*, 51, 885-887.
- Colton, S.P., Levine, E.G., Fitzpatrick, C.M., Dodd, K.H. & Targ, E. (1999). Exploring the relationships among spiritual well-being, quality of life, and psychosocial adjustment in women with breast cancer. *Psychooncology*, 8, 429-438.
- Compston, A. (2000). The genetics of multiple sclerosis. *Journal of Neurovirology*, 6(S2), S5-S9.
- Compston, A. (2006). Editorial. *Brain*, 129, 1345-1346.
- Coo, H. & Aronson, K.J. (2004). A systematic review of several potential non-genetic risk factors for multiple sclerosis. *Neuroepidemiology*, 23, 1-12.
- Cook, I. (2002). How were you told you had MS? *MS Matters*, 43, 8-9.
- Coomber, R. (1997). Using the internet for survey research. *Sociological Research Online*, 2.
- Costello, K. & Harris, C. (2003). Differential diagnosis and management of fatigue in multiple sclerosis: Considerations for the nurse. *Journal of Neuroscience Nursing*, 35, 139-148.
- Costello, K. & Harris, C. (2006). An overview of multiple sclerosis: Diagnosis and management strategies. *Topics in Advanced Practice Nursing eJournal*, 6.
- Counte, M.A., Bieliauskas, L.A. & Pavlou, M. (1983). Stress and personal attitudes in chronic illness. *Archives of Physical Medical Rehabilitation*, 64, 272-275.
- Coyle, P.K. (2000). Diagnosis and classification of inflammatory demyelinating disorders. In Burks, J.S. & Johnson, K.P. (Eds). *Multiple Sclerosis: Diagnosis, medical management and rehabilitation*. New York: Demos Medical Publishing

- Coyle, P. K. & Hartung, H. P. (2002). Use of interferon beta in multiple sclerosis: Rationale for early treatment and evidence for dose- and frequency-dependent effects on clinical response. *Multiple Sclerosis*, 8, 2-9.
- Coyne, J.C, Aldwin, C. & Lazarus, R.S. (1981). Depression and coping in stressful episodes. *Journal of Abnormal Psychology*, 90, 439-447.
- Cozzarelli, C. (1993). Personality and self-efficacy as predictors of coping with abortion. *Journal of Personality and Social Psychology*, 65, 1224-1236.
- Crayton, H., Heyman, R.A. & Rossman, H.S. (2004). A multimodal approach to managing the symptoms of multiple sclerosis. *Neurology*, 63(11), 12-18.
- Crigger, N. J. (1996). Testing an uncertainty model for women with multiple sclerosis. *Advances in Nursing Science*, 18(3), 37-49.
- Dalgard, O., Dowrick, C., Lehtinen, V., Vazquez-Barquero, J., Casey, P., Wilkinson, G., Ayuso-Mateos, J.L., Page, H. & Dunn, G. (2006). Negative life events, social support and gender difference in depression. *Social Psychiatry & Psychiatric Epidemiology*, 41, 444-451.
- Dalton, C.M., Brex, P.A., Miszkiet, K.A., Hickman, S.J., MacManus, D.G., Plant, G.T., Thompson, A.J. & Miller, D.H. (2002). Applications of the new McDonald criteria to patients with clinically isolated syndromes suggestive of multiple sclerosis. *Annals of Neurology*, 52, 47-53.
- Dean, G., McLoughlin, H., Brady, R., Adelstein, A.M. & Tallett-Williams, J. (1976). Multiple sclerosis among immigrants in greater London. *British Medical Journal*, 1, 861-864.
- Decker, S.D. & Schulz, R. (1985). Correlates of life satisfaction and depression in middle-aged and elderly spinal cord-injured persons. *American Journal of Occupational Therapy*, 39, 740-747.
- de Groot, V., Beckerman, H., Lankhorst, G. J., Polman, C.H. & Bouter, L.M. (2005). The initial course of daily functioning in multiple sclerosis: A three-year follow-up study. *Multiple Sclerosis*, 11, 713-718.

- de Judicibus, M.A. & McCabe, M.P. (2005). Economic deprivation and its effects on subjective well-being in families of people with multiple sclerosis. *Journal of Mental Health, 14*, 49-59.
- Demirkiran, M., Sarica, Y., Uquz, S., Yerdelen, D. & Aslan, K. (2006). Multiple sclerosis patients with and without sexual dysfunction: Are there any differences? *Multiple Sclerosis, 12*, 209-214.
- de Ridder, D., Scheurs, K. & Bensing, J. (2000). The relative benefits of being optimistic: Optimism as a coping resource in multiple sclerosis and Parkinson's disease. *British Journal of Health Psychology, 5*, 141-155.
- Devins, G.M., Seland, T.P., Klein, G., Edworthy, S.M. & Saary, M.J. (1993). Stability and determinants of psychological well-being in multiple sclerosis. *Rehabilitation Psychology, 38*, 11-26.
- Devins, G.M. & Shnek, Z.M. (2000). Multiple sclerosis. In R.G. Frank & T.R. Elliot (Eds.), *Handbook of rehabilitation psychology, 163-184*. Washington: American Psychological Association.
- Donoghue, P.J. & Siegel, M. E. (1994). The psychological impact of hidden MS. *Inside MS, 12*(2), 11-12.
- Dujmovic, I., Mesaros, S., Pekmezovic, T., Levic, Z. & Drulovic, J. (2004). Primary progressive multiple sclerosis: Clinical and paraclinical characteristics with application of the new diagnostic criteria. *European Journal of Neurology, 11*, 439-444.
- Dyment, D.A., Sadovnick, A.D., Ebers, G.C. & Sadnovich, A.D. (1997). Genetics of multiple sclerosis. *Human Molecular Genetics, 6*, 1693-1698.
- Ebers, G.A. (2006). Disease evolution in multiple sclerosis. *Journal of Neurology, 253*(S6), vi3-vi8.
- Ebers, G.C. & Dyment, D.A. (1998). Genetics of multiple sclerosis. *Seminars in Neurology, 18*, 295-299.

- Ebers, G.C. & Sadovnick, A.D. (1998). Susceptibility: Genetics in multiple sclerosis. In Paty, D.W. & Eber, G.C. (Eds.), *Multiple Sclerosis* (pp.3-42). Philadelphia: FA Davis.
- Edgley, K., Sullivan, M.J.L. & Dehoux, E. (1991). A survey of multiple sclerosis. Part 2: Determinants of employment status. *Canadian Journal of Rehabilitation*, 4, 1-6.
- Eeltink, C. & Duffy, M. (2004). Restorying the illness experience in multiple sclerosis. *The Family Journal: Counseling and Therapy for Couples and Families*, 12, 282-286.
- Eisenberg, D.M., Davis, R.B., Ettner, S.L., Appel, S., Wilkey, S., Van Rompay, M. & Kessler, R.C. (1998). Trends in alternative medicine use in the United States, 1990-1997: Results of a follow up national survey. *The Journal of the American Medical Association*, 280, 1569-1575.
- Eklund, V. & MacDonald, M.L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology: Research and Practice*, 22, 277-284.
- Elian, M. & Dean, G. (1985). To tell or not to tell the diagnosis of multiple sclerosis. *The Lancet*, July 6(2), 27-28.
- Ell, K.O., Mantell, J.E., Hamovitch, M.B. & Nishimoto, R.H. (1989). Social support, sense of control, and coping among patients with breast, lung, or colorectal cancer. *Journal of Psychosocial Oncology*, 7, 63-89.
- Epping-Jordan, J.E., Compas, B.E., Osowiecki, D.A., Oppedisano, G., Gerhardt, C., Primo, K. & Krag, D.N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology*, 18, 315-326.
- Esparza, M.L., Sasaki, S. & Kesteloot, H. (1995). Nutrition, latitude, and multiple sclerosis mortality: An ecologic study. *American Journal of Epidemiology*, 142, 733-737.
- European Medicines Agency. (2006). *Tysabri – European Public Assessment Report*. Retrieved 24/11/06 from the World Wide Web:
<http://www.emea.europa.eu/humandocs/Humans/EPAR/tysabri/tysabri.htm>

- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328, 1166.
- Eysenbach, G. & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *British Medical Journal*, 323, 1103-1104.
- Fazekas, F., Barkhof, F., Filippi, M., Grossman, R.I., Li, D.K., McDonald, W.I., McFarland, H.F., Paty, D.W., Simon, J.H., Wolinsky, J.S. & Miller, D.H. (1999). The contribution of magnetic resonance imaging to the diagnosis of multiple sclerosis. *Neurology*, 53, 448-456.
- Feagan, B.G., Bala, B.M., Yan, S., Olson, A., & Hanauer, S. (2005). Unemployment and disability with moderately to severely active Crohn's disease. *Journal of Clinical Gastroenterology*, 39, 390-395.
- Fedetz, M., Matesanz, F., Caro-Maldonado, A., Fernandez, O., Tamayo, J.A., Guerrero, M., Delgado, C., Lopez-Guerrero, J.A. & Alcina, A. (2006). OAS1 gene haplotype confers susceptibility to multiple sclerosis. *Tissue Antigens*, 68, 446-449.
- Filippini, G., Munari, L., Incorvaia, B., Ebers, G.C., Polman, C., D'Amico, R. & Rice, G.P. (2003). Interferons in relapsing-remitting multiple sclerosis: A systematic review. *Lancet*, 361, 545-552.
- Finlayson, M. (2004). Concerns about the future among older adults with multiple sclerosis. *American Journal of Occupational Therapy*, 58, 54-63.
- Finlayson, M. & van Denend, T. (2003). Experiencing the loss of mobility: Perspectives of older adults with MS. *Disability Rehabilitation*, 25, 1168-1180.
- Finney, J.W., Mitchell, R.E., Cronkite, R.C. & Moos, R.H. (1984). Methodological issues in estimating main and interactive effects: Examples from coping/social support and stress field. *Journal of Health and Social Behaviour*, 25, 85-98.

- Fitzgerald, T.E., Tennen, H., Affleck, G. & Pransky, G.S. (1993). The relative importance of dispositional optimism and control appraisals in quality of life after coronary artery bypass surgery. *Journal of Behavioral Medicine, 16*, 25-43.
- Foley, F.W., LaRocca, N.G., Sanders, A.S. & Zemon, V. (2000). Rehabilitation of intimacy and sexual dysfunction in couples with multiple sclerosis. *Multiple Sclerosis, 7*, 417-421.
- Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle aged community sample. *Journal of Health and Social Behaviour, 21*, 219-239.
- Foote, A. W., Piazza, D., Holcombe, J., Paul, P. & Daffin, P. (1991). Hope, self-esteem and social support in persons with multiple sclerosis. *Journal of Neuroscience Nursing, 22*, 155-159.
- Ford, H. L. & Johnson, M. H. (1995). Telling your patient he/she has multiple sclerosis. *Postgraduate Medical Journal, 71*, 449-452.
- Fournier, M., de Ridder, D.T.D. & Bensing, J. (1999). What does optimism mean? Optimism and adaptation to multiple sclerosis. *Journal of Behavioral Medicine, 22*, 303-326.
- Fournier, M., de Ridder, D. & Bensing, J. (2002). Optimism and adaptation to chronic disease: The role of optimism in relation to self-care options of type 1 diabetes mellitus, rheumatoid arthritis and multiple sclerosis. *British Journal of Health Psychology, 7*, 409-432.
- Fournier, M., de Ridder, D. & Bensing, J. (2003). Is optimism sensitive to the stressors of chronic disease? The impact of Type 1 diabetes mellitus and multiple sclerosis on optimistic beliefs. *Psychology and Health, 18*, 277-294.
- Frames, R. (1994). New options in mobility aids. *Inside MS, 12(1)*, 12-14.
- Freedman, D.M., Dosemeci, M. & Alavanja, M.C.R. (2000). Mortality from multiple sclerosis and exposure to residential and occupational solar radiation: A case control study based on death certificates. *Occupational and Environmental Medicine, 57*, 418-421.

- Freeman, J.A. (2001). Improving mobility and functional independence in persons with multiple sclerosis. *Journal of Neurology*, 248, 255-259.
- Freeman, J.A. & Thompson, A.J. (2000). Community services in multiple sclerosis: Still a matter of chance. *Journal of Neurology, Neurosurgery, and Psychiatry*, 69, 728-732.
- Fulcher, G. (2004). On the assessment of depression in multiple sclerosis. *International Journal of MS Care*, 6, 94.
- Gagliardi, B.A., Frederickson, K. & Shanley, D.A. (2002). Living with multiple sclerosis: A Roy adaptation model-based study. *Nursing Science Quarterly*, 15, 230-236.
- Galassi, J.P., Frierson, H.T. & Sharer, R. (1981). Concurrent versus retrospective assessment in test anxiety research. *Journal of Consulting and Clinical Psychology*, 49, 614-615.
- Gately, C., Rogers, A. & Sanders, C. (2007). Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science & Medicine*, 65, 934-945.
- Gard, G. & Söderberg, S. (2004). How can a work rehabilitation process be improved? A qualitative study from the perspective of social insurance officers. *Disability and Rehabilitation*, 26, 299-305.
- Gayle, C.R. & Martyn, C.N. (1995). Migrant studies in multiple sclerosis. *Progress in Neurobiology*, 47, 425-428.
- Ghezzi, A., Pozzilli, C., Liquori, M., Marrosu, M.G., Milani, N., Milanese, C., Simone, I. & Zaffaroni, M. (2002). Prospective study of multiple sclerosis with early onset. *Multiple Sclerosis*, 8, 115-118.
- Giovannoni, G. (2006). Multiple sclerosis cerebrospinal fluid biomarkers. *Disease Markers*, 22, 187-96.
- Goffman, E. (1963). *Stigma. Notes on the Management of Spoiled Identity*. New Jersey: Prentice-Hall.

- Goldacre, M.J., Seagroatt, V., Yeates, D. & Acheson, E.D. (2004). Skin cancer in people with multiple sclerosis: A record linkage study. *Journal of Epidemiology and Community Health, 58*, 142-144.
- Goldman Consensus Group. (2005). The Goldman Consensus statement on depression in multiple sclerosis. *Multiple Sclerosis, 11*, 328-337.
- Gold-Spink, E., Sher, T.G. & Theodos, V. (2000). Uncertainty in illness and optimism in couple with multiple sclerosis. *International Journal of Rehabilitation and Health, 5*, 157-164.
- Goodin, D.S., Frohman, E.M., Garmany, G.P., Halper, J., Likosky, W.H, Lublin, F.D., Silberberg, D.H., Stuart, W.H. & van den Noort, S. (2002). Disease modifying therapies in multiple sclerosis: Report of the therapeutics and technology assessment subcommittee of the American Academy of Neurology and the MS Council for Clinical Practice Guidelines. *Neurology, 58*, 169-178.
- Gray, E. (2004). The management of pain in multiple sclerosis: A case study approach. *British Journal of Nursing, 13*, 1017-1020.
- Greer, S. (1974). Delay in the treatment of breast cancer. *Proceedings of the Royal Society of Medicine, 6*, 470-471.
- Grytten, N. & Maseide, P. (2005). 'What is expressed is not always what is felt': Coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness, 1*, 231-243.
- Grytten, N. & Maseide, P. (2006). 'When I am together with them I feel more ill': The stigma of multiple sclerosis experienced in social relationships. *Chronic Illness, 2*, 195-208.
- Gulick, E.E. & Kim, S. (2004). Postpartum emotional distress in mothers with multiple sclerosis. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 33*, 729-738.
- Habeck, R.V. (1999). Job retention through disability management. *Rehabilitation Counseling Bulletin, 42*, 317-328.

- Haglin, L. (2004). Phosphate depletion is the link between growth, stress and diet in the aetiology of MS. *Medical Hypotheses*, 63, 262-267.
- Hainsworth, M.A., Burke, M.L., Lindegren, C.L. & Eakes, G.G. (1993). Chronic sorrow in multiple sclerosis. *Home Healthcare Nurse*, 11, 9-13.
- Halligan, F.R. & Reznikoff, M. (1985). Personality factors and change with multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 53, 547-548.
- Halper, J. (2001). *Symptom Management. Advanced Concepts in Multiple Sclerosis Nursing Care*. New York, NY: Demos.
- Hämäläinen, P. (2004). Understanding cognitive changes. *MS in Focus*, 4, 13-15.
- Hansen, T., Skytthe, A., Stenager, E., Petersen, H.C., Bronnum-Hansen, H. & Kyvik, K.O. (2005). Concordance for multiple sclerosis in Danish Twins: An update of a nationwide study. *Multiple Sclerosis*, 11, 504-510.
- Harden, C.L., Kossoy, A., Vera, S. & Nikolov, B. (2004). Reaction to epilepsy in the workplace. *Epilepsia*, 45, 1134-1140.
- Harrison, T., Stuidbergen, A., Adachi, E. & Becker, H. (2004). Marriage, impairment, and acceptance in persons with multiple sclerosis. *Western Journal of Nursing Research*, 26, 266-285.
- Hartung, H.P., Gonsette, R., König, N., Kwiecinski, H., Guseo, A., Morrissey, S.P., Krapf, H. & Zwingers, T. (2002). Mitoxantrone in progressive multiple sclerosis: a placebo-controlled double-blind, randomised, multicentre trial. *Lancet*, 360, 2018-2025.
- Hauser, S.L. & Oksenberg, J.R. (2006). The neurobiology of multiple sclerosis: Genes, inflammation, and neurodegeneration. *Neuron*, 52, 61-76.
- Hawkins, S.A. & McDonnell, G.V. (1999). Benign Multiple Sclerosis? Clinical course, long term follow up, and assessment of prognostic factors. *Journal of Neurology, Neurosurgery, and Psychiatry*, 67, 148-152.

- Heesen, C., Kasper, J., Segal, J., Köpke, S. & Mühlhauser, I. (2004). Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Multiple Sclerosis*, *10*, 643-650.
- Heesen, C., Kolbeck, J., Gold, S.M., Schulz, H. & Schulz, K.H. (2003). Delivering the diagnosis of MS - results of a survey among patients and neurologists. *Acta Neurologica Scandinavica*, *107*, 363-368.
- Heesen, C., Köpke, S., Richter, T. & Kasper, J. (2007). Shared decision making and self management in multiple sclerosis – a consequence of evidence. *Journal of Neurology*, *254*, 116-121.
- Hendley, J. (1997). The ten biggest myths about MS. *Inside MS*, *15*(2), 5-8.
- Henry, B., Moffitt, T.E., Caspi, A., Langley, J. & Silva, P.A. (1994). On the ‘remembrance of things past’: A longitudinal evaluation of the retrospective method. *Psychological Assessment*, *6*, 92-101.
- Hepworth, M. & Harrison, J. (2004). A survey of the information needs of people with multiple sclerosis. *Health Informatics Journal*, *10*, 46-69.
- Hewson, D.C., Phillips, N.A., Simpson, K.E., Drury, P. & Crawford, M.A. (1984). Food intake in multiple sclerosis. *Human Nutrition. Applied Nutrition*, *38A*, 355-367.
- Hibberd, P.L. (1994). Use and misuse of statistics for epidemiological studies of multiple sclerosis. *Annals of Neurology*, *36*, 218-243.
- Hickey, J. (2003). *The Clinical Practice of Neurological and Neurosurgical Nursing*. Philadelphia: Lippincott, Williams & Wilkins.
- Hickman, S.J., Dalton, C.M., Miller, D.H. & Plant, G.T. (2002). Management of acute optic neuritis. *Lancet*, *360*, 1953-1962.
- Hilton, B.A. (1988). The phenomenon of uncertainty in women with breast cancer. *Issues in Mental Health Nursing*, *9*, 217-238.

- Hobart, J., Freeman, J. & Thompson, A. (2000). Kurtzke scales revisited: The application of psychometric methods to clinical intuition. *Brain*, *123*, 1027-1040.
- Hobart, J., Kalkers, N., Barkhof, F., Uitdehaag, B., Polman, C. & Thompson, A. (2004). Outcome measures for multiple sclerosis clinical trials: Relative measurement precision of the Expanded Disability Status Scale and Multiple Sclerosis Functional Composite. *Multiple Sclerosis*, *10*, 41-46.
- Hogancamp, W.E., Rodriguez, M. & Weinshenker, B.G. (1997). The epidemiology of multiple sclerosis. *Mayo Clinic Proceedings*, *72*, 871-878.
- Holahan, C.J. & Moos, R.H. (1987). Personal and contextual determinants of coping strategies. *Journal of Personality and Social Psychology*, *52*, 946-955.
- Holahan, C.J. & Moos, R.H. (1991). Life stressors, personal and social resources, and depression: A four-year structural model. *Journal of Abnormal Psychology*, *100*, 31-38.
- Holahan, C.J., Moos, R.H., Holahan, C.K. & Cronkite, R.C. (1999). Resource loss, resource gain and depressive symptoms: A 10 year model. *Journal of Personality and Social Psychology*, *77*, 620-629.
- Holmoy, T. (2006). A Norse contribution to the history of neurological diseases. *European Neurology*, *55*, 57-58.
- Hopman, W.M., Coo, H., Brunet, D.G., Edgar, C. & Singer, M.A. (2000). Longitudinal assessment of health related quality of life (HRQL) of patients with multiple sclerosis. *International Journal of MS Care*, *2*(4), 16-24.
- Horowitz, M. (1976). *Stress Response Syndromes*. New York: Aronson.
- Huntley, A. & Ernst, E. (2000). Complementary and alternative therapies for treating multiple sclerosis symptoms: A systematic review. *Complementary Therapies in Medicine*, *8*, 97-105.

- Illingworth, N. (2001). The internet matters: Exploring the use of the internet as a research tool. *Sociological Research Online*, 6 (2).
- Isaksson, A.K. & Ahlstrom, G. (2006). From symptom to diagnosis: Illness experiences of multiple sclerosis patients. *Journal of Neuroscience Nursing*, 38, 229-237.
- Jablow, M. (2004). When is a prickle a pain? *Inside MS*, 22(1), 44-51.
- Janssens, A.C.J.W., de Boer, J.B., Kalkers, N.F., Passchier, J., van Doorn, P.A. & Hintzen, R.Q. (2004). Patients with multiple sclerosis prefer early diagnosis. *European Journal of Neurology*, 11, 335-337.
- Janssens, A.C.J.W., van Doorn, P.A., de Boer, J.B., van der Meché, F.G.A., Passchier, J. & Hintzen, R.Q. (2003). Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurologica Scandinavica*, 108, 389-395.
- Janssens, A.C.J.W., van Doorn, P.A., de Boer, J.B., van der Meche, F.G.A., Passchier, J. & Hintzen, R.Q. (2004). Perception of prognostic risk in patients with multiple sclerosis: The relationship with anxiety, depression, and disease-related distress. *Journal of Clinical Epidemiology*, 57, 180-186.
- Jean, V.M., Paul, R.H. & Beatty, W.W. (1999). Psychological and neuropsychological predictors of coping patterns by patients with multiple sclerosis. *Journal of Clinical Psychology*, 55, 21-26.
- Jelinek, G. (2005). *Taking Control of Multiple Sclerosis: Natural and Medical Therapies to Prevent its Progression, Revised Edition*. Sydney: Hyland House.
- Joachim, G. & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32, 243-248.
- Johnson, K. (2001). The multifaceted and widespread pathology of magnesium deficiency. *Medical Hypotheses*, 56, 163-170.

- Johnson, K.L., Amtmann, D., Yorkston, K.M., Klasner, E.R. & Kuehn, C.M. (2004). Medical, psychological, social, and programmatic barriers to employment for people with multiple sclerosis. *Journal of Rehabilitation*, 70, 38-49.
- Johnson, K.L., Yorkston, K.M., Klasner, E.R., Kuehn, C.M., Johnson, E. & Amtmann, D. (2004). The cost and benefits of employment: A qualitative study of experiences of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 85, 201-209.
- Johnson, K.P., Brooks, B.R., Cohen, J.A., Ford, C.C., Goldstein, J., Lisak, R.P., Myers, L.W., Panitch, H.S., Rose, J.W. & Schiffer, R.B. (1995). Copolymer 1 reduces relapse rate and improves disability in relapsing-remitting multiple sclerosis: Results of a phase III multicentre, double-blind placebo-controlled trial. The Copolymer 1 Multiple Sclerosis Study Group. *Neurology*, 45, 1268-1276.
- Jones, P. (2006). *Magnetic Resonance Imaging*. Retrieved 26/11/06 from the World Wide Web: <http://www.mult-sclerosis.org/magneticresonanceimaging.html>.
- Jones, P. (2002). *Visually Evoked Response*. Retrieved 28/11/06 from the World Wide Web: <http://www.mult-sclerosis.org/VisuallyEvokedResponse.html>.
- Kaczorowski, J.M. (1989). Spiritual well-being and anxiety in adults diagnosed with cancer. *Hospice Journal*, 5(3/4), 105-116.
- Kalb, R. (2007). The emotional and psychological impact of multiple sclerosis. *Journal of the Neurological Sciences*, 256 (Supp 1), 29-33.
- Kalb, R. (2000). Helping the mind move. *Inside MS*, 18(4), 52-55.
- Kalechstein, A.D., Newton, T.F. & van Gorp, W.G. (2003). Neurocognitive functioning is associated with employment status: A quantitative review. *Journal of Clinical and Experimental Neuropsychology*, 25, 1186-1191.
- Kalsi, V. & Fowler, C.J. (2005) Therapy insight: Bladder dysfunction associated with multiple sclerosis. *Nature Clinical Practice. Urology*, 2, 492-501.

- Kantarci, O. & Wingerchuk, D. (2006). Epidemiology and natural history of multiple sclerosis: new insights. *Current Opinion Neurology*, *19*, 248-254.
- Kardum, I. & Daskijevic, K.T. (2001). Absolute and relative accuracy in the retrospective estimate of positive and negative mood. *European Journal of Psychological Assessment*, *17*, 69-77.
- Kastrukoff, L.S. & Rice, G.P.A. (1998). Virology. In Paty, D.W. & Ebers, G.C. (Eds.), *Multiple Sclerosis* (pp. 370-402). Philadelphia: FA Davis.
- Keefe, F.J., Caldwell, D.S., Queen, K.T., Gil, K.M., Martinez, S., Crisson, J.E., Ogden, W. & Nunley, J. (1987). Pain coping strategies in osteoarthritis patients. *Journal of Consulting and Clinical Psychology*, *55*, 208-212.
- Kilpatrick, S.D. & McCullough, M.E. (1999). Religion and spirituality in rehabilitation psychology. *Rehabilitation Psychology*, *14*, 388-402.
- King, K.E. & Arnett, P.A. (2005). Predictors of dyadic adjustment in multiple sclerosis. *Multiple Sclerosis*, *11*, 700-707.
- King, M., Kraut, R. & Sullivan, G. (2006). Some people who are moving us. *Inside MS*, *24*(6), 18.
- Kobelt, G., Berg, J., Lindgren, P., Fredrikson, S. & Jonsson, B. (2006). Costs and quality of life of patients with multiple sclerosis in Europe. *Journal of Neurology, Neurosurgery, and Psychiatry*, *77*, 918-926.
- Kobelt, G. & Pugliatti, M. (2005). Cost of multiple sclerosis in Europe. *European Journal of Neurology*, *12*, 63-67.
- Koch, T., Kralik, D. & Eastwood, S. (2002). Constructions of sexuality for women living with multiple sclerosis. *Journal of Advanced Nursing*, *39*, 137-145.
- Koopman, W.J., Benbow, C.L. & Vandervoort, M. (2006). Top 10 needs of people with multiple sclerosis and their significant others. *Journal of Neuroscience Nursing*, *38*, 369-373.

- Koopman, W. & Schweitzer, A. (1999). The journey to multiple sclerosis: A qualitative study. *Journal of Neuroscience Nursing*, 31, 17-26.
- Korchin, S.J. & Schuldberg, D. (1981). The future of clinical assessment. *American Psychologist*, 36, 1147-1158.
- Kortte, K.B. & Wegener, S.T. (2004). Denial of illness in medical rehabilitation populations: Theory, research and definition. *Rehabilitation Psychology*, 49(3), 187-199.
- Kraft, G.H., Freal, J.E. & Coryell, J.K. (1986). Disability, disease duration, and rehabilitation service needs in multiple sclerosis: Patient perspectives. *Archives of Physical Medicine and Rehabilitation*, 67, 164-168.
- Krantz, D.S., Baum, A. & Wideman, M.V. (1980). Assessment of preferences for self-treatment and information in health care. *Journal of Personality and Social Psychology*, 39, 977-990.
- Kraut, R., Olson, J., Banaji, M., Bruckman, A., Cohen, J. & Couper, M. (2004). Psychological research online: Report of the board of scientific affairs' advisory group on the conduct of research on the internet. *American Psychologist*, 59, 105-117.
- Kroencke, D.C. & Denney, D.R. (1999). Stress and coping in multiple sclerosis: Exacerbation, remission and chronic subgroups. *Multiple Sclerosis*, 5, 89-93.
- Kurtzke, J.F. (1983). Rating neurologic impairment in multiple sclerosis: An expanded disability status scale. *Neurology*, 33, 1444-1452.
- Kurtzke, J.F. (2000). Epidemiologic theories seek true etiologic nature of MS. *International Journal of MS Care*, 6(2), 38.
- Kurtzke, J.F. (2000). Epidemiology of multiple sclerosis. Does this really point toward an etiology? *Neurological Sciences*, 21, 383-403.
- Kurtzke, J.F. (2005). Epidemiology and etiology of multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America*, 16, 327-349.

- Langgartner, M., Langgartner, I. & Drlicek, M. (2005). The patient's journey: Multiple sclerosis. *British Medical Journal*, 330, 885-888.
- Lanyon, R.I. (1984). Personality assessment. *Annual Review of Psychology*, 35, 667-701.
- LaRocca, N. (2004). Introducing MS-related emotional and cognitive issues. *MS in Focus*, 4, 4-6.
- Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 58, 234-247.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Leibowitz, U., Sharon, D. & Alter, M. (1967). Geographical considerations in multiple sclerosis. *Brain*, 90, 871-886.
- Leocani, L., Rovaris, M., Boneschi, F.M., Medaglini, S., Rossi, P., Martinelli, V., Amadio, S. & Comi, G. (2006). Multimodal evoked potentials to assess the evolution of multiple sclerosis: A longitudinal study. *Journal of Neurology, Neurosurgery, and Psychiatry*, 77, 1030-1035.
- Levin, N., Mor, N. & Ben-Hur, T. (2003). Patterns of misdiagnosis of multiple sclerosis. *The Israel Medical Association Journal*, 5, 489-490.
- Levine, J., Warrenburg, S., Kerns, R., Schwartz, G., Delaney, R., & Fontana, A. (1987). The role of denial in recovery from coronary heart disease. *Psychosomatic Medicine*, 49, 109-117.
- Lewis, T. (2006). Seeking health information on the internet: Lifestyle choice or bad attack of cyberchondria? *Media, Culture & Society*, 28, 521-539.
- Livneh, H. & Antonak, R.F. (1997). *Psychosocial Adaptation to Chronic Illness and Disability*. Gaithersburg, Maryland: Aspen Publishers.

- Lobentanz, I. S., Asenbaum, S., Vass, K., Sauter, C., Klösch, G., Kollegger, H., Kristoferitsch, W. & Zeitlhofer, J. (2004). Factors influencing quality of life in multiple sclerosis patients: Disability, depressive mood, fatigue and sleep quality. *Acta Neurologica Scandinavica*, 110, 6-13.
- Long, D.D. & Miller, B.J. (1991). Suicidal tendency and multiple sclerosis. *Health and Social Work*, 16, 104-109.
- Lopez, M.D. (2001). Exercising control in the face of uncertainty: Multiple Sclerosis and other chronic illnesses. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 62(4A), 1598.
- Lorence, D.P., Park, H. & Fox, S. (2006). Assessing health consumerism on the web: A demographic profile of information-seeking behaviours. *Journal of Medical Systems*, 30, 251-258.
- Lorig, K.R., Ritter, P., Stewart, A.L., Sobel, D.S., Brown, B.W. & Bandura, A. (2001). Chronic disease self management program: 2-year health status and health care utilization outcomes. *Medical Care*, 39, 1217-1223.
- Lublin, F.D. & Reingold, S.C. (1996). Defining the clinical course of multiple sclerosis: Results of an international survey. *Neurology*, 46, 907-911.
- Lyons, R., Sullivan, M.J.L., Ritvo, P. & Coyne, J. (1995). *Relationships in Chronic Illness and Disability*. Thousand Oaks, CA: Sage.
- Macleod, L. & Macleod, G. (1998). Control cognitions and psychological disturbance in people with contrasting physically disabling conditions. *Disability Rehabilitation*, 20, 448-456.
- McAdams, D.P. (1993). *The stories we live by: Personal myths and the making of the self*. New York: Morrow.
- McAlpine, D. (1961). The benign form of MS. A study based on 241 cases seen within three years of onset and followed up until the tenth year or more of the disease. *Brain*, 84, 186-203.

- McAlpine, D. (1964). The benign form of MS. Results of a long term study. *British Medical Journal*, 2, 1029-1032.
- McCabe, M.P. (2005). Mood and self-esteem of persons with multiple sclerosis following an exacerbation. *Journal of Psychosomatic Research*, 59, 161-166.
- McCabe, M.P. (2004). Exacerbation of symptoms among people with multiple sclerosis: Impact on sexuality and relationships over time. *Archives of Sexual Behaviour*, 33, 593-601.
- McCrae, R.R. (1984). Situational determinants of coping responses: Loss, threat and challenge. *Journal of Personality and Social Psychology*, 46, 919-928.
- McDonald, W.I., Compston, A., Edan, G., Goodkin, D., Hartung, H., Lublin, F., McFarland, H., Paty, D.W., Polman, C.H., Reingold, S.C., Sandberg-Wollheim, M., Sibley, W., Thompson, A., van der Noort, S., Weinschenker, B.Y. & Wolinsky, J.S. (2001). Recommended diagnostic criteria for multiple sclerosis: Guidelines from the international panel on the diagnosis of multiple sclerosis. *Annals of Neurology*, 50, 121-127.
- McDonnell, G.V. & Hawkins, S.A. (1998). Clinical study of primary progressive multiple sclerosis in Northern Ireland, UK. *Journal of Neurology, Neurosurgery, and Psychiatry*, 64, 451-454.
- McIvor, G.P., Riklan, M. & Reznikoff, M. (1984). Depression in multiple sclerosis as a function of length and severity of illness, age, remissions and perceived social support. *Journal of Clinical Psychology*, 40, 1028-1033.
- McLeod, J.G., Hammond, S.R. & Hallpike, J.F. (1994). Epidemiology of multiple sclerosis in Australia. *The Medical Journal of Australia*, 160, 117-122.
- McNulty, K., Livneh, H. & Wilson, L.M. (2004). Perceived uncertainty, spiritual wellbeing and psychosocial adaptation in individuals with multiple sclerosis. *Rehabilitation Psychology*, 49, 91-99.

- Makros, J. & McCabe, M. (2003). The relationship between religion, spirituality, psychological adjustment, and quality of life among people with multiple sclerosis. *Journal of Religion and Health, 42*, 143-159.
- Maloney, M. (2003). Multiple Sclerosis: A life sentence in two words. Article in 'The Age' newspaper, published June 1, 2003.
- Mann, C. & Stewart, F. (2000). *Internet Communication and Qualitative Research. A Handbook for Researching Online*. London: Sage.
- Marrie, R.A. (2004). Environmental risk factors in multiple sclerosis aetiology. *The Lancet Neurology, 3*, 709-718.
- Marrie, R.A., Cutter, G., Tyry, T., Hadjimichael, O., Campagnolo, D. & Vollmer, T. (2005). Changes in the ascertainment of multiple sclerosis. *Neurology, 65*, 1066-1070.
- Matson, R.R. & Brooks, N.A. (1977). Adjusting to multiple sclerosis: An exploratory study. *Social Science & Medicine, 11*, 245-250.
- Mayor, S. (2005). Early contact with infant siblings reduces risk of multiple sclerosis. *British Medical Journal, 330*, 216.
- Merkelbach, S., König, J. & Sittinger, H. (2003). Personality traits in multiple sclerosis (MS) patients with and without fatigue experience. *Acta Neurologica Scandinavica, 107*, 195-201.
- Messmer Uccelli, M., Mancuso Mohr, L., Battaglia, M.A., Zagami, P. & Mohr, D.C. (2004). Peer support groups in multiple sclerosis: Current effectiveness and future directions. *Multiple Sclerosis, 10*, 80-84.
- Metz, L. (2003). The psychosocial consequences of multiple sclerosis. In W.I. McDonald & J.H. Nosworthy (Eds.), *Multiple Sclerosis 2*. Philadelphia, PA: Butterworth-Heinemann.
- Michello, J.A. (1988). Spiritual and emotional determinants of health. *Journal of Religion and Health, 27*, 62-70.

- Miller, C.M. (1997). The lived experience of relapsing multiple sclerosis: A phenomenological study. *Journal of Neuroscience Nursing*, 29, 294-305.
- Miller, J.R. (2004). The importance of early diagnosis of multiple sclerosis. *Journal of Managed Care Pharmacy*, 10(3), S4-S11.
- Miller, S.M. & Mangan, C.E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: Should the doctor tell all? *Journal of Personality and Social Psychology*, 45, 223-236.
- Mishel, M. & Braden, C. (1987). Uncertainty: A mediator between support and adjustment. *Western Journal of Nursing Research*, 9, 43-57.
- Mitchell, A.J., Benito-Leon, J., Gonzalez, J.M. & Rivera-Navarro, J. (2005). Quality of life and its assessment in multiple sclerosis: Integrating physical and psychological components of wellbeing. *Lancet Neurology*, 4, 556-566.
- Mohr, D.C., Boudewyn, A.C., Likosky, W., Levine, E. & Goodkin, D.E. (2001). Injectable medication for the treatment of multiple sclerosis: The influence of self-efficacy expectations and injection anxiety on adherence and ability to self-inject. *Annals of Behavioural Medicine*, 23, 125-132.
- Mohr, D.C., Burke, H., Beckner, V. & Merluzzi, N. (2005). A preliminary report on a skills based telephone administered peer support programme for patients with multiple sclerosis. *Multiple Sclerosis*, 11, 222-226.
- Mohr, D.C. & Cox, D. (2001). Multiple sclerosis: Empirical literature for the clinical health psychologist. *Journal of Clinical Psychology*, 57, 479-499.
- Mohr, D.C. & Dick, L.P. (1998). Multiple Sclerosis. In P.M. Camic & S. Knight (Eds.), *Clinical handbook of health psychology: A practical guide to effective interventions* (pp.313-318). Seattle: Hogrefe & Huber.
- Mohr, D.C., Dick, L.P., Russo, D., Likosky, W. & Goodkin, D.E. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology*, 18, 376-382.

- Mohr, D.C., Goodkin, D.E., Gatto, N. & van der Wende, J. (1997). Depression, coping and level of neurological impairment in multiple sclerosis. *Multiple Sclerosis*, 3, 254-258.
- Mohr, D.C., Hart, S.L., Julian, L., Cox, D. & Pelletier, D. (2004). Association between stressful life events and exacerbation in multiple sclerosis: A meta-analysis. *British Medical Journal*, 328, 731-733.
- Moos, R.H. & Billings, A.G. (1982). Conceptualising and measuring coping resources and processes. In L. Goldberger & S. Breznitz (Eds.), *Handbook of Stress: Theoretical and Clinical Aspects* (pp. 257-276). New York: Free Press.
- Moos, R.H. & Schaefer, J.A. (1982). Coping resources and processes: Current concepts and measures. In L. Goldberger & S. Breznitz (Eds.), *Handbook of Stress: Theoretical and Clinical Aspects* (pp. 234-257). New York: Free Press.
- Mostert, S. & Kesselring, J. (2002). Effects of a short term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. *Multiple Sclerosis*, 8, 161-168.
- Mullen, B. & Suls, J. (1982). The effectiveness of attention and rejection as coping styles. *Journal of Psychosomatic Research*, 26, 43-49.
- Multiple Sclerosis International Federation. (2002). *MS - The disease. Types of MS*. Retrieved 30/09/02 from the World Wide Web:
http://www.msif.org/en/ms_the_disease/types_of_ms.html.
- Multiple Sclerosis International Federation. (2002). *MS - The disease. What is MS?* Retrieved 13/9/02 from the World Wide Web:
http://www.msif.org/en/ms_the_disease/what_is_ms.html.
- Multiple Sclerosis Society of Canada. (2005). *Overview of Provincial Government Coverage for Disease Modifying Therapies*. Retrieved 23/11/06 from the World Wide Web:
<http://www.mssociety.ca/en/research/pdf/drug-table-mar05.pdf>.
- Murray, T.J. (2002). Infection as a cause of multiple sclerosis. *British Medical Journal*, 325, 1128-1130.

- Mushlin, A.I., Mooney, C., Grow, V. & Phelps, C.E. (1994). The value of diagnostic information to patients with suspected multiple sclerosis. *Archives of Neurology*, 51, 67-72.
- Nanji, A.A. & Narod, S. (1986). Multiple sclerosis, latitude and dietary fat: Is pork the missing link? *Medical Hypotheses*, 20, 279-282.
- National Multiple Sclerosis Society (U.S.A.). (1999). Research grants and fellowships 1999. *National MS Society Publication*.
- National Multiple Sclerosis Society (U.S.A.). (2006). *Paying for a disease modifying drug: Some help is available*. Retrieved 24/11/06 from the World Wide Web: <http://www.nationalmssociety.org/Brochures-Comparing.asp>
- Navipour, H., Madani, H., Mohebbi, M.R., Navipour, R., Roozabayani, P. & Paydar, A. (2006). Improved fatigue in individuals with multiple sclerosis after participating in a short term self care programme. *NeuroRehabilitation*, 21, 37-41.
- Neri, M.T. & Kroll, T. (2003). Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disability and Rehabilitation: An International Multidisciplinary Journal*, 25, 85-96.
- Neutel, C.I. (1980). Multiple sclerosis and the Canadian climate. *Journal of Chronic Diseases*, 33, 47-56.
- Nicholl, L., Hobart, J.C., Cramp, A.F.L. & Lowe-Strong, A.S. (2005). Measuring quality of life in multiple sclerosis: Not as simple as it sounds. *Multiple Sclerosis*, 11, 708-712.
- Nicolson, P. & Anderson, P. (2001). The psychosocial impact of spasticity-related problems for people with multiple sclerosis: A focus group study. *Journal of Health Psychology*, 6, 551-567.
- Nodder, D., Chappell, B., Bates, D., Freeman, J., Hatch, J., Keen, J., Thomas, S. & Young, C. (2000). Multiple sclerosis: Care needs for 2000 and beyond. *Journal of the Royal Society of Medicine*, 93, 219-224.

- Norberg, A.L., Lindblad, F. & Boman, K.K. (2006). Support-seeking, perceived support, and anxiety in mothers and fathers after children's cancer treatment. *Psycho-Oncology*, *15*, 335-343.
- Norman, J.E., Kurtzke, J.F. & Beebe, G.W. (1983). Epidemiology of multiple sclerosis in US veterans: II. Latitude, climate and the risk of multiple sclerosis. *Journal of Chronic Diseases*, *36*, 551-559.
- Noseworthy, J., Paty, D., Wonnacott, T., Feasby, T. & Ebers, G. (1983). Multiple sclerosis after age of 50. *Neurology*, *33*, 1537-1544.
- Nowak, J., Januszkiewicz, D., Pernak, M., Liwen, I., Zawada, M., Rembowska, J., Nowicka, K., Lewandowski, K., Hertmanawska, H. & Wender, M. (2006). Multiple sclerosis-associated virus-related pol sequences found both in multiple sclerosis and healthy donors are more frequently expressed in multiple sclerosis patients. *Journal of Neurovirology*, *9*, 112-117.
- NUA Internet Surveys. (2002). *How many online?* Retrieved 26/09/02, from the World Wide Web: http://www.nua.ie/surveys/how_many_online/
- O'Brien, M.T. (1993). Multiple sclerosis: The relationship among self-esteem, social support, and coping behaviour. *Applied Nursing Research*, *6*, 54-63.
- O'Carroll, R., Smith, K., Grubb, N., Fox, K. & Masterton, G. (2001). Psychological factors associated with delay in attending hospital following a myocardial infarction. *Journal of Psychosomatic Research*, *51*, 611-614.
- O'Connor, P. (2002). Key issues in the diagnosis and treatment of multiple sclerosis: An overview. *Neurology*, *59* (S3), S1-S33.
- O'Connor, P., Detsky, A.S., Tansey, C. & Kucharczyk, W. (1994). Effect of diagnostic testing for multiple sclerosis on patient health perceptions. *Archives of Neurology*, *51*, 46-51.
- O'Connor, R.J., Cano, S.J., i Torrentà, L.R., Thompson, A.J. & Playford, E.D. (2005). Factors influencing work retention for people with multiple sclerosis: Cross-sectional studies using qualitative and quantitative methods. *Journal of Neurology*, *252*, 892-896.

- O' Day, B. (1998). Barriers for people with multiple sclerosis who want to work: A qualitative study. *Journal of Neurological Rehabilitation, 12*, 139-146.
- O'Hara, L., Cadbury, H., De Souza, L. & Ide, L. (2002). Evaluation of the effectiveness of professionally guided self care for people with multiple sclerosis in the community: A randomized controlled trial. *Clinical Rehabilitation, 16*, 119-128.
- Oken, B.S., Kishiyama, S., Zajdel, D., Bourdette, D., Carlsen, J., Haas, M., Hugos, C., Kraemer, D.F., Lawrence, J. & Mass, M. (2004). Randomized controlled trial of yoga and exercise in multiple sclerosis. *Neurology, 62*, 2058-2064.
- Olerup, O., Hillert, J., Frederickson, S., Olsson, T., Kam-Hansen, S., Moller, E., Carlsson, B. & Wallin, J. (1989). Primary chronic progressive and relapsing-remitting multiple sclerosis: Two immunogenetically distinct disease entities. *Proceedings of the National Academy of Sciences of the United States of America, 86*, 7113-7117.
- Opsahl, M.L. & Kennedy, P.G. (2006). Investigating the presence of human herpesvirus 7 and 8 in multiple sclerosis and normal control brain tissue. *Journal of the Neurological Sciences, 240(1-2)*, 37-44.
- Orton, S.M., Herrera, B.M., Yee, I.M., Valdar, W., Ramagopalan, S.V., Sadovnick, A.D. & Ebers, G.C. (2006). Sex ratio of multiple sclerosis in Canada: a longitudinal study. *Lancet Neurology, 5*, 932-6.
- Osberg, T.M. & Shrauger, J.S. (1986). Self-prediction: Exploring the parameters of accuracy. *Journal of Personality and Social Psychology, 51*, 1044-1057.
- Osberg, T.M. & Shrauger, J.S. (1990). The role of self-prediction in psychological assessment. In J.N. Butcher & C.D. Spielberger (Eds.), *Advances in Personality Assessment* (pp. 97-120). Hillsdale, NJ: Erlbaum.
- Pakenham, K.I. (2005). Relations between coping and positive and negative outcomes in carers of persons with multiple sclerosis (MS). *Journal of Clinical Psychology in Medical Settings, 12*, 25-38.

- Pakenham, K.I. (1999). Adjustment to multiple sclerosis: Application of a stress and coping model. *Health Psychology, 18*, 383-392.
- Pakenham, K.I. (2001). Coping with multiple sclerosis: Development of a measure. *Psychology, Health and Medicine, 6*, 411-428.
- Pakenham, K.I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine, 6*, 13-27.
- Pakenham, K.I. & Stewart, C.A. (1997). The role of coping in adjustment to multiple sclerosis-related adaptive demands. *Psychology, Health & Medicine, 2*, 197-211.
- Paloutzian, R.F. & Ellison, C.W. (1982). Loneliness, spiritual well-being and the quality of life. In L.A. Peplau & D. Perlman (Eds.), *Loneliness: A Sourcebook of Current Theory Research and Therapy*. New York, NY: Wiley.
- Papathanasopoulos, P., Nikolakopoulou, A. & Scolding, N. (2005). Disclosing the diagnosis of multiple sclerosis. *Journal of Neurology, 252*, 1307-1309.
- Papuc, E. & Pawlowska, B. (2005). Personality features in multiple sclerosis patients with a relapsing-remitting course of the disease. *Psychiatria Polska, 39*, 669-678.
- Park, C.L. & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology, 1*, 115-144.
- Parker, J.D. & Endler, N.S. (1992). Coping with coping assessment: A critical review. *European Journal of Personality, 6*, 321-344.
- Patton, M.Q. (1980). *Qualitative Evaluation Methods*. Beverly Hills, CA: Sage.
- Paty, D. (2001). Initial symptoms. In J. Burks & K. Johnson (Eds.), *Multiple Sclerosis Diagnosis, Medical Management and Rehabilitation*. New York, NY: Demos Publishing.
- Pearlin, L.I. & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*, 2-21.

- Petajan J. H. & White, A. (1999). Recommendations for physical activity in patients with multiple sclerosis. *Sports Medicine*, 27, 179-191.
- Pew Internet and American Life Project. (2005). *Health information online*. Retrieved on 28/12/05, from the World Wide Web:
www.pewinternet.org/pdfs/PIP%5fHealthtopics%5fMay05.pdf
- Pharmaceutical Management Agency (PHARMAC). (2006). *New Zealand Pharmaceutical Schedule. August 2006*. Retrieved on 21/11/2006, from the World Wide Web:
<http://www.pharmac.govt.nz/pdf/Sched.pdf>.
- Phillips, J.T., O'Connor, P.W., Havrdova, E., Hutchinson, M., Kappos, L., Miller, D.H., Polman, C.H., Lublin, F.D., Giovannoni, G., Wajgt, A., Lynn, F., Panzara, M.A. & Sandrock, A.W. (2006). Infusion-related hypersensitivity reactions during natalizumab treatment. *Neurology*, 67, 1717-1718.
- Pittock, S.J., McClelland, R.L., Mayr, W.T., Jorgensen, N.W., Weinshenker, B.G., Noseworthy, J. & Rodriguez, M. (2004). Clinical implications of benign multiple sclerosis: A 20-year population-based follow-up study. *Annals of Neurology*, 56, 303-306.
- Polman, C.H., O'Connor, P.W., Havrdova, E., Hutchinson, M., Kappos, L., Miller, D.H., Phillips, J.T., Lublin, F.D., Giovannoni, G., Wajgt, A., Toal, M., Lynn, F., Panzara, M.A. & Sandrock, A.W. (2006). A randomized, placebo-controlled trial of natalizumab for relapsing multiple sclerosis. *New England Journal of Medicine*, 354, 899-910.
- Polman, C.H., Thompson, A.J., Murray, T.J. & McDonald, W.W. (2001). *Multiple Sclerosis: The Guide to Treatment and Management*. New York: Desmos Medical Publishing.
- Polman, C.H., Reingold, S.C., Edan, G., Filippi, M., Hartung, H.P., Kappos, L., Lublin, F.D., Metz, L.M., McFarland, H.F., O'Connor, P.W., Sandberg-Wollheim, M., Thompson, A.J., Weinshenker, B.G. & Wolinsky, J.S. (2005). Diagnostic criteria for multiple sclerosis: 2005 revisions to the "McDonald Criteria". *Annals of Neurology*, 59, 727-728.

- Poser, C.M. (1994). The dissemination of multiple sclerosis: A Viking saga? An historical essay. *Annals of Neurology*, *36*, 231-242.
- Poser, C.M. & Brinar, V.V. (2004). The nature of multiple sclerosis. *Clinical Neurology and Neurosurgery*, *106*, 159-171.
- Prigatano, G.P. (1988). Anosognosia, delusions, and altered self-awareness after brain injury: An historical perspective. *Barrow Neurological Institute Quarterly*, *4*, 40-48.
- Prigatano, G.P. & Klonoff, P.S. (1998). A clinician's rating scale for evaluating impaired self-awareness and denial of disability after brain injury. *The Clinical Neuropsychologist*, *12*, 56-67.
- Prilleltensky, I. & Prilleltensky, O. (2003). Towards a critical health psychology practice. *Journal of Health Psychology*, *8*, 197-210.
- Pucci, E. (2003). Is the internet transforming the physician-consumer relationship? Preliminary data in a neurological setting. *European Journal of Neurology*, *10*, 192.
- Pucci, E., Cartechini, E., Taus, C. & Giuliani, G. (2004). Why Physicians need to look more closely at the use of complementary and alternative medicine by multiple sclerosis patients. *European Journal of Neurology*, *11*, 263-267.
- Rao, S.M., Leo, G.J., Ellington, L., Nauertz, T., Bernardin, L. & Unverzagt, F. (1991). Cognitive dysfunction in multiple sclerosis: II. Impact on employment and social functioning. *Neurology*, *41*, 692-696.
- Rasmussen, H.B. & Clausen, J. (2000). Genetic risk factors in multiple sclerosis and approaches to their identification. *Journal of Neurovirology*, *6*, 323-327.
- Rätsep, T., Kallasmaa, T., Pulver, A. & Gross-Paju, K. (2000). Personality as a predictor of coping efforts in patients with multiple sclerosis. *Multiple Sclerosis*, *6*, 397-402.
- Reid, D. (1984). Participatory control and chronic illness adjustment process. In H. Lefcourt (Ed.), *Research with Locus of Control Construct: Extensions and Limitations* (pp. 361-389). New York: Academic Press.

- Reinharz, S. (1992). *Feminist Methods in Social Research*. New York: Oxford University Press.
- Revenson, T.A. & Felton, B.J. (1989). Disability and coping as predictors of psychological adjustment to rheumatoid arthritis. *Journal of Consulting and Clinical Psychology*, 57, 344-348.
- Reynolds, F. & Prior, S. (2003). 'Sticking jewels in your life': Exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research*, 13, 1225-1251.
- Riazi, A., Thomson, A.J. & Hobart, J.C. (2004). Self-efficacy predicts self reported health status in multiple sclerosis. *Multiple Sclerosis*, 10, 61-66.
- Riva, G., Teruzzi, T. & Anolli, L. (2003). The use of the internet in psychological research: Comparison of online and offline questionnaires. *CyberPsychology & Behaviour*, 6, 73-80.
- Robins, L.N. (1988). Data gathering and data analysis for prospective and retrospective longitudinal studies. In M. Rutter (Ed.), *Studies in Psychosocial Risk* (pp.315-324). Cambridge, England: Cambridge University Press.
- Robinson, J.E. (2000). Access to employment for people with disabilities: Findings of a consumer-led project. *Disability and Rehabilitation*, 22, 246-253.
- Rokach, A. (2004). Loneliness in cancer and multiple sclerosis patients. *Psychological Reports*, 94, 637-648.
- Rosenstiel, A.K. & Keefe, F.J. (1983). The use of coping strategies in chronic low back pain patients: Relationship to patient characteristics and current adjustment. *Pain*, 17, 33-44.
- Roth, S. & Cohen, L.J. (1986). Approach, avoidance, and coping with stress. *American Psychologist*, 41, 813-819.

- Rothbaum, M.F., Weisz, J. & Snyder, S. (1982). Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology, 42*, 5-37.
- Rudick, R.A., Cutter, G.R., Baier, M., Weinstock-Guttman, B., Mass, M.K., Fisher, E., Miller, D.M. & Sandrock, A.W. (2005). Estimating long-term effects of disease modifying drug therapy in multiple sclerosis patients. *Multiple Sclerosis, 11*, 626-634.
- Rudick, R.A., Miller, D., Clough, J.D., Gragg, L.A., & Farmer, R.G. (1992). Quality of life in multiple sclerosis. *Archives of Neurology, 49*, 1237-1242.
- Ruggieri, R. M., Palermo, R., Vitello, G., Gennuso, M., Settiani, N. & Piccoli, F. (2003). Cognitive impairment in patients suffering from relapsing-remitting multiple sclerosis with EDSS \leq 3.5. *Acta Neurologica Scandinavica, 108*, 323-326.
- Russell, C.S., White, M.B. & White, C.P. (2006). Why me? Why now? Why multiple sclerosis?: Making meaning and perceived quality of life in a Midwestern sample of patients with multiple sclerosis. *Families, Systems, & Health, 24*, 65-81.
- Ryan, G. W. & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods, 15*, 85-109.
- Sadovnick, A.D. (1994). Genetic epidemiology of multiple sclerosis: A survey. *Annals of Neurology, 36*, 194-203.
- Sadovnick, A.D., Yee, I.M. & Ebers, G.C. (2005). Multiple sclerosis and birth order: A longitudinal cohort study. *Lancet Neurology, 4*, 793-794.
- Schaeffer-Duffy, C. (2005). Religious devotion sets U.S. apart from allies. *National Catholic Reporter, 41*, 13.
- Scheier, M.F., Matthews, K.A., Owens, J.F., Magovern, G.J., Lefebvre, R.C., Abbott, R.A., & Carver, C.S. (1989). Dispositional optimism and recovery from coronary artery bypass surgery: The beneficial effects on physical and psychological well-being. *Journal of Personality & Social Psychology, 57*, 1024-1040.

- Schloman, B.F. (2006). MedlinePlus: Key resource for both health consumers and health professionals. *Online Journal of Issues in Nursing, 11, 2.*
- Schwartz, C.E. (1999). Helping others help oneself: Response shift effects in peer support. *Social Science and Medicine, 48, 1563-1575.*
- Schwartz, C.E. (1999). Teaching coping skills enhances quality of life more than peer support: Results of a randomized trial with multiple sclerosis patients. *Health Psychology, 18, 211-220.*
- Schwartz, C.E., Foley, F.W., Rao, S.M., Bernardin, L.J., Lee, H. & Genderson, M.W. (1999). Stress and course of disease in multiple sclerosis. *Behavioural Medicine, 25, 110-116.*
- Schwartz, C.E., Laitin, E., Brotman, S & LaRocca, N. (1999). Utilization of unconventional treatments by persons with MS: Is it alternative or complementary? *Neurology, 52, 626-629.*
- Schwarz, S. & Leweling, H. (2005). Multiple sclerosis and nutrition. *Multiple Sclerosis, 11(1), 24-32.*
- Schwarz, S., Leweling, H. & Meinck, H.M. (2005). Alternative and complementary therapies in multiple sclerosis. *Fortschritte Neurologie-Psychiatrie, 73, 451-462.*
- Scott, L.J. & Figgitt, D.P. (2004). Mitoxantrone: A review of its use in multiple sclerosis. *CNS Drugs, 18, 379-396.*
- Scott, T.F., Schramke, C.J., Novero, J. & Chieffe, C. (2000). Short term prognosis in early relapsing-remitting multiple sclerosis. *Neurology, 55, 689-693.*
- Seymour, W.S. (2001). In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research, 1, 147-168.*
- Shaw, S. (2001). Remember Me: Opening Address. *The Multiple Sclerosis International Conference 2001*. Melbourne, Australia.

- Sheehan, K. (2001). E-mail survey response rates: A review. *Journal of Computer Mediated Communication*, 6(2).
- Shifren, K. (1996). Individual differences in the perception of optimism and disease severity: A study among individuals with Parkinson's disease. *Journal of Behavioral Medicine*, 19, 241–271.
- Shnek, Z.M., Foley, F.W., LaRocca, N.G., Smith, C.R. & Halper, J. (1995). Psychological predictors of depression in multiple sclerosis. *Journal of Neurological Rehabilitation*, 9, 15-23.
- Shontz, F.C. (1975). *The Psychological Aspects of Physical Illness and Disability*. New York: Macmillan.
- Simmons, R., Hendrie, D., McDonald, E., Tribe, K. & Vowels, L. (2004). *The economic impact of multiple sclerosis in Australia: Summary statement of 11 preliminary results from the Australian MS Longitudinal Study*. 26 November, Canberra Hospital.
- Sirvastava, S. & Chamberlain, M.A. (2005). Factors determining job retention and return to work for disabled employees: A questionnaire study of opinions of disabled people's organizations in the UK. *Journal of Rehabilitation Medicine*, 37, 17-22.
- Solaro, C. (2006). Epidemiology and treatment of pain in multiple sclerosis subjects. *Neurological Science*, 27, 291-293.
- Soldan, S.S., Berti, R., Salem, N., Secchiero, P., Flamand, L., Calabresi, P.A., Brennan, M.B., Maloni, H.W., McFarland, H.F., Lin, H.C., Patnick, M. & Jacobson, S. (1997). Association of human herpes virus 6 (HHV-6) with multiple sclerosis: Increased IgM response to HHV-6 early antigen and detection of serum HHV-6 DNA. *Nature Medicine*, 3, 1394-1397.
- Speck, P., Higginson, I. & Addington-Hall, J. (2004). Spiritual needs in health care may be distinct from religious ones and are integral to palliative care. *British Medical Journal*, 329, 123-124.

- Somerset, M., Peters, T.J., Sharp, D.J. & Campbell, R. (2003). Factors that contribute to quality of life outcomes prioritised by people with multiple sclerosis. *Quality of Life Research, 12*, 21-29.
- Spero, D. (2004). Achieving balance after my diagnosis. *RN, 67*, 48-50.
- Stanton, A.L., Danoff-Burg, S., Cameron, C.L. & Ellis, A.P. (1994). Coping through emotional approach: Problems of conceptualization and confounding. *Journal of Personality and Social Psychology, 66*, 35-362.
- Step toe, A. (1991). The links between stress and illness. *Journal of Psychosomatic Research, 35*, 633-644.
- Stewart, D.C. & Sullivan, T.J. (1982). Illness behaviour and the sick role in chronic disease: The case of multiple sclerosis. *Social Science Medicine, 16*, 1397-1404.
- Stone, A.A., Greenberg, M.A., Kennedy-Moor, E. & Newman, M.G. (1991). Self-report, situation-specific coping questionnaires: What are they measuring? *Journal of Personality and Social Psychology, 61*, 648-658.
- Strittmatter, R. (2004). Emotion-related issues of the newly diagnosed. *MS in Focus, 4*, 7-9.
- Stuifbergen, A.K., Becker, H., Blozis, S., Timmerman, G. & Kullberg, V. (2003). A randomized clinical trial of a wellness intervention for women with multiple sclerosis. *Archives of Physical Medicine Rehabilitation, 84*, 467-76.
- Stuifbergen, A., Becker, H., Rogers, S., Timmerman, G. & Kullberg, V. (1999). Promoting wellness for women with multiple sclerosis. *Journal of Neuroscience Nursing, 31*, 73-79.
- Stuifbergen, A.K. & Harrison, T.C. (2003). Complementary and alternative therapy use in persons with multiple sclerosis. *Rehabilitation Nursing, 28*, 141-147.
- Stuifbergen, A.K., Harrison, T.C., Becker, H. & Carter, P. (2004). Adaptation of a wellness intervention for women with chronic disabling conditions. *Journal of Holistic Nursing, 22*, 12-31.

- Stuifbergen, A.K., & Rogers, S. (1997). Health promotion: An essential component of rehabilitation for persons with chronic disabling conditions. *Advances in Nursing Science, 19*, 1-20.
- Sullivan, M.J.L. & D'Eon, J. (1990). Relation between catastrophizing and depression in chronic pain patients. *Journal of Abnormal Psychology, 99*, 260-263.
- Sullivan, M.J.L., Edgley, K., Mikail, S., Dehoux, E. & Fisher, R. (1993). Psychological correlates of health care utilization in chronic illness. *Canadian Journal of Rehabilitation, 6*, 13-21.
- Sullivan, M.J.L., Mikail, S. & Weinschenker, B. (1997). Coping with a diagnosis of multiple sclerosis. *Canadian Journal of Behavioural Science, 29*, 249-257.
- Sullivan, C.L., Wilken, J.A., Rabin, B.N., Demorest, M. & Bever, C. (2004). Psychosocial adjustment to multiple sclerosis. The contributions of coping style, perceived uncertainty, and social support. *International Journal of MS Care, 6*, 98-105.
- Suls, J. & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta-analysis. *Health Psychology, 4*, 249-288.
- Surakka, J., Romberg, A., Ruutiainen, J., Aunola, S., Virtanen, A., Karppi, S. & Mäentaka, K. (2004). Effects of aerobic and strength exercise on motor fatigue in men and women with multiple sclerosis: A randomized control trial. *Clinical Rehabilitation, 18*, 737-746.
- Sutherland, G. & Andersen, M.B. (2001). Exercise and multiple sclerosis: Physiological, psychological and quality of life issues. *Journal of Sports Medicine and Physical Fitness, 41*, 421-432.
- Swanborg, R.H., Whittum-Hudson, J.A. & Hudson, A.P. (2003). Infectious agents and multiple sclerosis – are Chlamydia pneumoniae and human herpes virus 6 involved? *Journal of Neuroimmunology, 136(1-2)*, 1-8.
- Swank, R.L. (1950). Multiple sclerosis; a correlation of its incidence with dietary fat. *American Journal of Medical Science, 220*, 421-430.

- Tabachnick, B.G. & Fidell, L.S. (1996). *Using Multivariate Statistics*, 3rd Edition. New York: Harper Collins.
- Taylor, S. (1995). *Health Psychology*, 3rd Edition. New York: McGraw Hill.
- Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.
- Taylor, S.E., Kemeny, M.E. & Reed, G.M. (2000). Psychological resources, positive illusions, and health. *American Psychologist*, 55, 99-109.
- Tedeschi, R.G., Park, C.L. & Calhoun, L.G. (1998). Posttraumatic growth: Positive changes in the aftermath of crisis. New Jersey: Lawrence Erlbaum Associates.
- Tennen, H. & Affleck, G. (1987). The costs and benefits of optimistic explanations and dispositional optimism. *Journal of Personality*, 55, 377-393.
- Then Bergh, F., Kumpf, T., Schumann, E., Held, U., Schwan, M., Blazevic, M., Wismuller, A., Holsboer, F., Yassouridis, A., Uhr, M., Weber, F., Daumer, M., Trenkwalder, C. & Auer, D.P. (2006). Monthly intravenous methylprednisolone in relapsing-remitting multiple sclerosis – reduction of enhancing lesions, T2 lesion volume and plasma prolactin concentrations. *BMC Neurology*, 6, 19.
- Thomas, P.W., Thomas, S., Hillier, S., Galvin, K., Baker, K. & Cole, J. (2003). Psychological interventions for multiple sclerosis. *The Cochrane Database of Systematic Reviews*, 4, 1-12.
- Thompson, R.J., Gil, K.M., Abrams, M.R. & Phillips, G. (1992). Stress, coping and psychological adjustment of adults with sickle cell disease. *Journal of Consulting and Clinical Psychology*, 60, 433-440.
- Thorne, S., Con, A., McGuinness, L., McPherson, G. & Harris, S. R. (2004). Health communication issues in multiple sclerosis: An interpretive description. *Qualitative Health Research*, 14, 5-22.

- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G. & Jillings, C. (2002). Chronic illness experience: Insights from a metastudy. *Qualitative Health Research*, 12, 437-452.
- Thorne, S., Paterson, B. & Russell, C. (2003). The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research*, 13, 1337-1352.
- Tintore, M., Rovira, A., Rio, J., Nos, C., Grive, E., Tellez, N., Pelayo, R., Comabella, M., Sastre-Garriga, J. & Montalban, X. (2006). Baseline MRI predicts future attacks and disability in clinically isolated syndromes. *Neurology*, 67, 968-972.
- Traboulsee, A.L. & Li, D.K. (2006). The role of MRI in the diagnosis of multiple sclerosis. *Advances in Neurology*, 98, 125-146.
- Trapp, B.D., Peterson, J., Ransohoff, R.M., Rudick, R., Mörk, S. & Bö, L. (1998). Axonal transection in the lesions of multiple sclerosis. *New England Journal of Medicine*, 338, 278-285.
- Trapp, B.D., Bö, L., Mörk, S. & Chang, A. (1999). Pathogenesis of tissue injury in MS lesions. *Journal of Neuroimmunology*, 98, 49-56.
- Tremlett, H. & Devonshire, V. (2006). Is late onset multiple sclerosis associated with a worse outcome? *Neurology*, 67, 954-959.
- Troster, H. (1997). Disclose or Conceal? Strategies of information management in persons with epilepsy. *Epilepsia*, 38, 1227-1237.
- te Wildt, B.T. & Schultz-Venrath, U. (2004). Magical ideation - Defense mechanism or neuropathology? A study with multiple sclerosis patients. *Psychopathology*, 37, 141-144.
- Tullman, M.J., Oshinsky, R.J., Lublin, F.D. & Cutter, G.R. (2004). Clinical characteristics of progressive relapsing multiple sclerosis. *Multiple Sclerosis*, 10, 451-454.
- Tunks, E. & Bellissimo, A. (1988). Coping with the coping concept: A brief comment. *Pain*, 34, 171-174.

- Uccelli, M.M., Fraser, C., Battaglia, M.A., Maloni, H. & Wollin, J. (2004). Certification of multiple sclerosis nurses: An international perspective. *International MS Journal*, 11(2), 44-51.
- UK Department of Health. (2005). *Cost Effective provision of disease modifying therapies for people with Multiple Sclerosis*. Retrieved 24/11/06 from the World Wide Web: <http://www.dh.gov.uk/assetRoot/04/01/22/14/04012214.pdf>
- Underwood-Gordon, L., Peters, D.J., Bijur, P. & Fuhrer, M. (1997). Roles of religiousness and spirituality in medical rehabilitation and the lives of persons with disabilities. *American Journal of Physical Medicine & Rehabilitation*, 76, 255-257.
- United Nations Department of Economic and Social Affairs/Population Division. (2004). *World Population Prospects: The 2004 Revision, Volume III: Analytical Report*. Retrieved 18/05/07 from the World Wide Web: http://www.un.org/esa/population/publications/WPP2004/WPP2004_Vol3_Final/Chapter6.pdf
- Van Denend, T. (2006). Employment needs of people with multiple sclerosis: A review of current literature and application to occupational therapy practice. *Occupational Therapy in Health Care*, 20, 61-77.
- van der Mei, I.A.F., Ponsonby, A-L., Dwyer, T., Blizzard, L., Simmons, R., Taylor, B.V., Butzkueven, H. & Kilpatrick, T. (2003). Past exposure to sun, skin phenotype, and risk of multiple sclerosis: Case control study. *British Medical Journal*, 327, 316-321.
- van der Mei, I.A.F., Ponsonby, A-L., Blizzard, L. & Dwyer, T. (2001). Regional variation in multiple sclerosis prevalence in Australia and its association with ambient ultraviolet radiation. *Neuroepidemiology*, 20, 168-174.
- Vander Plate, C. (1984). Psychological aspects of multiple sclerosis and its treatment: toward a biopsychosocial perspective. *Health Psychology*, 3, 253-272.
- Von Korff, M., Moore, J.E., Lorig, K., Cherkin, D.C., Saunders, K. & Gonzalez, V.M. (1998). A randomized trial of a lay person-led self management group intervention for back pain patients in primary care. *Spine*, 23, 2608-2615.

- Vrana, S.R. & Rollock, D. (2002). The role of ethnicity, gender, emotional content, and contextual differences in physiological, expressive, and self-reported emotional responses to imagery. *Cognition and Emotion, 16*, 165-192.
- Wagner, L.S. & Wagner, T.H. (2003). The effect of age on the use of health and self-care information: Confronting the stereotype. *The Gerontologist, 43*, 318-324.
- Walsh, P.A. & Walsh, A. (1987). Self-esteem and disease adaptation among multiple sclerosis patients. *Journal of Social Psychology, 127*, 669-671.
- Ward, C.D., Turpin, G., Dewey, M.E., Fleming, S., Hurwitz, B., Ratib, S., von Fragstein, M. & Lymberry, M. (2004). Education for people with progressive neurological conditions can have negative effects: Evidence from a randomized controlled trial. *Clinical Rehabilitation, 18*, 717-725.
- Warren, S., Cockeril, R. & Warren, K.G. (1991). Risk factors by onset age in multiple sclerosis. *Neuroepidemiology, 10*, 9-17.
- Wassem, R. (1992). Self-efficacy as a predictor of adjustment to multiple sclerosis. *Journal of Neuroscience Nursing, 24*, 224-229.
- Wassem, R. & Dudley, W. (2003). Symptom management and adjustment of patients with multiple sclerosis. A 4-year longitudinal intervention study. *Clinical Nursing Research, 12*, 102-117.
- Wehman, P., Targett, P., West, M. & Kregel, J. (2005). Productive work and employment for persons with traumatic brain injury: What have we learnt after 20 years? *Journal of Head Trauma Rehabilitation, 20*, 115-127.
- Weinert, C. (1987). Self-efficacy and social support: Commentaries. *Western Journal of Nursing Research, 9*, 76-78.
- Weinshenker, B.G. (1995). The natural history of multiple sclerosis. *Neurological Clinics, 13(1)*, 119-146.

- Weinshenker, B. & Miller, D. (1999). Multiple Sclerosis: One disease or many? In: A. Siva, J. Kesselring & A. Thompson (Eds.), *Frontiers in multiple sclerosis* (pp. 37-46). London: Martin Dunitz.
- Weinshenker, B.G., Rice, G.P.A., Noseworthy, J.H., Carriere, W., Baskerville, J. & Ebers, G.C. (1991). The natural history of multiple sclerosis: A geographically based study. *Brain*, *114*, 1045-1056.
- Wesselius, T., Heersema, D.J., Mostert, J.P., Heerings, M., Admiraal-Behloul, F., Talebian, A., van Buchem, M.A. & De Keyser, J. (2005). A randomized crossover study of bee sting therapy for multiple sclerosis. *Neurology*, *65*, 1764-1768.
- Whetten-Goldstein, K., Sloan, F.A., Goldstein, L.B. & Kulas, E.D. (1998). A comprehensive assessment of the cost of multiple sclerosis in the United States. *Multiple Sclerosis*, *4*, 419-425.
- Wiendl, H., Kieseier, B.C., Gold, R., Hohlfeld, R., Bedszus, M. & Hartung, H.P. (2006). Revision of McDonald's new diagnostic criteria for multiple sclerosis. *Nervenarzt*, *77*, 1235-1245.
- Willer, C.J., Dyment, D.A., Sadovnick, A.D., Rothwell, P.M., Murray, T.J. & Ebers, G.C. (2005). Timing of birth and risk of multiple sclerosis: Population based study. *British Medical Journal*, *330*, 120-125.
- Williams, D.R. & Sternthal, M.J. (2007). Spirituality, religion and health: Evidence and research directions. *Medical Journal of Australia*, *186*, 47-50.
- Williams, G. (2004). Management of patients who have relapses in multiple sclerosis. *British Journal of Nursing*, *13*, 1012-1016.
- Williams, R.M. (2004). Group based psychotherapy for military veterans with multiple sclerosis. *International Journal of MS Care*, *6*, 110-115.
- Williamson, D.M. (2006). Studies of multiple sclerosis in communities concerned about environmental exposures. *Journal of Women's Health*, *15*, 810-814.

- Wineman, N.M. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research, 39*, 294-299.
- Wineman, N.M., Durand, E.J., & Steiner, R.P. (1994). A comparative analysis of coping behaviors in persons with multiple sclerosis or a spinal cord injury. *Research in Nursing and Health, 17*, 185-194.
- Wollin, J., Bennie, M., Leech, C., Windsor, C. & Spencer, N. (2005). Multiple sclerosis and continence issues: An exploratory study. *British Journal of Nursing, 14*, 439-446.
- Wollin, J., Dale, H., Spenser, N. & Walsh, A. (2000). What people with newly diagnosed MS (and their families and friends) need to know. *International Journal of MS Care, 2*(3), 22-29.
- Yadav, V., Marracci, G. & Lovera, J. (2005). Lipoic acid in multiple sclerosis: A pilot study. *Multiple Sclerosis, 11*, 159-165.
- Yorkston, K.M., Klasner, E.R. & Swanson, K.M. (2001). Communication in context: A qualitative study of the experiences of individuals with multiple sclerosis. *American Journal of Speech-Language Pathology, 10*, 126-136.
- Zeldow, P.B. & Pavlou, M. (1984). Physical disability, life stress and psychosocial adjustment in multiple sclerosis. *The Journal of Nervous and Mental Disease, 172*, 80-84.
- Zhang, S.M., Hernan, M.A., Olek, M.J., Spiegelman, D., Willett, W.C. & Ascherio, A. (2001). Intakes of carotenoids, vitamin C, and vitamin E and MS risk among two large cohorts of women. *Neurology, 57*, 75-80.
- Zielinski, K.J. (2006). Adherence: I'm forever blowing bubbles. *Inside MS, 24*(6), 48-49.
- Zorzon, M., Zivadinov, R., Bosco, A., Bragadin, L.M., Moretti, R., Bonfigli, L., Morassi, P., Iona, L.G. & Cazzato, G. (1999). Sexual dysfunction in multiple sclerosis: a case control study. I. Frequency and comparison of groups. *Multiple Sclerosis, 5*, 418-427.

Appendix A

Breakdown of Participants' Country of Birth

Country of Birth	Participants		
	Total	Male	Female
Australia	134	20	114
United States of America	50	5	45
United Kingdom	41	8	33
New Zealand	34	7	27
Canada	18	3	15
Other	18	9	9
Germany	4	1	3
South Africa	3	3	0
Belgium	1	1	0
Brazil	1	1	0
Czech Republic	1	0	1
Denmark	1	0	1
France	1	0	1
India	1	1	0
Macedonia (FYROM)	1	1	0
Mexico	1	0	1
Philippines	1	1	0
Russia	1	0	1
Singapore	1	0	1
Total	295	52	243

Appendix B

Questionnaire

The questionnaire was posted online over eight web pages in the format prescribed by the Surveyor program (Object Planet Inc., <http://www.objectplanet.com>).

Part 1: Demographic Information at the Time of Participation in the Study

1. Date of Birth: / / 2. Sex: Male Female
3. Country of Birth: _____
4. What type of MS were you diagnosed with?
 - Relapse Remitting
 - Primary Progressive
 - Secondary Progressive
 - Progressive Relapsing
 - Benign

Part 2: Demographic Information at the TIME OF DIAGNOSIS

5. Age at TIME OF DIAGNOSIS: _____
6. Occupation at TIME of DIAGNOSIS: _____
7. Work Status at the TIME OF DIAGNOSIS:
 - Unemployed
 - Employed part time
 - Employed and student
 - Employed full time
 - Student solely
 - Home duties solely
 - Retired
8. Marital Status at the TIME OF DIAGNOSIS:
 - Single
 - Long term relationship
 - Married/living with partner
 - Separated/divorced
 - Widowed

9. Number of dependent children at TIME OF DIAGNOSIS: _____

10. Education level reached at TIME OF DIAGNOSIS:

- Primary
- Partial secondary
- Secondary
- Trade qualification
- Partial tertiary
- University graduate
- University post graduate

Part 3: MS Related Experience Prior to, and at the Time of, Diagnosis

11. What was/were your first symptom/s of MS (please select all that apply)?

- Fatigue
 - Numbness
 - Spasticity
 - Pain
 - Paralysis
 - Tremors
 - Visual difficulties
 - Bladder/bowel difficulties
 - Communication difficulties
 - Balance difficulties
 - Concentration difficulties
 - Other: Please Specify
-

12. What symptoms were you experiencing at the TIME OF DIAGNOSIS (please select all that apply)

- Fatigue
- Numbness
- Spasticity
- Pain
- Paralysis
- Tremors
- Visual difficulties

- Bladder/bowel difficulties
- Communication difficulties
- Balance difficulties
- Concentration difficulties
- Other: Please Specify

No symptoms

13. How old were you when you experienced your first symptom of MS? _____

14. How many exacerbations did you have before a diagnosis of MS was given? _____

15. Did you suspect you had MS before the diagnosis of MS was given?

Yes No

16. Were you admitted to a hospital due to MS symptoms BEFORE, OR AT THE TIME OF, the diagnosis?

Yes No

Part 4: Behaviour in the First 12 Months Following Diagnosis

17. In the FIRST 12 MONTHS FOLLOWING DIAGNOSIS did you seek out information about MS in any of the following ways? (please select all that apply)

Ask a medical professional for further information about MS

Contact the MS Society for information

Access information about MS from the internet

Access information about MS from a library

Attend an information session or conference on MS

18. Did you find out information about MS in any other way? If so, how?

19. In the FIRST 12 MONTHS FOLLOWING DIAGNOSIS did you register with your local MS Society? Yes No

20. Did you discuss your diagnosis with someone else who had MS in the FIRST 12 MONTHS FOLLOWING DIAGNOSIS? If so, how did you know/meet that person?

21. In the FIRST 12 MONTHS FOLLOWING DIAGNOSIS did you tell anyone about your diagnosis? If yes, who? Please select all that apply.

Partner/husband/wife

Mother

- Father
- Sister/brother
- Children
- Counsellor/psychologist
- Close friends
- Workplace colleagues
- Employer
- Other: Please Specify

22. Why did you choose to tell these people about your diagnosis? Please give as much detail as possible. _____

23. In the FIRST 12 MONTHS FOLLOWING DIAGNOSIS did you change your lifestyle due to MS? If yes, how?

- Change in diet
- Addition of vitamin supplements to diet
- Decreased exercise
- Increased exercise
- Change of career/work
- Reduction in work hours
- Started immunotherapy
- Increased interest in religion/spirituality
- Decreased interest in religion/spirituality

24. Can you think of any other lifestyle changes you made in the FIRST 12 MONTHS FOLLOWING DIAGNOSIS? If yes, what? _____

25. Can you identify anything that you found assisted or hindered you in coping with the diagnosis of MS in the FIRST 12 MONTHS FOLLOWING DIAGNOSIS? Please give as much detail as possible. _____

Appendix C

Plain Language Statement – Behaviour following a Diagnosis of Multiple Sclerosis

Investigators: Sally Shaw (doctoral student), Dr Simone Buzwell (supervisor).

What is the study about?

This study is being undertaken as part of the requirements of the Doctorate in Psychology (Health) at Swinburne University of Technology. It is attempting to identify the different types of behaviour that people newly diagnosed with Multiple Sclerosis can exhibit during the first twelve months following their diagnosis. It has been designed to find out some general information about people at the time of their diagnosis, some information on their experiences of Multiple Sclerosis, and the types of activities people participate in within the first 12 months following their diagnosis.

The information you provide will help develop a better understanding of the experiences people with MS have in the first twelve months after their diagnosis, and the ways in which people respond differently to a diagnosis of MS. There is very little information available on this topic, and so your assistance in completing this questionnaire will be invaluable in helping us discover the different ways people respond to a diagnosis, and to develop services to meet the different needs of people diagnosed with MS.

Who can participate?

Anyone over the age of 18, who has been diagnosed with Multiple Sclerosis.

What does participating in the study involve?

Participation in this study is voluntary and you are free to withdraw at any time without explanation. All answers are confidential. It is important that you read the questions carefully and answer each one as openly and honestly as possible. There are no right or wrong answers. Answer each item as carefully and accurately as you can. The questionnaire will take approximately 10 minutes to complete. Please complete all sections of the questionnaire. As mentioned earlier, the information you provide will be held in the strictest confidence. The results of this study may be published but they will refer to group data only; individual results will not be described. Return of this questionnaire will be taken as your having given consent to participate.

Any questions or concerns regarding this project can be directed to the Senior Investigator, Dr Simone Buzwell, of the School of Social and Behavioural Sciences, on 9214 0000. If you have further queries or concerns, please write to: The Chair, SBS Research Ethics Committee, Mail H24, Swinburne University of Technology, Victoria, 3122. If you have a complaint about the way you were treated during this study, please write to: The Chair, Human Research Ethics Committee, Swinburne University of Technology, PO Box 218, Hawthorn, Vic, 3122.