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Gabrielle Berea
University of Wollongong

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**Adjustment to Multiple Sclerosis: Application of the Fennell
Four Phase Model and Identification of Effective Social
Support**

A thesis submitted in partial fulfilment of the
requirements for the award of the degree

Doctor of Psychology (Clinical)

from

University of Wollongong

by

Gabrielle Berea

BPsych(UwS)

Department of Psychology

2010

Thesis Certification

I, Gabrielle Berea, declare that this thesis, submitted in partial fulfilment of the requirements for the award of Doctor of Psychology (Clinical), in the Department of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged below. The document has not been submitted for qualifications at any other academic institution.

Gabrielle S. Berea

April 2010

Abstract

This thesis investigated the specific aspects of support which people with Multiple Sclerosis (PwMS) perceive as helpful and unhelpful. While social support in general has been found to enhance adjustment, assist emotional wellbeing and maintain quality of life (QoL) for PwMS, the Multiple Sclerosis (MS) research does not provide a comprehensive understanding of the specific aspects of social support which are helpful and unhelpful. This thesis also tested the relevance of the Fennell Four Phase Model (FFPM) for adjustment to MS and explored whether perceptions of helpful and unhelpful social support differed according to adjustment levels. Many models of adjustment to chronic illness do not consider the support network and focus on only the psychological aspects of adjustment. The FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a) is a multistage model which maps the adjustment process of chronic illness by addressing the physical/behavioural domain, social/interactive domain and psychological domain. Most importantly the model acknowledges the importance of the support network in adjusting to chronic illness. Two studies were carried out. The initial study investigated social support and took into account not only different categories of support but also different sources of support. Twenty individuals with MS were interviewed regarding the specific actions they found helpful and unhelpful from various potential support providers. Results provided a comprehensive behavioural understanding of what PwMS experience as helpful and unhelpful from key support providers. Specifically, emotional support was considered crucial in intimate relationships. Other PwMS were uniquely helpful by providing informational support, optimism, hope and emotional support. Results indicated the importance and need for greater informational assistance from medical professionals. The second study investigated the adjustment process for PwMS through the FFPM

and aimed to examine if individuals in different phases of adjustment had different perspectives of helpful and unhelpful support. Results supported the relevance of the four phases (Crisis, Stabilisation, Resolution and Integration) of the model for PwMS. No significant findings were found among phases in perceptions of helpful and unhelpful social support, indicating that regardless of levels of adjustment PwMS have similar social support needs. Individuals in each of the phases were found to have significant differences in emotional states, ways of coping, satisfaction with life and self reported moodiness, anxiety, QoL and coping levels. Findings indicated that regardless of an individual's level of adjustment to MS, certain types of supportive and unsupportive behaviours continued to be relevant. The FFPM appears to accurately map the journey and struggles of PwMS. Results from this research can be used to enhance social support with interventions and educational programs for key support providers and also to understand a patient's current adjustment phase, implement appropriate treatment strategies and support.

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Abbreviations

| | |
|----------|--|
| CBT | Cognitive-Behaviour Therapy |
| CFS | Chronic Fatigue Syndrome |
| DASS-21 | Depression, Anxiety and Stress Scale-21 |
| df | Degrees of freedom |
| F | F-ratio – test statistic for ANOVA |
| FFPM | Fennell Four Phase Model |
| FPI | Fennell Phase Inventory |
| GP | General Practitioner |
| MS | Multiple Sclerosis |
| n | Number of scores in a subset |
| NSW/VIC | New South Wales/Victoria |
| PwMS | People with Multiple Sclerosis |
| QoL | Quality of life |
| r | Effect size |
| RRMS | Relapsing remitting Multiple Sclerosis |
| SD | Standard deviation |
| SEFT | Supportive emotion focused therapy |
| SWLS | Satisfaction with Life Scale |
| TTM | Transtheoretical Model |
| <i>U</i> | Mann-Whitney U |
| WOCQ | Ways of Coping Questionnaire |
| η^2 | Partial Eta Squared – effect size |
| χ^2 | Chi-square |
| Z | Z-approximation of <i>U</i> (corrected for ties) |

Key Terms

Adjustment: a process of adapting to chronic illness which signifies that an individual has been able to continue to grow and develop despite having a chronic illness (Marks & Millard, 1990).

Behavioural descriptions: a subjective description of a person's experiences when they are interacting with others and how they perceive this interaction.

Chronic illness: health conditions which continue indefinitely and may take many different forms (Lubkin & Larsen, 2006).

Fennell Four Phase Model: a model which maps the process of adjustment to chronic illness within four phases and focuses on stigma, illness traumatisation, the physical/behavioural and social/interactive domains, and the socio-cultural influences at each phase (Fennell, 2003a, Fennell, 2003b; Jason, Fennell, Klein, Fricano & Halpert, 1999).

Phases of model

Crisis: when an individual moves from the onset of illness to an emergency period (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Stabilisation: when an individual begins to recognise and understand his or her symptoms and have a greater sense of control over their lives than patients in Crisis (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Resolution: when a patient begins to acknowledge that his or her previous life will not return and struggles with life defining questions. Patients in this phase are beginning to also acknowledge the chronic

nature of their condition (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Integration: when an individual has a blended pre-illness and post-illness self and has been able to find new ways to express a new “personal best” (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Multiple Sclerosis: is a chronic and progressive neurological disease which leads to lesions to the brain white matter resulting from demyelization of nerve fibres and many different neurological abnormalities such as numbness, visual abnormalities, fatigue, mobility difficulties and cognitive dysfunction (Eeltink & Duffy, 2004).

Social support: the ways in which interpersonal relationships support individuals against the negative effects of stress (Cohen & McKay, 1984).

Types of social support

Esteem/emotional support: verbal and nonverbal communication of caring, concern, love, empathy and security (Helgeson & Cohen, 1996; House, 1981; Lafreniere & Cramer 2005; Schaefer, Coyne & Lazarus, 1981).

Informational support: the supply of information such as advice or guidance (Helgeson & Cohen, 1996, House, 1981; Schaefer et al, 1981).

Tangible support: the provision of direct aid such as money or transportation, or providing a service (Helgeson & Cohen, 1996; House, 1981; Schaefer et al, 1981).

Support network: people who are associated with, and care about, us and are able to provide assistance and support during times of stress (Vaughan & Hogg, 2002).

Introduction

This thesis originally arose from my own personal interest in understanding more about MS and the role that family and friends can play in supporting a MS sufferer. Having a family member with MS triggered my interest in how I might be able to gain a better understanding of their experiences. The MS sufferer seems to have an ongoing struggle expressing and explaining their experiences and symptoms to others. Given that MS symptoms are often unusual and not visual I had found myself not taking into consideration the impact of MS on an individual and so was unable to empathise with their experiences. I began to consider the likelihood that many family members and friends are unsure of how to provide support and also may fail to understand the journey of someone coping with a chronic illness. My own journey into attempting to understand the MS experience more fully both as an individual and as a Clinical Psychologist, led to this research project.

Multiple sclerosis (MS) literally means multiple scars; the disease involves lesions to the brain white matter resulting from demyelization of nerve fibres (Eltink & Duffy, 2004). The process of demyelization involves the loss of the insulation encasing the nerve endings. Nerve impulses are unable to travel at a normal rate along the nerve fibres. Multiple Sclerosis is a chronic and progressive disease; the onset is commonly between ages 20 to 40 years. It is five times more common in temperate latitudes than in tropics, two to three times more common among females than males and is the most commonly acquired neurological disease in young adults (Antonak & Livneh, 1995).

In the early stages individuals may experience neurological abnormalities such as numbness, double vision, fatigue and bladder control problems. Later symptoms may include leg weakness, vertigo, impaired coordination, severe fatigue, pain and

sexual dysfunction among an array of others possible complications (Eeltink & Duffy, 2004). Emotional difficulties such as depression are common in MS. Cognitive dysfunction may occur and lead to impairments in verbal and visual memory, slowness of mental processes, impairments with motor responses, deficiency in attention, poor verbal fluency, impaired concept formation and abstract reasoning (Andrade, Bueno, Oliveria, Oliveria, Oliveria & Miranda, 1999; Feinstein, 2004).

Previous research has shown the importance of social support for people with MS (PwMS). The research has not provided practical information about social support which may be useful for support providers and can be used when constructing interventions to enhance support for PwMS. The research has also proposed various adjustment processes that people with chronic illness may experience however little to no empirical research has been completed on adjustment models. Many adjustment models only considered the psychological aspects of adjustment and failed to acknowledge the social support network and community which I have come to believe are all affected by MS and play important roles in assisting or hindering adjustment.

The project reported in this thesis consisted of two studies. The initial study aimed to provide a comprehensive understanding of helpful and unhelpful social support from the perspective of PwMS. The focus of this study was to provide detailed instances of support which is experienced as helpful and unhelpful from key support network members. The second study aimed to understand the journey of PwMS by exploring the usefulness of the Fennell Four Phase Model (FFPM) of adjustment. This model of adjustment to chronic illness is unique as it considers the importance of the social support system (Fennell, 1993; Fennell, 1995; Fennell, 2003a). This model also addresses the physical-behavioural, psychological and social-interactive domains. The model acknowledges the trauma and stigmatisation which is often associated with chronic

illness (Fennell, 2003a). This study also aimed to determine if PwMS at different stages of adjustment have different perceptions of helpful and unhelpful support. Together, the studies provided both in-depth information on the kinds of social support that were relevant and how strongly they operate during the MS journey as mapped by the Fennell Four Phase Model.

Study 1 consisted of a qualitative approach to social support involving face to face interviews with PwMS. The study utilised an approach developed by Dakof and Taylor (1990) when studying social support and cancer. Although this approach was particularly challenging especially in relation to winning the trust of virtual strangers, I also found it to be highly rewarding. I had the opportunity to discuss and understand participants' experiences and gain insight into the everyday difficulties that they faced in terms of social support. Accessing this population was very difficult but was achieved with the help of the MS society of NSW/VIC.

Study 2 investigated the FFPM of adjustment for PwMS by examining the factor structure of the Fennell Phase Inventory (FPI) which was designed to measure the phases of chronic illness. The study also explored different features of each of the phases of adjustment (life satisfaction, coping styles and emotional states). Study 2 was an extension of Study 1 as it explored if differences in perceptions of helpful and unhelpful social support differed depending on level of adjustment. Social support was measured using a questionnaire which was developed from the findings from Study 1.

This research will assist PwMS and their support networks in better understanding of the journey of chronic illness and the type of support which is likely to be most helpful. A greater understanding of the specific aspects of social support

which are useful can help in the development of effective interventions to enhance support for PwMS. Having an understanding of adjustment phases and challenges faced by people with chronic illness can assist healthcare professionals to provide optimal treatment to enhance quality of life for PwMS.

This thesis has been organised in the following way:

Chapter One provides a general overview of the difficulties and challenges faced by PwMS. The chapter also explored the ways in which MS patients cope with the disease and the impact on family members and relationships. Despite the negative aspects of this disease, many PwMS are able to find benefits associated with the condition so benefit finding was also addressed in this chapter.

Chapter Two focused primarily on social support research. Social support has been found to be highly beneficial for PwMS; however it has not been researched in a comprehensive manner, in particular, in addressing some of the multidimensional aspects of support. This chapter initially reports on empirical research findings on the importance and need of social support for PwMS and also reviewed cancer research, an area in health psychology which has provided a detailed understanding of the aspects of support which are helpful and unhelpful and can be used as a guide to assist MS research. An exploration of the various theoretical models of social support in order to provide an understanding of the mechanisms and functions of support is also presented in this chapter.

Chapter Three concentrated on understanding adjustment to MS and chronic illness in general. The chapter identified some of the factors associated with adjustment to MS such as stress, coping and self-efficacy. Qualitative and theoretical research adjustment models were reviewed. A detailed description of the FFPM was

given along with the established empirical support for this model. Justification for adopting the FFPM over other proposed adjustment models was also addressed.

Chapter Four presents the first study of the thesis which explored helpful and unhelpful social support from the perspective of PwMS. Issues identified in the MS social support research were addressed using a qualitative approach with behavioural descriptions of social support from key support providers (that is, a description of a person's experiences when they are interacting with others and how they perceive this interaction). The results and discussion section of this chapter are extensive, such detail was required in order to provide a comprehensive understanding of support using this qualitative approach. A social support questionnaire was developed from the findings for use in the second study.

Chapter Five reports Study 2 of the research which tested the applicability of the Fennell Four Phase Model for understanding adjustment to MS. This chapter also explored whether perceptions of helpful and unhelpful social support differed according to levels of adjustment. It aimed to provide the reader with a deeper understanding of how MS patients in different phases of adjustment have different experiences and struggles.

Chapter Six, the Conclusion, provides an overall discussion of the significance of the thesis. The limitations of the thesis are addressed and also the directions for future research.

CHAPTER ONE

MULTIPLE SCLEROSIS – PSYCHOLOGICAL ISSUES, DIFFICULTIES AND CHALLENGES

“How sickness enlarges the dimensions of a man’s self to himself!”
Last Essays of Elia – 1833
Charles Lamb (1775-1834)

1.1 CLINICAL COURSES OF MULTIPLE SCLEROSIS

There are several clinical courses of MS including benign, relapsing remitting, secondary progressive, primary progressive and malignant. The benign course of MS is characterised by only minimal disability and extended periods of remission; approximately 10 to 15% of people diagnosed with MS have this form (Eeltink & Duffy, 2004; McReynolds, Koch & Rumrill, 1999). The relapsing remitting (most common) and the secondary progressive forms are associated with periodic exacerbations characterised by a worsening of symptoms. Approximately 65-70% of people with MS are diagnosed with either of these forms (Eeltink & Duffy, 2004). Due to the relapsing and remitting pattern of MS symptoms, patients are often on constant alert for the next relapse (McReynolds et al, 1999). Symptoms are unpredictable and may stabilise fully, partially or completely remit within hours, days, weeks or months (Eeltink & Duffy, 2004). Patients are often initially diagnosed with relapsing remitting MS (RRMS), the condition can then develop to secondary progressive as the baseline of functioning between relapses begins to deteriorate (Feinstein, 2007). The primary progressive course of MS involves a steady worsening of symptoms over time (Eeltink & Duffy, 2004). This course of MS consists of an ongoing decline in functioning with the possibility of minor fluctuations but no discrete relapses (Feinstein, 2007). Finally, the malignant form of MS is very rare, aggressive, persistent and life threatening. Fewer than 2% of individuals diagnosed with MS have this form (Eeltink & Duffy, 2004; McReynolds et al, 1999).

1.2 PSYCHOLOGICAL ISSUES

People with MS frequently suffer from mood disorders (Beiske, Svensson, Sandanger, Czujko, Pedersen & Aarseth, 2008; Dalton & Heinrichs, 2005; Feinstein, 2004). Depression is often described as a typical feature of MS and is the most common psychiatric diagnosis for PwMS (Uguz, Akpinar, Ozkan & Tokgoz, 2007). Chwastiak and Ehde (2007) reported that the prevalence of depression and anxiety disorders was high among PwMS and was associated with poorer adherence to MS treatments, lower functional status and QoL. The lifetime prevalence of major depression for PwMS is approximately 50% and has been found to be greater than other groups with chronic illness (Feinstein, 2004; Siegert & Abernethy, 2004). The rate of suicidal intent among PwMS is also noticeably higher than that of the general population (Feinstein, 2004). A longitudinal study by Beal, Stuifbergen and Brown (2007) found that within a seven year period depressive symptoms tended to fluctuate but no overall increase or decrease in depressive symptoms was found as a whole among participants with MS. Depression can be affected by the state of the illness (exacerbation of symptoms vs. no exacerbation of symptoms), degree of uncertainty experienced concerning the illness and coping strategies (Kroencke, Denney & Lynch, 2001; Uguz et al, 2007). Higher levels of depression are experienced by patients suffering an exacerbation of symptoms, who report greater uncertainty regarding their illness and use emotion focused coping strategies.

Studies have reported that MS patients are likely to experience elevated levels of anxiety but the research in this area is scarce (Beiske et al, 2008; Siegert & Abernethy, 2004). Korostil and Feinstein (2007) reported that the lifetime prevalence of any anxiety

disorder was 35.7% for MS patients; these disorders tended to be undiagnosed and untreated. Personality changes have also been noticed to occur (Benedict, Priore, Miller, Munschauer & Jacobs, 2001). Individuals who suffer from cognitive impairments associated with MS have been found to have elevated neuroticism, less empathy, agreeableness, and conscientiousness with minimal insight into these changes (Benedict et al, 2001).

One of the primary issues in the research on depression and MS is that many of the somatic symptoms in depression such as fatigue, slowed thinking and poor concentration are also common features of MS (Minden & Schiffer, 1991). Researchers have attempted to determine whether depression is a neurologically based disorder the result of demyelisation or a psychological reaction to having a chronic illness. Millefiorini, Padovani, Pozzilli, Lorio, Bastianello, Buttinelli, Di Piero and Fieschi (1992) showed that, in the early phases of MS, depression may be predominantly reactive and more closely linked to the extent of physical disability rather than the extent of brain pathology. This was further explored by Janssens, Van Doorn, De Boer, Van Der Meché, Passchie and Hintzen (2003) who established that recently diagnosed individuals with greater disability tended to experience higher levels of anxiety and depression in comparison to individuals with fewer functional limitations. Anxiety and depression tended to be a reactive response to the disclosure of a diagnosis due to the emotional burden experienced by MS patients and their partners during the early phases after diagnosis (Janssens et al, 2003).

Successful treatment of depression for PwMS can have positive outcomes including greater wellbeing, improved QoL, feeling more capable of managing every day

issues, increased positive self attitude, greater sense of meaning and purpose in life and the perception of having valued relationships with others (Hart, Fonareva, Merluzzi & Mohr, 2005). Treating depression can also lead to increased benefit finding (Hart, Vella & Mohr, 2008). Mohr, Classen and Barrara (2004) found that PwMS who were treated for depression had an increase in perceived social support, utilisation of available support and satisfaction with received support as well as a decreased need for emotional support. Results indicated that no actual improvements in structural support occurred (number of people in an individual's social network), rather improvements in depression during treatment led to improvements in the utilisation and satisfaction with available social support. Both psychotherapy and antidepressant medication are useful treatment approaches for depression for MS patients (Mohr & Goodkin, 1999). Despite the reported useful effects of antidepressant medications Mohr, Hart, Fonareva and Tasch (2006) examined a sample of MS patients and found that depression tended to be undertreated. Psychotherapy which focuses on improving coping strategies has been found to be more effective in reducing depression rather than psychotherapy aimed at increasing insight (Mohr & Goodkin, 1999). Telephone administered psychotherapy has been found to have positive outcomes for MS patients (Mohr, Hart, Julian, Catledge, Honos-Webb, Vella & Tasch, 2005; Mohr, Hart & Vella, 2007). Mohr et al (2005) and Mohr et al (2007) examined the outcomes of telephone administered cognitive-behaviour therapy (CBT) and supportive emotion focused therapy (SEFT). Both interventions were found to lead to reduced depression, improvements in positive affect and reduction in disability. Cognitive behaviour therapy was found to lead to greater improvements during treatment (Mohr et al, 2005). This specific therapy approach was also associated with greater

improvements in fatigue, this may be a result of the skills training in CBT which can assist in symptom management for MS patients (Mohr et al, 2007).

1.3 QUALITY OF LIFE AND COPING

Given the unique uncertainties and difficulties associated with MS it is not surprising that QoL is significantly affected. Individuals with MS and their caregivers experience lower levels of QoL in virtually all domains in comparison to the general population (Aronson, 1997; McCabe, 2006; McCabe & McKern, 2002; Murphy, Confavreux, König, Rouillet, Sailer, Swash, & Young, 1998; Nortvedt, Riise, Myher, & Nyland, 1999). People with MS experience lower levels of QoL in the areas of psychological functioning, social relationships and quality of the environment (McCabe & McKern, 2002). In a recent study by McCabe, Stokes, and McDonald (2009), PwMS were found to be more likely to have lower QoL in multiple domains when compared to the general population. However, PwMS reported higher psychological QoL and greater use of detachment and focusing on the positive as a means of coping. Results suggest that although PwMS tend to experience generally lower QoL they may be more likely to accept their circumstances and anticipate improvements (McCabe et al, 2009).

In general, females with MS experience lower levels of QoL than males (McCabe & McKern, 2002). These findings are in contrast to the general population in which females tend to have greater QoL than males (McCabe & McKern, 2002). The incapacity resulting from MS may have a greater influence on the QoL for females than males. This may be associated with having more restricted social relationships as a result of functional disability, which in turn affects QoL (McCabe & McKern, 2002). The impact

of MS on social activities has been shown to influence QoL substantially (Aronson, 1997). These findings signify the importance of encouraging and actively aiding individuals to maintain social activity despite functional limitations. The ability to maintain employment and an accepting attitude towards MS was found to result in improvements in QoL (Aronson, 1997).

The course of the disease can also affect QoL. Montel and Bungener (2007) found that participants with a diagnosis of secondary progressive MS had the lowest level of QoL when compared to participants with primary progressive MS who reported the highest level of QoL and participants with RRMS who were found to be able preserve their level of QoL. Individuals with secondary progressive MS also tended to rely on emotion focused coping strategies to deal with their illness (Montel & Bungener, 2007). Schwartz and Frohner (2005) identified a particular group of MS patients who are vulnerable to experiencing lower levels of QoL. This group included the recently diagnosed, those who have young children in their care, who report greater cognitive dysfunction and have lower levels of social support. Individuals who perceive themselves as having more social support tend to have better mental health (Schwartz & Frohner, 2005).

1.3.1 COPING STRATEGIES

Multiple Sclerosis researchers have made use of Lazarus and Folkman's paradigm of stress and coping (1984). This model suggests that when an individual is confronted with a stressor, such as MS, an evaluation takes place about the potential threat of the situation and also one's ability to manage the situation and negative emotional reactions.

An individual may then use different coping strategies aimed at dealing with the situation. The outcomes of these coping efforts can impact psychological wellbeing (Wenzel, Glanz & Lerman, 2002).

Coping efforts such as problem focused coping, positive reappraisal and acceptance coping tend to be associated with positive adjustment, lower levels of depression and higher QoL (Arnett et al, 2008; Arnett et al, 2002; Dennison, Moss-Morris & Chalder, 2009; McCabe, 2006; McCabe & De Judicibus, 2005; McCabe & McKern, 2002; McCartney Chalk, 2007; Mohr & Cox, 2001; Montel & Bungener, 2006; Pakenham, 2006; Siegert & Abernethy, 2004). Problem focused coping involves planned problem-focused efforts aimed at changing the situation. Positive reappraisal coping consists of attempts to construct positive meaning by concentrating on personal growth (Folkman & Lazarus, 1988). Acceptance coping involves efforts to evaluate the illness in a more positive light and to integrate the illness into daily life (Pakenham, 2006).

Emotion focused or escape avoidance coping efforts tend to be associated with poorer adjustment, higher levels of depression and lower QoL (Arnett et al, 2008; Arnett et al, 2002; Dennison, Moss-Morris & Chalder, 2009; McCabe, 2006; McCabe & De Judicibus, 2005; McCabe & McKern, 2002; McCartney Chalk, 2007; Mohr & Cox, 2001; Montel & Bungener, 2006; Siegert & Abernethy, 2004). Emotion focused coping involves efforts to reduce emotional distress associated with the situation (Lazarus, 1996). Escape avoidance coping consists of wishful thinking and behavioural attempts to escape or avoid the situation (Folkman & Lazarus, 1988). People with MS tend to use combinations of problem focus and emotion focused coping strategies to deal with difficult situations in relation to their condition (O'Brien, 1993).

The use of wishful thinking as a coping strategy has been associated with the lowest level of psychological adjustment among PwMS. Taking a passive stance and hoping that difficulties will cease to exist, will consequently lead to increased depression and confusion (McCabe, McKern & McDonald, 2004). Pakenham, Stewart, and Rogers (1997) found that that emotion focused coping such as avoidance and wishful thinking was generally associated with poorer adjustment. However, results also suggested that wishful thinking can have a positive impact on adjustment when used to deal with the physical aspects of MS by helping view difficulties more optimistically (Pakenham et al, 1997).

Successful adjustment has been related to less disability, greater reliance on problem focused coping and less reliance on emotion focused coping (Pakenham, 1999). Pakenham (1999) applied the stress and coping model of adjustment to MS. Findings supported the role of disability, appraisal, social support, and coping in adjusting to MS. Findings also indicated support for the protective function of social support and problem focused coping, however, emotion focused coping was associated with increased stress (Pakenham, 1999). Despite the benefits of problem focused coping and seeking social support, some research has indicated that PwMS are less likely to utilise these forms of coping in comparison to the general population and are more likely to exhibit a detached coping style (McCabe & Di Battista, 2004; McCabe, McKern & McDonald, 2004).

Disease activity (remission and exacerbation) can influence coping efforts of PwMS. McCabe (2005) compared coping styles of PwMS who had experienced an exacerbation of symptoms (exacerbation group) within the previous 18 months with those who had not experienced an exacerbation of symptoms (no exacerbation group) within

this period. The no exacerbation group tended to use fewer problem solving techniques and had greater levels of detachment in comparison to the exacerbation group (McCabe, 2005). Warren and Warren (1991) had different results in their study, indicating that participants experiencing an exacerbation of their symptoms tended to utilise emotion focused coping more than those in remission. McCabe (2005) suggests that these differences could be due to the fact that the sample in Warren and Warren's (1991) study were currently having an exacerbation whereas the sample in McCabe (2005) had experienced exacerbation in the previous 18 months. It is possible that PwMS initially coping with a relapse by using emotion focused strategies, then utilise problem focus strategies to deal with the exacerbation and possible residual impact (McCabe, 2005).

Recently diagnosed individuals have been found to benefit from using an avoidant/denial and present focused coping strategy (Sullivan, Mikail & Weinschenker, 1997). These individuals tend to focus primarily on current concerns and divert attention away from the more unpleasant aspects of living with a chronic illness. During the initial stages of MS only minimal physical disability is typically encountered. A present focus allows these individuals to continue to attend to daily responsibilities. Having a past or future focus may result in the development of depressive symptoms due to highlighting losses that the individual has experienced or that they may experience in the future (Sullivan et al, 1997). Methods of coping have been found to change overtime. In a longitudinal study, McCabe et al (2009) found that initially PwMS reported higher levels of social/emotional support and higher levels of detachment than the control group. Over time PwMS continued to show increases in social/emotional support indicating progress towards positive adjustment (McCabe et al, 2009). Findings also indicated that reliance

on wishful thinking decreased over time and detachment increased which was indicative of greater levels of acceptance (McCabe et al, 2009).

McCabe, McKern and McDonald (2004) found evidence suggesting that men and women with MS may benefit from different coping efforts. Men with MS are likely to have better adjustment if they attempt to solve problems in a task orientated manner. Whereas women with MS may experience better adjustment if they interact socially and seek support from others as a means of coping with their illness. Both men and women experience poor psychological adjustment when they use avoidant and emotion focused coping strategies such as wishful thinking. However, there were no gender differences in the degree to which men and women used these coping strategies (McCabe et al, 2004). Coping skills training has been found to improve psychosocial role performance, coping behaviour and several facets of wellbeing. Schwartz (1999) found that a coping skills training group assisted participants more so than a peer support telephone intervention. Despite the progressive nature of MS the coping skills training group was able assist with enhancing QoL (Schwartz, 1999). Research supports the use of problem focused coping, positive reappraisal and acceptance coping for adjustment to MS. However, studies suggest that the usefulness of these coping styles is also influenced by other factors such as gender, disease status and duration.

1.3.2 OCCUPATIONAL FUNCTIONING AND FINANCIAL DIFFICULTIES

Occupational functioning, that is an individual's ability to carry out tasks including work, school and home duties, among PwMS tends to be greatly reduced (Lobentanz, Asenbaum, Vass, Sauter, Klosch, Köllegger, Kristolferitsch & Zeitlhofer,

2004). It has been found to be affected by disease severity and duration, depression and fatigue (Lobentanz et al, 2004). Financial pressure is a common struggle for MS sufferers as many are unable to remain in the workforce and have additional illness related costs. McCabe and De Judicibus (2003) found PwMS to have lower family incomes and higher levels of economic stress.

1.3.3 IMPACT OF FATIGUE AND COMMUNICATION DIFFICULTIES

Fatigue is a considerably common, debilitating and unpredictable symptom of MS. Olsson, Lexell, Söderbreg (2005) found that women with MS reported planning their daily activities in a way that would not require excessive energy. Fatigue can affect relationships as others have difficulty understanding these symptoms. This symptom is not visible to others and can result in little empathy and understanding. Women with MS have reported being unable to participate in family activities, as fatigue often impacted sharing and communicating with others (Olsson et al, 2005). Fatigue can impact communication and conversation due to limited ability to maintain focus and fully participate (Olsson et al, 2005; Yorkston, Klasner and Swanson, 2001). Social relationships can be difficult to maintain due to low energy levels and mobility limitations. People with MS have reported that they can often not keep up with their friends during outings or participate in activities (Yorkson et al, 2001).

1.3.4 MAINTAINING QUALITY OF LIFE

Multiple Sclerosis is a progressive and degenerative condition which affects QoL. However, mediating variables, such as resources, self efficacy, and social support can

play an important role in maintaining and improving QoL. Social support has been found to have the largest mediating and moderating effect on QoL (Stuifbergen, Seraphine & Roberts, 2000). The process of meaning making has also been found to influence QoL and adjustment (Russell, White & White, 2006). There are many ways that people make meaning from situations, however, it has been found that religious faith, deepening connections with others and setting new priorities are related to higher QoL and life satisfaction among PwMS (Russell et al, 2006). Gordon, Feldman, Crose, Schoen, Griffing and Shankar (2002) found that PwMS who were coping well had found new meaning and purpose in life and relied on religion for support. The social aspect of religion such as friends and church members was also considered to be highly beneficial (Gordon et al, 2002).

People with MS can maintain QoL by preserving valued roles, such as mother, helper and also mutual relationships and finding new, realistic life pursuits (Reynolds & Prior, 2003). Actively engaging in the service of people with disabilities is a common form of fulfilment and empowerment (Reynolds & Prior, 2003). Research findings suggest positive outcomes among PwMS who provide assistance to other MS sufferers (Schwartz & Sendor, 1999). Maintaining autonomy and independence is also highly important among PwMS and has been associated with reduced depression and increased social functioning (Somerset, Peters, Sharp & Campbell, 2003). This ability to maintain autonomy and independence is a significant concern among older adults with MS (55 + years) and impacts their ability to plan for the future (Finlayson, 2004). Given the important role of autonomy and independence it is critical to facilitate this among older adults with MS

1.3.5 POSITIVE AND NEGATIVE ASPECTS OF LIVING WITH MS

The psychosocial consequences of MS can be both positive and negative. Benefit finding is the process of finding benefits in the face of adversity, for PwMS this involves finding advantages and gains as a result of MS (Pakenham, 2005). An increased appreciation for life and focus on spirituality has been identified among PwMS and this can involve the deepening of relationships with others (Mohr, Dick, Russo, Likosky & Goodkin, 1999). Benefit finding among PwMS been related to adaptive coping strategies such as positive reappraisal and seeking social support. People with MS report benefit finding significantly more than the negative aspects of MS such as demoralisation and deterioration in relationships (Mohr et al, 1999).

Finlayson, Van Denend and DalMonte (2005) identified positive benefits of living with MS, which included social benefits, becoming better helpers, realising potential, strengthening family relationships and discovering resources. Social benefits, such as support groups and new friendships, were the most commonly reported positive aspects. Multiple Sclerosis has been associated with opportunities to strengthen existing family and friend networks (Finlayson et al, 2005). Many individuals also reported social disadvantages which are associated with loss of mobility and difficulty access social venues. Other negative aspects of living with MS include a sense of uncertainty, loss of independence and control, missed opportunities and financial expenses (Finlayson et al, 2005). Hakim, Bakheit, Bryant, Roberts, McIntosh-Michaelis, Spackman, Martin and McLellan (2000) found that PwMS who were severely disabled and had lost their jobs as a result of the disease reported lower standards of living and had fewer social contacts

than prior to the disease onset. Also withdrawal from social activities and recoil from friendships were commonly reported (Hakim et al, 2000).

1.4 IMPACT ON CAREGIVERS, FAMILY AND RELATIONSHIPS

Multiple Sclerosis can be stressful for all parties involved; partners often experience many physical demands which may be related to experiencing stress related symptoms such as fatigue and bodily pain (Stuifbergen, 1992). In comparison to the general population, caregivers show higher levels of depression and global distress (Pakenham, 2001). Providing care and attending to the needs of people disabled by MS has an enormous impact on caregiver's lives, their physical and mental health and wellbeing, finances, social life and overall QoL (McKeown, Porter-Armstrong & Baxter, 2003). Social support can be a useful aid in reducing the distress among the significant others of MS patients (Sherman, Rapport, Hanks, Ryan, Keenan, Khan & Lisak, 2007).

Worrying is commonly experienced by carers in many forms. Cheung and Hocking (2004) found that spouses accepted the changed person and associated challenging behaviours of their partner with MS, although they worried about the effect this would have on their relationship. Carers also worried about their own health as this would limit their ability to provide future care. Concerns regarding their partner's health and the possibility that they would have to live in a nursing home were also common. Caregiving has been found to have several negative and positive consequences. Knight, Devereux and Godfrey (1997) found that caregivers often felt that their lives had become constrained and future plans altered due to the demands of caregiving. However, caregivers were able to identify positive aspects to caring, reporting that they had become

more caring and attuned towards the needs and problems of others. Carers in midlife were particularly concerned regarding their limited time for other family members, particularly children. The ability to cope and satisfaction with social support were found to be the strongest predictors of perceived burden. In addition care-recipients' psychological state has also been found to significantly influence caregiver adjustment (Pakenham, 2001).

Many caregivers are concerned with limiting the negative impact of MS and the preservation of QoL for themselves and their spouses. Courts, Newton and McNeal (2005) found that gender differences were evident regarding how the caregiving roles were experienced. Caregiving husbands described their experiences objectively but felt anger about human and environmental barriers. Husbands took on the role of protectors of their wives' time, energy and employment opportunities by taking upon more responsibility for household maintenance and participating in the management of their wives' illness (Courts et al, 2005). Caregiving wives described their experiences with much more emotion and pain. They took on the role of advocates for their husbands by encouraging them to maintain their independence and existing roles. Both groups experienced pain and frustration but also growth. Family and friends were considered an additional source of stress when they failed to understand MS (Courts et al, 2005).

1.4.1 THE EFFECT OF MARRIAGE AND/OR PARTNERS

Marital status can facilitate acceptance of disability among PwMS (Harrison, Stuifbergen, Adachi & Becker, 2004). Harrison et al (2004) found that PwMS who remained consistently married had a greater acceptance of disability in comparison to those who were not consistently married (became divorced, widowed, never married or

separated). Men with MS acquired greater benefits from being married than women. Men gained mental and physical benefits, experienced higher levels of acceptance of disability and a lower levels of perceived impairment. However, women experienced increased acceptance overtime regardless of their marital status (Harrison et al, 2004). One explanation for this finding is that women who are married gain greater acceptance of disability due to the benefits of their marriages, whereas, women who are not married may find these benefits elsewhere with other support providers. Men tend to have fewer sources of support within society and rely heavily on their partners for emotional support (Helgeson, 1995 as cited in Harrison et al, 2004). Interestingly, the longitudinal data from this study found that despite increasing disability and impairment, PwMS also gained greater acceptance over time (Harrison et al, 2004).

1.4.2 RELATIONSHIP AND SEXUAL SATISFACTION

People with MS generally experience higher levels of sexual dysfunction than the general population (McCabe, 2004). Relationship satisfaction can also be affected by MS. McCabe (2004) found that relationship satisfaction for those experiencing an exacerbation of symptoms was no different from the general population. However, PwMS who were not currently experiencing an exacerbation of symptoms had lower relationship satisfaction than the general population. McCabe (2004) suggested that the stress which is experienced by the exacerbation of symptoms may strengthen relationships as couples come together to cope. The non-exacerbation group does not have this additional stress to encourage union and therefore may experience both poorer sexual and relationship satisfaction (McCabe, 2004).

1.4.3 EFFECT OF PARENTS WITH MULTIPLE SCLEROSIS ON CHILDREN

Physical affection between parents with MS and their children can be impacted by the disease. Deatrick, Brennan and Cameron (1998) reported that mothers and their children recognised differences in physical affection during exacerbations of their symptoms. Mothers often tended to underestimate the extent of these differences (Deatrick et al, 1998). Children living with a parent with MS often have difficulties coping with the related stresses. Most children did adjust successfully but tended to have a greater risk of experiencing adjustment difficulties and peer group problems (De Judicibus and McCabe, 2004). Research findings suggested that children require more information regarding MS tailored to their developmental level. Cross and Rintell (1999) found that children tended to perceive their parents physical and emotional states accurately although very few children were educated about the physiological process of MS. Children often worried about developing MS themselves and had concerns of how their behaviour may worsen their parents illness (Cross & Rintell, 1999).

1.4.4 EFFECTS OF MULTIPLE SCLEROSIS ON GENERAL SUPPORT NETWORKS

Social support networks generally provide social structure and can benefit to members of the network (O'Reilly, 1988). The social support network of an individual with MS is impacted by the disease. Barrett (1995) found that the members of the social network experiences feelings of powerlessness, fear, incomprehension and anger regarding MS. The social network was also found to have an unexpressed reliance on the person with MS and his or her ability to be independent. Barrett (1995) reported members

of the support network believe that they can not assist and have no role to play in alleviating the individual's condition; therefore they are separated from the person with MS. The thought that the person with MS may become incapacitated by the illness is acknowledged by members of the support network, although it was not readily expressed or discussed (Barrett, 1995).

1.5 SUMMARY

Multiple sclerosis is a chronic and progressive neurological disease which is characterised by uncertainty and fear. People with MS tend to experience significant levels of depression and anxiety and have a lower QoL in comparison to the general population. Those who have increased resources, greater self efficacy, adequate social support, are able to make meaning of this illness experience and maintain valued roles or find new suitable pursuits in their lives tend to preserve levels of QoL. The way in which PwMS cope with this disease also has a significant impact on QoL and adjustment. Those who use problem focused coping and positive reappraisal tend to have better adjustment and psychological health than those who use emotion focused or escape avoidance coping. Research clearly indicates that PwMS and their support networks face difficult challenges which can impact their psychological wellbeing and QoL. Social support also plays an important role in the adjustment, QoL and coping of the MS patient and therefore will be discussed further in the following chapter.

CHAPTER TWO

SOCIAL SUPPORT AND MULTIPLE SCLEROSIS

*“True kindness presupposes the faculty of imagining as one’s own the suffering and joy
of others.”*

André Gide (1869-1951)

2.1 SOCIAL SUPPORT

Social support has been defined as the means by which interpersonal relationships guard against the negative effects of stress (Cohen & McKay, 1984). Generally, support consists of the resources and interactions supplied by others that may be helpful for aiding a person to cope with a problem or stressful situation (Wills & Fegan, 2001). The social support network consists of people who care about the others welfare and can provide aid during difficult times (Vaughan & Hogg, 2002). Social support has been found to protect against and moderate the negative psychological impact of physical illness and stressful life events (Cohen & Wills, 1985; Dennison et al, 2009).

2.1.1 THEORETICAL BACKGROUND

This section will provide a general theoretical background to social support by exploring the multidimensional aspects of support which have been proposed by various theorists and also theoretical models of support aimed to provide a greater understanding on the effects and mechanisms of support.

2.1.1.1 MULTIDIMENSIONAL ASPECTS OF SOCIAL SUPPORT

Theorists and researchers have identified various components of social support which are important to consider due to the complex nature of support (Wortman & Conway, 1985; Wortman & Dunkel-Schetter, 1987). Many social support researchers have emphasised the importance of multidimensional aspects of social support, although within the area of MS very little research explores this multidimensional perspective and often only measures social support as a general concept. When researching social support

as a multidimensional variable researchers need to consider exploring functions of support (emotional, informational and tangible), sources of support and positive and negative types of support. The following section will describe the multidimensional aspects of social support which have been identified in the literature.

Structural and Functional Aspects of Social Support

Structural investigations of social support focuses on the number of linkages people have in their social networks. This approach assumes that it is the quantity of regular social contact which is important for adequate social support. Measures of structural aspects explore the existence of primary social relationships and frequency of contact (Wills & Fegan, 2001). Functional investigations of support explore the quality of social relationships. Measures of functional aspects investigate the degree to which supportive interactions are available and the specific aspects and functions of support which are beneficial (Wills & Fegan, 2001).

Social support can be investigated by examining either structural or functional aspects of support. Wortman and Conway (1985) suggest that assessing the function of support (emotional, informational and tangible) is essential as different types of support can have different impacts on particular health outcomes. Considering the functions of support can also provide insight into the type of assistance which is predominantly helpful to individuals with certain illnesses at certain times.

Sources of Support

Researchers have identified the importance of considering the support provided by various sources such as the spouse, family, medical professionals and peers. It is likely that the experience of specific acts as helpful may depend on who provides such support

(Wortman & Conway, 1985). Wortman and Dunkel-Schetter (1987) suggest that in the case of a serious illness it is important to enquire about support provided by the spouse and immediate family members as reactions from these individuals can significantly impact adjustment to the illness. It may also be beneficial to assess the support provided by physicians and examine reactions to peer support as those who have similar experiences as they are in a unique position to provide effective assistance (Wortman & Dunkel-Schetter, 1987).

Provider Intentions and Recipients Experience of Support

Assessing the perspective of both the recipient and the provider of social support is also advantageous as people often have mistaken beliefs regarding how individuals in distress should act and be treated by others (Wortman & Conway, 1985). Behaviours thoughts to be supportive are often not perceived as such by the recipient and may actually be unhelpful (Wortman & Dunkel-Schetter, 1987). Understanding of the discrepancies between the support provider's intentions and the recipient's perception of support can be helpful in comprehending the transactional nature of interactions.

Positive and Negative Components of Social Support

It is important to consider the negative aspects of social interactions experienced by the physically ill as support providers can often misunderstand the process and difficulties of coping with an illness (Wortman & Conway, 1985). These misunderstandings can lead to behaviours that are experienced as inappropriate and unsupportive. Experiencing more negative social interactions has been associated with increased life stress, poorer health, difficulty with daily activities and increasing disability (Mavandadi, Rook, & Newsom, 2007; Newsom, Mahan, Rook & Krause, 2008; Rook,

2003). Most importantly it has been found that negative social interactions have a more powerful effect on wellbeing than positive social exchanges (Rook, 1984).

Potential support providers may also have little knowledge of the patient's illness which can result in offers of information that are well intentioned but wrong or misguided. Ill individuals are often not in a position to end relationships that do not satisfy their needs (Wortman & Conway, 1985). They may be dependent on these relationships and are often not in relationships that are reciprocal and equal. In addition, illnesses can provoke negative feelings in others. These factors suggest that people with a physical illness are likely to experience both positive and negative interactions within their intimate and significant relationships (Wortman & Conway, 1985).

General and Specific Aspects of Support

Research often assesses social support with general measures of perceived support which explore whether different types of support are provided in the abstract. Another method to investigate support in a more specific manner is to explore naturally occurring behaviours (Wortman & Conway, 1985). The investigation of naturally occurring behaviours involves exploring support or lack of support that occurs naturally in the individuals life, rather than applying a measure of general social support or asking individuals about different types of support in the abstract. Information from naturally occurring support may increase awareness of the specific types of emotional, informational or tangible assistance which are experienced as helpful (Wortman & Conway, 1985). Knowledge of natural helping behaviours can also provide additional understanding about particular persons or interactions that express a sense of support (Wortman & Dunkel-Schetter, 1987). Having a greater understanding of naturally

occurring support can assist with comprehending the processes by which support can affect health and appropriate interventions which can be developed to enhance available support (Wortman & Conway, 1985).

2.1.1.2 THEORETICAL MODELS OF SOCIAL SUPPORT

Understanding theoretical social support models is important for MS. Chronic illness can be viewed as a significant ongoing stressor and social support may impact adjustment, disease progression and psychological health for PwMS. Social support has frequently been related to physical health, recovery from illness, improved health and wellbeing. Many different mechanisms have been suggested on how social support functions to assist individuals (Wills & Fegan, 2001). Social support is generally described as resources and interactions supplied by others that may be helpful for aiding a person to cope with a problem or stressful situation such as a chronic illness (Wills & Fegan, 2001). Stress occurs when a situation is perceived as threatening or demanding and no adequate coping response is available (Cohen & Wills, 1985). This can lead to negative affect, increase in physiological responses and negative behavioural adaptations. Some researchers have suggested that social support is protective as it is able to reduce levels of stress and directly encourage improved health (Cobb, 1976; House, 1981). The quantity and quality of social relationships has an important influence on the levels of stress endured, wellbeing and the probability that stress will negatively affect overall wellbeing (House, 1981). The management of stress for MS patients is critical as researchers have found a significant association between stressful life events and exacerbation in MS (Mohr, Hart, Julian, Cox & Pelletier, 2004).

The Main Effect Hypothesis

The main effect hypothesis of social support suggests that support improves health and wellbeing irrespective of stress levels (Cohen & Syme, 1985; Cohen & Wills, 1985; Wills & Fegan, 2001). An increase in social support will result in improved wellbeing regardless of the current level of stress (Cohen & Wills, 1985; Wills & Fegan, 2001). Various underlying mechanisms have been suggested regarding how the main effect hypothesis can improve health and wellbeing.

It has been suggested that the direct assistance of social support could be a result of the belief that others will provide help in the occurrence of a stressful event or purely as a result of integration in a social network (Cohen & Syme, 1985). Support can lead an individual to perceive the situation as less threatening or stressful which consequently reduces psychological, physiological or behavioural reactions which may result in disease (House, 1981). Social support may provide a generalised advantage as a larger social network can supply a person with regular positive experiences and various stable, socially rewarded roles within a community (Cohen & Wills, 1985). Social support can directly improve health and wellbeing as it provides for human needs such as security, social contact, approval, belonging and affection which can then counteract the negative effects of stress (House, 1981). Social support can be associated with physical health outcomes via emotionally induced effects on the neuroendocrine or immune system functioning (Cohen & Syme, 1985; Cohen & Wills, 1985). Support can also encourage health related behavioural patterns such as increased exercise which can improve an individual's capacity to tolerate psychosocial stress and physical, chemical or biological threats to health (Cohen & Syme, 1985; Cohen & Wills, 1985; House, 1981).

The Buffering Hypothesis

The buffering hypothesis proposes that support has a positive impact in the presence of stress by protecting individuals from the negative consequences of such stress (Cohen & Syme, 1985; Wills & Fegan, 2001). The degree of usefulness of social support is assumed to be greater with higher levels of stress (Wills & Fegan, 2001). The experience of increased life stress is said to intensify vulnerability to illness, though the effect of such stress may be counterbalanced by the presence of adequate social support (Gore, 1985).

It is proposed that support may play a role at two different points in the connection between stress and illness (Cohen & Syme, 1985; Cohen & Wills, 1985). Firstly, support may intercede between the stressful event and a stress reaction by reducing or averting a stress appraisal response (Cohen & Syme, 1985; Cohen & Wills, 1985; House, 1981). Secondly, support may intervene between the experience of stress and the onset of an illness or health related problems by reducing or removing the stress reaction or by influencing physiological processes. This can occur by support providers offering a solution to the problem, by reducing the apparent significance of the problem, by calming the neuroendocrine system so that individuals are less reactive to the stressor, or by facilitating healthy behaviours (Cohen & Syme, 1985; Cohen & Wills, 1985).

Cohen and Wills (1985) propose that in order for the buffering to be effective there must be correspondence between the coping requirements and the available support. The provision of esteem support can offset threats to self esteem which occur in response to stress (Cohen & Wills, 1985). Having a sense of belonging, increased self esteem and security provided by social support can assist in recovery from illness by enhancing the

immune system functioning and encouraging self care (Cohen & Syme, 1985).

Informational support can assist one to reappraise the stressor as less threatening or provide a coping response to deal with the perceived lack of control. Instrumental support and social companionship can be effective when the resources they provide correspond with the specific need raised by the stressor (Cohen & Wills, 1985; Cohen & Syme, 1985). It has been suggested that esteem and informational support will be more effective in a wide variety of situations (Cohen & Wills, 1985; Cohen & Syme, 1985).

Cohen and McKay (1984) suggested a stress buffering model which is separated based upon the distinctions between tangible, appraisal and emotional support. This model assumes that an assessment of the buffering hypothesis is incomplete if it does not take into consideration the multidimensionality of both the stressful events and support system. Cohen and McKay (1984) propose that support will only be beneficial if the type of assistance matches the coping requirements evoked by the particular stressor.

The Main Effect Hypothesis vs. The Buffering Hypothesis

Evidence indicates that both the main effect hypothesis and the buffering hypothesis assist health outcomes (Cohen & Wills, 1985). Evidence supporting the buffering model is found when social support is measured by evaluating interpersonal resources that are responsive to the needs evoked by stressful events. Evidence for the main effect model is found when support is measured by evaluating an individual's level of integration in a large social network. The evidence does not suggest that the buffering effect and the main effect occur simultaneously (Cohen & Wills, 1985). Cobb (1979) reported that it is unnecessary to be concerned about the differences between main effects

and interaction effects; however, many theorists have provided explanations for this phenomenon.

Several explanations have been provided as to why the stress buffering effect occurs only when support is measured by evaluating interpersonal resources that an individual is able to rely upon to provide aid and assistance when needed. Wethington and Kessler (1986) suggest that the perception of having available support can indirectly suggest that an actual supportive response would occur in a stressful situation and therefore more directly encourages healthier adjustment. Alternatively, the perception of available support may impact adjustment directly by changing appraisals of the situation to less threatening. Cohen and Wills (1985) suggest that particular support resources act only in the existence of increased stress levels. Certain support functions are effective in stressful situations while social network integration functions by preserving feelings of stability and wellbeing regardless of stress levels (Cohen & Wills, 1985).

House, Umberson and Landis (1988) have suggested that the buffering effects of social support are active in the presence of a significant stressor. Alternatively, a main effect occurs when support is measured by the existence of social relationships. If the same underlying mechanisms occur for both the buffering and the main effects, then they would function more strongly in the occurrence of a stressful event. If the presence of others or their support has a tranquilising impact on the neuroendocrine system which in turn encourages general health then this effect would be more intense in the presence of stress. On the other hand there may be differences between these mechanisms, for example social support may assist psychological and behavioural processes when coping and adapting to a stressor therefore buffering the effects of stress, whereas social

relationships may satisfy base human needs of attachment therefore having a main effect (House et al, 1988).

The Theory of Person-Environment Fit

It has been suggested that typical research models of social support are too simplistic as they tend to not consider the transactional nature of support and typically only assess the positive consequences of social interactions (Shinn, Lehmann & Wong, 1984). According to Shinn et al (1984) it is possible for actions that are perceived as helpful to have negative consequences if they do not correspond with the current circumstances. The theory of person-environment fit suggests that adjustment depends on the connection or fit between individual demands and environmental supplies (French, Rogers, & Cobb, 1974). If support is considered to be an environmental supply, its usefulness would be dependent upon its suitability to an individual's circumstances. Shinn et al (1984) claimed that there are five areas of fit between the characteristics of the recipient and the supportive acts which need to be considered and include the following: amount, timing, source, structure and function of support.

According to Shinn et al (1984) the amount of support is important to consider as too much support can be problematic and increase dependency. With an appropriate amount of support an individual will feel both supported and also challenged (Shinn et al, 1984). The timing and amount support which is most helpful to a distressed individual may also change over time. It is essential to have an understanding of the appropriate timing for support in order for it to correspond with an individual's circumstances (Shinn et al, 1984). With respect to illness and disease it has been suggested that the effectiveness of social support will depend on the state of the health condition or illness

(Wallston, Alagna, DeVellis & DeVellis, 1983). Wallston et al (1983) indicates that along the illness cycle the manner in which social support functions, the amount and type of support that is most advantageous may differ. The source of support can also impact the effectiveness of assistance as different sources can differ in their level of usefulness for various situations (Shinn et al, 1984). Some sources of support may be more appropriate than others in certain circumstances. The structure of the support network can also either match or be at odds to the person's situation; the density of the social network can influence the effectiveness of support. Finally, the function of support can affect its usefulness as different types of support may either be effective or ineffective for an individual's situation. Based on these factors Shinn et al (1984) suggests that when trying to improve health and wellbeing via social support one must consider the individuals needs and the limitations on supplies of social support. This will enhance the goodness of fit between the situation and social support.

The Theory of Optimal Matching

The theory of optimal matching focuses on which types of support are most beneficial for specific needs (Cutrona & Russell, 1990). The usefulness of social support depends on the correspondence between the functions provided by support and the needs elicited by the problem (Wills & Fegan, 2001). Within this model stressful events are considered to comprise of four dimensions including; desirability, controllability, duration of consequences, and life domains. Events which involve possible achievement or growth are deemed to be desirable (Cutrona & Russell, 1990). The primary difference between a desirable and undesirable stressful situation is the type and severity of negative emotions they evoke. Desirable events in which stress develops from doubt regarding the

achievability of a goal tends to elicit anxiety whereas an undesirable event tends to result in depression. Social support to assist with lessening anxiety would be helpful in coping with a positive situation and support to assist with lessening depression would assist with coping with a negative event (Cutrona & Russell, 1990).

A controllable event involves a situation in which an individual could achieve a certain desired goal, avoid an undesirable loss or reduce the severity of the consequences of an experienced loss. It is proposed that a controllable event would require social support which encourages problem focused coping, consists of expressions of esteem and also information to assist with solving and avoiding problems (Cutrona & Russell, 1990). Cutrona and Russell (1990) postulate that an uncontrollable event would require social support which promotes emotion focused coping and consists of expressions of love and also tangible support to replace possible lost resources.

The duration of the consequences involves a distinction between situations whose stressful effects are long term or events with a shorter period of consequences. Cutrona and Russell (1990) suggest that the longer the consequences of an event the greater the need for emotional support in order to strengthen esteem. Additional tangible support would also be required for situations with long term consequences as the needs will continue for an extended duration.

Finally, life domains consist of four areas in which stressful events may occur including assets (resources and physical health) relationships (interpersonal challenges, relationship losses), achievement (status, evaluation or competition) and social roles (role loss or attainment of new roles). The loss or risk of loss to assets would be related to a greater need for tangible support (Cutrona & Russell, 1990). The loss or risk of loss to a

relationship may result in a reduction in perceived attachment or social integration. Social support which focuses on attachment would be required in the case of the loss of an intimate relationship whereas support which focuses on social integration would be required in the case of the loss of a network membership. Losses in the achievement area would require reassurance of capabilities. The loss of valued social roles would require greater social integration to counter these losses. These four dimensions of stress (desirability, controllability, duration of consequences, and life domains) are considered to determine psychological consequences (Cutrona & Russell, 1990).

Cutrona and Russell (1990) hypothesise that certain stressful circumstances will result in a particularly distinct need for certain kinds of support. Uncontrollable events will require support which encourages emotion focused coping and therefore greater levels of emotional support would be needed. A medical illness can be classified as an undesired uncontrollable event which can lead to limited physical capacities, reduced income, loss of contact with others and loss of a sense of achievement. In order to assist with these stressful aspects Cutrona and Russell (1990) suggest that individuals have a greater need for emotional support to assist with reducing fear, depression and anger. Such an uncontrollable event requires emotional support which is focused on providing comfort, encouraging acceptance, and emphasising that one is loved and valued (Cutrona & Russell, 1990). Tangible support is also beneficial in order to assist with loss of physical abilities. Furthermore, to compensate for the potential losses of social contacts, social roles and loss of achievement both esteem support and social integration are essential in assisting the individual to cope with this particular stressor (Cutrona & Russell, 1990). In contrast, it is suggested that controllable events require social

assistance which encourages problem solving coping. According to Cutrona and Russell (1990) informational support would be more relevant for controllable events than for uncontrollable events. The life domain in which the loss occurred would also impact the specific support required. Cutrona and Russell (1990) emphasise the importance of matching social support to the particular stressful event.

The Victimisation Model

Wortman and Dunkel-Schetter (1979) have suggested that cancer (like MS) can create conflicting reactions in significant others and have developed a theoretical victimisation model and applied this model to the experience cancer. The model proposes that individuals who have been victims of an uncontrollable event such as cancer or a chronic illness are in particular need of support and reassurance. The patient experiences fear and uncertainty when diagnosed and has an increased need for clarification, validation and normalisation of feelings and fears (Wortman & Dunkel-Schetter, 1979). The risk to one's self concept can also increase needs for reassurance that one is still loved and will not be discarded (Wortman & Conway, 1985).

By being provided with comparison information, opportunities to ventilate and social interactions, the patient is able clarify the uncertainty and confusion they experience (Wortman & Dunkel-Schetter, 1979). Unfortunately, individuals dealing with an illness have many barriers to support and validation. Many have minimal access to others suffering from a similar problem and therefore are required to depend on family members and friends for support (Wortman & Dunkel-Schetter, 1979). Patients may hesitate to share their struggles and fears due to having concerns that this will upset or

hurt others and become unsure about seeking this much needed support (Wortman & Dunkel-Schetter, 1979).

Victimising events such as an chronic illness can create conflicting reactions in significant others. Firstly, others have negative feelings about the cancer and experience fear and aversion. Secondly, others have the belief that appropriate behaviours towards the patient consist of maintaining an optimistic and cheerful front and believe it is incorrect to discuss the difficulties coping with the illness (Wortman & Dunkel-Schetter, 1979). The conflict between having unexpressed negative feelings about the illness and believing it most helpful to act cheerful and encouraging when interacting with the patient can produce ambivalence and anxiety about interacting with him or her. Therefore, significant others may physically avoid the patient, avoid open communication about the illness, engage in forced cheerfulness, minimisation of the patients experience or engage in inconsistent behaviours such as being supportive to the patient at one moment and then rejecting the patient the next moment (Wortman & Dunkel-Schetter, 1979). As a result of these factors interactions can be awkward, tense and uncertain and can leave the patient to feel rejected or abandoned by significant others.

Patients may attempt to resolve interpersonal problems by amplifying the negative features of their situation in order to elicit a response from others and results in greater distancing and rejection (Wortman & Dunkel-Schetter, 1979). Alternatively, patients may also assume a more positive self presentation in order to maintain social connections, rather than have feelings validated through discussion, patients feel the best way to obtain support is to indicate that they are coping well (Wortman & Dunkel-Schetter, 1979). Dakof and Taylor (1990) proposed that the victimisation hypothesis is more relevant to

relationships that have few social restrictions which hold the parties together, than to relationships in which the prospect of withdrawing is limited. The tension experienced in interpersonal relations will differ according to the type of relationship between the patient and the support provider (Dakof & Taylor, 1990). Dakof and Taylor (1990) suggest that the victimisation model is incomplete as it does not take into consideration the relationship between the support provider and the patient.

2.1.2 RESEARCH FINDINGS ON THE IMPORTANCE AND NEED FOR SOCIAL SUPPORT

Social support research has indicated the beneficial effects of adequate support for MS patients and the negative impact of inadequate support. This research has primarily focused on measuring general social support and adjustment outcomes (Dennison et al, 2009). Previous research does not provide detailed descriptions as to the aspects and components of social support which are beneficial to MS patients. This may lead to misguided and unhelpful attempts at providing social support for PwMS.

Social support can assist PwMS to maintain psychological health, adjust and cope with the disease. The use of social support as a coping mechanism has been found to mediate the effects of emotional distress on activities of daily functioning among PwMS (Gulick, 2001). Miller and Murphy (1997) also found that the families' internal resources (finances, physical assistance, and emotional support) as well as resources from their social networks enhanced wellbeing. Maintaining a sense of hope was also found to be particularly important for PwMS, as this was a means of coping with the uncertainty of

the disease (Miller & Murphy, 1997). Support networks and honest, factual information have been found to promote better adjustment and coping (Miller & Murphy, 1997).

Strengthening the social support network can lead to improvements in QoL. The use of social support as a coping mechanism also enhances adjustment, mediates the effects of emotional distress and improves wellbeing (Crigger, 1996; Gordon et al, 2002; Gulick, 2001; Miller & Murphy, 1997; Stuifbergen et al, 2000). Multiple Sclerosis patients with greater social support are also less likely to suffer from depression (Arnett et al, 2008). The MS research indicates that social support plays a critical role facilitating coping and adjustment to MS. Relationships are often impacted by the disease as family and friends are unable to cope and therefore withdraw from social contact (Reynolds & Prior, 2003). A stressful event such as an illness can cause disruptions to support and social networks (Shinn, Lehmann, & Wong, 1984). A stigmatising event or condition may reduce others' willingness to provide support as they experience discomfort in the face of disability (Shinn et al, 1984).

It is often the needs associated with physical disability which are more readily addressed than the emotional needs of PwMS (Black, Grant, Lapsley & Rawson, 1994). People with MS frequently report not receiving support from other PwMS or from family members (Black et al, 1994). Family and friends have been found to be unsympathetic particularly during the initial stages of the disease when it manifests itself as overwhelming fatigue and presents with very few visible signs of physical disability; this often results in relationship breakdowns (Black et al, 1994). Excessive or inappropriate support can also cause distress among MS patients. People with MS have expressed fear of losing physical abilities because family members insist on helping them (Miller &

Murphy, 1997). Such concerns from MS patients highlights the need for support members to learn to be supportive rather than stifling. People with MS report retaliating to negative social support by refusing to allow others to treat them in a condescending manner and avoiding situations which made them upset or uncomfortable. Miller and Murphy (1997) found that despite having difficulty with certain daily activities PwMS refused to seek assistance but would complete these activities at a comfortable pace; thus increasing their sense of independence.

The disease can impact an individual's ability to participate in social activities and result in social disadvantages; maintaining social relationships can be problematic as PwMS report struggling to keep up with others during social outings (Aronson, 1997; Finlayson et al, 2005; Yorkston et al, 2001). Research findings suggest that the longer the illness duration and the greater the functional disability the less perceived social support a person with MS experiences (O'Brien, 1993). The uncertainty related to MS symptoms also impacts an individual's ability to plan social events. However, support networks often lack understanding regarding these difficulties (Stuifbergen, 1992). People with MS tend to experience less satisfaction with social relationships compared to the general population and a reduction in social contact and recoil of friendships (McCabe & DiBattista, 2004; Hakim et al, 2000; McCabe & McKern, 2002).

Multiple sclerosis patients have been found to have a need for greater informational support about the disease and medical interventions following their diagnosis (Black et al, 1994; Thorne, Con, McGuinness, McPherson & Harris, 2004). This type of assistance helps patients to remain positive, to take one day at a time, to feel productive and to maintain control of their lives (Black et al, 1994). Patients also express

a desire for encouragement, support, acceptance and reassurance from medical professionals (Black et al, 1994). Lode, Larsen, Bru, Klevan, Myhr and Nyland (2007) found that coping styles were related the quality of information provided during diagnosis. Specifically, individuals who were found to be more satisfied with information provided were more likely to engage in adaptive coping strategies such as problem solving and seeking social support. These individuals were found to be more equipped to cope with the burden of living with MS than individuals who were provided with inadequate information. This research reinforces the need for adequate informational support to be provided for PwMS to assist with adaptation to the disease (Lode et al, 2007). However, as this study was not longitudinal the results must be interpreted with caution as other factors such as personality or optimism, may have also played a role

Effective healthcare relationships have a critical role in supporting PwMS (Thorne et al, 2004). Both supportive and obstructive communication with healthcare providers is common. The extent and quantity of unhelpful communications has been found to be troublesome. Effective communication has been identified as essential to providing effective MS care as patients have a need for supportive, realistic and encouraging communication from healthcare providers (Thorne et al, 2004). Healthcare professionals can communicate effectively to their patients by being enthusiastic, encouraging a problem solving approach and assisting with the issues arising from the disease and facilitating adaption. Thorne et al (2004) suggests that ineffective healthcare communication can be distressing and unsettling, whereas an approach that is engaged and empowering encourages successful adaption. Also, supportive, hopeful, realistic and

empathetic communications are effective in assisting the attitudinal and psychological states of the MS patient (Miller & Murphy, 1997; Thorne et al, 2004).

While the MS literature demonstrates the importance and necessity for adequate social support no research has specifically investigated the types of social support which PwMS perceive as helpful and unhelpful from various individuals in the support network. The importance of exploring perceptions of social support has been noted in other areas of health psychology. Prati and Pietrantonio (2010) conducted a meta-analysis exploring perceived and received social support to mental health outcomes for first responders (such as fire-fighters, police officers and emergency workers) dealing with a traumatic event. Findings indicated that perceived social support had a greater effect than actual received social support for mental health. A study conducted by Serovich, Kimberly, Mosack and Lewis (2001) investigated the relationship between perceived and actual social support and mental health for HIV-positive women. Findings indicated that perceived social support rather than actual social support was associated with mental health outcomes (Serovich et al, 2001). Results indicate the importance of exploring the perceptions of patients suffering from chronic illnesses and degenerative diseases. Furthermore, having a thorough understanding of constitutes support from the perspective of patients is critical. Serovich et al (2001) also found that friendships were reported to be more supportive than family relationships but family relationships had a stronger association with mental health outcomes. Serovich et al (2001) suggested that family relationships may be more predictive of mental health due to the emotional importance of these connections. Friendships tend to be pursued and maintained because of the mutual satisfaction and support within the relationship and therefore may be perceived as more

supportive than family relationship which may or may not be supportive. These findings suggest the importance of investigating different relationships within the social support network. It is likely that different types of support are perceived as helpful and important from different sources. Utilising a general social support measure may not provide to complete picture of the experience of social support for the chronically ill.

Some MS researchers have attempted to explore social support in greater detail. Stuifbergen (1992) indicated that PwMS identified their spouses and physicians as the main support providers for managing the physical demands of the disease. Spouses provided emotional and tangible support and physicians provided emotional and informational support. Emotional support from the spouse, family, friends and other PwMS was viewed as helpful when dealing with the experience of MS and exploring the personal meaning of MS (Stuifbergen, 1992). Stuifbergen (1992) provided some insight into the primary sources and types of support for particular illness demands. However, this research does not address what PwMS perceived as the most helpful and unhelpful types of support from each key support provider. Furthermore, the study does not provide an in-depth behavioural description of the social support experiences of PwMS and does not explore the potentially negative or inadequate areas of social support. A detailed behavioural description is important when developing interventions to improve social support, providing a deeper understanding of specifically what is helpful and unhelpful and the unique role of each support network member from the perspective of PwMS.

Wineman (1990) provided a more detailed investigation of social support. Participants were asked to identify 20 important people in their social network and rate these network members with respect to five different types of support including,

socialisation, tangible aid, advice and guidance, social reinforcement and emotional support. An overall score was then obtained for both supportiveness and unsupportiveness. Results suggested that, when PwMS experienced unsupportive acts from support members, they experienced emotional reactions which affected their mood (increasing depression) and also led to a sense of being devalued which impacted their sense of purpose in life (Wineman, 1990). This perceived unsupportiveness also resulted in increased uncertainty which further exacerbated depression and lowered sense of purpose in life (Wineman, 1990). With respect to perceived supportiveness, the greater the perceived supportiveness the greater the person's sense of belonging within the network which then promoted the individual's sense of purpose in life, despite living with this unpredictable chronic disease. Perceived supportiveness from support providers was not found to affect mood (Wineman, 1990).

Wineman (1990) provided evidence for the negative impact of perceived unsupportiveness and the positive impact of perceived supportiveness. However, the study did not indicate what participants specifically identify as supportive and unsupportive from various support providers. In a review of the MS literature, Dennison et al (2009) concluded that the research is lacking in that it does not provide detailed descriptions of the aspects of social support which are important in adjustment. Studies tended to link a general social support score to adjustment outcomes and failed to explore information about different support providers or types of support (Dennison et al, 2009). Some researchers have recommended the importance of addressing the multidimensional aspects of social support in order to advance the understanding of the role of social

relationships in health and disease (Schaefer et al, 1981, Shinn et al, 1984, Wills & Fegan, 2001; Wortman & Conway, 1985; Wortman & Dunkel-Schetter, 1987).

2.1.3 TYPES OF SOCIAL SUPPORT

Research suggests that there are primarily three types of social support. These are: esteem/emotional support, informational support and instrumental/tangible support (Helgeson & Cohen, 1996; Schaefer, Coyne & Lazarus, 1981). Esteem/emotional support consists both the verbal and nonverbal communication of caring, concern, love, empathy and security (Helgeson & Cohen, 1996; House, 1981; Lafreniere & Cramer 2005; Schaefer et al, 1981). It assists with building self esteem, reducing feelings of inadequacy and encouraging the expression of feelings which may decrease distress. Greater attention to, and enhancement of, interpersonal relationships may also occur as a result of esteem/emotional support (Helgeson & Cohen, 1996).

Informational support involves the supply of information such as advice or guidance (Helgeson & Cohen, 1996, House, 1981; Schaefer et al, 1981). This type of support can enhance perceived control by providing strategies to manage an illness and lead to increased optimism regarding the future. Informational support can assist in reducing the sense of confusion associated with being diagnosed with an illness (Helgeson & Cohen, 1996). Those who provide informational support can provide feedback and advice to assist the life circumstances of an individual (House, 1981).

Finally instrumental/tangible support involves giving direct aid such as money or transportation, or providing a service (Helgeson & Cohen, 1996; House, 1981; Schaefer et al, 1981). This support may counterbalance the sense of loss of control experienced by

people with a serious illness by providing tangible resources that can be used to regain control (Helgeson & Cohen, 1996).

2.1.4 SOCIAL SUPPORT AND CANCER

Many parallels can be drawn between MS and cancer. Both PwMS and cancer patients who receive more social support experience less anxiety and depression and better QoL (Parker, Baile, Moor & Cohen, 2003). Again much like PwMS, cancer patients have been found to make better adjustments to their situation when they have adequate social support and also experience poorer adjustment when social support is absent or insufficient (Bloom, 1982; Northhouse, 1988; Peters-Golden, 1982).

However, unlike MS research, cancer research has identified the types and sources of social support which are most beneficial. Findings have indicated that emotional support is the most helpful regardless of the source of this support. Informational support has been found to be helpful from health care professionals but unhelpful from family and friends (Dunkel-Schetter, 1984; Helgeson & Cohen, 1996). Dunkel-Schetter (1984) noted that support from medical care providers was viewed as unhelpful unless it consisted of both emotional and informational support. The most effective type of support from medical professionals involved a combination of information, advice, guidance and emotional support (Dunkel-Schetter, 1984).

Failure to provide emotional support has been found to be the most frequently reported unhelpful behaviour by cancer patients. Avoidance of the patient, minimisation of the problem and forced cheerfulness all prevent the patient with cancer from being able to discuss the illness. Of central importance to emotional support is the availability

of someone with whom the cancer patient can discuss illness related concerns. It has been found that patients often desire to discuss worries and concerns regarding the illness. However, support providers may believe that talking about cancer will be detrimental to the patient and upsetting to themselves (Dunkel-Schetter, 1984; Helgeson & Cohen, 1996). Many patients with cancer have been found to cope with their illness by keeping thoughts and feelings to themselves (Dunkel-Schetter, 1984). Norton, Manne, Rubin, Hernandez, Carlson, Bergman and Rosenblum (2005) found that unsupportive behaviours from family and friends was associated with lower self esteem and greater psychological distress. In particular, lower self esteem and greater psychological distress was experienced by patients when family and friends were experienced as being critical to their response to their illness or seemed uncomfortable or disinterested when discussing the illness (Norton et al, 2005).

Although insufficient emotional support can be harmful to a cancer patient it has also been found that there are limits to the extent to which family and friends can provide certain kinds of emotional support. Reassurance or empathy may be viewed as minimisation of the problem when expressed by family and friends (Helgeson & Cohen, 1996; Wortman & Lehman, 1985). Similar responses may be interpreted as genuine and helpful when expressed by peers facing a similar stressor (Wortman & Lehman, 1985). Thoits (1986) suggests that support such as empathy from peers who are facing a similar stressor is likely to normalise an individual's emotional reactions. Peers may be able to provide knowledge on the situation and recommend coping techniques which are most effective. Support from similar others is likely to reduce distress by correctly and suitably targeting threatening feelings and the characteristics of the situation which cause the most

distress. In contrast, assistance from dissimilar non empathic supporters may increase distress by unsuccessfully attempting to address the most distressing aspects of the situation or feelings (Thoits, 1986).

Dakof and Taylor (1990) conducted a study which took into account not only different categories of helping but also different sources of aid for cancer patients. Findings revealed that overall esteem/emotional support was perceived as the most beneficial and also most likely perceived as unhelpful when absent or misguided. Taking the support provider into account provided a clearer understanding (Dakof & Taylor, 1990). Intimate others were undoubtedly most valued for the emotional support they provided. Informational support and tangible aid were less commonly experienced as helpful in intimate relationships. Other cancer patients and physicians were most valued for the information they provided rather than for emotional support. However in the case of the cancer patients both types of support were perceived as helpful. Misguided or absent informational support was perceived as unhelpful regarding these two types of supporters (Dakof & Taylor, 1990).

Dakof and Taylor (1990) found that minimisation of the impact of cancer was a frequently mentioned complaint regarding the spouse, family and physicians; it was regarded as unhelpful despite the source. Cancer patients were not particularly disturbed by the lack of communication between themselves and their family, friends or other network members. Dakof and Taylor (1990) found that the interpersonal problems created by cancer varied according to the source involved. Different types of social support were valued to varying degrees depending upon the support provider.

The approach adopted by Dakof and Taylor (1990) provides a fine grained and thorough understanding of the helpful and unhelpful aspects of social support from the perspective of people with cancer. This knowledge is vital in informing interventions aimed to enhance support received by individuals suffering from an illness.

Other cancer researchers have also taken more detailed approach to studying social support. Manne, Alfieri, Taylor and Dougherty (1999) found that cancer patients expressed different preferences on the amount and type of social support from their spouses. These preferences were influenced by gender, dispositional and contextual variables. Unsupportive behaviours from partners of cancer patients has been found to predict more avoidant coping, distress and contribute to long term distress reactions (Manne, Ostroff, Winkel, Grana & Fox, 2005). Manne, Ostroff, Sherman, Glassman, Ross, Goldstein and Fox (2003) found that most women with breast cancer rely on their family and close friends for emotional and tangible support. However, these support providers may not meet the emotional and practical needs of the cancer patient or may respond critically. Without appropriate support, cancer patients adopt more avoidant coping strategies and appraise their coping efforts as less effective (Manne & Glassman, 2000). Manne et al (2003) found that support from family and friends can buffer the negative impact of unsupportive behaviour from partners. As the patient has support from others partners unsupportive and insensitive behaviours are less likely result in negative outcomes and coping strategies by the patient.

The MS literature does not provide such a comprehensive and complete understanding of the helpful and unhelpful aspects of support. Given the beneficial

effects of support, this knowledge is necessary in understanding the types of social support that are critical in providing adequate assistance for PwMS.

2.2 SUMMARY

The empirical research clearly indicates the importance of social support for PwMS. With adequate support PwMS are likely to experience lower levels of depression, better adjustment and greater QoL. People with MS are often unsatisfied with the support they receive and have many unmet needs. Given the significance of social support for PwMS it is crucial to have a thorough understanding about the specific aspects of support which are beneficial and detrimental. Social support researchers have proposed the importance of measuring support as a multidimensional construct; however, MS research has provided minimal insight into this area. Two studies were found which attempted to address some of these aspects of social support. Wineman (1990) investigated the positive and negative aspects of support and the consequences of such support for PwMS. This research provided valuable insight into the detrimental effects of negative support and the beneficial impact of positive support. This study did not identify what PwMS specifically experience as helpful and unhelpful from various potential support providers. Stuifbergen (1992) provided knowledge about the primary sources and types of support for particular illness demands of MS. This research did not allow for the analysis of naturally occurring helping behaviours, did not allow participants to express the most helpful and unhelpful types of support from key support providers and did not address the negative aspects of social support. Cancer research has provided several studies which measure social support from a multidimensional perspective. This research has identified

the types and sources of support which are most helpful and most unhelpful. Such detailed information is crucial for developing interventions and training programs which aim to enhance social support. Without this detailed information interventions and training programs to improve support are likely to be deficient.

With respect to the theoretical models of social support, the buffering hypothesis is likely to be most relevant for PwMS. Multiple Sclerosis patients are dealing with a particular stressor and require social support to assist with adjustment, maintaining QoL and wellbeing. The optimal matching theory and the theory of person-environment fit propose that the benefits of social support are dependent on their correspondence with an individual's needs and circumstances. With respect to MS, the optimal matching theory would propose that increased emotional support would be most important in this situation in addition to tangible assistance to provide support for physical limitations and informational support would be less important. Finally, the victimisation model suggests that people with chronic illness have a greater need for support due to uncertainty and fear which can create a greater need for validation and normalisation. The disease is also likely to create conflicting reactions in support network members and may result in inappropriate or inadequate support. These theories suggest the importance of exploring the needs of PwMS in terms of the types and sources of support which are deemed as most useful and also most unhelpful or inadequate. Having this information will provide insight into the circumstances of PwMS and the type of support which is most likely to be most beneficial and provide optimal buffering effects against the negative impact of having a chronic illness.

CHAPTER 3

ADJUSTMENT TO MULTIPLE SCLEROSIS

“There is nothing that the body suffers the soul may not profit by.”
Diana of the Crossways (1885)
George Meredith (1828-1909).

3.1 ADJUSTMENT

The initial section of this chapter will discuss a variety of factors which are associated with adjustment. The second section of this chapter will be focused on providing an overview of models of adjustment to chronic illness including qualitative research findings. Finally, the chapter will focus on the Fennell Four Phase Model (Fennell, 1993; Fennell, 1995; Fennell, 2003a) of adjustment which is argued to be a highly comprehensive and useful approach to understanding the adjustment process.

Adjusting and accommodating to MS has been found to be extremely challenging due to the unpredictable nature and the array of potentially disabling symptoms. Adjustment has been described as the process by which an individual continues to grow and develop despite having MS (Marks & Millard, 1990). People with MS have been found to have significantly poorer levels of adjustment and self-esteem in comparison to the general population (McCabe & Di Battista, 2004). Research has indicated that most PwMS successfully adapt to the disease. However, those who do not succeed tend to experience suicidal feelings, disruptions in interpersonal relationships, less positive affect and lower self-esteem (Eklund & MacDonald, 1991).

Research findings have identified commonalities among PwMS in how they react and adjust to being diagnosed. Initial negative reactions include denial, reduced confidence, repression, a sense of isolation, vulnerability and confusion (Irvine, Davidson, Hoy & Lowe-Strong, 2009; Kralik, Brown & Koch, 2000). Individuals have been found to suffer psychological distress by experiencing anxiety, depression and anger (Westbrook & Viney, 1982). This initial period tends to be associated with a time of crisis (Irvine et al, 2009; Westbrook & Viney, 1982). An identity crisis may also be

experienced as individuals realise similarities between themselves and the chronically ill (Irvine et al, 2009). This crisis is resolved as beliefs and values are adjusted. During the initial five years of being diagnosed with the disease, individuals are also likely to experience significantly higher body image anxiety with anxiety regarding the body's weakness and awareness of the uncontrollable nature of the disease (Halligan & Reznikoff, 1985).

Over time, PwMS report positive changes associated with the disease including an increased appreciation for life. Satisfaction with life can be gained by maintaining valued roles (such as mother, helper), finding new realistic interests and maintaining mutual relationships (Reynolds & Prior, 2003). People with MS have been found to adapt their pre-illness skills and interests to their current level of functioning (Reynolds & Prior, 2003). The integration of the pre- and post-illness self can improve QoL. Positive growth and life satisfaction are the result of clarification of priorities, finding new meaningful occupations, making contributions to others and retaining valued goals (Reynolds & Prior, 2003).

3.2 FACTORS ASSOCIATED WITH ADJUSTMENT

Various factors have been associated with positive adjustment to MS. Although some research findings differ, there are certain factors which are found to be consistently associated with adjustment, these are discussed below.

3.2.1 STRESS AND COPING

Strong links have been found between levels of perceived stress associated with MS and adjustment (Dennison et al, 2009). Pakenham (1999) examined a model of stress, stress appraisal and coping in MS. Results indicated that better adjustment was associated with less disability, greater use of problem focused coping and less use of emotion focused coping. Specifically, it was found that individuals who appraised high levels of stress and used emotion focused coping suffered higher levels of distress and therefore poorer adjustment.

The use of particular coping styles is frequently associated with levels of adjustment (Marks & Millard, 1990). Problem focused coping is associated with better adjustment and wishful thinking coping has been associated with poorer adjustment (Marks & Millard, 1990). McCartney Chalk (2007) found that greater psychosocial adjustment was associated with the use of problem solving or acceptance coping, greater use of challenge appraisals and less use of harm or threat appraisals. Generally, the positive outcomes of problem focused coping, positive reappraisal and acceptance coping include higher QoL, lower levels of depression and improved adjustment. Emotion focused coping and escape avoidance coping leads to negative outcomes including poorer adjustment, greater depression and lower QoL (Arnett et al, 2008; Arnett et al, 2002; Dennison et al, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007; Montel & Bungener, 2006; Siegert & Abernethy, 2004).

People with MS who take a passive and defeatist stance towards the disease have been found to have low levels of adjustment (Matson & Brooks, 1977). Pakenham (2006) found that positive outcomes for PwMS were associated with coping strategies that

involved emotional release, personal health control and physical assistance, and were associated with benefit finding. Negative outcomes of distress were associated with coping strategies which involved avoidance and were also associated with greater depression and anxiety. Accepting MS by actively integrating the illness into one's life has been found to be the greatest predictor of positive outcomes. People with MS who have lower levels of acceptance tend to suffer greater distress (Pakenham, 2006).

Pakenham (2006) found evidence indicating the benefits of accepting and integrating MS into one's life and the negative impact of resisting change and adaptation or avoiding the situation.

3.2.2 CONTROL AND SELF-EFFICACY

Illness representations also play a significant role in psychological adjustment. Individuals who attribute an extensive range of symptoms to MS, have negative beliefs about the consequences of MS, have a limited sense of control over the illness and limited understanding about the illness have been found to have lower levels of psychological adjustment (Jopson & Moss-Morris, 2003). A patient's initial belief in symptom variability also negatively impacts future adjustment (Schiaffino, Shawaryn & Blum, 1998). Focus on the unpredictable nature of MS can heighten future depression and hinder adjustment (Schiaffino et al, 1998).

People with MS attempt to gain control over their condition by changing certain aspects of their lifestyle and environments in order to facilitate functioning. Over time the uncertainty experienced by PwMS is reduced as they become familiar with relapses and learn to accept the fluctuating nature of symptoms (Miller & Murphy, 1997). Individuals

who have an internal locus of control and believe they have the capacity to influence the course of the disease demonstrate self concepts that improve over time and are more likely to view themselves as more fortunate than others (Brooks & Matson, 1982). Having an internal locus of control has also been related to lower levels of depression among PwMS (Halligan & Reznikoff, 1985).

Self-efficacy is related to an individual's evaluation of his or her ability and capacity to manage potential future situations (Bandura, 1977). Self-efficacy can assist in adjusting to challenging circumstances. In a review of the MS literature Dennison et al (2009) found that self efficacy for health and MS management was associated with improved adjustment. Barnwell and Kavanagh (1997) found that self-efficacy for PwMS predicted positive coping efforts and was useful for controlling negative thoughts and maintaining social activity (Barnwell & Kavanagh, 1997).

3.2.3 SENSE MAKING AND BENEFIT FINDING

The way in which PwMS make sense of their experiences and their perceptions of the illness can significantly impact psychosocial adjustment. Pakenham (2007a) found that sense making of MS which involved a realistic sense of controllability and predictability or which maintained self-worth was associated with greater adjustment. In contrast, sense making which involved perceiving the illness as completely random and uncontrollable or that did not maintain self-worth was associated with poorer adjustment (Pakenham, 2007a).

In another study exploring sense making Pakenham (2008) found that PwMS were able to recreate meaning through various sense making explanations. Three sense

making themes were found to be frequently reported including; causal attributions, acceptance and experienced growth. With respect to causal attributions, participants were found to have developed their own explanations as to why they had developed MS. The acceptance explanation involved recognition that the disease is part of life and integration of the illness into their lives. The experienced growth explanation was characterised by acknowledgment of the potential benefits of MS; in particular MS was viewed as a means for personal growth and positive change. A greater degree of sense making was found to be associated with positive adjustment and related to greater life satisfaction, positive mental states, and lower depression (Pakenham, 2008). Many PwMS are often able to report personal growth as a result of the disease (Pakenham, 2007b). Mohr, Dick, Russo, Likosky & Goodkin (1999) found that one of the most frequently reported psychosocial consequences of MS was benefit finding. Benefit finding for PwMS can involve a deepening of relationships with others, greater appreciation for life and enhanced spirituality (Mohr et al, 1999).

The perception that MS has resulted in the opportunity for growth and positive change or integration of MS have been found to be the strongest predictor of adjustment (Pakenham, 2007a). Benefit finding can counterbalance the negative effects of the disease such as uncertainty and depression (Irvine et al, 2009). Pakenham (2005) reported that benefit finding was directly associated with adjustment but was not associated with levels of distress. Pakenham (2005) suggests that benefit finding for PwMS influences the stressors related to the chronic illness and results in continued positive engagement in life which does not decrease in the presence of distress. Therefore, both levels of benefit

finding and distress may remain high but the positive impact of benefit finding will continue to facilitate adjustment.

3.2.4 DEMOGRAPHIC AND DISEASE RELATED VARIABLES

Brooks and Matson (1982) found that demographic factors and disease related variables can influence adjustment to MS when adjustment is measured by levels of positive self concept. Females were found to be more likely than males to have improved self concepts over time. Furthermore, higher family income, employment and greater degree of independence within the home were also related to better adjustment (Brooks & Matson, 1982). Disease related variables have also been associated with adjustment (Brooks & Matson, 1982). Brooks and Matson (1982) found that when individuals experienced more relapses of symptoms their self-concepts (adjustment) were negatively impacted. Pakenham (1999) also found that lower levels of disability were associated with better adjustment. Other studies have not found the association between adjustment and demographic or disease related variables (Maybury & Brewin, 1984; McCartney Chalk, 2007).

3.2.5 SOCIAL SUPPORT

The positive impact of social support for PwMS has been addressed in the previous chapter; however, it is crucial to note the importance of social support in facilitating adjustment. Relationships with others are highly important to adjusting to the condition and coping with the uncertainty (Irvine et al, 2009). The perception of high levels of social support has consistently been associated with better adjustment for PwMS

(Dennison et al, 2009). Relying on the support network as a coping mechanism can improve adjustment, mediate the effects of emotional distress and increase wellbeing (Crigger, 1996; Gordon et al, 2002; Gulick, 2001; Miller & Murphy, 1997; Stuifbergen et al, 2000).

3.2.6 SECTION SUMMARY

Various factors have been associated with adjustment. In particular problem focused coping, positive reappraisal and acceptance coping have been linked with greater adjustment (Arnett et al, 2008; Arnett et al, 2002; Dennison et al, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007; Montel & Bungener, 2006; Siegert & Abernethy, 2004). Cognitive appraisals which perceive MS as less threatening and more challenging have also been related to better adjustment (McCartney Chalk, 2007).

Individuals with a greater sense of control and self efficacy are likely to have better adjustment (Dennison et al, 2009; Jopson & Moss-Morris, 2003). Higher levels of sense making and benefit finding assist with positive outcomes (Pakenham, 2005; Pakenham, 2008). Finally, perceived social support has also been found to play an important role in living with this chronic illness (Dennison et al, 2009). It is important to consider these factors when attempting to understand the process of adjustment to MS. These factors may highlight barriers which are hindering adjustment to the disease. These factors may also highlight individuals who require assistance as they are at a greater risk of poorer adjustment.

3.3 MODELS OF ADJUSTMENT TO CHRONIC ILLNESS

The following section of this chapter will review qualitative research regarding the process of adjustment to MS. This section will also present various models of adjustment to chronic illness including the Fennell Four Phase Model of adjustment (Fennell, 1993; Fennell, 1995, Fennell, 2003a). The FFPM is unique as it addresses multiple domains of adjustment, provides assessment and treatment guidelines and has established empirical support for another chronic illness, Chronic Fatigue Syndrome (CFS). Many models of adjustment to chronic illness have been proposed in the literature, although most models have limited empirical research. Stage models have been suggested in the chronic illness literature and tend to differ in the number of stages which they propose to occur in the adjustment process. Stage models have been criticised for being time limited and implying that an end point is reached despite adjustment to chronic illness being a recurrent and ongoing process (Kendall & Buys, 1998). However, many stage models of chronic illness acknowledge the cyclical and ongoing nature of adjustment and do not suggest that an end point is reached once initial adjustment is achieved. Typically models have an overall common process where an individual experiences initial shock and denial, followed by distress and finally reaches a level of acceptance.

3.3.1 QUALITATIVE RESEARCH

Qualitative research findings have attempted to map the adjustment process for chronic illness and MS. The majority of findings consistently report on the initial shock, trauma, uncertainty and fear experienced by patients. As the patients learn to live with the

condition they find new hope, life purpose and personal meaning of their experiences and begin to integrate the disease into their lives. Patients are also able to move towards integration by accommodating for physical limitations and readjusting life goals and directions.

Based on findings from qualitative interviews with individuals suffering from a chronic illness Salick and Auerbach (2006) developed a stage model of trauma and recovery. The researchers explored the psychological process by which individuals with chronic illness who are visibly disabled progress from the initial trauma towards recovery. Salick and Auerbach (2006) suggest that individuals move from a sense of devastation to integration via five stages.

The first stage was identified as ‘apprehension’ when initial symptoms of the illness are experienced leading to a sense of uncertainty about physical changes and confusion about the trauma of having a chronic illness (Salick & Auerbach, 2006). The second stage was identified as ‘diagnosis and devastation’ during which a diagnosis is clarified, the psychological impact of the diagnosis is encountered, and a sense of loss of the physical self is experienced along with social withdrawal, psychic pain and hopelessness (Salick & Auerbach, 2006). The third stage was identified as ‘choosing to go on’ when individuals make a decision to move forward with their lives by finding an inner strength, reclaiming their lives, developing a plan and accommodating for functional limitations (Salick & Auerbach, 2006). The fourth stage was named ‘building a way to life’ which involves reclaiming the physical body, enhancing social support, finding personal meaning around experiences, developing hope and using humour to cope. Finally, the fifth stage was identified as ‘integration of the trauma and expansion of

the self” and involves making a new commitment to move forward with life, contributing to the social world, developing self compassion, increasing meaning and life purpose (Salick & Auerbach, 2006).

The stages presented by Salick and Auerbach (2006) provide some understanding of the experiences of the chronically ill. Caution needs to be taken when generalising these results to PwMS. The focus of this study was on adjustment to physical impairments associated with chronic illness or a traumatic injury. Only three participants suffered from MS and the other participants had below-knee amputations, visual impairment and spinal cord injuries. The experiences of PwMS can often differ from the experiences of individuals suffering from a disability associated with a traumatic event (Antonak & Livneh, 1995).

Through a qualitative study of the experiences of women living with chronic illness Kralik (2002) identified two common themes; extraordinariness and ordinariness. The study proposes that when coping with a chronic illness individual’s experience an ‘extraordinary’ phase of chaos and distress. A shift then occurs towards an ‘ordinary’ phase which involves integrating the chronic illness into their lives. ‘Extraordinariness’ was characterised by a period of chaos and distress when initially confronted with the chronic illness. Participants reported a sense of being separated from their post-illness lives and experienced a sense of limited control. During this period patients encountered grief for the loss of their pre-illness self and decreased self worth due to internalised social expectations (Kralik, 2002). ‘Ordinariness’ was characterised by change and transformation as participants engaged in a search for empowerment and clarification. During this period participants accepted and viewed the illness experience as an

opportunity to learn and grow. They worked on accommodating the illness into their lives and achieved this by making appropriate choices and taking suitable risks. Individuals reconstructed their identities and integrated chronic illness into their lives. Kralik (2002) proposed that living with a chronic illness involves movement from 'extraordinariness' to 'ordinariness', this movement can be cyclical and reoccurring. The themes identified in the study acknowledge some of the primary difficulties faced by individuals with a chronic illness and capture the cyclical nature of adjustment.

Koopman and Schweitzer (1999) explored the journey of the lived experience of PwMS. Participants reflected on their lifetime experiences from diagnosis to adjustment. During the early stages of MS, participants reported having initial symptoms which tended to be dismissed. As symptoms persisted; individuals experienced increased concern and sought medical tests and opinions (Koopman & Schweitzer, 1999). This period was characterised by worrying, prolonged waiting and great uncertainty. When diagnosed with MS, many reported experiencing traumatic reactions, feeling shocked and numb. Following the diagnosis, patients were required to consider treatment options and also begin learning how to live with MS. With time MS was integrated into their current and future lives by including the diagnosis of MS and refocusing plans and hopes for the future (Koopman & Schweitzer, 1999).

In another study by Selder and Breunig (1991) the experiences and transitions of people living with MS were explored. It was found that PwMS would seek medical assistance when symptoms were impacting their ability to complete daily activities. Relief was often initially experienced when diagnosed with MS as alternative and potentially life threatening diagnoses were ruled out. Participants reported experiencing a

significant sense of uncertainty and fear (Selder & Breunig, 1991). Despite this uncertainty participants reported attempting to control the disease by pacing themselves, containing the impact of the MS, making adjustments to facilitate mobility and normalise their experiences. Participants expressed that the experience of having MS helped them become emotionally stronger and be better able to cope with other difficulties in life. The process of making meaning involved learning to live to their fullest potential and accepting the restrictions imposed by their condition (Selder & Breunig, 1991).

In summary, qualitative research has provided insight into the struggles and changes experienced by PwMS when adjusting to this disease. The findings indicate a similar pattern of adjustment across qualitative studies. These findings can provide useful guidance for theoretical models of chronic illness adjustment.

3.3.2 THE MODEL OF ADAPTATION

The Model of Adaptation to chronic illness was developed by Crate (1965) and is a stage model with a similar pattern to the grief process. The model proposes that during the initial stage of ‘disbelief’ the person first becomes aware that they have a particular chronic condition and experience this as a threat to the self. Denial is used as a means to protect against the threat (Crate, 1965). When denial is unable to be maintained due to increased awareness the patient moves into the second stage which involves ‘development of awareness’ of the illness. During this stage the person experiences anger which may be openly expressed or projected onto others. With time the person becomes better able to cope with information regarding the illness and its implications and begin to take some responsibility for his or her illness related behaviour (Crate, 1965). During the

‘reorganisation of relationships’ stage the person begins to restructure relationships with family and friends so that they too can adjust to the chronic illness. It is during this time that the person requires understanding and sympathy from others. During the ‘resolution of the loss’ stage the individual resolves the loss but experiences a sense of not being a whole person. With time the individual begins to perceive themselves as a person worthy of respect and identifies with others who suffer similar problems. Finally, the person experiences an ‘identity change’ during which there is acknowledgement of the loss and the person behaves in ways to protect themselves from unsafe or damaging positions.

Crate (1965) suggests that with a progressive disease an individual may experience reactivation of grief with each new loss and implies the recurrent nature of adjustment. This theoretical approach does not provide information on how the reactivated grief process will be experienced. The model suggests that with each new loss the entire reactivation of grief is likely to occur and does not acknowledge the possibility that an individual may have developed the skills necessary to more efficiently deal with losses and possibly progress through the stages more promptly than the initial adaptation process.

Lawerence and Lawerence (1979) proposed a similar model to Crate (1965) but suggested that rather than five stages, adjustment consists of only three stages. The initial stage proposed by Lawerence and Lawerence (1979) of ‘shock and disbelief’ consists of denial, failure to accept reality and independent behaviour. The second stage of ‘developing awareness’ involves anger and dependent behaviour. The third stage of ‘resolution of the loss’ consists of an identity and role transition and both dependent and independent behaviour. The model proposes that adaptation will involve achievement of

self dependency which is an ongoing process during which the individual realises his or her greatest potential for wellbeing. The model suggests that there is a beginning to each stage but no end as each stage contributes certain aspects which are essential to adaptation. For example, if the denial stage were to completely end that this would also result in the end of any hope. Adaptation is suggested to be a continual identity change with reoccurring changes in lifestyle to accommodate for disease progression (Lawerence & Lawerence, 1979).

3.3.3 THE RECURRENT MODEL OF PSYCHOSOCIAL ADJUSTMENT

Kendall and Buys (1998) have proposed a recurrent model of adjustment which conceptualises adaptation to chronic illness as a slow process involving learning to tolerate extremely difficult circumstances. The model suggests that when individuals are confronted with a chronic illness the applicability of existing schemas to understand the world is challenged. Individuals tend to continue with these schemas even though they are no longer useful for interpreting the environment. This persistence may present itself as denial or having a distorted reality and can lead to depression (Kendall & Buys, 1998). As additional information about these new circumstances is collected and integrated, new schemas are developed which allow for a more realistic perspective. Kendall and Buys (1998) propose that the process of new schemas is ongoing as they are developed gradually and will be revised, modified or restructure as various aspects of the environment are experienced.

3.3.4 A THEORY OF COGNITIVE ADAPTATION

Taylor (1983) proposed a model of cognitive adaptation to threatening events. Within this model the adjustment process is proposed to be based on three themes. The first theme involves a search for meaning, which is an attempt to comprehend why the event occurred. Meaning can be found via causal explanations for the experience and reorganising life meaning around the experience. The second theme involves an effort to reclaim a sense of mastery which consists of regaining control and can occur through attempting to manage an illness. Finally, the third theme involves an attempt to increase one's self esteem which can occur through social comparisons with others who are less fortunate. Based on this theory Taylor (1983) postulates that when an individual experiences personal difficulties in life such as a chronic illness they react by adapting cognitively in order to regain a satisfactory level of psychological functioning.

3.3.5 THE SHIFTING PERSPECTIVES MODEL OF CHRONIC ILLNESS

Paterson (2001) proposed a model of adjustment to chronic illness based on a meta-synthesis of 292 qualitative research studies. The model developed is the 'shifting perspectives model' which proposes an ongoing shifting process in which people experience changing perspectives through which they make sense of their illness. Within this model the perspectives of 'illness in the foreground' and 'wellness in the foreground' shift due to changes in personal or social environments (Paterson, 2001).

During the 'illness in the foreground' the individual is focused on sickness and is overwhelmed by loss and suffering. Patients experience difficulty focusing on other areas of their lives and are consumed by the illness experience. This perspective can be

beneficial as it encourages the newly diagnosed to focus and learn about the illness and discover how to live with their condition (Paterson, 2001). During 'wellness in the foreground' the individual views chronic illness as an opportunity for growth and change in which harmony is sought between the self identity and the identity that is created by the illness. This distancing from the illness provides opportunities for the individual to focus on other aspects of life (Paterson, 2001). Paterson (2001) suggests that the shift from 'wellness' to 'illness' can be triggered by a threat to one's sense of control such as disease progression, disease related stigma and interactions with others that result in a sense of powerlessness or helplessness. The shift from 'illness' to 'wellness' occurs when an individual has successfully resolved or adjusted to the changed situation.

3.3.6 THE ADJUSTMENT PROCESS OF MULTIPLE SCLEROSIS

Matson and Brooks (1977) proposed a model of adjustment to MS consisting of four temporally ordered phases. The model is based on Kübler-Ross's (1969) model of reactions to death and dying and data from surveys and interviews of PwMS. The first stage of the model is 'denial' which is the stage that the newly diagnosed patient is likely to enter. During 'denial' individuals are unwilling to accept the diagnosis and will search for an authority to deny it. Patients are likely to attempt to continue their previous behaviours and not accept assistance from others. The second stage is 'resistance'; with time an individual comes to minimally accept the diagnosis but they seek information regarding the disease and a cure. During 'resistance' the patient is interested in meeting other PwMS only as a means of gaining information and increased control over the disease. The third stage is 'affirmation', which is a time of self confrontation. The patient

comes to the realisation that life's priorities must be rearranged and they must learn to accept help from others. There may be grieving for the individual's pre-illness life but also the development of a new sense of self and the creation of new meaning of MS. The final phase is 'integration' which must be re-established with each exacerbation, as worsening of symptoms as they are reminders of vulnerability. During this stage individuals deal with MS related problems with little emotion and are able to engage in benefit finding and have a deepening sensitivity to life experiences (Matson & Brooks, 1977).

Within this model it is proposed that patients may not follow these stages sequentially, may not progress through all stages, may remain in one stage indefinitely and may regress into earlier stages when relapses occur. Matson and Brooks (1977) indicate that the general process of adjustment is accomplished by the majority of individuals (Brooks & Matson, 1982). Most of the adjustment process was found to take place in the initial 10 years of having the disease (Matson & Brooks, 1977). After modifications of self image occurred in the initial stages, the person is able to establish a stable life pattern and a generally positive self-concept (Brooks & Matson, 1982; Matson & Brooks, 1977).

Walsh and Walsh (1987) explored self esteem levels according to the stages proposed by Matson and Brooks (1977). Results indicated support for Matson and Brooks model of adaptation as the individuals with the lowest levels of self esteem were also found to be in the 'denial' stage of adaptation and have the greatest physical restrictions. Individuals with the highest levels of self esteem were found to be in the 'integration' stage of adaptation and have the least physical restrictions (Walsh & Walsh, 1987).

The model proposed by Matson and Brooks (1977) provides valuable information about the process of adjustment to MS. Unfortunately the researchers measured adjustment as the uni-dimensional variable of self-concept and did not provide empirical evidence to test their model. The model also only addresses the psychological aspects of adjustment and does not attend to physical, social and environmental aspects of adjustment.

3.3.7 THE FENNEL FOUR PHASE MODEL

The Fennell Four Phase Model (FFPM) is system for assessing and treating the chronically ill (Fennell, 1993; Fennell, 1995; Fennell, 2003a). The model provides a thorough and flexible systems approach to understanding adjustment to chronic illness. The approach proposes that an individual's body and mind, family members, friends, clinicians, work colleagues and general community are fundamental providers to a total situation in which changes that take place in one part of the system impact all other areas (Fennell, 2003a). The model is comprised of four broad phases experienced by the chronically ill including, Crisis, Stabilisation, Resolution, and Integration (Fennell, 2003a). It suggests that when dealing with a chronic illness individuals go through various phases as they learn to cope with the illness experience (Jason, Fennell, Klein, Fricano & Halpert, 1999). Within each phase the model identifies characteristic events and responses that occur within the physical and psychological self as well as the wider social environment. The model also identifies procedures for assessing and treating individuals in each of the phase (Fennell, 2003a).

The FFPM views chronic illness as a cyclical experience (Fennell, 2003a, Fennell, 2003b; Jason et al, 1999). Patients may have successfully attained the psychological and social integration goals of the final phase, Phase four; however, it is possible that relapse of symptoms or negative life experiences may result in a return to an earlier phase (Fennell, 2003a, Fennell, 2003b). These regressions tend to be partial and of a shorter duration than the original progression as patients are more equipped to cope with the phases (Fennell, 2003a, Fennell, 2003b). Fennell (2003a) contends that while patients must initially progress through the phases in a fixed sequence, it is likely, that given the relapsing and remitting nature of chronic illness, to regress back to an earlier phase and also to be in more than one phase at any given time. Phase four, is not viewed as a cure or end to the patient's struggles with chronic illness as individuals do not leave the phases, the process of sustaining or regaining integration is continuous and does not reach a conclusion (Fennell, 2003a).

The FFPM is related to previous stage theories such as the Transtheoretical model (Prochaska & DiClemente, 1983). The distinguishing factor between these frameworks is that stage theories focus on intentional changes in the psychological spheres only. The FFPM maps a process that essentially individuals do not enter into willingly and stresses the importance of problems associated with stigma and illness traumatisation, the physical/behavioural and social/interactive domains, and the socio-cultural influences at each phase (Fennell, 2003a, Fennell, 2003b; Jason et al, 1999). In a similar fashion to the Transtheoretical model (TTM), the FFPM structure allows clinicians to identify those times and places when it is possible to make meaningful interventions that can assist patients to escape from an endless loop of successive crises (Prochaska, DiClemente &

Norcross, 1992). Phase theories may present a particularly strong base for comprehending the mediators of change and the longitudinal processes that characterise people's attempts to cope with the external and internal demands and challenges presented by chronic illness (Jason et al, 1999; Fennell, 2003a; Weinstein, Rothman & Sutton, 1998). The FFPM provides information regarding the optimal timing and types of interventions to assist with enhancing QoL (Fennell, 2003a; Fennell, 2003b; Fennell & Bateman 2005,). The model provides a map which can assist individuals to locate their illness experience and also become aware of the unknown aspects of chronic illness (Jason et al, 1999). It is also important to note that patients may experience these phases in different ways which can lead to responses on standardised measures varying depending on phase status. Jason, Fennell, Taylor, Fricano & Halpert (2000) suggests that if responses from groups of patients who are in different phases are collapsed together findings may be misleading as patients are essentially going through different processes (Jason, Fennell, Taylor, Fricano & Halpert, 2000).

3.3.7.1 THE FENNEL FOUR PHASE MODEL AND OTHER MODELS OF ADJUSTMENT

Other proposed models of adjustment are limited in their scope, completeness and utility in comparison the FFPM. The other models which have been presented in this chapter focus primarily on only one or two domains such as psychological or cognitive adaptation. The research clearly indicates that MS impacts so many other domains of an individual's life. Given the importance of the support network and the social and cultural environment for individuals who are coping with a chronic illness, it is valuable for a model of adjustment to consider these areas. The FFPM not only addresses the

psychological areas of adjustment but also considers the physical-behavioural and social-interactive domains as well as the trauma and stigmatisation associated with chronic illness (Fennell, 2003a). The FFPM provides the most comprehensive approach to understanding adjustment to chronic illness and is superior to other models of adjustment.

The FFPM provides phase-specific assessment methods and interventions to assist the patient and the social network to cope with the particular issues within each phase. The model also incorporates these assessment and treatment methods into a wide collection of spiritual and philosophical traditions (Fennell, 2003a). The other adjustment models presented have not provided such a comprehensive guide to assessment and treatment and have supporting empirical evidence. Researchers have proposed these models and no further investigations have taken place whereas the FFPM has been empirically verified for CFS.

The FFPM has similarities to the other models of adjustment such as the model proposed by Matson and Brooks (1977). Both models propose that patients experience four phases and acknowledge the cyclical and reoccurring nature of adjustment. The phases proposed by each of the models are similar. However, the FFPM addresses multiple domains of adjustment whereas Matson and Brooks (1977) only consider psychological aspects of adjustment and have no empirical verification of their model. The following section will provide a review of each of the phases of the FFPM and empirical evidence for the FFPM.

3.3.7.2 CRISIS PHASE

During the Crisis phase the patient moves from the onset of the illness to an emergency period when they are acutely aware that something is wrong (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999). During Crisis denial may be used as a coping mechanism. However, if symptoms continue to increase individuals are unable to maintain denial which leads to a sense of fear, hopelessness and confusion (Fennell, 1995; Fennell, 2003b). Patients present with an intense sense of urgency and maintain an external locus of control for treatment and a cure; they have little capacity to accept the uncertainty of their condition (Fennell, 2003b). Within the social environment some friends, family members and acquaintances may believe the individual to be fabricating or exaggerating symptoms or have psychological issues (Fennell, 1995; Fennell, 2003a). This social environment can lead the individual to become guarded and socially withdrawn in order to avoid rejection or negative evaluation (Fennell, 1995; Fennell, 2003b; Jason et al, 1999).

Fennell (2003b) identifies three critical issues which occur in Phase 1 including, (a) The individual can be traumatised by the physical, psychological and social impact of the acute emergency state, (b) support network members can be vicariously traumatised, and (c) significant others begin to range from being suspicious to supportive in response to the individual. The goal during this phase is to manage the crisis, deal with the urgency experienced and reduce potential trauma from the illness experience. Interventions during this period focus on establishing rapport with the patient, validating the patient's illness and struggles and teaching the patient to focus on the immediate situation (Fennell, 2003c).

3.3.7.3 STABILISATION PHASE

Phase 2 is characterised by stabilisation, in which the patient begins to recognise and understand his or her symptoms (Fennell, 1993; Fennell, 1995; Fennell, 2003a; Jason et al, 1999). Patients continue to experience confusion about the illness, however, often their symptoms have stabilised and they have regained some sense of control over their lives (Fennell, 2003a). Confusion and a sense of hopelessness can increase as individuals seek advice from various medical professionals and encounter conflicting opinions (Fennell, 2003b).

It is possible that without appropriate guidance provided by an informed clinician patients may find themselves either continuously in crisis or stuck cycling between the first two phases (Fennell, 2003a). Each stabilisation may be perceived by the patient and the support network as an indication of a cure and they may attempt to return to their previous life; however, patients then experience another relapse which triggers a new crisis (Fennell & Bateman, 2005). The difficulty within this phase is the accommodation of the condition into daily living by learning to balance daily activities and develop a sustainable level of activity (Fennell, 2003a; Fennell & Bateman, 2005). Patients may reject their limitations and be confused about physical boundaries. They are unable to perform as they previously did but due to familial, community and personal pressures, they attempt to maintain their pre-illness roles and responsibilities (Fennell, 1995; Fennell, 2003b; Jason et al, 1999). Many individuals fail and experience intensified feelings of guilt and shame (Fennell, 1995). With assistance patients can come to understand the link between their activities and their symptoms (Fennell, 2003b). Within the social environment, patients may experience increased conflict as support network

members have reduced tolerance levels. The person may begin to seek support from others also experiencing similar difficulties (Fennell, 1995; Fennell, 2003b). The task during Phase 2 is to instigate stabilisation and the reorganisation of life patterns and views (Fennell, 2003a). Interventions during this period should focus on assisting the patient to collect information about their experiences, distinguish among their experiences, develop insight and create new standards and goals within their lives (Fennell, 2003c).

3.3.7.4 RESOLUTION PHASE

Phase 3 is known as Resolution, during which the patient recognises that his or her old life will not return and wrestles with life defining existential questions. Some patients may continue to have a plateau of symptoms whereas others may experience a relapse of symptoms (Fennell, 1995). Patients have learned how the illness behaves and how the world responds and have a profound realisation that their illness is chronic (Fennell, 2003a). During the early periods of this phase the patient may also suffer deep despair and grieve the loss of their pre-illness life (Fennell, 1995; Fennell & Bateman, 2005). Fennell (2003b) describes that patients may endure a secondary emotional crisis or grief reaction. Patients may seem more distressed in this phase than in Phase 2 as they have now comprehended the chronic nature of their condition and understand that their lives have changed (Fennell, 2003b; Fennell & Bateman, 2005; Jason et al, 1999). Within the social environment an individual may experience greater losses than in the earlier phases as significant others and clinicians withdraw and depart. New friendships are developed and support is sought from similar others (Fennell, 1995; Fennell, 2003b).

The task during this phase is to develop meaning in life and generate a new sense of self as patients move towards accepting the chronic and uncertain nature of their illness (Fennell, 2003a). Fennell (2003b) proposes that meaning is developed through three transformational processes; (a) the acceptance rather than rejection of suffering and the suffering self, (b) an approach to the suffering self which is compassionate, and (c) developing respect for one's own suffering and ability to endure distress. Interventions during this phase should focus on assisting the development of meaning, supporting and facilitating the grieving process, assisting with maintaining insight and reframing experiences (Fennell, 2003c).

3.3.7.5 INTEGRATION PHASE

Phase 4 is known as Integration, in which the patient has incorporated aspects of his or her pre-illness and post-illness self and find new ways to express a new “personal best” (Fennell, 2003a). During Integration individuals review their values and develop new norms for living (Fennell, 1995). The patient understands the cyclical nature of the condition and a relapse is viewed as the commencement of another cycle which must be integrated (Fennell, 2003b). Within this phase individuals have surpassed the trauma of phase one, have developed the stabilisation of phase two and the meaning of phase three (Fennell, 2003a).

Due to greater self confidence the individual may also attempt to reintegrate old support network members who have become distant (Fennell, 2003b) The task during this phase is to continue working towards new goals, to rejoin or develop new social networks, find other vocations, activities or suitable employment and to consider the

illness experience within a philosophical and spiritual context. The process during this phase is essentially to develop a meaningful life which incorporates but is not defined by the chronic illness (Fennell & Bateman, 2005).

3.3.7.6 EMPIRICAL EVIDENCE FOR THE FENNEL FOUR PHASE MODEL

The Fennell Phase Inventory (FPI) was developed to classify patients into phases (Fennell, Jason & Klein, 1998). It consists of four groups of five items, with each group representing characteristics of a phase. Several studies in the area of Chronic Fatigue Syndrome (CFS) have sought to empirically investigate the FPI and the FFPM. The initial investigation into the FPI explored the factor structure of the inventory (Jason et al, 1999). Four hundred participants with CFS were included in the study and divided into two randomly assigned groups.

Results indicated comparable factor solutions between the two groups with both signifying a three factor solution including a Crisis, Stabilisation and an Integration phase. The factors identified were deemed to theoretically capture the FFPM (Jason et al, 1999). The Crisis items were found to load together, as did the Integration items and as suggested by Fennell (2003a) this indicates support for the convergent and discriminant validity of these two phases. The Stabilisation and Resolution items were found to load together which indicated support for the convergent validity but not their discriminant validity (Fennell, 2003a). Jason et al (1999) provided further evidence for the construct validity of the FPI by investigating characteristic differences between members of each of the phases. Participants with a high Crisis score were also found to have higher levels of disability, higher fatigue severity, lower education level and higher levels of illness

severity. Results suggest that phase 1 is associated with greater illness severity and disability (Jason et al, 1999). Participants with higher Integration scores were found to have a higher education levels, lower levels of disability and higher occupational status. Finally, the Stabilisation factor was associated with shorter illness duration (Jason et al, 1999).

An additional study was then performed by Jason, Fennell et al (2000) using the data from Jason et al (1999). A cluster analysis was performed on the regression factors scores from Jason et al (1999) and a four cluster solution emerged which was consistent with all four phases; Crisis, Stabilisation, Resolution and Integration. The researchers then examined differences between individuals in each of the four clusters. Cluster one was identified to have similarities to the Crisis phase of the model. Members of this cluster were found to have a significantly higher raw score mean on the crisis factor and the lowest raw score mean on the Integration factor. Cluster one members had greater loss in functioning, higher illness severity and believed their illness to be more severe and disabling than members of the other clusters who may have had greater familiarity with symptoms or be experiencing a stabilisation of symptoms (Jason, Fennell, et al, 2000). Cluster one members were also found to have the shortest illness duration implying that they have had a shorter period of time to manage and cope with the illness.

Cluster two was identified by moderate range scores on the four raw score factor means which was related to the Stabilisation phase. Results indicated that members of cluster two were found to have less illness severity, lower fatigue and disability levels than the other clusters which suggests the experience of a plateau of symptoms (Jason, Fennell et al, 2000). Jason, Fennell et al (2000) suggests that the moderate range of factor

mean scores signifies that individuals are shifting towards emotional stability but are still in the initial periods of learning how to deal with and understand the illness.

Cluster three was identified by the highest Stabilisation factor mean but also high scores on the Crisis and Integration factors which Jason, Fennell et al (2000) suggest that this is associated with the Resolution phase of the model. Members of cluster three were found to be experiencing greater illness severity, higher levels of fatigue and disability which is consistent with Resolution as individuals may encounter a relapse of symptoms although are better able to cope with these symptoms than when they initially became ill. Jason, Fennell et al (2000) suggests that higher scores on the Crisis and Integration factor means indicates that members of cluster three may be experiencing a secondary emotional crisis due to the grief associated with the realisation of the chronic nature of their condition.

Finally, cluster four was found to have the highest Integration score and lowest Crisis and Stabilisation factor means and was associated with the Integration phase of the FFPM. Members of this cluster were more likely to indicate an understanding of the illness experience, acknowledge that they had developed a greater sense of self and integration of the pre- and post-illness self. Cluster four members were also found to have the longest illness duration (Jason, Fennell et al, 2000).

In another study by Jason, Fricano, Taylor, Fennell, Klein and Levine (2000) the phases of FFPM were investigated. However, participants had been diagnosed with CFS by a physician rather than self reporting their diagnosis. Participants were grouped into the four phases and relationships between the phases, symptoms, disability and coping were explored. Specific procedures were used for allocating each participant to one of the

four phases. These procedures involved applying an algorithmic criterion to FPI which was developed from the cluster analysis of Jason, Fennell et al (2000). Jason, Fricano, et al (2000) allocated 65 participants to their relevant groups in order to explore the characteristics of each group. Only one participant met the criteria for the Integration group therefore this group was not further analysed.

Results indicated that those in the Crisis group had greater illness, symptom and fatigue severity, increased psychological distress, and greater functional impairment than members of the other phases. Furthermore, this group was found to be less likely to use Accommodating to the Illness or Information Seeking as a coping style (Jason, Fricano et al, 2000). As suggested by Jason, Fricano et al (2000) individuals experiencing Crisis are more likely to engage in denial and be less active in dealing with their illness. Those in the Stabilisation group appeared to be experiencing a plateau or decrease of symptoms in addition to increased adaptation to the illness. They were found to use more strategies to cope with the illness and also tended to seek illness related information more so than the Crisis group. Jason, Fricano et al (2000) suggests that individuals in the Stabilisation phase are demonstrating movement away from denial into a more active approach to coping with the illness. Participants in the Resolution group were found to be more likely to be experiencing a relapse of symptoms but were more psychologically equipped to deal with these symptoms than participants in the Crisis phase (Jason, Fricano et al, 2000). Those in the Resolution phase reported intermediate levels of impairment in general health, physical and psychological functioning that were greater than the Stabilisation group but lower than the Crisis group. The Resolution group was also

significantly more likely to engage in coping strategies to deal with the illness and seek information about their illness than the Crisis group (Jason, Fricano et al, 2000).

In another study, Van Hoof, Coomans, Cluydts, and De Meirleir (2004) tested the FPI with a Belgian sample of CFS patients. The study consisted of 44 participants and results supported the FFPM. The researchers performed a factor analysis which was limited to four factors and was found to explain 57.4% of the sample variance. Using an unlimited factor analysis explained more variance but had lower reliability scores. Two items of the FPI were removed as they failed to load at the .45 level. All four factors emerged with moderate to excellent reliability. The researchers found that participants in the Crisis phase experienced more somatic problems, more sleep problems, increased subjective fatigue, low motivation and more social functioning which was explained by the possibility of increased attention by family and friends to provide support (Van Hoof et al, 2004). The Stabilisation phase reflected better coping strategies by seeking order and also active information seeking. The Resolution phase was found to have improved immune defence suggesting that perhaps with increased coping and decreased stress the body becomes stronger. Finally, the Integration phase was characterised by seeking support which indicated a willingness to become active in the disease process (Van Hoof et al, 2004).

3.3.8 SECTION SUMMARY

The FFPM provides a comprehensive and flexible approach to mapping the adjustment process to chronic illness. It is superior to other models of adjustment due to its scope, utility and empirical support. Understanding the adjustment process of PwMS

is highly important as individuals who do not adjust to the disease are at risk of having lower QoL and greater psychological distress. The FFPM warrants further empirical verification and investigation for other chronic illnesses such as Multiple Sclerosis. This model can provide useful information regarding the adjustment processes as well as assessment and treatment options for PwMS.

3.4 THE CURRENT RESEARCH

The purpose of the research in this thesis was to gain a greater understanding of the journey of PwMS by exploring social support and phases of adjustment. By having a greater understanding of the experiences of PwMS and the possible struggles and challenges they face, health professionals will be able to provide improved assistance and support. Living with chronic illness poses many uncertainties and the majority of people are unaware of what the journey entails. With a greater understanding of this journey, PwMS can be supported appropriately and have greater QoL and sense of security.

3.4.1 STUDY 1 – HELPFUL AND UNHELPFUL SOCIAL SUPPORT

Study 1 specifically aimed to provide a comprehensive multidimensional understanding and description of social support for PwMS by exploring the types of support which are most helpful and unhelpful from various support network members and the unique value of each social support network member. Exploring social support from a multidimensional perspective involves considering the functions of support (emotional, informational and tangible), sources of support and positive and negative types of support. This study provided detailed behavioural descriptions about what PwMS

specifically perceive as supportive and unsupportive from each support network member. This detailed understanding and description of social support aimed to be beneficial in the development of effective interventions to enhance support for PwMS. The study adopted the methodology of Dakof and Taylor (1990) who investigated social support and cancer. The study utilised Dakof and Taylor's (1990) interview questions and also the researchers established data coding categories. It also formed the basis for the creation of a social support questionnaire for use in Study 2.

3.4.2 STUDY 2 – ADJUSTMENT TO MULTIPLE SCLEROSIS

Study 2 aimed to provide empirical support for the Fennell Four Phase Model of adjustment; this model acknowledges the importance and influence of the social support system. The study aimed to explore whether individuals in different phases of adjustment had different perceptions of helpfulness and unhelpfulness support from various support network members. The study also explored the experiences of individuals in each of the phases of the adjustment proposed by the FFPM by examining coping styles, emotional states and satisfaction with life.

**CHAPTER 4: STUDY 1 - HELPFUL AND UNHELPFUL
SOCIAL SUPPORT: THE PERSPECTIVE OF PEOPLE
WITH MULTIPLE SCLEROSIS**

4.1 BACKGROUND

As established earlier, the buffering hypothesis of social support proposes that support has a positive impact in the presence of stress by protecting individuals from the negative consequences of such stress (Cohen & Syme, 1985; Wills & Fegan, 2001). Social support has been found to significantly assist PwMS (Arnett et al, 2008). The use of social support as a coping mechanism enhances adjustment, mediates the effects of emotional distress and improves wellbeing (Crigger, 1996; Gordon et al, 2002; Gulick, 2001; Miller & Murphy, 1997; Stuifbergen et al, 2000). Those with greater social support have been found to be less likely to suffer from depression (Arnett et al, 2008).

Multiple sclerosis often negatively impacts relationships as family and friends are unable to cope and therefore withdraw social contact with the patient (Reynolds & Prior, 2003). People with MS experience negative reactions from family and friends which can result in relationship breakdowns (Black et al, 1994). They tend to experience less satisfaction with social relationships compared to the general population and a reduction in social contact and recoil of friendships (McCabe & DiBattista, 2004; Hakim et al, 2000; McCabe & McKern, 2002). People with MS have a strong desire and need for social support; however, these needs often remain unmet (Black et al 1994; Olsson et al, 2005).

The MS literature indicates the importance of, and necessity for, adequate social support and explores the positive effects of this support but fails to examine this area in a comprehensive and detailed manner. No research has focused on examining social support from a multidimensional perspective by taking into consideration functions of support, sources of aid and both positive and negative aspects of support. Some

researchers such as Stuifbergen (1992) and Wineman (1990) have investigated social support for PwMS in a more detailed manner. However, these studies have not provided insight into what PwMS perceive as the most helpful and unhelpful types of naturally occurring support from various support network members. The research in MS reports on the importance of social support for MS patients, however, no comprehensive descriptions which specifically explain and describe the acts of support which are experienced by PwMS as helpful and unhelpful have been provided. Cancer research has identified the forms and sources of social support which are most beneficial. Dakof and Taylor (1990) used an approach to studying social support for people with cancer which provided a fine grained and thorough understanding of the helpful and unhelpful aspects of support by taking into consideration not only sources of aid but also categories of social support. This knowledge is vital for informing interventions that may enhance the support received by individuals suffering from an illness.

Various theoretical models of social support such as the optimal matching theory (Cutrona & Russell, 1990) and the theory of person-environment fit (French et al, 1974; Shinn et al, 1984) propose that in order for support to be beneficial it must be appropriately linked to an individual's circumstances. The victimisation model (Wortman & Dunkel-Schetter, 1979) suggests that victimising events, such as a chronic illness, can have a significant impact on social interactions. These events create conflicting reactions in others which can result in inappropriate or inadequate support. Having awareness about the types and sources of support which are viewed as most useful and also most unhelpful will provide insight into the circumstances of PwMS and the type of support which is likely to be most beneficial and provide optimal buffering effects against the

negative impact of having a chronic illness. Furthermore, this information can be used to enhance interventions which focus on improving social support for PwMS.

4.2 AIMS AND OBJECTIVES

Study 1 attempted to explore the multidimensional aspects of social support for PwMS by asking participants to specify what particular acts are helpful and unhelpful from each of seven designated individuals in the support network. Exploring social support from a multidimensional perspective involved considering the functions of support (emotional, informational and tangible), sources of support and positive and negative types of support. The study utilised the approach adopted by Dakof and Taylor (1990) which examined helpful and unhelpful support for people with cancer. Dakof and Taylor (1990) provided a comprehensive approach and were able to identify helpful and unhelpful types of support and also sources of aid. Study 1 used the same designated individuals in the support network as Dakof and Taylor (1990) with some adjustments for PwMS. Dakof and Taylor (1990) have included physicians and nurses, whereas Study 1 has replaced physicians and nurses with the neurologist and GP. The neurologist is the primarily treating specialist for PwMS and the GP tends to provide the ongoing care for the MS patient, therefore these medical professionals were considered key members of the support system for PwMS. The present study looked at the function of different types of naturally occurring support (e.g. emotional assistance, informational assistance and tangible aid) the specific acts of support from different sources (e.g. spouses, family members, friends, acquaintances, GP and neurologist) and both positive and negative attempts at providing support (e.g. helpful and unhelpful acts). For the purpose of the

present study an acquaintance was defined as a person with whom one may have a relationship which is not as close as a friendship. It is assumed that different relationships have different obligations, limitations, commitment levels and interactions and therefore exploring various relationships is essential for a thorough understanding of social support. The interview and classification frame provided by Dakof and Taylor was used to address the following objectives:

- 1) An understanding of the experiences of PwMS of helpful and unhelpful attempts at providing support
- 2) Identification of the unique value of each support network member and the specific behaviour/support that they provide
- 3) Identification of the unmet social support needs of PwMS

4.3 METHOD

4.3.1 PARTICIPANTS

One hundred potential participants were randomly selected from the computerised database register of the Multiple Sclerosis Society of New South Wales and Victoria (NSW/VIC) Australia. In total 20 individuals from this pool of 100 contacted the researcher and agreed to participate in the study. The MS society is an organisation which supports and helps PwMS by providing services such as support groups and educational and lifestyle programs. The overall aim of the MS society is to assist people to achieve a full and healthy lifestyle while effectively managing MS symptoms.

To be eligible for the study individuals must have been diagnosed with MS for a minimum period of five years. This five year period aimed to ensure that participants

were no longer classified as newly diagnosed and had began to adjust and experience social interactions which may have been impacted by MS. Table 1 reports participants demographic information. The sample was predominately female with an average age of 46 years. Most participants were either married or in a defacto relationship and had children. Relapsing remitting MS was the most common diagnosis among participants and the average duration of living with the diagnosis was 10.5 years.

Table 1

Study 1 Participant Demographic Information

| | | | |
|-----------------------------|---|---|---|
| Gender | Female = 80% | Male = 20% | |
| Age | Age Range = 23-63 years | Mean Age = 46 | |
| Martial Status | Married = 55% | Defacto = 20% | |
| | Divorced = 15% | Single = 10% | |
| Residential Status | Living with family = 85% | Living alone/shared housing = 15% | |
| Children | Participants with children = 70% | Mean number of children = 2 | |
| Association with other PwMS | Participants with association with other PwMS = 80% | Currently attending support groups = 10% | Past attendance at support groups = 20% |
| Type of MS | Relapsing remitting MS = 85% | Secondary progressive MS = 10% | Primary progressive MS = 5% |
| Duration since diagnosis | Duration Range = 6-17 years | Mean duration = 10.5 yrs Median duration = 9.0 yrs | SD = 3.67 |

4.3.2 MATERIALS

Interview

The interview contained eight initial questions regarding demographic information, MS related information and the extent of support group participation. The following general statement from Dakof and Taylor (1990) was used:

I would like to ask you some questions about how people have been helpful to you. After being diagnosed as having MS, people may behave toward you in a number of different ways. Some of these ways may be helpful and others may not. It is important for families, friends and doctors of people with MS to know what people with MS think about how others treat them. We would like to know about your experiences with seven different groups of people: your spouse or partner, other family members, your friends, support group members or others you may know who have MS, your doctor, your neurologist, and, finally, acquaintances or strangers.

Four questions about each of the seven potential support providers were also obtained from Dakof and Taylor (1990). The questions were:

- (1) In the time since your diagnosis, what is the most helpful thing that (support provider) has said or done to help you with your MS?
- (2) As I mentioned before, sometimes people who are close to us may say or do things that make us feel bad. They may have had the best intentions, or maybe they were not thinking at the time. In the time since your diagnosis, what has (support provider) said or done that you experienced as most annoying, or that upset you, made you angry, or just somehow rubbed you the wrong way?
- (3) Sometimes we find that certain people can help us in ways that nobody else can. For instance, there may be some things that (support provider) can do or say that nobody else can do or say. It would not mean the same coming from anybody else. Since your

diagnosis, what, if anything has (support provider) done or said to help you with the MS that nobody else could do in quite the same way?

(4) We have all had the experience at one time or another when we wished a certain person would do or say things that, unfortunately, he or she never did. Since you received your diagnosis, what have you wished that (support provider) had done or said to help you with your MS that he or she did not do?

4.3.3 PROCEDURE

The MS society of NSW/VIC provided the researchers with a list of 100 randomly selected members from their computerised database who were then contacted by mail requesting their participation in the study. An invitation letter and participant information sheet was posted to the potential participants and can be viewed in Appendix 1. Interested participants contacted the researcher directly and interview arrangements were made. All interviews took place in private settings which were suitable and comfortable for participants, usually in the participant's homes or workplaces. At the beginning of the interview participants were given an informed consent form to complete and permission to audiotape the interview was also obtained. Interviews were conducted by a trained intern clinical psychologist and lasted between 45 minutes to 1.5 hours. The interview questions were initially piloted on two PwMS; the questions were evaluated and considered to be relevant and suitable for this population. At the interview, demographic questions were initially asked, followed by the general statement about the research, the remaining questions were then asked. The complete social support interview can be viewed in Appendix 2. Although participants were asked to discuss the

most helpful and unhelpful actions it was not requested that responses be limited to one action per question. Participants were allowed to discuss as many “most helpful” or “most unhelpful” actions as they wished.

4.3.4 DATA ANALYSIS

Deductive content analysis can be used when predetermined codes have been already established in the research (Elo & Kyngäs, 2008). Deductive content analysis techniques were applied in the present studying by coding the interview data with predetermined categories which were developed by Dakof and Taylor (1990). Using predetermined codes which were developed from research with cancer patients may have some limitations when applied to MS. However, both populations are suffering from a chronic illness and have been found to benefit from social support. The coding categories developed by Dakof and Taylor (1990) were not only derived from interview data but also from other theoretical and empirical social support research. Therefore, these categories are rather general and likely to be applicable to the study of social support and MS. These coding categories and the process that Dakof and Taylor (1990) used for developing these categories are described below.

4.3.4.1 PROCEDURES BY DAKOF AND TAYLOR (1990) TO ESTABLISH CATEGORIES

Dakof and Taylor (1990) developed social support coding categories from interviews with 55 cancer patients. Firstly, they selected a random sample of interviews that were then examined and an initial set of codes were developed. Next, 10 randomly selected interviews were coded by a minimum of two coders using this initial coding method. Reliability was examined and coding categories were modified to be more

defined and accurate. Additional categories which had significant theoretical importance or had been uncovered in previous studies were also added to the list of codes. The final set of categories was established and the Cohen's kappa (Cohen, 1960) across all codes was .79. The final categories developed by Dakof and Taylor were:

Helpful Esteem/Emotional Support - physical presence; expressed concern, empathy or affection; calmly accepted the participants condition; expressed a special understanding because of being a similar other; was pleasant and kind.

Helpful Informational Support - provided useful information or advice; optimistic about the prognosis or the participants ability to successfully live with the condition; acted as a positive role model.

Helpful Tangible Support - provided practical assistance; provided technically competent medical care.

Unhelpful Esteem/Emotional Support -expressed too much worry or pessimism; expressed little concern; empathy or affection; avoided social contact with the participant; rude and inappropriate behaviour.

Unhelpful Informational Support - critical of the participant's response to the condition (MS); minimised of the impact of the condition on the participant; acted as a poor role model; provided insufficient information.

Unhelpful Tangible Support - provided technically incompetent medical care; provided unwanted practical assistance.

4.3.4.2 CURRENT PROCESS OF DATA ANALYSIS

The audio taped interviews were transcribed for analysis. Initially, the transcribed interviews were read thoroughly several times in order for the researcher to become entirely familiar with the data. After thorough review of the transcripts, each case was coded, using the categories proposed by Dakof and Taylor (1990), by two trained researchers (the interviewer of that respondent and one other coder). The average Cohen's kappa (Cohen, 1960) across all codes was .88. Discrepancies between coders were settled by discussion after independent ratings were completed. One additional code was added to Dakof and Taylor's codes as it was a consistently mentioned behaviour and was agreed upon by the researchers. This coded behaviour was described as 'understanding the nature of MS and its emotional impact' and was classified as helpful emotional support.

The same procedures as Dakof and Taylor's (1990) were also used for participants' responses to questions regarding sources of support that could have related to multiple members, such as the category of family members which could consist of children, parents, siblings or other extended family. Participants usually focused on one member of that category or referred to the category in general without specification of particular individuals involved. However, in instances when two or more members of a single category were discussed and the same behaviour was mentioned, this response was coded once. If a different behaviour was given for each member then these were coded separately. For example, if a participant described the same type of helpful act of "expressing concern" from both their children and parents then this was assigned one code. However, if the participant described the helpful act of their parents "being there"

and their children “expressing concern” then this was assigned separate codes as two different behaviours were described.

As participants were allowed to report as many “most helpful” and “most unhelpful” actions as they wished, many reported multiple actions in response to a single question. When participants described multiple most helpful and most unhelpful behaviours from the one support provider then each behaviour was coded separately.

4.4 RESULTS

4.4.1 PERCEPTIONS OF HELPFUL AND UNHELPFUL SUPPORT

The number and percentage of reported helpful and unhelpful actions from the seven target network members (spouse, other family, friends, other PwMS, GP, neurologist and acquaintances/strangers) is presented in Table 2. The percentages represent the proportion of helpful and unhelpful support reported for each support provider. The results indicate that PwMS tended to experience and report more helpful acts of support rather than unhelpful across the support providers with the exception of acquaintances/strangers. Participants tended to report multiple helpful acts from each support provider category.

Table 2

Number of Reported Helpful and Unhelpful Social Support Acts From Each of the Seven Providers

| Provider | Helpful acts of support | | Unhelpful acts of support | |
|--------------|-------------------------|----|---------------------------|----|
| | number of reported acts | % | number of reported acts | % |
| Spouse | 24 | 67 | 12 | 33 |
| Other family | 26 | 62 | 16 | 38 |
| Friend | 22 | 58 | 16 | 42 |
| PwMS | 18 | 69 | 8 | 31 |
| GP | 23 | 70 | 10 | 30 |
| Neurologist | 24 | 59 | 17 | 41 |
| Acquaintance | 23 | 50 | 23 | 50 |

4.4.2 TAXONOMIC ANALYSIS OF PERCEIVED SOCIAL SUPPORT

The categories of helpful and unhelpful actions were divided into the social support taxonomy of (a) esteem/emotional support, (b) informational support, and (c) tangible support. These are presented in Table 3, the percentages represent the proportion of helpful or unhelpful esteem/emotional, information and tangible support reported for each support provider. A large proportion of respondents reported that esteem/emotional support was the most helpful form of assistance provided by the spouse, other family members and friends (over 69% in each source category). Tangible support was also mentioned as helpful from these intimate support members (spouse, other family members and friends). With respect to unhelpful actions, a large percentage of participants reported being subjected to inappropriate or inadequate attempts at esteem/emotional support from intimate support providers (spouse, other family and friends). There were few reports of the spouse and other family members providing inadequate or inappropriate informational support and no reports by participants of the spouse, other family members or friends providing unwanted tangible assistance. Acquaintances shared a similar pattern of supportive and unsupportive acts as intimate support providers (spouse, other family members, and friends).

Other people with MS were perceived as most helpful for the informational support they provided (61%) and also for the helpful esteem/emotional support (39%). No instances of tangible support from other PwMS were reported. Unsupportive actions from other PwMS were rarely reported with only few instances mentioned by participants. These few instances tended to centre on misguided or inappropriate esteem/emotional support.

The General Practitioner (GP) was most valued for tangible support in the form of medical care (44%). The GP was also considerably important for the information they provided (39%) and marginally valued for esteem/emotional support (17%). The neurologist was identified as the most helpful source for informational support (79%). No reports of helpful esteem/emotional support from the neurologist were recorded. With respect to unhelpful actions, both the GP and neurologist were most unhelpful for inadequate or inappropriate informational support. The GP had no reported instances of unhelpful esteem/emotional support but participants reported some instances from the neurologist. Inadequate or inappropriate tangible support was reported to be unhelpful from both the GP and neurologist and was related to inadequate medical care. Across other support providers no instances of unhelpful tangible support were reported by participants.

Table 3

Taxonomic Analysis of Perceptions of Social Support

| Provider | Esteem/Emotional | | Informational | | Tangible | |
|-------------------|------------------|-----|----------------|----|----------------|----|
| | number of acts | % | number of acts | % | number of acts | % |
| Helpful actions | | | | | | |
| Spouse | 19 | 79 | 0 | 0 | 5 | 21 |
| Other family | 18 | 69 | 2 | 8 | 6 | 23 |
| Friends | 17 | 77 | 0 | 0 | 5 | 23 |
| PwMS | 7 | 39 | 11 | 61 | 0 | 0 |
| GP | 4 | 17 | 9 | 39 | 10 | 44 |
| Neurologist | 0 | 0 | 19 | 79 | 5 | 21 |
| Acquaintances | 14 | 61 | 0 | 0 | 9 | 39 |
| Unhelpful actions | | | | | | |
| Spouse | 11 | 92 | 1 | 8 | 0 | 0 |
| Other family | 13 | 81 | 3 | 19 | 0 | 0 |
| Friends | 16 | 100 | 0 | 0 | 0 | 0 |
| PwMS | 7 | 88 | 1 | 12 | 0 | 0 |
| GP | 0 | 0 | 9 | 90 | 1 | 10 |
| Neurologist | 2 | 12 | 12 | 70 | 3 | 18 |
| Acquaintances | 22 | 96 | 1 | 4 | 0 | 0 |

4.4.3 SPECIFIC ACTS OF SUPPORT AND NONSUPPORT

In order to provide a more detailed description of the participant's views of specific helpful and unhelpful acts from the various support providers the behaviours that comprised each of the categories of social support were thematically explored. Coded responses to open ended questions regarding the perceived value of social support across the seven social network members are discussed below. Appendix 3 provides all of the coded statements regarding each type of supportive or unsupportive act.

When discussing the specific helpful behaviours provided by the spouse, 38% of coupled participants mentioned their spouse's physical presence (just being there), 21% mentioned the provision of practical assistance, and 17% talked about expressions of concern, empathy and affection. The calm acceptance of the individual's MS and the understanding the nature of MS and its emotional impact were each mentioned by 13% of participants. When asked about negative experiences with the spouse, 67% reported that the expression of little concern, empathy or affection was particularly unhelpful; however, 25% of participants noted the unhelpfulness of too much worry or pessimism. Finally, 8% of participants felt that their spouse minimised the impact of MS.

Helpful experiences from other family members consisted of the provision of practical assistance (23%), physical presence of just being there (19%), understanding the nature of MS and its emotional impact (19%), expression of concern, empathy or affection (15%), calm acceptance of the patients MS (15%) and finally, optimism about the prognosis or individuals ability to successfully live with MS (8%). With respect to unhelpful actions from other family members, the most frequently reported unhelpful act was the expression of too much worry or pessimism (44%) followed by the expression of

little concern, empathy or affection (31%). Participants also mentioned the unhelpfulness of family members minimising the impact of the MS (19%) and being rude and inappropriate (6%).

The most helpful act from friends was the calm acceptance of the patients MS (36%), followed by the provision of practical assistance (23%). Participants also mentioned the helpfulness of the physical presence of a friend (18%), understanding the nature of MS and its emotional impact (14%) and the expression of concern, empathy or affection from friends (9%). Friends were perceived to cause the most upset to participants due to the expression of little concern, empathy and affection (38%) and the avoidance of social contact with the participant (31%). Participants also mentioned the unhelpfulness of the expression of too much worry or pessimism (19%) and rude and inappropriate behaviour (13%) from friends.

Helpful experiences with other PwMS centred on four behaviours: the expression of a special understanding due to being in a similar situation (39%); providing helpful information and advice (28%); expressions of optimism about the participant's ability to successfully live with MS (17%) and behaving as a positive role model (17%). Unhelpful acts from other PwMS involved rude and inappropriate behaviour (75%), acting as a poor role model (12.5%) and expression of too much worry or pessimism (12.5%).

The most helpful act from the General Practitioner (GP) was the provision of competent medical care (43%) followed by useful information and advice (22%). The GP was also perceived as helpful for being optimistic about the patients ability to live successfully with MS (17%), for being pleasant and kind (9%), for the calm acceptance of the patients MS (4%) and for understanding the nature of MS and its emotional impact

(4%). The GP was most unhelpful for providing insufficient information (90%) and also for technically incompetent medical care (10%).

Three actions were mentioned as most helpful from the neurologist including the provision of useful information and advice (54%), optimism regarding the patient's ability to live with MS (25%) and competent medical care (21%). In regards to unhelpful acts from the neurologist, the provision of inadequate or insufficient information or advice was viewed as highly unhelpful (53%) along with technically incompetent medical care (18%). The neurologist was also viewed as unhelpful for minimising the impact of MS on the patient (12%), expressing little concern, empathy or affection (6%), acting as a poor role model (6%) and being rude or inappropriate (6%).

Finally, acquaintances were most helpful for the provision of practical assistance (39%), participants also mentioned the helpfulness of acquaintances ability to calmly accept the patients MS (17%), being pleasant and kind (17%), expressing concern, empathy or affection (13%), understanding the nature of MS and its emotional impact (9%) and being physical present (4%). With respect to unhelpful acts by acquaintances, participants reported rude and inappropriate behaviour (65%), expression of little concern, empathy or affection (17%), expression of too much worry or pessimism (9%), minimisation of the impact of MS (4%) and avoidance of social contact (4%).

4.4.4 UNIQUELY HELPFUL AND WISHED FOR HELPFUL SOCIAL SUPPORT

The questions of the interviews which asked “What if anything, has (support provider) done or said to help you with your MS that nobody else could do in quite the same way?” and “What have you wished that (support provider) had done or said to help

you with your MS that he/she did not do?” provided minimal additional information. The pattern of responses to these questions was similar to the pattern of responses to enquiries about examples of helpful and unhelpful support. Generally, the uniquely helpful responses were a reproduction of the most helpful responses and the wished-for responses were the opposite of the most unhelpful responses. For example, if a participant reported that the most helpful act from friends was calmly accepting his or her MS; the participant usually indicated that that this was also the uniquely helpful behaviour from that support provider. Furthermore, if the participant reported that the most unhelpful behaviour from friends was socially avoiding them, they also reported that social inclusion or acceptance was the most wished for support from friends. Consequently, no significant additional information was obtained from these last two questions. Dakof and Taylor (1990) also found that these last two interview questions did not provide additional information when interviewing people with cancer.

4.5 DISCUSSION

The present study aimed to provide a thorough and multidimensional approach to exploring social support for PwMS by considering the functions of support, sources of support and positive and negative types of support. The study investigated the types of social support which PwMS perceive as helpful and unhelpful from various key support providers, as well as the unique value of each support network member and the specific behaviours which are experienced as most support and most unsupportive. The study also aimed to explore the ways in which support is inadequate or not meeting the needs of PwMS. The theoretical implications of the present study suggest the importance of

measuring social support as a multidimensional construct rather than a general unitary concept. The findings indicate the importance of considering the source and function of social support. Furthermore, having this detailed description of social support can also facilitate with developing interventions for support network members which can provide concrete descriptions of what is experienced as helpful and unhelpful by MS patients.

4.5.1 PERCEPTIONS OF HELPFUL AND UNHELPFUL SUPPORT

The frequency of helpful and unhelpful actions from the seven support providers indicates that participants tended to provide more examples of supportive rather than unsupportive acts. This difference is particularly evident in regards to experiences with other PwMS and the GP. However, no differences were found between the frequency of reported helpful and unhelpful acts from acquaintances.

Participants may have been hesitant to express their negative experiences with support providers due to a social desirability bias. The tendency for lower reports of negative social support is consistent with previous studies which have found lower frequencies of negative social interactions in comparison to positive social interactions (Dunkel-Schetter, 1984; Revenson et al, 1991). Furthermore, these results are similar to those reported by Dakof and Taylor (1990) who found that cancer patients were able to provide significantly more examples of helpful actions rather than unhelpful actions across all support providers with the exception of acquaintances.

4.5.2 TAXONOMIC ANALYSIS OF PERCEIVED SOCIAL SUPPORT

Intimate support network members including the spouse, other family members and friends were undoubtedly most valued for providing esteem/emotional support and also for tangible assistance although to a lesser extent than esteem/emotional support. These support providers (spouse, other family members and friends) shared a similar pattern across both reported helpful and unhelpful actions. The finding of the value of esteem/emotional support from close relationships is similar to results reported by Dakof and Taylor (1990). Cancer patients also perceived intimate others as most helpful for emotional support and less essential for informational or tangible support.

It was also identified that when esteem/emotional support was inappropriate or inadequate it was most unhelpful. Some participants reported unhelpful informational support from the spouse and other family members although not to the extent of unhelpful esteem/emotional support. Furthermore, there were no reports of unhelpful or unwanted tangible aid from intimate support providers. Absent or misguided emotional support may be associated with the support providers own personal discomfort with the disease. Social networks have been found to experience a sense of powerlessness, fear and anger regarding the disease while also having an unexpressed reliance on the person suffering to cope independently (Barrett, 1995). It is possible that these significant others may experience difficulty coping with the impact of MS, the unpleasant experiences and symptoms and attempt to normalise or not acknowledge the situation which is then experienced by the person with MS as inadequate emotional support.

Acquaintances shared a similar pattern of supportive and unsupportive acts as intimate support provides; however, acquaintances were similarly valued for

esteem/emotional support and tangible support. Similar to intimate others, misguided or absent esteem/emotional support was perceived as the most unhelpful behaviour from acquaintances. Interestingly, despite less established and close relationships with acquaintances and strangers PwMS still valued esteem/emotional support and also felt the unhelpful effects of the absence of this type of assistance.

Participants' reports regarding the remaining support providers (other PwMS, GP and neurologist) had a noticeably different pattern to that of intimate others.

Informational support was almost exclusively reported as most helpful when provided by medical professionals and fellow MS patients. Other PwMS were valued for providing both informational and esteem/emotional support. No instances of tangible support were reported for other PwMS whereas this type of support was valued and commonly reported for intimate others. With respect to unsupportive actions unhelpful esteem/emotional support was the most commonly reported unhelpful behaviours from other PwMS. Dakof and Taylor (1990) reported similar findings as other cancer patients were most valued for informational assistance and also highly appreciated for providing emotional support.

Both the GP and the neurologist were considered essential for providing informational support but the neurologist was most likely to be mentioned as being most helpful for informational assistance. The GP was primarily valued for providing tangible support involving competent medical care and to some extent appreciated for providing esteem/emotional support. Although informational support was highly valued from these medical professionals it was also viewed as extremely unhelpful when physicians provided too little or misguided information. These results correspond with previous

research which found that PwMS often experience insufficient informational assistance from healthcare providers (Thorne et al, 2004).

Support from medical professionals is clearly important and viewed as unhelpful when inadequate information is provided. It appears as though the GP and the neurologist play slightly different roles in the care of PwMS. The neurologist is the primary source of MS related information whereas the GP cares for general health along with providing esteem/emotional support and some general MS related information. It is possible that patients feel more at ease with their General Practitioners and are more able to express emotional difficulties therefore eliciting esteem/emotional support. With the likelihood of less frequent contact with the neurologist this relationship may not be as well established and therefore the focus of assistance is on areas that are lacking from the GP leading to increased informational support.

People with MS have consistently reported that they wish to have more information following their diagnosis (Black et al, 1994). Research has suggested that realistic, supportive and encouraging communication from healthcare professionals is essential to MS care and without such support patients may have difficulty maintaining a sense of control over their lives and suffer increased distress and worry (Black et al, 1994; Thorne et al, 2004). It is evident from the present study that informational support is lacking from both the neurologist and GP. Although participants reported informational support as highly helpful from the GP and neurologist many respondents also reflected on experiences with medical professionals which were lacking in this type of support. People with MS have a strong desire for more information and advice from these medical professionals. There is a need for a greater focus on providing adequate information in

order to reduce the possible detrimental affects of not having such support. People with MS require realistic information which is tailored to their individual needs in order to assist with adaptation to the disease (Thorne et al, 2004).

The results from this taxonomic analysis of perceived social support also build upon the knowledge established by Stuifbergen (1992) who reported that the spouse was the primary source of emotional and tangible support and the physicians were the primary source of emotional and informational support. The present study provides information as to the types of support that are perceived as most helpful from the support providers. In accordance with Stuifbergen (1992), the present study found that the spouse was valued for both emotional and tangible support but was most valued for emotional assistance. In contrast with Stuifbergen's (1992) findings, the present study found that the physicians were not most valued for emotional support but rather informational and tangible support. The differences between these findings may be associated with the fact that Stuifbergen (1992) assessed support in relation to specific illness demands whereas the present study examined naturally occurring support which was perceived as helpful and unhelpful. Assessing naturally occurring support has been reported to be helpful in increasing awareness about the specific types of emotional, tangible and informational support which are most useful (Wortman & Conway, 1985).

The categories of support (esteem/emotional, informational and tangible support) are rather broad and distinctions between these can be difficult. It is assumed that esteem/emotional support provided by the spouse is rather different to the esteem/emotional support provided by other PwMS or the GP (Dakof & Taylor, 1990). A

more fine grained analysis was conducted in which behaviours comprised of each of the taxonomic categories of social support were explored. These are discussed below.

4.5.3 SPECIFIC ACTS OF SUPPORT AND NON-SUPPORT

The outcome of the present study indicates that different types of support were perceived as helpful and unhelpful from different sources. The following discussion on specific helpful and unhelpful acts has been separated into three sections including: 1) intimate support providers (spouse, other family members and friends) and acquaintances; 2) other Multiple Sclerosis sufferers; and 3) medical professionals.

4.5.3.1 INTIMATE SUPPORT PROVIDERS AND ACQUAINTANCES

Intimate support providers (spouse, other family members and friends) shared a similar pattern of helpful and unhelpful behaviours. The behaviours from intimate support providers which were frequently reported as helpful will be discussed initially and examples provided. These include the following; physical presence, expression of concern, empathy and affection, understanding of the nature of MS and its emotional impact, calm acceptance of MS and practical support.

The physical presence of these intimate others was found to be highly valued by PwMS and was the most valued act of support from the spouse. This support was associated with a greater sense of security, a sense of knowing that their partner would be there in the most testing of situations, in addition to having a sense of companionship on the journey of adapting and coping with MS. This is illustrated in the following example provided by a participant about her spouse,

“...there is nothing that he said or done, I just knew that he was going to be there...”

Participants placed a high degree of importance on the expression of concern, empathy and affection from intimate support members. Often such support involved participants being asked how they were feeling, being asked about the outcome of appointments and offered assistance if needed. These expressions of concern validated the individual's sense of worth and importance. Such validation is highly important for PwMS as research has indicated that individuals often experience a sense of demoralisation (Mohr et al, 1999). This particular act may aid in maintaining and supporting self-esteem. One lady described this type of support from her partner, "Making sure that you take your medication...that says to me that you care and love me a lot..."

Given the unpredictable and uncertain nature of MS, understanding from intimate support providers is critical. Participants reported that the understanding from intimate support providers was extremely beneficial. Participants valued the helpfulness of not having to provide in-depth explanations of their experiences and difficulties. Intimate support providers understood the impact of MS and therefore explanations for not being able to attend social outings or complete regular daily activities were not required. One lady described her husband's understanding of her MS as follows, "MS is the type of thing that's unpredictable, I can be good and then all of a sudden I am bad, and I don't have to explain; now he understands"

Such understanding from significant others is highly beneficial for PwMS given the nature of symptoms. As well as being unpredictable, they vary in severity and duration (Eeltink & Duffy, 2004). Symptoms are also often not visible to others and therefore may be difficult to understand (Black et al, 1994). The understanding of the

nature of MS and its emotional impact eliminates the demand to justify and explain these struggles.

The calm acceptance of the disease and its consequences by intimate support providers was also important and seemed to provide a sense of security and strength. This acceptance offered validation to the individual that they were still the same person, that MS had not impacted the core of their close relationships; they were still valuable as a person, companion and friend. Participants expressed the importance of their partners, family and friends not changing their perception of them, not treating them differently and being able to accept the disease and its related consequences with a sense of strength. This type of supportive behaviour was perceived to be the most helpful act from friends as participants reported that friends who were able to calmly accept their MS continued to include them in social activities and treated them as they were still the same person, just sometimes with some limitations. One participant described his experience as follows, “...it’s recognition that what I was before, I am still the same person but with some limitations...”

Given the possible negative impact of MS on social relationships and the beneficial aspects of maintaining relationships, the calm acceptance by friends is highly important. Friendship groups that are able to accept and adjust to an individual’s MS will facilitate maintenance of social relationships.

Due to the physical limitations associated with MS, practical support was also important from intimate others and often involved assisting with daily activities and tasks. Many participants described that their partners, family members and friends provided assistance which enabled them to continue to participate in other areas of life,

such as employment. Family members were most valued for this type of assistance; one participant described this practical support from her sister as follows:

“My sister has been great...if you need to buy a gift; you need to run around...she does a lot of that for me, which is great...”

Previous MS research has indicated the importance that PwMS place on their ability to maintain autonomy and control (Somerset et al, 2003). Miller and Murphy (1997) found that PwMS expressed fear of losing their independence because of family members’ insistence on helping. In contrast to these findings, the present study found no instances of unwanted practical assistance, in fact practical assistance was found to be welcomed and appreciated. It is possible that in the present study participants’ experiences of practical assistance were positive as the level of assistance corresponded with the level of need. Cohen and McKay (1984) suggest that tangible aid will assist with coping if perceived as appropriate by the recipient.

Frequently reported negative experiences with intimate support providers will be discussed and detailed below and include the following acts; expression of too much worry or pessimism, expression of little concern, empathy or affection, minimisation of the impact of MS and avoidance of social contact.

The expression of too much worry or pessimism was reported across these support providers. Participants described intimate others excessively worrying about MS which would often result in the MS patient taking on the role of comforting and supporting others. Pessimism from intimate support providers regarding the person’s ability to live normally and follow through with life goals was also viewed as upsetting

by participants. One participant described her experience of other family's members as follows,

"I know family...had a lot to say about me being pregnant and that it was a silly thing on my part and that I shouldn't do that...that was really annoying and frustrating and you sort of think, would you all prefer that I lie in bed and do nothing"

Spouses have been found to have difficulty coping with the disease and often endure significant levels of stress (Stuifbergen, 1992). Providing care can have a negative impact on the carers' physical and psychological wellbeing, social life, work like and financial situation (McKeown et al, 2003). Partners often experience a significant emotional burden after a diagnosis of MS and suffer from high anxiety and worry (Janssen et al, 2003). Worry is commonly experienced by spouses, who report having concerns about their ability to continue to care and support the person with MS (Cheung & Hocking, 2004). Furthermore, spouses are also troubled by the impact that MS has on their ability to spend time with other family members in particular children (Knight et al, 1997). Spouses of PwMS have a need for appropriate and adequate social support to assist with increasing their ability to cope (Sherman et al, 2007). However, spouses often carry this emotional burden alone and find friends and family unhelpful as they do not understand MS (Courts, 2005). These findings together with the present results indicate that intimate support providers may struggle to maintain hope and a positive attitude about their ability to cope with MS. The present study suggests that PwMS find such worry and pessimism highly unhelpful as it impacts their own ability to maintain optimism and hope for the future.

Although too much worry or pessimism was view as unhelpful, the expression of little concern, empathy and affection was the most unhelpful act reported for all intimate support members. This lack of support commonly involved dismissing the participants expressed difficulties, providing little acknowledgement of personal struggles, expression of minimal concern for their health and wellbeing, and also having consistent expectations of the person with MS and a lack of understanding and concern about any possible limitations. Although PwMS report that they desire to be treated in the same manner as prior to having the disease, they also require understanding and consideration of their limitations and difficulties. An important balance is needed between understanding limitations, expressing concern and empathy and also treating the person in the same manner despite having MS. One participant described her experience with her children as follows,

“...they don’t want to know anything about it. I think they want to put it in the back of their minds. So they don’t tend to help too much around the house or understand sometimes how tired I get because they can’t see a physical problem...”

Minimisation of the impact of MS was also reported to occur from the spouse and other family members. This minimisation often involved the person with MS being told how they should be coping with the illness with little acknowledgement of his or her struggles and symptoms. One participant described this behaviour from her sister as follows,

“My sister and lack of understanding and thinking that it’s all made up, it’s just the same as anyone else that physically can’t see anything wrong, than there is nothing wrong and what are you complaining about”

Support network members have been found to have difficulty understanding the impact of MS symptoms, in particular the symptom of fatigue (Olsson et al, 2005). Fatigue affects an individual's ability to participate in family activities, share and communicate with others (Olsson et al, 2005). Several symptoms of MS are not visible to the outside eye such as fatigue, pain, cognitive problems, weakness, numbness and unusual sensations. Previous research has found that family members and friends often lack sympathy towards the person with MS when invisible symptoms are present (Black et al, 1994). Those within the social network may have difficulty understanding the entire impact of such symptoms resulting in inappropriate or inadequate emotional support. Support network members may struggle to be sympathetic and understanding when these inner experiences do not match the person's outside appearance. This lack of understanding and empathy may explain the frequency of reported unhelpful acts from intimate support providers which involved the expression of little concern, empathy or affection and also the minimisation of the impact of MS.

Avoidance of social contact was also commonly reported to occur from friends; however, no instances were reported for the spouse or other family members. This avoidance tended to consist of friends becoming distant and excluding of the person with MS from social events, one participant described her experience as follows, "...one girlfriend that I have had for 100 years has pulled away a lot...I get the impression that she is frightened by the disease...and she is pulling away"

No reports of social avoidance were found from the spouse or other family members. It appears that physical avoidance is a rare reaction among those closest to the individual. As the distance between intimate others increases, social avoidance becomes

more likely to occur. Dakof and Taylor (1990) found similar results for cancer patients and suggested that withdrawal or avoidance of an individual is more difficult from the spouse and family members due to close ties and obligations.

Research has indicated that PwMS experience more restricted social relationships as a result of their MS related limitations, this then impacts QoL (Aronson, 1997; McCabe & McKern, 2002). People with MS have difficulty maintaining social relationships due to low energy levels and mobility limitations (Yorkston et al, 2001). They tend to hesitate to participate in activities because of an inability to predict fatigue levels. Multiple sclerosis has been found to result in withdrawal from social activities and recoil of friendships (Hakim et al, 2000). Previous research and the findings from the present study indicate the importance of encouraging and supporting PwMS to maintain social activity and social relationships. Furthermore, assisting friendship groups to calmly accept the MS and associated limitations is critical to improving support.

Finally, acquaintances tended to display a similar pattern of supportive and unsupportive acts as intimate support members with some exceptions. With respect to supportive acts, acquaintances were also found to provide support through physical presence, expressing concern, empathy and affection, calmly accepting the patients MS and understanding the nature of MS and its emotional impact. These acts were not as frequently mentioned in comparison to the intimate others and typically centred on people expressing their concern and willingness to provide assistance and also work colleagues and workplaces accepting and understanding the nature of MS and its emotional impact. Such support was regarded by participants as highly important as it often was the primary reason that they were able to continue working. The ability for

PwMS to maintain employment is highly important as it has been found to significantly improve levels of QoL (Aronson, 1997). In addition to these acts, PwMS also reported kind and pleasant behaviours from acquaintances, these descriptions tended to involve considerate gestures. One participant described the following act of kindness, “...the most helpful thing an acquaintance has done is that she got her husband to carve me the most beautiful walking stick...she thought it was unfair for young people to have to use horrible walking sticks...”

The most helpful act from acquaintances was practical assistance, this tended to involve a stranger assisting the person with MS in public. One participant reported the following act of practical assistance, “Giving you assistance, helping you get out of the car or in the car, or opening the door, those little things...”

The pattern for unhelpful acts from acquaintances also followed a somewhat similar pattern to intimate support members. Participants reported that acquaintances were unhelpful due to expressing too much worry or pessimism, expressing little concern, empathy or affection, minimising the impact of MS and avoiding social contact. These unhelpful acts were not as frequently mentioned for acquaintances as they were for intimate others. The most frequently reported unhelpful behaviour was rude and inappropriate acts. Typically, this involved public displays of rudeness, offensive actions from work colleagues and poor boundaries. One participant described the following, “...a couple of times I have bumped into people with this frame and they have become a bit testy about that. And it’s just my clumsiness I have bumped into them and they have got a bit jerky about it”

Another participant described the lack of boundaries that he experienced with acquaintances as follows,

“...it’s the work factor because I don’t work anymore...I find it very annoying when people start throwing the 20 questions at you...when I say I don’t do anything, you get this look like well why not...”

4.5.3.2 OTHER MULTIPLE SCLEROSIS SUFFERERS

The following section will firstly discuss and describe frequently mentioned helpful actions from other PwMS followed by frequently mentioned unhelpful acts. Other PwMS were most valuable for providing a special understanding as they were also experiencing and coping with MS. Participants expressed the value of having their struggles normalised, a sense of not being alone and also expressed that sharing humour with similar others was very helpful. One participant explained her experience as follows, “it’s was very helpful...to meet people who were laughing and cracking jokes about the whole situation you know...I found that I couldn’t really joke about things like that, because most people don’t know about MS”

Previous research has found that reassurance and empathy can be viewed as minimisation of the problem when expressed by family and friends. The same support may be viewed as helpful when expressed by peers facing a similar stressor (Wortman & Lehman, 1995). Participants in the present study explained how making light of their situation and MS symptoms with other MS patients was helpful. It is likely that a similar response from a spouse, family member, friend or healthcare professional would be perceived as hurtful and minimising. This unique support from other PwMS is clearly invaluable and can only be provided by similar others.

Information and advice from other PwMS was also useful. The sharing of how to best manage symptoms, identification of competent and supportive neurologists, medication options and how to best to live with the uncertainty of MS were commonly reported as shared information and advice. One participant provided the following example,

“they gave me advice...don’t be ashamed to ask for help because you need it...so that’s how I have been from the beginning”

Often participants described having an increased sense of optimism as other PwMS provided encouragement. One participant described this support as follows,

“...she was in a wheelchair, but she said to me “I have just got it bad, and you could have it mildly...my legs don’t work but the rest of me works just beautifully, I am more than just a pair of legs”, that always stuck in my mind about there is more to me than a pair of legs that don’t work”

Other PwMS were viewed as positive role models providing hope and confidence. Often these people were optimistic about the future or had commendable strength of character and determination. One lady described this experience as follows,

“...she had done all sorts of incredible things...I found that inspiring I suppose, to know that you can still go ahead...”

Such optimistic attitudes and approaches to MS have been found to be highly beneficial. Coping strategies such as focusing on the positive have been associated with higher levels of QoL (McCabe, 2006; McCabe & McKern, 2002; McCabe & De Judicibus, 2005). The present study suggests that having experiences with other PwMS

who are positive role models with optimistic attitudes helps the individual to maintain his or her own sense of hope and confidence.

With regards to unsupportive acts from other PwMS, the most commonly reported behaviour was rude and inappropriate actions. This typically took place during social interactions. This can be expected due to differences in personality, stages of acceptance of MS and personal characteristics. One interviewee reported the following experience with another person with MS,

“...and one day she got stuck into me very aggressively...that turned me off going to support groups for a long time because it sort of brought me down”

4.5.3.3 MEDICAL PROFESSIONALS

The following section will describe frequently reported helpful acts from medical professionals followed by frequently reported unhelpful acts. The GP and neurologist had a somewhat different pattern of supportive and unsupportive acts. The most helpful behaviour from the GP was technically competent medical care. This usually involved the administration of regular health checks, appropriate referrals and adequate medical care with common illnesses. Many participants expressed that the GP would put additional effort into their medical care because of MS. The neurologist was also valued for providing technically competent medical but not to the same extent as the GP. One participant explained the following support from her GP,

“...he doesn't take things at face value and he always takes what I say as serious...”

The neurologist was most valued for providing useful information and advice, this type of support was also somewhat valued from the GP. The neurologist often provided guidance and advice about how best to live with MS. People with MS are dealing with

the unknown; when initially diagnosed they have a great sense of uncertainty and therefore the neurologist is able provide some sense of direction. One participant explained her experience with her neurologist as follows,

“...his biggest advice to me was to make decisions in your life how you would’ve if you hadn’t been diagnosed and then make plans around it...”

Both the neurologist and the GP were also valued for providing optimism. These medical professionals commonly played a role in comforting their patients and providing hope for the future. One participant described this type of support from her neurologist as follows,

“I said “so what will I be doing in ten years time?” and he said “exactly what you want to be doing” and so he was really wonderful”

The GP was also noted to be supportive for calmly accepting the patients MS, understanding the nature of MS and its emotional impact and being kind and pleasant. No instances of these type of supportive acts were reported to occur from the neurologist.

When information and advice about MS was insufficient or inadequate this was viewed as the most unhelpful act from both the neurologist and GP. Participants indicated that many GP’s were uneducated on the nature, impact, symptoms and medications for MS. Participants also commonly recalled that when initially diagnosed the neurologist supplied minimal MS related information, leaving the patient feeling overwhelmed and confused. Participants expressed a need to have trust in the competency of their neurologist as this provided a sense of confidence to cope with the unpredictable nature of the disease. Participants wanted to be informed and take part in decisions about their treatment. One participant described this experience with a neurologist as follows,

“You want him to tell you all about it and what is going to happen...he just explained it briefly and then said “here is the book to read” and that’s when I got in contact with the MS society”

Some instances of providing technically incompetent medical care were reported to occur from both the neurologist and GP. Some participants also reported that the neurologist minimised the impact of MS; one participant described this experience as follows,

“... he just told me it wasn’t that bad and I didn’t have to end up in wheelchair...and then he gave me a few brochures by the MS society and he sent me away”

Participants also reported some instances of the neurologist expressing little concern or empathy, rude or inappropriate behaviour, and acting as a poor role model. These instances were rare and were not reported to occur by the GP only the neurologist.

People with MS desire more informational support from medical professionals. Black et al (1994) found they PwMS wanted more information about the disease and increased medical interventions following their diagnosis. In the present study participants often mentioned the lack of information that they received when initially diagnosed. No participant reported the unhelpfulness of having too much information from medical professionals. High quality information from medical practitioners during diagnosis can have a significant impact on the patients future coping strategies (Lode et al, 2007). When MS patients are satisfied with information they tend to engage in more adaptive coping strategies (Lode et al, 2007). People with MS require adequate informational support, however, many participants in the present study expressed a dissatisfaction with the amount of information they had received.

There is a need for realistic, supportive and encouraging information from medical professionals (Thorne et al, 2004). Previous research has indicated that when healthcare professionals communicate hope it assists with dealing with the uncertainty of MS (Miller & Murphy, 1997). Results from the present study indicate that greater information is desired; however, the communication of this information should be encouraging and supportive in order to assist with the adjusting and coping with MS.

4.5.4 THEORETICAL IMPLICATIONS

In regards to Wortman and Dunkel-Schetter (1979) victimisation model, the results of the present study indicate that some aspects but not the entire model applied to PwMS and their support networks. The model predicts that significant others may have negative feelings about the victimising event and believe it is inappropriate to openly discuss the difficulties with coping with the disease. Significant others may physically avoid the person, avoid open communication, engage in forced cheerfulness or minimise the impact of the individual's experiences. The present study found that avoidance of social contact was one of the most frequently mentioned unhelpful behaviours displayed by friends; however, no reports of avoidance of contact was recorded from the spouse or other family members. Minimisation of the impact of MS and the expression of little concern, empathy or affection were found to be common with respect to all of intimate support providers. Dakof and Taylor (1990) also found no reports of avoidance from the spouse or close family members. It appears that physical avoidance is a rare reaction among those closest to the individual such as the spouse and family members.

When taking into account the nature of the relationship, problematic patterns differ among support network members. The victimisation model does not take this factor

into consideration (Dakof & Taylor, 1990). By considering the support provider the present study revealed that interpersonal strengths and problems created by MS varied according to those involved. Patterns indicate that those closest to the person with MS tend to minimise the impact of the condition and express little concern, empathy or affection. As the distance between intimate others increases social avoidance becomes more likely to occur.

Some aspects of the present study's results are in accordance with Cutrona and Russell's (1990) model of optimal matching. The model suggests that an individual suffering from a medical illness has a greater need for emotional support to combat the uncontrollable event of becoming ill. In addition, tangible support is also required in order to compensate for possible physical limitations. The present study found these aspects of the model to be accurate with respect to support provided by intimate support network members and acquaintances. These support providers were highly valued for both emotional and tangible assistance. When emotional support was absent or misguided this was perceived by participants as the most unhelpful from these support providers.

Cutrona and Russell (1990) also suggest that with an uncontrollable event such as a medical illness individuals have less demand for informational support in comparison to when enduring a stressful controllable event in which information, advice and feedback are considered essential. The present study does not support this notion as participants frequently reported that most helpful type of support from other PwMS and the neurologist was information. When informational support from medical professionals was insufficient this was viewed as particularly unhelpful. These results and previous

research (Black et al, 1994; Thorne et al, 2004) indicate that PwMS place great importance on informational assistance.

The discrepancies between Cutrona and Russell's (1990) model and the present findings may be associated with the nature of MS. The disease is highly unpredictable and many people are unsure of what living with chronic illness entails. Multiple Sclerosis patients may have a stronger need and desire for information to assist with coping with this uncertainty and regaining a sense of control. Cutrona and Russell's (1990) model does not take into consideration the source of support and therefore the model may be incomplete as it does not consider the relationship between the provider and recipient. The present findings suggest that when the support provider is taken into consideration, the type of support which is viewed most beneficial varies according to the relationship.

The buffering hypothesis proposes that support has a positive impact in the presence of stress by protecting individuals from the negative consequences of such stress (Cohen & Syme, 1985; Wills & Fegan, 2001). Research has found that social support assists people who are coping with MS and leads to greater QoL, lower levels of depression and adjustment to the disease (Crigger, 1996; Gordon et al, 2002; Gulick, 2001; Miller & Murphy, 1997; Stuifbergen et al, 2000). The present study has provided a multidimensional approach to exploring social support for PwMS by examining naturally occurring helpful and unhelpful acts of support from various support providers and analysing these in terms of types of support and specific behaviours.

4.5.5 LIMITATIONS AND FUTURE DIRECTIONS

One limitation of this study is that it explored only the perspective of PwMS and not the actual support providers, thus not providing a transactional analysis of social support which explores the perspective of the provider, the recipient and considers the environment (Lazarus & Folkman, 1984). As suggested by Dakof and Taylor (1990) future research could address this limitation by investigating both the providers' and recipients' perspectives on social support. However, due to the minimal amount of prior research on perceived supportive and non supportive acts from the perspective of PwMS, it was appropriate that the initial focus was on establishing specific supportive and non supportive behaviours. A second limitation, was that participants' responses were reliant on the format of the questions asked. Dakof and Taylor (1990) also identified this limitation; however, the use of an open ended format was required in the present study as no other MS research had identified categories of helpful or unhelpful support for each support provider. This format may have limited the possible responses from participants. Although many participants consistently reported specific helpful and unhelpful acts from support providers, some may not have been able to spontaneously identify these behaviours.

A third possible limitation is that in an effort to provide a comprehensive qualitative evaluation of sources of social support each interviewee was asked a total of 28 questions. This may have resulted in participant fatigue. Several measures were taken in order to minimise the risk of fatigue. A pilot study was initially conducted, interviews were in a conversational style, beverages were provided and rest breaks were taken as needed. No participant displayed any sign of fatigue and interviews lasted between 45

minute to 1.5 hours. However, it is important to note to possible presence of fatigue as a limitation.

Fourthly, the generalisability of the results may be limited as all participant were members of the MS society, although many of them had minimal contact with the society. It is possible that PwMS who are not members of this society may have a different perspective of helpful and unhelpful social support as they may be less reliant on social support than individuals who are members of the MS society. It must also be noted that possible differences in the perceptive of helpful and unhelpful social support may be present between those who volunteered to participant in the study and those who did not wish to participate. The generalisability of results may also be limited by the fact that only 20 of the 100 individuals contacted responded and participated in the study. It possible that individuals who did not respond may have different perceptive and experiences of social support. Another possible limitation is that participants in Study 1 had been diagnosed with MS for a minimum of five years. This sampling strategy was used to ensure that participants were no longer newly diagnosed and had began to adjust and experience social exchanges which may have been impacted by MS. However, this may limit the generalisability of the results as newly diagnosed MS patients were not included in the study.

Finally, it is important to acknowledge that many participants noted that certain actions were particularly helpful or unhelpful during various times in their journey with MS. It was frequently reported by participants that a particular action was relevant given the state and stage of their MS at the time. For example, one participant mentioned the unhelpfulness of family members obtaining and sharing MS related information with him

at the time of his diagnosis. The participant desired emotional support at this time, However, he reported that once he had gained some level of acceptance this informational assistance was helpful. The results of the present study indicate that PwMS experience different actions as helpful and unhelpful from various potential support providers. Future research should explore the transactional nature of social support by investigating recipients, providers and interactions. Furthermore, research should explore what is helpful and unhelpful from various potential support providers at various stages of MS acceptance. By examining different stages of MS and what types of support or lack of support are perceived as most helpful and unhelpful a thorough understanding of social support for PwMS will be achieved. This information will allow for further refinement of interventions for PwMS.

4.6 SUMMARY

The results from Study 1 confirm the advantages taking into consideration both categories of helping and sources of aid. Results demonstrate that when taking the support provider into account different types of support are experienced as helpful and unhelpful. The study has provided a greater understanding of the social support experiences of PwMS by detailing specific acts which are viewed as helpful and unhelpful and also exploring the types of social support (emotional, informational and tangible) which are most useful from each support provider. The present study also provided some evidence for and against the various social support models such as the theory of optimal matching (Cutrona & Russell, 1990) and the victimisation model (Wortman & Dunek-Schetter, 1979). It provides a detailed description of naturally

occurring supportive and unsupportive behaviours whereas previous research tends to link general social support measures to adjustment outcomes and does not provide detailed descriptions of the aspects of support which are beneficial (Dennison et al 2009).

These findings will be critical to developing interventions which aim at improving social support for PwMS by informing support network members in behavioural terms what is commonly perceived as helpful and unhelpful. Interventions which focus on specific actions may provide a more concrete and clear understanding of appropriate support from the social network (Dakof & Taylor, 1990). The findings from this study will be used in Study 2 and a Social Support Questionnaire (Appendix 4) will be developed which explores helpful and unhelpful support from the seven potential support providers. This questionnaire aims to address the multidimensional nature of support and will be used in Study 2 to assist with identifying if perceptions of helpful and unhelpful support differ depending on levels of adjustment to MS.

**CHAPTER 5: STUDY 2 - ADJUSTMENT TO MULTIPLE
SCLEROSIS: APPLICATION OF THE FENNELL FOUR
PHASE MODEL**

5.1 BACKGROUND

Adjusting to MS can be challenging due to the unpredictable nature of the disease and symptoms. The process of adjustment involves a continual struggle to cope with these trying circumstances. Although research has suggested that the majority of PwMS adjust successfully to the condition, PwMS have been found to have significantly poorer levels of adjustment and self esteem in comparison to the general population (McCabe & Di Battista, 2004).

Various factors play a role in facilitating the process of adjustment for PwMS. Research has found that problem focused coping, positive reappraisal and acceptance coping assist adjustment (Arnett et al, 2008; Arnett et al, 2002; Dennison et al, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007; Montel & Bungener, 2006; Siegert & Abernethy, 2004). Emotion focused coping such as wishful thinking coping has been associated with poorer adjustment, greater depression and lower QoL (Arnett et al, 2008; Arnett et al, 2002; Dennison et al, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007; Marks & Millard, 1990; Montel & Bungener, 2006; Siegert & Abernethy, 2004). Perceiving MS as a challenge rather than a threat to the self has been linked to better adjustment levels (McCartney Chalk, 2007). Having a greater sense of control and self efficacy has also been found to facilitate adjustment (Dennison et al, 2009; Jopson & Moss-Morris, 2003). People with MS who attempt to make sense of their situation and are able to find positive elements in their experiences with the illness have more favourable outcomes (Pakenham, 2005; Pakenham, 2008). Finally, perceived social support has also been found to play an important function to adjusting to this chronic illness (Dennison et al, 2009).

Various models of adjustment to chronic illness have been proposed in the research; however, these models are limited in their comprehensiveness and usefulness. Most models tend to focus on only one or two domains such as psychological or cognitive adaptation and have limited empirical support. Fennell (1993; 1995; 2003a) proposed a four phase model of adjustment to chronic illness which is superior to other models as it provides a comprehensive and flexible approach. The Fennell Four Phase Model (FFPM) addresses the physical/behavioural domain, social/interactive domain, psychological domain as well as the possible trauma and stigmatisation associated with chronic illness (Fennell, 2003a). The approach postulates that an individual's body and mind, family members, friends, clinicians, work colleagues and general community are fundamental providers to a total situation in which changes that take place in one part of the system impact all other areas (Fennell, 2003a). The model views adjustment as a cyclical experience and provides phase-specific assessment methods and interventions to assist the patient and the social network to cope with the particular issues within each phase (Fennell, 2003a, Fennell, 2003b; Jason et al, 1999).

The overall goal of the FFPM is integration of the illness into the patient's life and improved QoL (Fennell, 2003a). Phase 1 is characterised by Crisis, in which the individual moves from the onset of illness to an emergency period. Phase 2 is characterised by Stabilisation, when the patient begins to recognise and understand his or her symptoms (Fennell, 1995; Fennell, 2003a). Phase 3 is known as Resolution, in which the patient recognises that his or her old life will not return and wrestles with life defining existential questions. Patients have learned how the illness behaves and have a profound realisation that their illness is chronic. Finally, Phase 4 is known as Integration, in which

patients have incorporated aspects of their pre- and post-illness self and finds new ways to express a new “personal best” (Fennell, 1995; Fennell, 2003a).

Empirical support has been found for the FFPM with CFS, although, the majority of adjustment models have no empirical support only theoretical justification. The FFPM warrants further empirical verification for other chronic illnesses such as Multiple Sclerosis as it is yet to be applied to this particular chronic illness. This model can provide useful information regarding the adjustment process as well as assessment and treatment options. Health professionals will have an improved understanding of the optimal types of interventions for PwMS depending on their phase status.

5.2 AIMS AND OBJECTIVES

Study 2 investigated the FFPM of adjustment for PwMS. The study examined the factor structure of the Fennell Phase Inventory (FPI) which was designed to measure the phases of chronic illness. Conducting a factor analysis will assist in determining whether the FPI does measure different possible phases of adjustment and allows for the examining of the factor structure of the FPI for PwMS. In order to further examine the experiences of individuals within each phase the present study also measured life satisfaction, coping styles, emotional states and perceived helpful and unhelpful social support. The study aimed to foster a greater understanding of the journey and struggles of PwMS from a systems approach by determining the appropriateness of the FFPM which maps common experiences of individuals with chronic illness. Study 2 is an extension of Study 1 as it explored if differences in perceptions of helpful and unhelpful social support

differed depending on level of adjustment. Social support was measured using a questionnaire which was developed from the findings from Study 1.

The study will address the following objectives:

1. To evaluate the appropriateness of the Fennell Phase Inventory in identifying the phases of adjustment in MS.
2. To examine the level of life satisfaction, coping styles, levels of depression, anxiety, and stress and levels of perceived illness severity, coping and QoL associated with each phase of the FFPM.
3. To explore if individuals in different phases of adjustment have different perceptions on the types of social support that most helpful and unhelpful from various support network members.
4. If the FPI is found to be an appropriate measure of adjustment for PwMS, to identify a scoring procedure for the FPI which can be used for PwMS.

Based on previous empirical research on adjustment and MS and the theoretical and empirical findings from the FFPM it was hypothesised for Study 2 that:

- The four phases identified in the FFPM will occur for PwMS. This FFPM is a model for mapping the adjustment process of chronic illness. Therefore, this model is likely to represent the adjustment journey for PwMS.
- Individuals in the Crisis phase of adjustment would have lower levels of life satisfaction, engage in unhelpful coping strategies such as wishful thinking and have higher levels of depression, anxiety and stress than individuals in the other phases of adjustment.

- Individuals in the Integration phase of adjustment would report the most favourable outcomes with greater life satisfaction, engage in useful coping strategies such as problem focused coping and seeking social support, and have lower levels of psychological distress.

No hypotheses were developed for the Stabilisation or Resolution phase as the research for these phases was primarily exploratory in nature.

5.3 METHOD

5.3.1 PARTICIPANTS

The sample consisted of 152 individuals registered with the Multiple Sclerosis Society of New South Wales and Victoria (NSW/VIC), Australia and 11 individuals from and the Australian MS online chat room. Six returned questionnaires were excluded from the study as important aspects were incomplete. Table 4 provides the socio-demographics of the sample. In general, the sample was primarily female with a mean age of 46.47 years. Most participants were married, had children and lived with their partner and children, children only or partner only. Most participants reported suffering from relapsing remitting MS and only few participants regularly attended support group meetings. The average duration since the most recent exacerbation of symptoms was three years with an average severity. The average current symptom state was perceived by participants to be average to good.

Table 4

Socio-demographics of Participants in Study 2

| | | <i>n</i> |
|----------------------------------|-------|----------|
| Gender | | |
| Female | 73.0% | 119 |
| Male | 26.4% | 43 |
| Missing data | .6% | 1 |
| Age | | |
| Mean | 46.47 | - |
| SD | 10.18 | - |
| Marital Status | | |
| Married | 63.2% | 103 |
| Single | 12.3% | 20 |
| Divorced | 11.0% | 18 |
| Defacto | 4.9% | 8 |
| Other | 8.0% | 13 |
| Missing data | .6% | 1 |
| Residential Status | | |
| Living with Partner and Children | 33.1% | 54 |
| Living with Partner Only | 37.4% | 61 |
| Living with Children Only | 6.1% | 10 |
| Living Alone | 16.0% | 26 |
| Other | 6.7% | 11 |
| Missing data | .6% | 1 |
| Children | | |
| Yes | 74.2% | 121 |
| No | 25.2% | 41 |
| Missing data | .6% | 1 |
| Average Number of Children | 1.81 | - |
| SD of Number of Children | 1.34 | - |
| Employment Status | | |
| Unemployed | 23.3% | 38 |
| Retired | 22.7% | 37 |
| Part time employment | 22.7% | 37 |
| Fulltime employment | 22.1% | 36 |
| Other | 8.0% | 13 |
| Missing Data | 1.2% | 2 |

| | | | |
|-----------------------------------|------------------------|-----|--|
| Support Group Attendance | | | |
| Regularly Attend | 13.5% | 22 | |
| Irregularly Attend | 9.8% | 16 | |
| Past Attendance | 25.8% | 42 | |
| Never Attended | 50.3% | 82 | |
| Missing Data | .6% | 1 | |
| Type of MS | | | |
| Relapsing Remitting MS | 69.3% | 113 | |
| Secondary Progressive MS | 14.7% | 24 | |
| Primary Progressive MS | 6.1% | 10 | |
| Unsure of Diagnosis | 8.0% | 13 | |
| Missing Data | 1.8% | 3 | |
| Duration Since Exacerbation | | | |
| Mean | 3 years | - | |
| SD | 4.48 | - | |
| Severity of Previous Exacerbation | | | |
| Mean | 5.82 – Average | | |
| SD | 2.18 | | |
| Current Symptom State | | | |
| Mean | 2.62 – Good to Average | | |
| SD | 1.05 | | |

5.3.2 MATERIALS

Several measures were used to obtain information regarding demographics, illness state, coping styles, emotional states, adjustment levels, satisfaction with life and perceived helpful and unhelpful social support.

5.3.2.1 DEMOGRAPHICS INFORMATION

Demographic details were obtained regarding participant's age, gender, relationship status, living situation, employment status, number of children, extent of support group attendance, course of MS, date and severity of the most recent relapse of symptoms and current symptom state. This demographic questionnaire also asked participants to indicate on scale of 1 to 10 their subjective levels of anxiety, moodiness, coping and quality of life.

5.3.2.2 MEASUREMENT OF PHASE CLASSIFICATION

Adjustment to MS was explored through the Fennell Phase Inventory (FPI; Fennell, Jason, & Klein, 1998). This inventory consists of 20 items which were generated to address the physical/behavioural, psychological and social/interactive aspects of the illness experience (Fennell et al, 1998). The inventory contains 5 items from the 4 phases of adjustment proposed by the FFPM. Participants were asked to rate each item on a five-point scale (1= definitely do not agree, 5 = very strongly agree).

5.3.2.3 COPING STYLE

Coping styles were assessed using a shorten version of Folkman and Lazaru's (1988) Ways of Coping Questionnaire (WOCQ; Scherer, Luther, Weiebe & Adams, 1988) which was made up of 30 items. This questionnaire contains a list of different cognitive and behavioural strategies that an individual may use to cope with a stressful situation. Five subscales are calculated including; problem-focused coping (10 items), detachment (6 items), wishful thinking (6 items), seeking social support (5 items) and focusing on the positive (4 items).

Participants were asked to rate the frequency with which they use each strategy on a four-point Likert type scale, ranging from 0 = not used to 3 = used a great deal. For the purpose of the present study, the stressful situation for participants was their illness. The WOCQ has been used extensively to investigate coping strategies in a variety of populations. Research examining the underlying factor structure of the shortened version of this scale supports its construct validity (Scherer et al, 1988; Brown, 1994).

5.3.2.4 SATISFACTION WITH LIFE

General life satisfaction was measured using the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). This scale avoids making assumptions about the importance individuals ascribe to particular domains of their life and allows individuals to place their own standards of evaluation. The SWLS contains five-items with a 7-point Likert-type response format. Responses are added to create a total score ranging from 5 to 35. A score of 20 represents a neutral point at which the respondent is equally satisfied and dissatisfied with life. The SWLS has demonstrated

good internal consistency with alpha coefficients consistently exceeding .80 (Pavot & Diener, 1993).

5.3.2.5 EMOTIONAL STATES

Emotional states were examined by using the Depression, Anxiety, Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995). This scale was designed to measure the negative emotional states of depression, anxiety and stress. This scale has been reported to distinguish between the major factors of depression (Anthony, Beiling, & Cox, 1998; Crawford & Henry, 2003). Participants used a 4-point Likert scale ranging from 0 = did not apply to me at all, to 3 = applied to me very much, or most of the time for each symptom over the past week. Scores for Depression, Anxiety and Stress are calculated by summing the scores of the relevant items. The DASS-21 has demonstrated good internal reliability (Anthony et al, 1998; Crawford & Henry, 2003). Caution must be taken when interpreting the anxiety scores of the DASS-21 for individuals with MS as many of the items measure physiological symptoms which may be related to MS rather than anxiety.

5.3.2.6 PERCEIVED HELPFUL AND UNHELPFUL SOCIAL SUPPORT

Social support was explored by using a questionnaire which was constructed from the qualitative findings in Study 1. Study 1 adopted the methodology used by Dakof and Taylor (1990) who investigated social support and cancer. The study demonstrated the usefulness of measuring social support as a multidimensional variable. All data obtained from Study 1 was included in the questionnaire. The questionnaire aimed to examine participant's perspectives of helpful and unhelpful social support behaviours from seven

potential support providers. The questionnaire asked participants to rank emotional, informational, and tangible support or lack of support within the three types of social support in order helpfulness and unhelpfulness for seven potential support providers; spouse, other family members, friends, other PwMS, neurologist, GP and acquaintances. The questionnaire aimed to identify differences in participants' perceptions of helpful and unhelpful social support from various support network members.

5.3.3 PROCEDURE

Participants were randomly selected from the Multiple Sclerosis Society of NSW/VIC register. Six hundred potential participants were sent a letter of endorsement from the MS Society, an information sheet, a consent form, a prepaid return envelope and the questionnaire package (see Appendix 4). A notice was also placed on the Australian MS online chat room (see Appendix 5). The notice provided information regarding the study and requested potential participants to contact the researcher either by telephone or email. Respondents who volunteered were sent the questionnaire package with a prepaid return envelope.

5.4 RESULTS

5.4.1 FACTOR ANALYSIS

In order to investigate the underlying structure of the 20-item Fennell Phase Inventory, data were collected from 163 participants with MS. In total 155 of the 600 potential participants returned the completed questionnaire package. The other eight participants were recruited from the notice placed on the MS online chat room. The

response rate from the mail out survey was 26%. Twork, Wirtz, Schipper, Klewer, Bergmann and Kugler (2007) found an average response rate of 44.8% by PwMS. The response rate for the present study is somewhat lower than this average response rate which may be result of length of the questionnaire package.

Results were subjected to a principal component factor analysis with varimax rotation. Evaluation of assumptions was generally satisfactory, although the data indicated that not all variables were perfectly normally distributed. The variable which corresponded with item 13 of the inventory “It is my fault I got sick” was found to have minimal variability, therefore this item was excluded from further analysis. The remaining 19 items demonstrated a relatively normal distribution with only minor deviations which were not considered problematic. There were no missing data.

Following the recommendations of Tabachnick and Fidell (2001) no univariate outliers were found in the data as no z scores in excess of ± 3.29 were located. Examination for multivariate outliers was performed by requesting the Mahalanobis distance for each participant. By applying the recommendations of Tabachnick and Fidell (2001) significant multivariate outliers were identified by extreme Mahalanobis distance scores ($p < .001$). In total seven multivariate outliers were deleted from the analysis as Mahalanobis distance scores were greater than the critical value of 43.82 (Tabachnick & Fidell, 2001). The internal consistency of the questionnaire found to have a Cronbach’s alpha of .824 which was considered adequate for research purposes.

A factor analysis (limited to four factors) was then performed on the 19 items with a total of 156 participants as seven participants were deleted from the analysis due to being multivariate outliers. The factor loadings ($>.45$) for each of these factors are

presented in Table 5. In total these four factors accounted for 55.07% of the variance in the questionnaire data. Cronbach's alpha was recalculated for the four factors and two the values were within the moderate range and two of the values were in the lower range (Factor 1, .85; Factor 2, .72; Factor 3, .61; Factor 4, .65).

Factor one consisted of six items (8, 12, 15, 16, 19, and 20) which reflected phase 4 of the FFPM and was labelled the Integration Factor. This factor accounted for 20.33% of the total sample's variance. Factor two consisted of five items (2, 6, 7, 14, and 18) and was consistent with phase 2 of the model. This factor was labelled the Stabilisation Factor and accounted for 14.00% of the sample's variance. Factor three was comprised of four items (1, 5, 9, and 17) and resembled phase 1 of the model. This factor was labelled the Crisis Factor and accounted for 11.05% of the variance for the sample. Finally, factor four included four items (3, 4, 10, and 11) and was consistent with phase 3 of the model. This factor was identified as the Resolution Factor and accounted for 9.70% of the total variance for the sample.

An unlimited factor analysis was also performed and a five factor solution (with Eigenvalues exceeding 1) was identified as underlying the 19 questionnaire items. Factor five was found to contribute minimally to the analysis with an Eigenvalue of only 1.08 and with only two items loading on this factor, both which also loaded on other factors. The examination of the scree plot indicated a four factor solution and the theoretical background of the inventory also supports a four factor solution (Fennell, 1993; Fennell, 1995; Fennell, 2003a). The inclusion of the unlimited factor analysis further strengthens the rationale for performing and examining a limited four factor analysis. Results for the

unlimited factor analysis have been fully reported in Appendix 6, there is no further reference to this unlimited factor analysis in the following analysis.

Following the procedures used by Jason, Fennell et al (2000) the 19 items used in the analysis were grouped according to the factor loading patterns. This resulted in four Crisis items in one group, five Stabilisation items in the second group, four Resolution items in the third group and six Integration items in the fourth group. The mean for each participant was calculated for the four item groups by adding the sum of the responses (ranging from 1 = strongly disagree to 5 = strongly agree) and dividing these by the total number of items for each factor.

In the analysis by Jason, Fennell et al (2000) factor mean scores were substituted for the factor regression scores. Jason, Fennell et al (2000) reported that when the correlation matrix from Jason, Fennell et al (1999) was re-performed with the regression scores results were similar to when the factors mean scores were used and therefore further analyses used the regression scores. The present study also substituted the factor mean scores for factor regression scores and performed two correlation matrixes with non-categorical variables. Results were comparable and therefore the present study also substituted the factor mean scores with factor regression scores in the analyses that follow.

Table 5

Varimax Rotated Component Loading for Factor Analysis Limited to Four Factors

| Item | Factors | | | |
|---|---------|-----|-----|-----|
| | 1 | 2 | 3 | 4 |
| I have gained a sense of myself that is blended | .65 | ... | ... | ... |
| I have better more satisfying relationships with people | .70 | ... | ... | ... |
| My illness experience has some value | .73 | ... | ... | ... |
| I am proud of myself for living with this illness | .75 | ... | ... | ... |
| I am beginning to have compassion for myself | .65 | ... | ... | ... |
| I am a better and wiser person since I first got sick | .83 | ... | ... | ... |
| Beginning to recognise how my symptoms occur | ... | .69 | ... | ... |
| Beginning to seek support and information from others | ... | .48 | ... | ... |
| I am in the early process of creating meaning | ... | .50 | ... | ... |
| There may be things I can do to help myself feel better | ... | .65 | ... | ... |

| | | | | |
|--|-------------|---------------|--------|------------|
| I am just beginning to stabilise | ... | .69 | ... | ... |
| I feel like I am falling apart | ... | ... | .56 | ... |
| My physician must find me the right treatment | ... | ... | .67 | ... |
| I need to know with certainty if/when I am going to get better | ... | ... | .79 | ... |
| I think about my illness all of the time | ... | ... | .53 | ... |
| I will need to become a new person | ... | ... | ... | .64 |
| Illness involves getting sicker, at times, and improving, at times | ... | ... | ... | .77 |
| Starting to feeling like I have some control of my life | ... | ... | ... | .46 |
| I am beginning to learn how to live with the unknown | ... | ... | ... | .48 |
| % of variance | 20.33 | 14.00 | 11.05 | 9.70 |
| Label | Integration | Stabilisation | Crisis | Resolution |

Note: Values <.45 have been suppressed

5.4.2 CLUSTER ANALYSIS

Each participant now had a factor regression score for each of the four factors (Crisis, Stabilisation, Resolution, and Integration). Jason, Fennell et al (2000) employed a hierarchical cluster analysis in order to determine if participants could be categorised into distinct clusters based on these scores. The present study also conducted a hierarchical cluster analysis in order to group participants for further analysis. In performing the cluster analysis, the squared Euclidean distance measure was selected; this method assigns participants to clusters based on the distance between participants (Jason, Fennell et al, 2000). In grouping participants into clusters, the agglomerative hierarchical clustering method was utilised. The present study employed the Ward's method as this method maximises between group differences and minimises within-group differences (Borgen & Barnett, 1987; Ward, 1963). The dendrogram was examined and four clusters clearly emerged.

5.4.3 CLUSTER PROFILING

Forty-three participants were assigned to Cluster one, Cluster two consisted of 32 participants, Cluster 3 included 60 members and Cluster 4 had 21 individuals. A one-way between groups analysis of variance (ANOVA) was used to investigate the differences between the clusters on variables which met the assumption of normality. The ANOVA test assumptions of normality were found to be satisfactory for variables including the four factor mean scores, the five scores for the WOCQ (problem focused coping, detachment, wishful thinking, seeking social support and focusing on the positive), age, and SWLS under the four cluster conditions. Some variables displayed a pseudonormal

distribution possibly due to the smaller sample sizes. Generally these variables were normally distribution and deemed suitable for parametric testing. Alpha coefficients for the coping subscales in the current study were .64 for detachment coping, .73 for seeking social support coping, .81 for wishful thinking coping and problem solving coping and .68 for positive reappraisal coping. The alpha coefficient for the SWLS in the present study was .87. Any cases with missing data were excluded completely from the relevant analysis.

One participant was excluded from the ANOVA for the WOCQ and one participant from the ANOVA for the SWLS. These participants were repeatedly found to be extreme outliers (with more than 2 SD difference) on these variables and were therefore excluded from the relevant analysis. The results from the one-way ANOVA using $\alpha = .05$ are shown in Table 6. Significant differences were examined with post hoc analyses using a Bonferroni test for variables which met the assumption of homogeneity of variance and the Games –Howell test for variables which did not met the assumption of homogeneity of variance (including the Resolution and Integration factor means), results are shown in Table 7. The ANOVA analysis indicated no significant differences across clusters in age, wishful thinking coping, seeking social support coping and focusing on the positive coping.

The Kruskal-Wallis nonparametric test was used for the variables which were found to have non normal distributions including the DASS-21, self reported items including number of children, severity of most recent acute episode, current symptom state, anxiety levels, moodiness levels, QoL and coping. The alpha coefficients for the subscales of the DASS-21 for the present study were .87 for the stress scale, .58 for the

anxiety scale and .93 for the depression scale. Alpha was set at .05 for the Kruskal-Wallis nonparametric test. Results from the Kruskal-Wallis are shown in Table 8. Significant results were further investigated with post hoc comparisons between pairwise means using the Mann-Whitney test with an adjusted alpha of .008 in order to maintain a family-wise alpha rate over multiple comparisons (Allen & Bennett, 2008) . Results from these analyses are shown in Table 9. The Kruskal-Wallis revealed no significant differences between clusters in number of children, severity of most recent acute episode and current symptom state.

Chi-squared tests were used to explore relationships between cluster membership and categorical variables including gender, marital status, living situation, presence of children, employment status, support group involvement and type of MS. No significant differences were found across the four clusters on these variables. Chi-squared tests of contingencies were also used to evaluate whether individuals in the four clusters had different perceptions of helpful and unhelpful social support across seven potential support providers (spouse, friends, other family members, other PwMS, GP, neurologist and acquaintances). Fourteen chi-squared tests were performed (helpful and unhelpful support from each of the seven potential support providers) and no statistically significant results were found.

Table 6

One-Way Analysis of Variance Results Across Cluster Grouping

| Variable | <i>F</i> | <i>df</i> between groups, within groups | η^2 |
|--------------------------------------|----------|--|----------|
| Crisis Raw Score Mean | 53.36** | 3,152 | .513 |
| Stabilisation Raw Score Mean | 42.17** | 3,152 | .454 |
| Resolution Raw Score Mean | 5.28** | 3,152 | .094 |
| Integration Raw Score Mean | 39.22** | 3,152 | .436 |
| WoCQ – Detachment Coping | 5.01** | 3,150 | .091 |
| WoCQ – Seeking social support Coping | .62 | 3,150 | .012 |
| WoCQ – Wishful Thinking Coping | 1.04 | 3,150 | .020 |
| WoCQ – Problem Solving Coping | 3.07* | 3,150 | .058 |
| WoCQ – Positive Reappraisal Coping | .72 | 3,150 | .014 |
| Satisfaction with Life | 3.55* | 3,149 | .067 |

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

Table 7

One-way ANOVA Post Hoc Analyses on Variables Across Clusters

| Variable | Cluster 1 | | Cluster 2 | | Cluster 3 | | Cluster 4 | |
|-------------------------------|---------------------|-------|---------------------|-------|--------------------|-------|--------------------|-------|
| | M | SD | M | SD | M | SD | M | SD |
| Crisis Raw Score Mean | 3.22 ^{abc} | .59 | 2.02 ^a | .38 | 2.17 ^b | .52 | 1.86 ^c | .52 |
| Stabilisation Raw Score Mean | 2.99 ^a | .63 | 3.43 ^{ab} | .49 | 2.70 ^b | .54 | 1.76 ^{ab} | .42 |
| Resolution Raw Score Mean | 3.65 | .68 | 3.97 ^a | .53 | 3.67 | .55 | 3.19 ^a | 1.20 |
| Integration Raw Score Mean | 2.95 ^a | .69 | 4.05 ^{ab} | .49 | 2.51 ^a | .64 | 2.92 ^b | .81 |
| WOCQ – Detachment Coping | 20.16 ^a | 9.22 | 27.13 ^{ab} | 7.29 | 18.90 ^b | 10.47 | 21.62 | 11.49 |
| WOCQ – Problem Solving Coping | 15.58 ^a | 11.24 | 23.74 ^a | 13.38 | 19.02 | 11.86 | 16.33 | 11.80 |
| Satisfaction with Life | 18.33 ^a | 7.43 | 23.80 ^a | 7.06 | 20.75 | 7.75 | 22.65 | 7.58 |

Note: Means with common superscripts across row are significantly difference at the <.05 level.

Table 8

Kruskal-Wallis Results Based on Cluster Grouping

| Variable | χ^2 |
|------------------------------|----------|
| DASS -21 - Anxiety levels | 3.14 |
| DASS -21 - Stress levels | 7.87* |
| DASS- 21 - Depression levels | 17.82** |
| Self Rated Anxiety | 20.43** |
| Self Rated Moodiness | 25.43** |
| Self Rated Coping Level | 12.66** |
| Self Rated QoL | 15.82** |

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

Table 9

Mann-Whitney Post Hoc Analyses on Variables Across Clusters

| Variable | Cluster 1 | Cluster 2 | Cluster 3 | Cluster 4 | | |
|----------------------|-----------|-----------|-----------|-----------|----------|----------|
| | Mean Rank | Mean Rank | Mean Rank | Mean Rank | <i>U</i> | <i>z</i> |
| DASS-21 Stress | 36.63 | | | 22.05 | 231.00 | -2.94 |
| DASS-21 Depression | 46.01 | 25.69 | | | 300.50 | -4.03 |
| | 61.40 | | 45.27 | | 886.00 | -2.71 |
| | 37.37 | | | 20.45 | 199.00 | -3.42 |
| Self Rated Anxiety | 44.41 | 29.39 | | | 412.50 | -2.98 |
| | 61.91 | | 44.90 | | 864.00 | -2.88 |
| | 38.48 | | | 20.26 | 194.50 | -3.74 |
| Self Rated Moodiness | 46.24 | 26.92 | | | 333.50 | -3.84 |
| | 62.36 | | 44.58 | | 844.50 | -3.01 |

| | | | | | |
|-------------------|-------|-------|-------|--------|-------|
| | 38.69 | | 44.58 | 185.50 | -3.84 |
| Self Rated Coping | 27.60 | | 42.52 | 241.00 | -3.03 |
| Self Rated QoL | 27.43 | | 42.88 | 233.50 | -3.18 |
| | | 35.74 | 56.02 | 314.00 | -3.45 |

Note: Mean Ranks across rows are significantly different at the <.008 level

5.4.3.1 CLUSTER ONE

An analysis of the characteristics of Cluster 1 showed considerable similarities with Fennell's (Fennell et al 1998; Fennell, 2003a; Jason et al, 1999; Jason, Fennell et al, 2000) first phase of Crisis. The participants in this cluster had a significantly higher mean on the Crisis factor in comparison to participants from the other three clusters.

Individuals in Cluster 1 were also found to have a significantly higher mean on the Stabilisation factor than individuals in Cluster 4 but a significantly lower Stabilisation factor mean than Cluster 2. No significant differences were found with respect to the Resolution factor mean. Participants in Cluster 1 were found to have a significantly higher Integration factor mean than individuals in Cluster 3; however, a significantly lower Integration mean than those in Cluster 2.

Participants in Cluster 1 were significantly less likely to use detachment coping or practice problem solving coping as a means of dealing with their MS than participants in Cluster 2. With respect to satisfaction with life, Cluster 1 demonstrated the lowest level of satisfaction with life across all clusters and a significantly lower level of satisfaction with life than individuals in Cluster 2. Participants in Cluster 1 were also found to have significantly high levels of depression (measured on the DASS-21) than all other clusters and significantly higher levels of stress (measured on the DASS-21) than members of Cluster 4. With respect to the self rated items, participants in Cluster 1 had significantly higher self rated anxiety and moodiness than all the other clusters and significantly lower self rated coping level and QoL than Cluster 4.

5.4.3.2 CLUSTER TWO

Cluster 2 was characterised by a significantly higher score on the Integration factor mean than all the other clusters and a significantly lower Crisis factor mean score than Cluster 1. This cluster was deemed to represent Fennell's fourth phase (Fennell et al 1998; Fennell, 2003a; Jason et al, 1999; Jason, Fennell et al, 2000) of Integration. Individuals in Cluster 2 also demonstrated a significantly higher Stabilisation score than all the other clusters and a significantly higher Resolution mean than Cluster 4.

Participants in Cluster 2 reported the greatest use of problem solving coping and detachment coping in comparison to all other clusters. Cluster 2 members were significantly more likely to use detachment coping than those in Clusters 1 and 3 and were significantly more likely to use problem solving coping than those in Cluster 1. This cluster demonstrated the overall highest score on the SWLS and was found to have a significantly higher satisfaction with life than Cluster 1. No significant differences were found with levels of anxiety or stress (measured by the DASS-21) but Cluster 2 members reported significantly lower levels of depression as measured by the DASS-21 than participants in Cluster 1. Individuals in Cluster 2 also reported significantly less anxiety and moodiness than individuals in Cluster 1.

5.4.3.3 CLUSTER THREE

Cluster 3 and 4 demonstrated a similar pattern of scores across the factor means. Cluster 3 was deemed to be most representative of the third phase of Fennell's model (Fennell et al 1998; Fennell, 2003a; Jason et al, 1999; Jason, Fennell et al, 2000) identified as Resolution. Cluster 4 demonstrated moderate to low ranges of scores across

all factor means which is more representative of the second phase of Fennell's four phase model known as Stabilisation (Jason, Fennell et al, 2000). Individuals in Cluster 3 had a significantly lower Crisis mean than Cluster 1 and a significantly lower Stabilisation mean than Cluster 2; however, a higher Stabilisation mean than Cluster 4. No significant differences across the Resolution mean were found but participants in Cluster 3 had a significantly lower Integration mean than those in Cluster 1 and 2.

Cluster 3 was found to be significantly less likely to engage in detachment coping than Cluster two. No significant differences were found in problem focused coping or satisfaction with life for Cluster 3; however, participants were found to have the second highest problem focused coping score. With respect to the emotional states measured by the DASS-21, no differences were found with stress levels but members of Cluster 3 were found to have significantly lower depression levels than those in Cluster 1. In addition, self rated anxiety and moodiness levels were found to be significantly lower than those in Cluster 1. Self rated QoL was found to be significantly lower than members of Cluster 4.

5.4.3.4 CLUSTER FOUR

Cluster 4 was found to have moderate to low scores across all the factor means and was found to be most representative of the Stabilisation phase (a et al 1998; Fennell, 2003; Jason et al, 1999; Jason, Fennell et al, 2000). Participants in this cluster had a significantly lower Crisis mean score than members of Cluster 1 and the significantly lowest Stabilisation mean score across all other clusters. In addition, Cluster 4 members were found to have a significantly lower Resolution mean and Integration mean than participants in Cluster 2.

No significant differences in ways of coping or satisfaction with life were found, however participants were found to have the second highest satisfaction with life score and detachment coping score. Individuals in Cluster 4 had significantly lower stress and depression levels as measured by the DASS-21 than members of Cluster 1. With respect to the self rated items, members of Cluster 4 reported significantly lower anxiety and moodiness levels and higher coping levels than members of Cluster 1. Individuals in Cluster 4 also reported significantly higher QoL than Clusters 1 and 3.

5.4.4 PROPOSED SCORING METHOD FOR THE FENNEL PHASE INVENTORY FOR PEOPLE WITH MULTIPLE SCLEROSIS

A discriminant analysis was used in order to classify individual using a discriminant prediction equation. The purpose of this procedure was to develop a scoring equation which can classify individual and be utilised in clinical practice for assessing PwMS with the FPI. With the use of a discriminant analysis the classification function coefficients were obtained. The solution results indicated that 84.6% of the total cases were classified correctly, this is substantially higher compared with 28% of cases who would be classified correctly by chance alone (Tabachnick & Fidell, 2001). The classification function coefficients are presented in Table 10. Using the Crisis, Stabilisation, Resolution and Integration mean scores, regression equations can be applied in order to assign individuals to one of the four phases of the FFPM. The Crisis mean is calculated by adding items 1, 5, 9 and 17 of the FPI and dividing by four. The Stabilisation mean is calculated by adding items 2, 6, 7, 14, and 18 of the FPI and dividing by five. The Resolution mean is calculated by adding items 3, 4, 10 and 11 of the FPI and dividing by four. Finally, the Integration mean is calculated by adding items

8, 12, 15, 16, 19 and 20 of the FPI and dividing by six. The regression equations for each of the four phases are listed below and can be applied in order to determine which phase of the FFPM an individual is likely to be experiencing. The phase with the highest score is most likely to be the phase that the person with MS is currently experiencing.

1. *Regression equation 1 for Crisis* = $-37.498 + 11.320 (\text{Crisis mean}) + 5.263 (\text{Stabilisation mean}) + .976 (\text{Resolution mean}) + 5.670 (\text{Integration mean})$
2. *Regression equation 2 for Integration* = $-37.290 + 6.314 (\text{Crisis mean}) + 3.379 (\text{Stabilisation mean}) + 1.992 (\text{Resolution mean}) + 7.140 (\text{Integration mean})$
3. *Regression equation 3 for Resolution* = $-24.580 + 6.197 (\text{Crisis mean}) + 4.976 (\text{Stabilisation mean}) + 3.200 (\text{Resolution mean}) + 3.432 (\text{Integration mean})$
4. *Regression equation 4 for Stabilisation* = $-21.420 + 6.315 (\text{Crisis mean}) + 1.026 (\text{Stabilisation mean}) + 2.491 (\text{Resolution mean}) + 5.940 (\text{Integration mean})$

Table 10

Classification Function Coefficients

| | Phase – Cluster | | | |
|----------------------------|-----------------|-------------|------------|---------------|
| | Cluster 1 | Cluster 2 | Cluster 3 | Cluster 4 |
| | Crisis | Integration | Resolution | Stabilisation |
| Crisis Mean | 11.320 | 6.314 | 6.197 | 6.315 |
| Stabilisation Mean | 5.263 | 6.379 | 4.976 | 1.026 |
| Resolution Mean | .976 | 1.992 | 3.200 | 2.491 |
| Integration Mean | 5.670 | 7.140 | 3.432 | 5.940 |
| Constant | -37.498 | -37.290 | -24.580 | -21.420 |
| Cases Correctly Classified | 81.4% | 93.8% | 83.3% | 81.0% |

5.4.5 PERCEIVED HELPFUL AND UNHELPFUL SOCIAL SUPPORT

Results from the Chi-squared-tests demonstrated no significant differences between clusters on perceptions of helpful and unhelpful types of social support from seven key support network members. Although no differences were found among clusters on perceptions of helpful and unhelpful social support, the results from this questionnaire were also explored as a whole to provide additional support for the qualitative findings from Study 1. In order to investigate the most helpful and unhelpful types of support from each of the potential support providers the 14 questions from the questionnaire were subjected to statistical analyses. Friedman two way ANOVA's were conducted followed by Wilcoxon Signed Rank tests to determine significant differences. A summary of the findings is reported below and the complete statistical results can be viewed in Appendix 6.

Helpful Support from the Spouse

Findings indicated that the rankings of helpful types of support from the spouse varied significantly. Helpful emotional support from the spouse was perceived as significantly more valuable than tangible support and informational support. Tangible support was perceived as more helpful than informational support.

Unhelpful Support from the Spouse

Results signified that rankings of unhelpful types of support from the spouse varied significantly. Hurtful or inadequate emotional support was perceived as significantly more unsupportive than inadequate or unwanted tangible assistance and unhelpful informational support. No significant differences were found between unhelpful informational and tangible support.

Helpful Support from Other Family Members

Significant differences were found in the rankings of helpful types of support from other family members. Emotional support were perceived as significant more important than tangible assistance and informational support. No differences were found between rankings for helpful informational and tangible support from other family members.

Unhelpful Support from Other Family Members

Unhelpful types of support from other family members varied significantly. unhelpful or inadequate emotional support was perceived as significantly more detrimental than unwanted tangible assistance and unhelpful informational support. No significant differences were found between rankings for unhelpful informational and tangible support.

Helpful Support from Friends

Significant differences were found in the rankings of helpful types of support from friends. Emotional support from friends was found to be the most valued type of assistance in comparison to informational and tangible support. No differences were found between helpful informational and tangible support.

Unhelpful Support from Friends

Unhelpful types of support from friends varied significantly with unhelpful or inadequate emotional support from friends being perceived as significantly more hurtful and unsupportive than unwanted tangible or informational assistance. Differences

between unhelpful informational and tangible support from friends was found to be non significant.

Helpful Support from Other PwMS

Findings indicated significant differences in the rankings of helpful types of support from other PwMS. Emotional support from other PwMS was considered significantly more important than tangible support. Informational support was found to be significantly more valuable than tangible assistance from other PwMS. No significant difference was found between helpful informational and emotional support indicating that other PwMS are equally valued for both emotional and informational support.

Unhelpful Support from Other PwMS

Results signified that rankings of unhelpful types of support from other PwMS varied significantly. Unhelpful or inadequate emotional support was perceived as significantly more unsupportive than unwanted tangible or informational assistance. No differences were found between unhelpful informational and tangible support.

Helpful Support from the GP

Helpful types of support from the GP varied significantly as tangible support in the form of competent medical care and also informational assistance was perceived as significantly more valuable than emotional support. No differences were found between helpful informational and tangible support, which indicates that the GP was similarly valued for providing both competent medical care and MS related information.

Unhelpful Support from the GP

Findings indicated that rankings of unhelpful types of support from the GP varied significantly. Unhelpful or inadequate tangible support in form of incompetent medical

was perceived as significantly more unhelpful than inadequate emotional and informational support. No significant differences were found between unhelpful emotional and informational support from the GP.

Helpful Support from the Neurologist

Helpful types of support from the neurologist varied significantly with tangible support in the form of competent medical care and also informational support being viewed as significantly more valuable than emotional support. No significant difference was found between helpful informational and tangible (competent medical care) support from the neurologist.

Unhelpful Support from the Neurologist

Results indicated that rankings of unhelpful types of support from the neurologist varied significantly. Unhelpful or inadequate tangible and informational support in form of incompetent medical care from the neurologist was perceived as significantly more unsupportive than inadequate emotional assistance. No differences were found between unhelpful tangible and informational support.

Helpful Support from Acquaintances

Significant differences were found in the rankings of helpful types of support from acquaintances. Emotional support and tangible assistance from acquaintances was viewed as significantly more helpful than informational support. No significant differences were found between helpful emotional and tangible support.

Unhelpful Support from Acquaintances

Rankings of unhelpful types of support from acquaintances varied significantly with unhelpful or inadequate emotional support being experienced as significantly more

unsupportive than unwanted tangible assistance and informational support. Unwanted tangible assistance was also perceived as more unhelpful than inadequate informational support.

5.5 DISCUSSION

Study 2 aimed to evaluate the applicability of the FFPM of adjustment to Multiple Sclerosis. This aim was achieved by exploring the structure of the Fennell Phase Inventory in a sample of PwMS. The study aimed to identify characteristics of each of the phases of the Fennell model by examining levels of life satisfaction, coping styles and emotional states. The study was also an extension of Study 1 which identified the importance of studying social support from a multidimensional approach. Study 2 aimed to extend Study 1 by exploring if individuals experiencing different phases of the FFPM had different perceptions of helpful and unhelpful types of social support from seven key support providers.

5.5.1 STRUCTURE OF THE FENNEL PHASE INVENTORY FOR MULTIPLE SCLEROSIS

The present study supports a distinction between four factors within the FPI as a model for evaluating MS patients. The four factors appear to theoretically capture the FFPM of the adjustment for PwMS. Study 2 is the first empirical investigation of the FFPM for PwMS and one of the few studies which has provided empirical evidence for an adjustment model for MS patients. All four factors presented with moderate reliability,

with the Integration factor having the strongest statistical qualities and the Crisis and Resolution factors having slightly lower reliability scores.

Several differences were evident in comparison with Jason et al (1999) who examined the structure of the inventory for CFS patients. Table 11 presents the different items in the FPI for each factor, item 1 refers to factors scores found by Jason et al (1999) and item 2 refers to factors scores found in the current study. Jason et al (1999) found a three factor solution including Crisis, Stabilisation and Integration, whereas the present study found a four factor solution including all four phases of the model. The Crisis factor was comprised of the same four items for both studies (1, 5, 9, and 17). The Stabilisation factor in Jason et al (1999) included 10 items whereas the present study found five items within this factor. These five items were all found by Jason et al (1999) to also be in the Stabilisation factor. The additional items in the Jason's et al (1999) Stabilisation factor were found in the present study to either load on the Resolution or Integration factor. As Jason et al (1999) did not find a Resolution factor no comparison can be made with the present study. Finally, with respect to Integration factor some differences were evident as several items identified by Jason et al (1999) as comprising the Integration factor were found in the present study to be linked to either the Stabilisation or Resolution factors.

These differences suggest that the experience of PwMS may be somewhat different to the experience of CFS patients. Multiple Sclerosis involves lesions to the brains white matter and the disease is chronic and progressive in nature (Eeltink & Duffy, 2004). Although CFS like MS can affect multiple systems in the body, MS has a clear progressive element. With each relapse of symptoms an individual's baseline of

functioning slightly deteriorates (Feinstein, 2007). Although most individuals with MS are initially diagnosed with RRMS a future diagnosis of secondary progressive MS is common (Feinstein, 2007). The media portrayal of MS is also likely to differ from that of CFS. Multiple Sclerosis is often associated with loss of mobility and being wheelchair dependent, which is another aspect of adjustment that MS patients need to confront and consider. These differences may explain some of the variances between the factor structure of the FPI found in the present study and that found by Jason et al (1999).

A cluster analysis was performed using the regression factor scores from the factor analysis. The results indicated that four groups were present which resembled the four phases suggested by Fennell (1993; 1995; 2003a). Findings were similar to those reported by Jason, Fennell et al (2000) who also found a distinction between four groups based on the regression factor scores of CFS patients. The characteristics of each cluster were examined and will be discussed below.

The present study has also proposed scoring method for the FPI for PwMS. This scoring method allows a clinician to administer the inventory, apply four regression equations and gain an impression as to which of the four phases the patient is currently experiencing. Jason, Fricano et al (2000) also provided a scoring method which was designed for CFS patients. This scoring method can not be utilised for PwMS as the research supporting the method was obtained from CFS patients. The current study has provided a unique scoring method based on the results from the factor and cluster analysis and is specifically designed for PwMS. This scoring method can be used by clinicians to assist with determining optimal treatment and interventions based on phase status.

Table 11

The Fennell Phase Inventory Structure

| Item | 1 | 2 |
|--|---|----------------|
| 1. I feel like I am falling apart | C | C |
| 2. I am just beginning to recognise when and how my symptoms occur | S | S |
| 3. I am beginning to accept the fact that I will never be completely like I was before the illness and that I will need to become a new person | S | R |
| 4. I now have learned that living with the illness involves getting sicker, at times, and improving, at times | I | R |
| 5. The primary way for me to improve is if my physician finds me the right treatment | C | C |
| 6. I am beginning to seek support and information from others who have or who know about the illness | S | S |
| 7. I am in the early process of creating meaning about my illness experience | S | S |
| 8. I have gained a sense of myself that is blended – a combination of my life before and after I first got sick | I | I |
| 9. I need to know with certainty when and if I am going to get better | C | C |
| 10. I just want to feel like I have some control over my life | S | R |
| 11. I am beginning to learn how to live with the unknown or chronic nature of my illness | S | R |
| 12. I have better and more satisfying relationships with people I care about since I first became sick | X | I |
| 13. It is my fault I got sick | X | X ¹ |
| 14. I am just starting to realise that there may be things I can do to help myself feel better | S | S |
| 15. I am starting to see my illness experience as having some value | S | I |
| 16. I am proud of myself for living with this illness | I | I |

| | | |
|---|---|---|
| 17. I think about my illness all of the time | C | C |
| 18. I am just beginning to stabilise (i.e., feeling a bit less confused and a bit more ordered) | S | S |
| 19. For the first time, I am beginning to have compassion and love for myself and for what I have endured | S | I |
| 20. I am a better and wiser person since I first got sick | I | I |

1: Factor scores found by Jason et al (1999)

2: Factor scores found in the present study

C: Crisis Factor

S: Stabilisation Factor

R: Resolution Factor

I: Integration Factor

X: Did not significantly load

X¹: Was removed from analysis

5.5.1.1 CLUSTER ONE

Cluster 1 resembled the experience of individuals in the first phase of FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a), the Crisis phase. It was hypothesised that individuals in the Crisis phase would be more likely to engage in unhelpful coping strategies, such as wishful thinking, be experiencing higher levels of depression, anxiety, stress and lower levels of QoL than the other phases. This hypothesis was supported in the findings. Participants in this cluster were found to have the highest Crisis mean score than any other cluster and were found to be less likely to use detachment coping or problem focused coping when dealing with MS. Cluster 1 members reported the lowest satisfaction with life, higher levels of depression and stress, higher self-rated anxiety and moodiness, and lower self-rated QoL and coping. These findings correspond with the struggles associated with the Crisis phase of the model (Fennell, 1993; Fennell, 1995; Fennell, 2003a). Furthermore, the items of the FPI which were associated with the Crisis phase indicated that individuals felt a lack of control, had an external locus of control, had minimal tolerance for uncertainty associated with their illness and were consumed by the illness. These aspects clearly represent the Crisis phase of the model (Fennell, 1993; Fennell, 1995; Fennell, 2003a).

During the Crisis phase denial may be utilised as a means of coping (Fennell, 1995; Fennell, 2003b). The present study did not find participants in Crisis to be significantly more likely to use denial as a means of coping with MS. Fennell (1995; 2003b) suggests that when symptoms continue to increase patients are unable to continue to engage in denial and therefore suffer from a sense of fear, hopelessness and confusion. The participants in the present study appear to be suffering from this fear, hopelessness

and confusion as they are experiencing poorer emotional outcomes with higher depression, stress, lower satisfaction with life, greater anxiety and moodiness and difficulty coping.

Findings indicate that the Crisis group were suffering from clinically moderate levels of depression and stress. Multiple Sclerosis patients have often been found to suffer from mood disorders (Beiske et al, 2008; Dalton & Heinrichs, 2005; Feinstein, 2004). Levels of depression have been related to levels of uncertainty associated with the illness (Kroencke et al, 2001; Uguz et al, 2007). Research has indicated that depression can be successfully treated in MS patients and leads to a range of positive outcomes including increased wellbeing and QoL, increased benefit finding, increased perceived social support and utilisation of support, improved positive affect and reduced disability (Hart et al, 2005; Hart et al; 2008; Mohr et al, 2004; Mohr et al, 2005; Mohr et al; 2007). Fennell (2003a) reports that during the Crisis phase patients have no tolerance for ambiguity or uncertainty concerning their illness (Fennell, 2003). Higher levels of depression in Crisis may be associated with this limited tolerance for the uncertainty associated with MS. Psychotherapy using cognitive-behavioural interventions have been found to be more useful in assisting with symptom management for PwMS (Mohr et al, 2007). It is possible that this therapeutic approach provides MS patients with an increased sense of control over MS symptoms and reduces the sense of uncertainty associated with symptoms. This approach may be particularly effective for patients in the Crisis phase of adjustment.

Having an external locus of control is also common for individuals in Crisis as they were more likely to believe that improvement was possible only through the

physician (Fennell, 2003). Previous research has indicated that having a limited sense of control and limited understanding about MS is related to lower levels of psychological adjustment (Jopson & Moss-Morris, 2003). People with MS who have an internal locus of control and have the belief that they have the capacity to influence the course of the illness have been found to have improving self concepts over time and also lower levels of depression (Brooks & Matson, 1982; Halligan & Reznikoff, 1985).

Individuals in the Crisis phase were not found to be more likely to engage in unhelpful coping strategies such as wishful thinking as the other phases but they were found to be less likely to engage in helpful coping strategies. They were less likely to actively deal with their illness as they were less likely to use problem focused coping than the Integration group. These findings correspond with Jason, Fricano et al (2000) who found that CFS patients in Crisis were less likely to use active coping strategies. The use of coping strategies such as problem focused coping has been associated with better psychological adjustment (Arnett et al, 2008; Arnett et al, 2002; Dennison et al, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007). The Crisis group was also less likely to employ detachment as a means of coping with MS. The use of detachment coping may be of assistance as it allows the individual to focus on other aspects of life. Given the limited use of detachment coping by individuals in Crisis it is probable that participants felt overwhelmed by the illness and unable to distance themselves.

Lower QoL and satisfaction with life has commonly been found for PwMS. Research has indicated that individuals with MS experience lower levels of QoL in virtually all domains in comparison to the general population (Aronson, 1997; McCabe, 2006; McCabe & McKern, 2002; Murphy, Confavreux, König, Roullet, Sailer, Swash, &

Young, 1998; Nortvedt, Riise, Myher, & Nyland, 1999). The present study supported these findings with the Crisis group, who reported a tendency to be 'slightly unsatisfied' with life, had the lowest level of satisfaction with life and reported lower QoL than other clusters.

Stress was found to be common difficulty for MS patients in Crisis phase. These findings correspond with previous research which found strong links between levels of perceived stress associated with MS and adjustment (Dennison et al, 2009). It has been reported that individuals who appraised high levels of stress and used emotion focused coping suffered higher levels of distress and therefore poorer adjustment (Pakenham, 1999).

Jason, Fennell et al (2000) and Jason, Fricano et al (2000) found that CFS patients experiencing the Crisis phase perceived and experienced their illness as more severe and disabling and had greater symptom severity than individuals in the other phases of adjustment. The present study did not find any significant differences among clusters in regards to their reported symptom severity. The present study did not utilise a formal method of assessing disability and symptoms associated with MS but asked participants to rate their current symptom state from 'very poor' to 'excellent'. It is possible that with a formal method of assessment, symptom severity may have differed between groups. In summary, the Crisis group was found to have the highest Crisis mean score, greater psychological distress with higher depression, stress, anxiety, moodiness and difficulty coping and be less likely to engage in active coping strategies to deal with MS.

5.5.1.2 CLUSTER TWO

Cluster 2 was considered to be associated with the Integration phase of the FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a). It was hypothesised that individuals in the Integration phase would present with more favourable outcomes by having greater life satisfaction, use helpful coping strategies and have lower psychological distress than the other phases of the model. This hypothesis was supported in the findings from the present study. Participants in this cluster scored the highest on the Integration factor and second lowest on the Crisis factor. Interestingly, the Integration group had one of the highest Stabilisation and Resolution scores in comparison to the other groups. Jason, Fennell et al (2000) found that the Integration group for CFS patients had the highest Integration score and lowest Crisis and Stabilisation scores in comparison to the other groups. Although the Integration group in the present study did not present with the same profile of scores as Jason, Fennell et al (2000) it was evident that this group was most representative of the Integration phase for PwMS. It is possible that with MS a state of integration and adjustment involves elements of earlier phases of adaptation. Individuals in Integration may have been beginning to stabilise and understand symptoms from a recent relapse but are able to maintain a state of Integration despite having relapses of symptoms. Fennell (2003b) reports that patients in Integration understand the cyclical nature of their condition and a relapse is viewed as the commencement of another cycle which must be integrated (Fennell, 2003b). Within this phase individuals have surpassed the trauma of phase one, have developed the stabilisation of phase two and the meaning in phase three (Fennell, 2003a). Moderate to high scores on the Stabilisation and Resolution mean can

therefore be expected as the Integration phase has elements of each of these earlier phases.

The patterns of results from cluster 2 support the expected profile of the individuals in the Integration phase (Fennell, 1993; Fennell, 1995; Fennell, 2003a). The FPI items which were found to be linked to Integration signified that individuals had recognised that they had integrated their pre- and post-illness lives, experienced more satisfying relationships, engaged in benefit finding from their illness experience, had developed as a person, and were able to have pride and compassion for themselves. Fennell (2003a) reports that during Integration patients are able to blend aspects of their pre-illness and post-illness lives and find new ways to express a new “personal best”. Individuals in Integration have developed emotionally, are proud and have compassion for themselves and their struggles (Jason, Fennell et al, 2000).

The profile of the Integration group is also similar to the ‘Integration’ stage of Matson and Brooks (1977) proposed adjustment model. Matson and Brooks (1977) report that during this stage individuals deal with MS related problems with little emotion and can even find benefits and a deepening sensitivity to life experiences (Matson & Brooks, 1977). Integration members in the present study were able to detach themselves from MS related issues when required, reported benefit finding and also personal development.

Findings from the present study indicate that during Integration PwMS are more likely to engage in problem focus coping and detachment coping as a means of dealing with MS. The benefits of using problem focused coping have been well documented in the MS literature. Research demonstrates that when PwMS use problem focused coping they experience positive outcomes including adjustment, lower levels of depression and

greater QoL (Arnett et al, 2008; Arnett et al, 2002; Dennison, Moss-Morris & Chalder, 2009; McCabe & De Judicibus, 2005; McCartney Chalk, 2007; Mohr & Cox, 2001; Montel & Bungener, 2006; Siegert & Abernethy, 2004). By using problem focused coping individuals in Integration are demonstrating that they are taking an active stance to dealing with MS related problems.

The use of detachment coping has also been found to be beneficial for PwMS. McCabe et al (2009) found that over time PwMS tended to use less wishful thinking and more detachment as a means of coping. McCabe et al (2009) reported that these changes were indicative of greater levels of acceptance over time. The combination of problem focused and detachment coping appears to be beneficial for PwMS. An individual in Integration may be able to detach themselves emotionally from many MS related issues. When an issue requires attention they are able to use effective problem solving methods. The combination of these coping strategies is suggestive of greater adjustment.

Individuals in the Integration group also demonstrated the lowest level of depression, highest satisfaction with life and reported lower anxiety and moodiness than the Crisis group. Greater psychological wellbeing also suggests that this group has reached a level of adjustment and understanding of their condition. Lower levels of depression among the Integration group may be associated with acceptance of the illness, use of more effective coping strategies and also lower levels of disease related uncertainty.

Making meaning of MS and benefit finding has been found to significantly impact adjustment. It is evident that based on the items of the FPI, the Integration group has been able to make meaning and also find benefits associated with MS such as becoming a

better and wiser person and having more satisfying relationships. Viewing MS as an opportunity for growth and positive change has been found to be the strongest predictor of adjustment (Pakenham, 2007a). Many PwMS are often able to report personal growth as a result of the disease (Pakenham, 2007b). Research has found that benefit finding is commonly reported by PwMS and can involve a deepening of relationships with others, greater appreciation for life and enhanced spirituality (Mohr et al, 1999). Acceptance of MS as part of life, integration of the illness and experienced growth and positive change have been associated with positive adjustment with greater life satisfaction, positive mental states and lower depression (Pakenham, 2008). When MS patients have the belief that their illness has led to a deepening faith and connections to others and setting of new priorities in life they are likely to experience higher QoL and life satisfaction (Russell et al, 2006). These findings correspond with results of the Integration group as this group had greater acceptance of MS, a blended pre-and post-illness self, personal development and benefit finding. This group also was found to have lower depression and greater satisfaction with life in comparison to other phases. The process of benefit finding and creating meaning are key aspects of adjustment to MS and have been found to occur in the Integration group of the present study. Overall, individuals in the Integration group were found to have the highest Integration mean score, engage in active coping strategies and also detachment as a means of dealing with MS, have the highest satisfaction with life and psychological functioning.

5.5.1.3 CLUSTER THREE

Cluster 3 was considered to be associated with the Resolution phase of the FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a). Only slight differences were evident between cluster 3 and 4; however, cluster 3 was found to be more representative of Resolution. Individuals in cluster 3 demonstrated high scores on the Stabilisation and Resolution factors and moderate scores on the Crisis and Integration factors. The Resolution group in Jason, Fennell et al (2000) demonstrated high scores on the Crisis, Stabilisation and also the Integration factors and also reported high symptom severity which was deemed to be representative of a possible relapse of symptoms which can be encountered during the Resolution phase. As previously mentioned the present study did not find any significant differences among clusters in regards to symptom severity but disability and MS symptoms were not formally assessed.

The FPI items which were found to be linked to the Resolution phase corresponded with the characteristics described by Fennell (1993; 1995; 2003a). Items signified that individuals in this phase recognised the need to become a new person, had an understanding of the relapsing and remitting nature of their illness, had a sense of control over their lives and were learning to live with the chronic and ambiguous nature of their illness. These aspects are strongly associated with the Resolution phase of the FFPM (Fennell 2003a).

The Resolution group were found to have the second highest score on problem focused coping and the lowest score on the detachment coping. It appears that the Resolution group were more actively dealing with MS related issues with problem solving strategies but struggled to detach and emotionally distance themselves as

individuals in the Integration group were able to do. Individuals in Resolution had a greater internalised locus of control which is evident by this group having the second highest problem solving coping score (Fennell, 2003a). Participants appeared to be actively managing their MS and taking control of the situation. During Resolution an individual is working towards making meaning and is learning to tolerate the chronic and ambiguous nature of their illness (Fennell, 1995, Fennell, 2003a). While in this phase it may be difficult for patients to detach and distance themselves from their MS related issues as they are still emotionally adjusting. These characteristics correspond with the findings that the Resolution group utilised problem focused coping but were less reliant on detachment as means of coping.

The Resolution group were found to have a neutral level of satisfaction with life, indicating that they were neither satisfied nor dissatisfied. This group was also found to report lower perceived QoL in comparison to Cluster 4 (Stabilisation). Lower perceived QoL and neutral level of satisfaction with life may be a result of the emotional struggles that individuals in Resolution are confronting. During this period patients must acknowledge that their old life will not return and they struggle with life defining existential questions (Fennell, 1995). As patients in this phase are coming to accept the chronic nature of their illness and searching for meaning they may experience deep despair and grieve the loss of their pre-illness life (Fennell, 1995; Fennell & Bateman, 2005). It is possible that the findings from the present study indicating that individuals in the Resolution group have lower QoL than Cluster 4 (Stabilisation) and report a neutral satisfaction with life are associated with the grief reaction and emotional struggle during Resolution. During this period patients are working towards finding new meaning and

quality in their lives and therefore may experience lower QoL and satisfaction with life until this struggle is resolved and they progress towards Integration. Fennell (2003a) reports that higher QoL is experienced by patients who find a means to accept and live meaningfully with the chronic and ambiguous nature of their condition.

Although this group appear to be experiencing a secondary emotional crisis they do not report the same degree of psychological distress as the Crisis group. The Resolution group was found to have lower depression and lower self reported anxiety and moodiness than the Crisis group. In addition, the mixed factor scores indicate that individuals in Resolution may be experiencing elements of Crisis possibly associated with a secondary emotional crisis but are also moving towards Integration as they are better able to deal with this crisis. In summary, members of the Resolution phase were found to have high scores on the Stabilisation and Resolution means and moderate scores on the Crisis and Integration means. Participants in this phase were also found to engage in active coping strategies; however, struggle to detach from MS. They reported a neutral level of life satisfaction and lower QoL than the Stabilisation group.

5.5.1.4 CLUSTER FOUR

Cluster 4 was considered to represent the Stabilisation phase of the FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a). Individuals in Cluster 4 demonstrated low to moderate scores on the Crisis, Stabilisation, Resolution and Integration factors. Jason, Fennell et al (2000) also found that the Stabilisation group of CFS patients to have moderate range scores on the Crisis, Stabilisation and Integration factors. Jason, Fennell et al (2000) suggested that moderate scores across factors indicate that patients are

moving towards emotional stability but are in the initial stages of understanding how to cope and live with their illness.

The FPI items which were found to be linked to the Stabilisation phase signified that individuals in this phase were in the initial stages of learning about their symptoms and illness, were seeking out information and support from others, gaining a greater internal locus of control, feeling less confusion, beginning to stabilise and also moving towards creating meaning about their illness experiences. During the Stabilisation phase it is expected that patients will begin to gain some sense of control and feel less confusion (Fennell, 2003a). Patients also begin to regain an internal locus of control. It is during this period that individuals seek out others like themselves as their sense of self slowly increases (Fennell, 2003a). Individuals during this phase continue to have a limited tolerance for the chronic and ambiguous nature of their condition but begin to understand that their condition is long term (Fennell, 2003a). During Stabilisation patients may also begin to create meaning and perceive some value in their illness experience but also struggle with losses associated with their pre-illness lives (Jason, Fennell et al, 2000).

The Stabilisation group demonstrated improved psychological functioning in comparison with the Crisis group with lower depression, stress, self reported anxiety and moodiness and greater coping and QoL. Improved psychological functioning is characteristic of Stabilisation as individuals move towards emotional stability and are less consumed by the illness and problems in comparison to when in Crisis (Fennell, 2003a; Jason, Fennell et al, 2000). Jason, Fennell et al (2000) also found that the Stabilisation group of CFS patients exhibited increased emotional stability. In addition Jason, Fricano et al (2000) found the Stabilisation group to have the lowest levels of psychological

impairment. Much like the present study Jason, Fricano et al (2000) found that the Resolution group had greater psychological impairment than the Stabilisation group.

During Stabilisation patients are not be focused on accepting the chronic nature of their condition as when in Resolution. Many patients attempt to resume their normal lives and activities (Fennell, 2003a). During this phase patients may slowly come to understand that they are unable to return to their pre-illness lives although they are still in the process of learning about how their illness behaves. Greater psychological functioning during Stabilisation is possibly due to the fact the patients do not yet have a profound understanding of the chronic nature of their condition and are not struggling with issues of integrating their pre- and post-illness lives to the extent of the Resolution group. This may explain the present findings of the Stabilisation group having the second highest satisfaction with life score which indicated that they were 'slightly satisfied' with life and also significantly high self reported QoL than the Resolution group. Overall, the Stabilisation group had low to moderate scores on all factor means and greater psychological functioning and emotional stability in comparison to the Crisis group.

5.5.2 PERCEPTIONS OF HELPFUL AND UNHELPFUL SOCIAL SUPPORT

A social support questionnaire was constructed based on the findings from Study 1 which signified the importance of measuring social support as a multidimensional variable. The questionnaire aimed to explore the types of most helpful and unhelpful social support from key support network members. Using the questionnaire and also cluster membership, the present study investigated differences between clusters on perceptions of helpful and unhelpful social support. No differences between clusters were

found which indicates that regardless of the adjustment phase that PwMS are experiencing, perceptions of helpful and unhelpful support from various support providers are similar.

The results from the questionnaire were also examined to determine the most helpful and unhelpful types of support for each support provider. These quantitative results can be compared to the qualitative findings from Study 1. Much like Study 1 the present study found that intimate support providers including the spouse, other family members and friends shared a similar pattern of supportive and unsupportive acts. These support providers were most likely to be valued for emotional support and also somewhat valued for tangible aid. Inadequate or inappropriate emotional support was viewed as the most hurtful and unhelpful type of acts from intimate support providers. These findings are similar to Study 1 which found that intimate support providers were most valued for emotional assistance; however, when emotional assistance was absent or misguided this was viewed as the most damaging.

The present study found that acquaintances were equally valued for tangible aid and emotional assistance. Absent or misguided emotional support was viewed as the most hurtful act from these support providers. Again these findings correspond with results from Study 1 which found that acquaintances were similarly valued for esteem/emotional and tangible support and viewed as most unhelpful when inadequate emotional support was provided. Similar results were found between Study 1 and 2 in regards to other PwMS. These support providers were found to be equally valued for informational and emotional assistance in both studies. Other PwMS were viewed as most unhelpful when providing inadequate or misguided emotional assistance in both studies.

The present study found that both the GP and neurologist were equally valued for providing competent medical care (tangible aid) and also informational support. No significant differences were found between these types of support. Study 1 found that the neurologist was most likely to be identified as helpful for informational assistance rather than competent medical care; however, the present study found that both types of support were equally important. The present study found that the GP was viewed as most unhelpful when providing inadequate or insufficient medical care. However, the neurologist was viewed as most unhelpful when providing either inadequate medical care or insufficient informational support. These results indicate that PwMS expect the neurologist to provide both competent medical care and adequate informational assistance. However, expectations of the GP tend to centre on providing competent medical care. Therefore the neurologist is likely to be perceived as the most important source for MS related informational support.

These results support the qualitative findings from Study 1 and indicate the importance of intimate support providers to be informed and educated on the significance of providing adequate emotional assistance for PwMS. The findings also signify the important and unique role of other PwMS as they are able to provide both emotional assistance and also useful information and advice. Results indicate the importance of both the GP and neurologist to provide informational assistance for PwMS.

5.5.3 LIMITATIONS AND FUTURE DIRECTIONS

One limitation of the present study was that it did not utilise a formal method for assessing MS symptoms or level of functioning. Participants were asked to indicate their

current symptom state from ‘very poor’ to ‘excellent’. No significant differences were found between phases on reported symptom state. Without a formal method of assessment of functioning and impairment the participants were required to make a subjective judgment regarding MS symptoms and therefore comparisons between individuals is difficult. Future research should address this limitation with the inclusion of a formal functional assessment and also investigation of biological markers to ensure consistency between findings regarding MS symptoms and functioning.

The duration of MS was also not investigated in the present study. Previous research has found mixed results in regards to disease duration and levels of adjustment. The present study did not explore this variable and therefore future research should investigate the relation between duration of MS and phase status. It is possible that longer disease duration may be associated with greater adjustment and therefore the Integration phase of MS. Participants were also self reported MS sufferers, the present study did not verify diagnosis with treating neurologists or medical professionals. Future research should aim to address this limitation by verifying diagnosis and also disease status.

Participants were primarily recruited through the MS Society of NSW/VIC. Individuals who were not registered with this organisation were not accessible in the present study. A community sample may have yielded different results as non MS Society members could have different profiles in comparison to MS Society members. Furthermore, it is also important to note that those individuals who received the questionnaire package and chose not participate may also have different profiles to individuals who volunteered and took part in the study. Therefore the generalisation of these results may be limited due to the participants involved in the study. Finally, when

the participants were allocated to phases and clusters, sample sizes were relatively small. It is possible that with larger sample sizes other significant differences may have emerged.

The present study represents the first empirical investigation of the FFPM for PwMS. Previous research has provided minimal empirical support for adjustment processes for PwMS. Study 2 provides preliminary support for the FFPM but could not address and measure all aspects of adjustment and MS. Future research should evaluate the model more thoroughly with the inclusion of additional outcome tools measuring variables such as functional and disease status, perceptions of control, quality of life, benefit finding, self-esteem, self-concept and additional aspects of social support. Future research should also explore and rule out alternative explanations for finding four phases, such as personality factors. Findings from this study indicate four phases of adjustment for PwMS. However, longitudinal research will need to be conducted in order to investigate if PwMS actually move through these phases. The FFPM for PwMS may also warrant further investigation by exploring if differences in adjustment occur between different courses of MS. Future research can also explore the usefulness and timing of intervention techniques proposed by Fennell (2003a). In addition, conducting a qualitative study of PwMS who are identified as being in the Integration phase of adjustment will also be beneficial. Such research can provide thorough descriptions and insight into the characteristics of Integration for PwMS and will also provide guidance for intervention programs.

5.6 SUMMARY

Study 2 examined the usefulness of the FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a) for mapping the adjustment process for PwMS. Investigation of the structure of the FPI indicated the presence of four adjustment phases which are proposed by the model. Factor regression scores were then subjected to a cluster analysis which indicated the presence of four groups each representing one of the Fennell phases.

Cluster 1 was identified as the Crisis phase and individuals in this group were found to have the highest Crisis mean score, suffer from greater psychological distress and be less likely to engage in active coping strategies to deal with MS. Cluster 2 was found to be associated with the Integration phase and individuals in this group were found to have the highest Integration mean score, use active coping strategies and also detachment as a means of dealing with MS, have the highest satisfaction with life and psychological functioning. Cluster 3 was associated with the Resolution phase of adjustment. This group was found to have high scores on the Stabilisation and Resolution means and moderate scores on the Crisis and Integration means. The Resolution group was found to engage in active coping strategies but have difficulty detaching from MS related issues. This group had a neutral level of life satisfaction and lower QoL than the Stabilisation group. The Resolution group may have been encountering a secondary emotional crisis due to coming to terms with the chronic nature of MS and loss of their pre-illness lives. Finally, Cluster 4 was identified as the Stabilisation group and was found to have low to moderate scores on all factor means. The Stabilisation group was found to have improved psychological functioning and emotional stability in comparison to the Crisis group.

The FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a) provides a valuable method for assessing, treating and understanding adjustment to chronic illness. Study 2 has provided empirical verification for the model for PwMS. Findings indicate that PwMS experience the phases proposed by the model and differences are evident between the phases. Although the FFPM provides a structure for the adjustment process it is important to not consider the model as a linear model which is inflexible and rigid (Jason, Fricano et al, 2000). Fennell (2003a) proposes that while patients must initially progress through the phases in a fixed sequence, it is likely, that given the relapsing and remitting nature of chronic illness, to regress back to an earlier phase and also to be in more than one phase at any given time. Furthermore, patients may even skip a phase or remain in a single phase without further movement (Fennell, 2003a, Jason, Fricano et al, 2000). The FFPM provides a flexible and comprehensive approach which explores the physical/behavioural domain, social/interactive domain, psychological domain and possible trauma and stigmatisation of chronic illness (Fennell, 1993; Fennell, 1995; Fennell, 2003a). Further research into the FFPM will be beneficial as this approach provides useful guidance regarding the adjustment processes, assessment and treatment options to assist PwMS to improve their QoL.

CHAPTER 6

CONCLUSION

Multiple sclerosis is the most commonly acquired neurological disease in young adults (Antonak & Livneh, 1995). It is a chronic and progressive disease which affects the nerve fibres leading to demyelisation and slowing of nerve impulses (Eeltink & Duffy, 2004). Adjusting and coping with MS can be extremely challenging. People with MS often suffer from mood disorders and experience lower QoL in comparison to the general population (Beiske et al 2008; Dalton & Heinrichs, 2005; Feinstein, 2004; McCabe & McKern, 2002).

Social support has been found to protect against and moderate the negative psychological impact of physical illness and stressful life events (Cohen & Wills, 1985; Dennison et al, 2009). The use of social support as a coping mechanism has been found to enhance adjustment, mediate the effects of emotional distress, maintain QoL and improve wellbeing for PwMS (Arnett et al, 2008; Crigger, 1996; Gordon et al, 2002; Gulick, 2001; Miller & Murphy, 1997; Reynolds and Prior, 2003; Stuifbergen et al, 2000). Unfortunately support and social interactions experienced by PwMS are not consistently positive. Relationships are often impacted by the disease as family and friends are unable to cope and therefore withdraw from social contact (Reynolds & Prior, 2003).

Multiple Sclerosis research indicates the importance of adequate social support and identifies the positive impact of such support. No research has specifically investigated the types of social support which PwMS perceive as helpful and unhelpful from various individuals in the support network. Cancer research has produced several studies which measure social support from a multidimensional perspective (Dakof & Taylor, 1990; Dunkel-Schetter, 1984; Helgeson & Cohen, 1996). This research has

identified the types and sources of support which are most helpful and most unhelpful for people with cancer. Study 1 employed a fine grained approach to the investigation of social support which was initially developed by Dakof and Taylor (1990) to study social support and cancer. Findings indicated the importance of taking the support provider into consideration. Results provided a comprehensive behavioural description of the most helpful and unhelpful acts from each of the key support providers. Findings indicated the important emotionally supportive role that intimate support providers play (spouse, other family members and friends), the unique value of other PwMS by providing informational assistance, optimism, hope and emotional support and the criticalness and need for greater informational resources from medical professionals.

Results from Study 1 offer concrete and behavioural descriptions of what PwMS perceive as useful assistance. Each support network member was identified as most helpful or unhelpful for providing or not providing a certain type of support. This support has then been described in specific acts to provide a comprehensive understanding of the unique role of each support provider. Findings indicate the importance for PwMS to have an adequate and supportive network of family, friends, peers and medical professionals as each support provider plays a unique and important role in assisting the individual with MS. These findings correspond with previous research which has suggested that the helpfulness of specific acts may be dependent on the provider of the support (Wortman & Conway, 1985).

The perception of high levels of social support has consistently been associated with better adjustment for PwMS (Dennison et al, 2009). Adjusting to MS is advantageous as individuals who do not adjust often experience negative outcomes

including suicidal feelings, disruptions in interpersonal relationships, less positive affect and lower self-esteem (Eklund & MacDonald, 1991). The Fennell Four Phase Model (Fennell, 1993; Fennell, 1995; Fennell, 2003a) is a comprehensive approach to mapping the adjustment process of chronic illness. The model addresses the physical/behavioural domain, social/interactive domain and psychological domain. Most importantly the model acknowledges the importance of the support network in adjusting to chronic illness. Fennell (1993; 1995; 2003a) proposes that adjustment is a cyclic process consisting of four phases including, Crisis, Stabilisation, Resolution and Integration. Empirical verification of the model has been obtained for CFS (Jason et al, 1999; Jason, Fennell, et al, 2000; Jason, Fricano et al, 2000).

Study 2 provided preliminary empirical support and verification for the FFPM for MS. The study also utilised findings from Study 1 and examined helpful and unhelpful social support from the key support providers to determine if individuals in different phases of adjustment had different perspectives of helpful and unhelpful support. No significant findings were found among the different phases in perceptions of helpful and unhelpful social support. These results indicate that regardless of adjustment level PwMS have similar social support needs. Participants were not asked to indicate the helpfulness of each specific supportive behaviour but rather the overall categories of support including esteem/emotional, informational and tangible. Perhaps taking a more specific approach and asking individuals to identify the most supportive and non supportive behaviours may have yielded significant differences among members of different phases. The quantitative social support findings from Study 2 corresponded with the results from

the taxonomic analysis from Study 1. Results indicated the types of social support from each of the support providers which were viewed as most helpful and unhelpful.

The individuals in each of the FFPM phases were found to have significant differences in emotional states, ways of coping, satisfaction with life and self reported moodiness, anxiety, QoL and coping levels. Jason, Fennell et al (2000) have reported that patients are likely to experience phases in qualitatively difference ways and therefore responses on standardised measures may vary according to phase status. Study 2 found that MS patients experienced phases in different ways which corresponded with the characteristics of each phase. The FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a) provides a comprehensive approach for assessing, treating and understanding adjustment to chronic illness. Study 2 has provided empirical support for the model for PwMS along with identification of differences between individuals in each of the phases. Future research should aim to provide further empirical support and assess the model more thoroughly with the use of additional outcome measures.

The current research has provided a fine grained study of social support for PwMS and has identified the unique value and role of each key support network member. This research can play a crucial role in the development of interventions to enhance support for MS patients. Social network members can be provided with concrete and behavioural examples of the types of support which are likely to be most beneficial and also most detrimental. Dakof and Taylor (1990) have suggested that such detailed descriptions can be a useful guide for intervention concerning effective support among providers. For example, assisting spouses to understand what it means to be physically

present and express empathy, understanding and affection with concrete examples, is more informative than simply advising spouses to provide general emotional support.

This research has also identified the importance of intimate support providers. Findings highlighted that individuals who do not have these relationships may have a significant deficiency in emotional support. Emotional support can be helpful for assisting the person with MS to explore and develop personal meaning concerning MS (Stuifbergen, 1992). Esteem/emotional support can also offset threats to self esteem, reduce fear, depression and anger, increase sense of belonging and security and assist with enhancing immune system functioning and encouraging self care (Cohen & Syme, 1985; Cohen & Wills, 1985; Cutrona & Russell, 1990). It is beneficial to consider how healthcare professionals may be able to fill the role of these intimate support providers in an appropriate and professional manner. The important and unique role of fellow MS patients also highlights the possibility that perhaps peer supporters can play a role in providing emotional support along with informational assistance and therefore peer support training is important. Peer supporters who have similar experiences are in a unique position to provide effective assistance (Wortman & Dunkel-Schetter, 1987).

Regardless of an individual's level of adjustment to MS, certain types of supportive and unsupportive behaviours continue to be relevant. The current research has also provided empirical support for the FFPM (Fennell, 1993; Fennell, 1995, Fennell, 2003a) for PwMS. This model appears to accurately map the journey and struggles of PwMS. By understanding these phases of adjustment, interventions can be tailored to meet the needs of individuals in each phase at the appropriate time and in a cost effective manner. Healthcare professionals will be able to assist patients to reach a level of

integration and have greater QoL (Fennell, 2003a). Findings from this research can be used to assist with social support interventions and educational programs for key support providers and also add to the understanding of a patient's current adjustment phase so appropriate treatment strategies and support can be implemented.

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APPENDIX 1

STUDY 1 INVITATION LETTER AND INFORMATION SHEET



Dear XXXXXX

Let me introduce myself, my name is Gabrielle Berea and I am a research student at the University of Wollongong. I am contacting you to invite you to participate in a study that I am conducting. The MS society has provided me with your contact details and they are fully supportive of this research. The purpose of the research is to investigate helpful and unhelpful attempts at providing support for people with MS and to explore the unique value of each support provider (family, friends, etc). Participation involves having a 90 minute face to face interview. This interview can take place at any location that you feel comfortable with (I will travel to you). We have conducted several interviews at participants' homes, workplaces, and even local libraries and quiet cafes. In order for this research to be successful in helping us understand what people with MS need in terms of social support, we require your assistance and a small amount of your time.

Attached is a participant information sheet which further explains the background and benefits of the research as well as more information about what participation entails.

If you are interested in participating in this highly valuable research or have any questions or enquiries please contact me by any of the following means:

Phone – 0414 66 7902 or (02) 9832 7902

Email – gb799@uow.edu.au

Your participation and assistance with this research would be greatly appreciated.

Kind Regards,

Gabrielle Berea



PARTICIPATION INFORMATION SHEET

TITLE: *Helpful and Unhelpful Social Support: From the perspective of people with MS*

PURPOSE OF THE RESEARCH

This is an invitation to participate in a study conducted by researchers at the University of Wollongong. The purpose of the research is to investigate helpful and unhelpful attempts at providing support for people with MS and to explore the unique value of each support network provider and the specific behaviour/support that they provide.

INVESTIGATORS

Gabrielle Berea
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Dr Nadia Crittenden
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BACKGROUND AND POSSIBLE BENEFITS OF THE RESEARCH

This research will provide an understanding of how support network members can assist people with MS in the most helpful manner. As the majority of people are unaware of what living with a long-term chronic illness entails, the journey is often unknown and misunderstood by others. Therefore this research will provide a greater awareness and understanding among others. Confidentiality is assured, and you or any of the support network providers mentioned during the interview will not be identified in any part of the research.

METHOD AND DEMANDS ON PARTICIPANTS

If you choose to be included, you will be asked to participate in a 90 minute interview which will be conducted by a member of the research team. This interview will be audiotaped to ascertain the types of social support that have been both helpful and unhelpful. An example of typical questions will be as follows: In the time since your diagnosis, what is the most helpful thing that your spouse has said or done to help you with your MS? What have you wished that your General Practitioner had done or said to help you with your MS that he or she did not do?

RISKS, INCONVENIENCES AND DISCOMFORTS

Apart from the 90 minutes of your time for the interview we can foresee no risks for you. The interview will be carried out in a place that is most convenient for you (your home or local library) and refreshments will be provided, as well as rest breaks any time you feel you need to pause. Your involvement in the study is voluntary and you may withdraw your participation from the study at any time and withdraw any data that you have provided to that point.

ETHICS REVIEW AND COMPLAINTS

This study has been reviewed by the Human Research Ethics Committee (Social Science, Humanities and Behavioural Science) of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UoW Ethics Officer on (02) 4221 4457.

Below is the contact information for several counselling services if you feel that you are in need of assistance.

MS Connect

1800 042 138 (free call)

A support and referral service, which enables you to speak to one of a team of health professionals about MS, its symptoms and a range of lifestyle considerations.

Monday – Friday (9am – 4.30pm)

Lifeline Australia

24-hour telephone counselling and referral service

13 11 14

Lifeline Sydney

For face-to face counselling services

9951 5577

Centre for NSW Mental Health

24-hour contact numbers for NSW Area Mental Health Services

Northern Sydney/Central Coast

Northern Sydney area: 1300 302 980

Central Coast area: 02 4320 3500

South Eastern Sydney/Illawarra

South Eastern Sydney area: 1300 300 180

Illawarra area: 1300 552 289

Sydney South West

Central Sydney area: 1800 636 825

South Western Sydney area: 1300 787 799

Sydney West

Western Sydney area: 02 9840 3047

Wentworth area: 1800 650 749

Thank you for your interest in this study.

APPENDIX 2

SOCIAL SUPPORT INTERVIEW



CONSENT FORM FOR PARTICIPANTS

HELPFUL AND UNHELPFUL SOCIAL SUPPORT: THE PERSPECTIVE OF PEOPLE WITH MS

GABRIELLE BERE A
DR NADIA CRITTENDEN

I have been given information about the research project Helpful and Unhelpful Social Support: the perspective of people with MS and discussed the research project with Gabrielle Berea who is conducting this research as part of a Masters Degree in Clinical Psychology supervised by Dr Nadia Crittenden in the department of Psychology at the University of Wollongong.

I have been advised of the potential risks and burdens associated with this research, which may include some emotional upset and have had an opportunity to ask Gabrielle Berea any questions I may have about the research and my participation.

I understand that my participation in this research is voluntary, I am free to refuse to participate and I am free to withdraw from the research at any time. My refusal to participate or withdrawal of consent will not affect me in any adverse manner.

If I have any enquiries about the research, I can contact Gabrielle Berea 02 9832 7902 *and* Dr Nadia Crittenden 02 4221 4515 or if I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

By signing below I am indicating my consent to

- A 90 minute interview regarding my experiences of social support from various social support network members

Please indicate whether you agree for the interview to be audiotaped (please circle your response)

Agree

Disagree

I understand that the data collected from my participation will be used for purpose of a thesis and possibly a journal publication, and I consent for it to be used in that manner.

Signed

Date

.....
Name (please print)

...../...../.....

.....

Participant Demographic Data Sheet

What is your gender? (please circle appropriate answer)

FEMALE

MALE

What is your age current age? (please circle appropriate answer)

18-25

26-35

36-45

46-55

56-65

66-75

75+

In what year were you diagnosed with MS?

What is your martial status? (please circle appropriate answer)

Married

Single

Divorced

Defacto

What is you current living situation? (please circle appropriate answer)

Live with partner/spouse and children

Live with partner/spouse

Live with children

Live alone

Other: _____

Do you have children, if so how many? (please circle appropriate answer)

0
1
2
3
4
5+

Do you attend support group meeting regularly? (please circle appropriate answer)

YES
SOMETIMES
NO

What form of MS do you have?

If relapsing remitting....

When was your last acute episode?

How would you rate the severity of your last acute episode? (please circle appropriate answer)

| | | | | | | | | | |
|------------------|----------|-------------|----------|----------------|----------|---------------|----------|----------|--------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Very mild | | mild | | average | | severe | | | Very Severe |

What is your current symptom state?

Interview extracted and modified from Dakof and Taylor (1990)

The interview will begin with a general introduction to the purpose of the present study

“I would like to ask you some questions about how people have been helpful to you. After being diagnosed as having MS, people may behave toward you in a number of different ways. Some of these ways may be helpful and other may not. It is important for families, friends and doctors of people with MS to know what people with MS think about how others treat them. We would like to know about your experiences with seven different groups of people: your spouse or partner, other family members, your friends, support group members or others you may know who have MS, your doctor, your neurologist, and, finally, acquaintances or strangers.”

The interviewer will then ask the same set of four questions about each of the seven potential support providers. The questions were:

1. In the time since your diagnosis, what is the most helpful thing that (support provider) has said or done to help you with your MS?
2. As I mentioned before, sometimes people who are close to us may say or do things that make us feel bad. They may have had the best intentions, or maybe they were not thinking at the time. In the time since your diagnosis, what has (support provider) said or done that you experienced as most annoying, or that upset you, made you angry, or just somehow rubbed you the wrong way?

3. Sometimes we find that certain people can help us in ways that nobody else can.
For instance, there may be some things that (support provider) can do or say that nobody else can do or say. It would not mean the same coming from anybody else. Since your diagnosis, what, if anything has (support provider) done or said to help you with the MS that nobody else could do in quite the same way?
4. We have all had the experience at one time or another when we wished a certain person would do or say things that, unfortunately, he or she never did. Since you received your diagnosis, what have you wished that (support provider) had done or said to help you with your MS that he or she did not do?

APPENDIX 3

CODED SOCIAL SUPPORT INTERVIEW RESPONSES

Helpful – Spousal Support

Emotional/esteem

Physical presence (just being there)

- She has been there for me when I really needed it
- So I suppose the most helpful thing was that we found in the experience of looking after kids, not that I had any experience either, but he wound up his business and took on the role of carer and um, so I suppose being at home and looking after me and the kids
- So he was very helpful in that and he really reinforced that by him following me to first check up visit at the MS clinic in Camperdown and he drove me there, not that I needed anyone to drive me there because I could have hopped on the bus, but he actually put me there and he sat there in the waiting room, you know with specialists they're always late and he sat there with me and he came in to see the neurologist and he sat there with me through that and I thought wow that's huge, so that's probably the most helpful thing he has done
- He is my rock, he is there to support me when I have been down he has been the strength behind me
- Well one she has been there for me the whole time
- So we were secure with each other and there was nothing that he said or done I just knew that he was going to be there with me and that was it
- She does anything; there is nothing that she doesn't do
- It more knowing that there is back up there rather than the use of it. Just that knowing if I need him, he is there.
- Yes, just being there and he is aware of because when I was first diagnosed I gave him the book and we read the book together. We both became aware of what the implications of it were and how it might manifest itself. The book is a big extreme to be honest, published by the MS society. We both read that to become aware of it and also when I first was on Beta interferon he was there when the nurse came so, he took the afternoon off so he could sort out the injections. But I took the injections myself he is just there as a back up. He is great because he is able to help without question or without me having to tell him, if I looked tired he knows exactly what it is and he knows exactly what to do

Understanding the nature of MS and its emotional impact

- MS is the type of thing that's unpredictable, I can be good and then all of a sudden I am bad, and I don't have to explain now he understands

- She understands, I mean at times when I am not feeling good
- Yeah, he understands and he just helps me, and he knows when to stay out of the way. Especially in summer if I have been out in the sun everyone knows to stay out of the way. And he is good because he knows that I can't go out into the sun so we plan things that aren't in the sun. I just have to tell him if I am tired or whatever he will just say "well you go to bed and I will look after the kids" and he will come to the support groups with me, and he goes "if you don't feel comfortable, we won't go but if you want to I will come with you", so he is very good like that

Calmly accepting patients MS

- I said to him one day I feel more tinglingly today and oh I don't know if this the start of something and I should stop this and that, and he said well if it is, it is and you can't do anything about so just sit back and enjoy it and chill out about
- Well I can't remember his exact words but I remember, he did verbalise and told me that it wouldn't change anything, because I remember that I was terrified of telling him because I thought that he would leave me.
- Biggest thing is that he doesn't mind if sometimes I wet myself, and I know that sounds terrible but if I have an accident and it's nothing for him to clean it up and he hasn't got the slightest problem with doing anything for me he is just a fantastic support that way.

Expressed concern, empathy or affection

- He is always calling and there for me very time, if I go to hospital he takes time of work. He has been really good
- Last time I was unwell he came to the room three times and asked me if I wanted a drink, he usually says "are you alright?" and I say "yes" and so he just leaves me alone
- And if you know if I get headaches he will go 'do you want me not to go' so that's probably where he is most helpful
- Making sure you take your medication, she is always reminding me and on my back about it and we would have these arguments about it. And I would refuse to take them even though I know she would be totally right about it. And that was probably one of the most important things was reminding me to take it because that says to me that you care and love me a lot. So that was probably one of the most important things

Informational

No instances of informational support

Tangible

Practical assistance

- Because that's the main support that I need, so that on those days when I just feel like crap I don't have the responsibility he takes over
- He helps now with house work and things like that
- There will be times that we'll normally share doing chores around the house and there might be the odd night or day that I am not good and she will just get up and do it for me and things like that.
- There has never been a question it's just done. It has never been anything that we have role swapped because it has been a gradual thing.
- Again the very practical things, very practical, the things that take the energy out me

Unhelpful – Spousal Support

Emotional/esteem

Expressed little concern, empathy or affection

- I have forgotten something because the memory is not as good as it use to be and things like that you get sort of dismissed , “oh well that's just you, you should hurry up an think about it and write things down and stuff”
- I remember feeling very hurt by him I don't remember the exact words, if he called me lazy, he said “oh you should be able to do this” he made me feel like... and I thought God you should know why, don't you understand?
- Yeah, just to be able to let her know how I feel rather than being told to go to doctor every time
- Yes when I first diagnosed he couldn't accept the diagnosis like me, he was in denial also. Because I was the type that would run around in high heels working long hours but at the start he couldn't accept it either
- There are heaps of things, but I can't remember them. When I was diagnosed he was most put out about it and he thought that was most unfair that he should be stuck with someone who is diagnosed with MS, he didn't deserve that. He doesn't give me time to things, he thinks that you look normal than you should be normal.
- I guess probably if you sort of go “gee I am tired” and they go “I am tired too” and yeah you probably are but it's different and that's probably annoying when it's late at night and someone needs to go if the kids are calling out, so

that can be frustrating because yeah you probably are tired but you don't know just how tired I really am. It's a different type of fatigue which is different

- I get really bad headaches if I am in the sun, and I might say "look I just can't be in the sun I get really bad headaches" and they will say "well so do we" so it's just that lack of understanding and they don't want to understand because they physically can't see anything.
- Anyway he told his whole bible group and it was all about him. Nothing was about how I felt everything was about how he felt. He came to one doctors appointment with me and while my sister would do what ever I wanted, and I would rush to the doctors appointment 30 minutes early because I felt comfortable but I couldn't do that with him because it was all about what he wanted to do and I found that very unhelpful

Too much worry or pessimism

- When I went into hospital and they weren't sure whether I definitely was or wasn't initially. He got himself in such a state that he ended up getting a cold or got sick and couldn't come and see me in hospital, because he didn't want to come in when he was sick
- The really upsetting are the comments like "I hope you will be dependent on me in a wheelchair" and that's not very helpful when your not sure what is going to happen.
- But for me when we were arguing over it at the time we were discussing it none of those things were important I just wanted to go, it was my chance to go and do something because I know I could do it now but I don't know after

Informational

Minimising the impact of MS

- But the only thing I can say is that when people ask him "how is she?" he always gives them a really glossy account like he would say "oh yeah she manages really well she does everything really well" and I find that probably compounds the problem of people making judgements

Tangible

No instances

Helpful – Other Family Members

Emotional/esteem

Physical presence (just being there)

- My mother she came up from interstate and came into the hospital everyday which was good
- Mum is my constant support, mum, dad and my sister they stick by me
- Well my kids are my rock as well if anything happens they are straight on the phone with the ambulance
- If I was to ring up and say look I need somebody, they will be here as fast as a plane will get them here, any one of them sisters or children anyone of them will do it. But they would be prepared to go anything that I wanted them to do, if I wanted to go to them they would look after me or whatever, and they are all the same, sisters, children they are all the same. I have plenty of support if I need it
- To be there, to be the biggest support and my mum pretty much and my grandmother the three of us are very close and my grandmother suffers from very bad nerves so she has that understanding from the emotional side. My mum has been there with my Nan, so my mum has that acceptance as well, so it's like a bit triangle So those two have been my backbone they have been my support ever since I was 20 and got it.

Expressed concern, empathy and affection

- So some have been really helpful in just being there and ringing up regularly and saying “how are things” , they don't push it if I don't want to talk and if I do they're willing to listen
- As far as the kids go they were very sad when they came into hospital but again they did come in and it was you know the cuddling and the caring that they showed and the concern for me
- They always say if I ever need any help to just contact them
- Obviously they were incredibly supportive of me and things like that and they would be really concerned if I got tired or something like that

Understanding the nature of MS and its emotional impact

- In a way yes most definitely because it has helped them understand a lot of the things that have happened to me
- With regard to family members at the time I made a deal with mum, well we discussed it between us and she said “I will support you at home, you go to work” because to say home for me I would have gone crazy, I need outside contact and things like that

- So for her she has always been the backbone for me because we talk quite a bit about it and her attacks and my attacks so she been very good and just listening as well as also helping me to understand this problem better
- Yes, and that understanding and knowing like I remember when I first got the MS I was a real cow, like if I was in the sun my mum would know that she couldn't talk to me, no one could talk to me because I would just explode. I would always explain it as I am in myself and I know I am talking but there is someone inside me talking and I can't stop it. So you are trying to stop yourself because you know that you are abusing the hell out of that person but can't stop yourself from doing it. And they don't take that personally she still always has been there, we might have a big yelling match for five minutes
- My sister and mother are great; they understand as well, you know with the fatigue aspect which is a major aspect. Yes, its being aware and the fact that they have educated themselves it more important than anything, even my mum sat down and read this book and was able to give herself the knowledge

Calmly accepted the MS

- But everybody has been OK everybody has been fine. I think they take the lead from you, I don't know what it would have been like if they had known at the same time as me when I was still trying to get my head around but I was well and I knew what my MS name was and I knew how to cross swords with it and I think that they took the lead from me.
- They have been really good in how they treat me, rather than treating me like I am an invalid just letting me be what I am. And just acceptance. Not being overly protective.
- The grandkids love me as I am and they know I walk with this and sometimes I stumble a bit, they don't notice they don't point it out and they don't care. So they treat me as a normal person and I feel normal around them.
- And when I would get upset or cry or whatever, and as I said sometimes you're fine and you're happy in your head but it all comes out. And I remember her just saying just let it out, don't worry it's got to come out, that just let it out and that just put me at ease not to try and hold it in.

Informational

Optimistic about patient's ability to cope or prognosis

- They have constantly been supportive they have reinforced how lucky it is in a way that, I don't know how to say this. I am a writer that is what I do and that's what is most important for me and they have been very good at

reinforcing that it doesn't really matter so much that I have MS because that doesn't affect my writing and I can still continue to do what it is that I want to do in life

- I don't know, probably when I was first diagnosed I could remember my brother going "I have been on the internet and it's really not that bad" and that's probably been the most helpful because someone has bothered to look at it and it's not as bad as I thought. Because when I first diagnosed I didn't have much acknowledge about. He was good that way because he was like "if you want to talk about it any time ring me but let's just go on".

Tangible

Practical assistance

- My sister has been great and she loves to shop and I don't, I do my own grocery shopping because I go to a place that I can park and it's not as difficult. But if you need to buy gift for example and you need to run around because you don't know what you want, she does a lot of that for me which is great.
- They help me with the washing and the drying, they do everything, if I say "I don't feel like cooking tonight" they say immediately "oh I'll cook for you" and the washing.
- My mum was the nurse in the family and knew a lot about it and she actually helped me get to the doctors and everything. So without my mum I wouldn't even had the doctor there, I was in hospital for two days waiting for the neurologist that they were trying to get and that neurologist was on holidays and I sat there waiting and I was a private patient in a public hospital paying a fortune and I sat there waiting for two days
- If there is support with money or things like that and dad gives me a lift somewhere or something like that, that's OK
- Um I guess by doing some of the cooking and also if there is something I can't reach or hold he gets it for me
- My sister being a nurse, she is actually an emergency sister nurse and she has been fantastic because I get a lot of help for her, whether or not, she will occasionally do the injections for me when I need it. She has talked to doctors for me; she actually came with me when I was diagnosed so that I could get all the information.

Unhelpful – Other Family Members

Emotional/esteem

Expressed little concern, empathy or affection

- I think what gets me especially when they haven't seen you for a really long time they say "oh but you look so good" but I think what did you think I would look like. If I know I going to something especially if it is family you put on your best behaviour you try your best, you want to appear good
- Not ringing when I have been sick in hospital that was really hurtful. Dad would come everyday and visit me but my sisters wouldn't so that was the most hurtful thing or them not ringing to see how you are
- I have got a brother as well, he is better but he also went through throat cancer so he rings every now and again and usually it's me who rings him up to see how he is going if he is alright. But they don't come over to see what they can do for me or anything like that and I don't ever see them. A great lack of support
- No, and they don't want to know anything about it. I think they want to put it in the back of their minds. So they don't tend to help too much around the house or understand sometimes how tired I get because they can't see a physical problem and so they weren't really involved when I had that episode
- My sister cut me of completing because I think that everyone is worried that they may get stuck with me. If I get worse they might get settled with me. My sister didn't speak to me for probably about three years and I did get a phone call just before Christmas and nearly fainted

Too much worry or pessimism

- Probably the most annoying is that they look to much into symptoms
- That's probably the worse one and then there are some linguistic ones, because my language is not English I am Swedish, so I remember a postcard, that one of my sisters sent me, when she found out and I hadn't actually spoken to her so she must of spoken to somebody else and she sent me a postcard, saying something that she was terribly sad that she hadn't been able to talk to me and blah blah, and how devastated she was that I had been, the word that she used in Swedish was the worse word, that it had happen to me, that this MS had been, sort like I had been victimised by it
- My mum burst out in tears and she was howling, she was not just sniffing and crying she was on the phone beside herself and I was finding myself having to comfort her and this was something terrible that had happen to her and I calmed her down and I comforted her and I put down the phone and I was furious
- They were more concerned and worried for the long term for me because I am on my own here. I probably often had to say to them stop worrying
- Um, only my mum tends to fuss a bit too much

- I know family; extended family had a lot to say about being pregnant and that it was a silly thing on my part and that shouldn't do that and all that sort of thing. And that was really annoying because I hadn't just gone "ok I am going to get pregnant" because that's what I wanted to do. And then of course because mum cleared out and then I go and have an episode with my eye, so of course they all then had the "I told you so" and they all knew, so that was really annoying and frustrating and you sort of think would you all prefer that I just lie in bed and do nothing.
- The annoying thing was that they crumbled and that they would be over protective and that excessive worry, the over protectiveness that was my personal experience because they handled it so much worse and they were so over protective.

Rude and inappropriate

- Yes, my husband's brother he called me a retard because of the MS, because I actually had like where my mouth dropped and I looked like I had a stroke

Informational

Minimising the impact of MS

- I have one of my sisters who doesn't sort of recognise that I have MS, she says she has friends that have MS and they run successful businesses look after their children, you know basically the wonder woman type. And she just doesn't recognise that it is something that can impact or something that you know
- My daughter said to me just after, I was trying to tell her how tired I was but it sort just went over her head. And then they would ask me to do something or go somewhere or one of them my youngest son he said "well dad just get on with life you know". Yes more so because they didn't understand and they just brushed it off. They are three lovely kids but I just don't think they realise what it was about.
- My sister and lack of understanding and thinking that it's all made up, it's just the same as anyone else that physically can't see anything wrong, than there is nothing wrong and what are you whingeing about, what are you complaining about.

Tangible

No instances

Helpful –Friends Support

Emotional/esteem

Physical presence (just being there)

- And I had someone come with, I was doing to catch the bus because I had taken the valium, and so she came with me to the hospital, she even came into the room with me and she sat next to the MRI and she had to sign all these forms and she came in and she sat there
- The support is incredible; they will pick me up and take me to their places.
- And one particular lady I met through that creative writing course, I mean her and her husband took me out and I mean I never got to go out because I certainly wouldn't go out at night on my own. They took me one night to dinner and to a play and I love the theatre which was lovely. They took me to restaurants and she would come regularly and go to the movies with me. I actually had about three friends with me down there who took me to the movies. Yes as well as that friendship and being there, that emotional support.
- I think friends are just the fact that they are positive, they are a different level they are very encouraging and they are there if you want to have a whinge about something or stuff, like my best girlfriend probably bears the brunt of that if I had a bad week, haven't slept very well that sort of thing. So it's probably the usual thing with your girlfriends who you share those little annoyances with and this is just another little annoyance in your life that you share the same sort of thing

Understanding the nature of MS and its emotional impact

- I am really grateful for the group of people that I work with they are fantastic in the fact that if we have outings at work they are all understanding that I might take longer to walk there
- Again, understanding of illness, they have not sat down and read the book, they have not educated themselves but I think they try to understand it, if I do get tired when we go out or something
- It's understanding about everything it's about what I have gone through, what I am going through and what I will go through. And not putting the pressure on me, they are understanding if I don't want to do it than that's fine. They are not putting pressure on me. If I say no, than no it is, and I have changed that way because I would always push on and end up being sick. I have gotten to the stage that if I say no than no it is but I have to be that way for my health. I don't want any hassles and I have had to do that because even though it's not major MS to me but it could change tomorrow and so I have to do things properly.

Expressing concern, empathy or affection

- And she is always mindful, if she knows I have an appointment she will ring the day after or something and see how it went. So she just keeps on track
- My girlfriend sometimes comes up and she spends the weekend with me and we have a great time, just talking and she is also very perceptive, she knows if there is something wrong not just with me and with my MS. She is OK with that.

Calmly accepted

- But the most helpful thing is that my friends that are still my friends they have not changed their outlook on me and they have accepted that sometimes I am not feeling well I can't meet them for lunch or I can't go with them or if I have said yes and then I can't go and I ring them and say that, that have accepted that
- Just be non judgemental and take it at face value. I guess that's really important. Just accepting and it's not some wicked hebe gebe thing
- Really one, friend have been there and they have acknowledged it, I think the important thing is that there is recognition that what I was before, I am still the same person but with some limitations or some potential issues
- Well when I told people I said to them you can ask me lots of questions now and then unless I bring it up, we won't talk about it again and they honoured that. Because I said to them that I don't do sympathy, I do understanding and if you want them to understand you have got to give them information you have got to let them ask questions. So they did, they asked lots of questions and we were a bit sad at the time but then we just moved on.
- All my friends are good; they don't treat me as though I am any different I guess because I am not so much different. I think if I was different then I would get treated differently.
- And friends are probably more helpful in that they are that space away, because I often say things to my girlfriend that I wouldn't say to my mum because my mum would stress out about it, my girlfriend can go "you will be right..." Because she has got that distance even though we are quite close it's just different. Even to my husband there are things that I thought that I wouldn't, not that I hid things from him but there are things I wouldn't share with him that I would share with my girlfriends it's just different.
- They had to have time to adjust to that as well. They would just not treat me any differently and that's what I really liked. Everyone knew that I had this but they would not treat me any differently and I knew if I needed something I could turn to them for that support and that's what I really like about them. If I need something I mean I haven't

spoken to one of my friends in a couple of months but I know if I wanted to I could just ring her up and we could just talk as if we had spoken yesterday. So the most helpful thing that they have done is that they have just left me alone and made it exactly the same as it was before, they are not going to treat me any different and no special treatment and that's exactly what I want.

- The one absolute best thing that my friends have done is take me to play golf, in the cart he drove around and we had a good time it was great. Just going on like normal, I may as well curl up and die if I don't. And my friends have taken that attitude as well.

Informational

No instances

Tangible

Practical assistance

- I have one very supportive friend who has done a lot from looking after the kids when I was in hospital to doing a lot of things
- Sometimes they will walk in and go "alright what do you need?" and I will go "well that light bulb needs changing" and they just are unbelievable how they help me and always shout me dinner and drinks, I can't fault that
- Yes, when ever she can yes. If we're stuck with shopping she will do it if we're stuck with anything where ever she can help out she will do it.
- Always there to drive me somewhere if I need to be driven somewhere
- They are very helpful; a couple of my friends will come and help me occasionally. I have been renovating the house because it was a bit of mess. So they come in and just give me a bit of hand. So I have been very lucky once again and it has not been asked, they will say "look we are coming over to give you a hand" isn't that nice. They have all been very supportive.

Unhelpful- Friends Support

Emotional/esteem

Expressed little concern, empathy or affection

- Um, I have friends which I didn't see when I was really sick so they know I have MS but they again look at the appearance and don't really understand what that means. Um and I find they are not very helpful because a lot of the times they will you know invite us to something that really isn't a good activity for me like going to beach in summer or something like that
- I remember that I thought that it was so sad in a way that no matter what I say or what I do people have no idea and she is just trying to do the right thing and she is just trying to be nice and she just wants to catch up, but the fact that she even suggested that I walk around Taronga zoo for me it was like have you looked at me how could you even expect that, I am struggling to get to the lift and if you want to catch up with me you have to come here, I can't walk around Taronga zoo and it's not anger, annoyed or upset but it is sadness there
- Without knowing, some days I don't feel as good as others and um, there is no understanding, their expectations of me are the same day in and day out so it's sort of, there is not compensation for it
- It's probably more hurtful, "just get on with it and there are other people worse off then you are" you do not say that
- One particular friend who has been a friend for some time and she actually with the move she was the most unhelpful of the lot she did not come down once to help me or even when I got here didn't come over and she only lives in Cronulla. Didn't come over and say "would you like some help with unpacking boxes" because it's just impossible for me.
- There was one occasion, which I don't see this girl anymore but we went out and there was about six of us, it was about eleven o'clock at night and I was really tired and I said "I am going to have to go I am just so tired" and she got really annoyed and she said "every time we go out you have to go because you are tired, why don't you stay and have another coffee, we are going to do this" and I said "look I am dead, I have got to go" and I actually said to her "you know the situation I am in and you are aware of what the implications are if I don't sleep, I am dead the next day" but there was no understanding

Too much worry or pessimism

- "Are you right?", well friends say that too, "are you right?" has become...aaww, oh don't tell me that, people have to ask you every six seconds if you're right and that really annoys me, so even if you stay at someone's house, or friends or whatever or someone will visit and they will be like are you right, are you right, are you right, are you right, are you right and that becomes annoying, like if I need help I will call out and ask

- It's that excessive worry, where she tells me all these things I need to do and sometimes I have to say I do as much as I can and I can't do anything beyond that. You have to put a stop to it because she is an over energised women
- I have got a girlfriend that knows two other people with MS who shares their stories which at times can be a bit negative do you know what I mean. And she doesn't do it in a mean way and that's the thing it's a bit like when you get those booklets in the mail, I just throw them away I just don't want to go there. And I think I have been having a really happy week and you are mailing me this, I don't want to look at this. It's that sort of thing that she starts talking about it and one of the people is a guy who is quite affected by it and hearing that even knowing that it's different because it's still under that umbrella under MS, it is still quite stomach turning that someone is so unwell

Rude and inappropriate

- Probably that was the absolute worse thing that I friend has ever said and this is basically a verbatim quote "how do you feel now that you are not a contributing member of society anymore".
- There is occasional comments that might be around, this is one thing that people don't realise and it does occasionally cut into you, is that for me being sporty and trying to keep fit and healthy and potentially losing my mobility could be something I encounter, some jokes around people, whether it be disabled for whatever, occasionally can hurt and that's something that people don't often think about at the time

Avoided social contact

- We wanted to go away camping, because I love going camping and he turned around and said "I would love to take to you but I just don't want to be responsible for you"
- So when he turned 40 he had a party and I wasn't invited and I thought why because you are having it at a club and you have got other friends and she doesn't walk right or look right what is it?... I mean they were all things that came into my mind whether or not that was the reason or not, I don't know
- The friends that you thought would stick around disappeared
- One girlfriend that I have had for 100 years has pulled away a lot so I don't know about that, she is the only one that I have found that has had any problems with it. I don't know what her problem is, um whether it is with her in herself I don't think it's with us. I just get the impression that she is frightened by the disease or frightened by what might happen to me either by seeing other people with it and she is pulling away.

- Yes, there has never been support from friends or anything like that. They drifted away and they and I just never had time. They would do things and I thought well I can't do that and it just got to the stage where I thought I would just stay at home and do things at home.

Informational

No instances

Tangible

No instances

Helpful - Other PwMS Support

Emotional/esteem

Special understanding

- Someone to tell you that has it, is more I suppose not believable but it makes it much more realistic than somebody who doesn't, its like a diabetic trying to explain what it is like going into a diabetic coma to somebody who has never had a cold in a day of their life, and they sit there going "hang on I don't really understand, I understand but I don't".
- I remember her saying "I had the monkey on my back" and she would keep sitting there waiting for it to come and get you again. And I remember that that was so true and I remember that that was what I experienced and I remember that I broke down in the meeting because went "oh that's exactly how I feel"
- In a way that's good because you can talk about things and they can sort of understand where you are coming from. They have that history and the background and they know what sort of things might be problems for you
- And it was also very helpful of course to go to these support group meeting and to meet the people who were laughing and cracking jokes about the whole situation you know. That life doesn't have to end and you know everything is easier if you laugh at it and you can't really I found that I couldn't really joke about things like that because most people don't know about MS and they don't know, they don't know whether they are suppose to laugh or not.
- I think it helped me put a lot of things into perspective because you could go there and say a stupid thing like "I lost my bladder control" or something like that and we would just all sit there and laugh, it wasn't something that you had to give reason for or explanations. So just hearing the different experiences that each of us had had and thinking that I am not the only one and been there done that
- Knowing that they have got the same thing wrong with them that I do, because people will say to you not everything is MS that happens to you, so it is very hard to determine what is and what isn't.
- When I first started going to those group meetings people would come down and they would start talking about the different things that had happened to them and then I would say "oh that happen to me the other day" and by talking to other people like them who then gave me a better understanding of what was going on with me and what was happening with me

Informational

Provided useful information and advice

- Or you know say you wet yourself and you say “is that normal?” and “yeah that’s ok don’t worry about that, that happens that’s normal”. Or even to the point with my needles in the morning, he said “what ever you do don’t do a cold injection, because it kills, it hurts, just warm it up with your hands for a couple of minute, before you do it” whereas a nurse would say “oh you got to do your needle” and just wack it in and it’s just done
- There is guy who I did the MS classes with who does all this research on his computer, because I don’t have one at the moment unfortunately because it is broken, so he does all the research on the computer and gives me all the information and sends it to me by post.
- I think the most helpful thing was Jean saying that I could go with her to Newport to that doctor. So help in the sense of her sharing that information and assisting me to go there. Somebody had told her about this machine and she just didn’t keep it to herself she told me about it. And I said to her “could I come with you?” and she said “yes” so her husband was driving both of us. Just I guess you know, they just really support each other and sort of exchange information.
- I got introduced to people who had it. And they gave me the advice that not to take it to heart when other people don’t get an idea of what it is about. Don’t be ashamed to ask for help because you need help and don’t be afraid to ask for it. So that’s how I was from the beginning
- Just treatment, alternative therapies, one person that I found out was able to put me on different things like fish oil and that was one of the things at the beginning and they told me what they actually took so I started taking it as well. Fish oil, B12 and Vitamin D to help with the nerves.

Acted as positive role model

- So to go from that to see the women who really had not had a sick day off work, so you could go the other way as well. It wasn’t all bad, because before that all I knew was that people ended up in wheelchairs
- I met her and she was wonderful she has a brilliant sense of humour and she said she had recently gone to Japan, she was a woman who is my age now, she was about 10 years older than me and she had recently gone to Japan and her neurologist had said “oh you are not quite well at the moment don’t go, don’t go” and she said “look the time I wait in your waiting room I could jump on a plane and be back from Japan” and I thought, that’s the way I am going to be, I’m going to be really positive, so that was really good to met her.
- I found it very helpful the girl I met in Parramatta who had it, she was considerably younger than me. And I only found out 15 years ago that I had it and she had done all sorts of incredible things with her physical wellbeing, she

had done, black belt karate and all sort of fantastic stuff and I found that very inspiring I suppose, to know that you can still go ahead and do that if I ever wanted to.

Optimistic of patient's ability to cope or prognosis

- Well again, the most helpful thing is probably in hind sight would have been that man who looked at me and said what are you doing here, because he kicked me out of that oh I am victim of MS and I am going to sit here and for the next 20 years in the support group, so he kicked me out of that and I thought OK I might have to come back here one day but until then I am not going to sit here and do this anymore
- I spoke to a lady that had MS and had five kids as well, but her kids were older than mine, she said to me to keep your life going and solider on and asked me what sort of medication I was on and stuff like that
- This lady I knew down in Mittagong she was in a wheelchair, she was such a nice down to earth lady and I was only newly diagnosed and I was scared and she was in a wheelchair. But she said to me "I have just got it bad, and you could have it mildly, there is a whole range of things, don't go everything on me, my legs don't work but the rest works just beautifully, I am more than a pair of legs". That always stuck in my mind about there is more to me than a pair of legs that don't work. That was the thing that stands out the most to me

Tangible

No instances

Unhelpful – Other PwMS Support

Emotional/esteem

Too much worry or pessimism

- And there has been a support group and times that I have been there and they have been really negative and that negativity sometimes if you're going along and you're happy, you walk away on a low, so that's the main thing

Rude and inappropriate

- And one day she got stuck into me very aggressive, I know what she said was more about her than it was about me, but it took me a long time to get to that realisation and that turned me off going to support groups for a long time because it sort of brought me down

- I remember once I saw a guy at the RPA where you do physio and he is the wheelchair and I hadn't seen him for a long time and he saw me arrive there with a wheelchair and he said "welcome to the club"
- First time diagnosis there were people who pushed and pushed to get their business in and I used to get very irritated with them because I would say I can't do this.
- Only this girlfriend and that comparing all the time and I haven't spoken to her in 3-4 months because we are both busy and she will ring up and it's not like "oh what have you been doing, what have you been up to" because I do courses at home. It was always like "I suppose you are still walking around" and that sort of stuff. And I don't like that I don't think there is need for that. She makes me feel guilty that I have a milder dose of it or what I don't know.
- Yes, there was one; there is always one which is a bit weird. There was one lady down there who was really quite bossy with the group and I thought "you are not in charge" and I remember that they were having a bus trip to Sydney. They were going out on the harbour and I seemed to be the only one of the ladies that I spoke to in the group that had the incontinence problem. And I said "would the bus be able to stop at the service station so that I could go to the toilet" and she said "no" and I should have really taken it further and gone to Mark who really does run the group and asked him.
- The fact that she was so dependent and I understood it and I saw her side of it and I did everything I possibly could and yeah I want to help you out and we spoke a lot and then it just got to the point that it was too demanding, I would turn around and she would be standing right behind me it was too overbearing and annoying.

Informational

Acting as a poor role model

- Absolutely, it sort of trivialises it, and to me it's not something that is trivial. You have some wonderful days and you actually have some wonderful experiences and you met people and they are great and they do wonderful things for you, but don't ever tell me it's the greatest thing that's ever happened to you cause that's just bull, it's absolute crap

Tangible

No instances

Helpful – GP Support

Emotional/esteem

Kind and pleasant

- My GP is lovely so much so that sometimes she makes cakes and things and I am invited in for a cup of tea and a piece of cake
- I applied for a department of housing place and there had been a big mix up with the paper work and because they didn't hear from me they thought I didn't want it and they cancelled it. So when I went there to find out I had no papers so I had to fill it all in again and I got a letter from him and the girl behind the counter said "gee that's a good letter from the doctor" and when I went back to him I said "oh you wrote me a good letter" and he said "I'll look after you mate don't worry"

Understanding the nature of MS and its emotional impact

- I don't like to do them (pap smears) and so normally he would send you out, so he is a little bit more understanding in that respect

Calmly accepted

- One is that acceptance of what I was going through and he supported me

Informational

Provided useful information and advice

- If I ask him questions he will answer them to about MS. He doesn't necessary know about MS but he does know how to answer to give you a right concept of it all
- If I ever have a problem I just go to him I don't have to make an appointment he just takes me straight in and sits me down and says "right what's wrong", his a real go go Doctor, he is very old. If you ask him a question he has the answer to your question.
- He was good like that, so he was able to give me a bit more information about drugs that were out there and available and things like that.
- He has been good, he knows everything about it, he has got all this information on his computer, and all the drugs that I take he looks it up. He is really really good like that.

- He does also know a lot about MS, he is a brilliant doctor and you can't even get into to see him.

Optimistic about patient's ability to cope and prognosis

- So that was all good and that helped, so he was able to give me a bit more reassurance that there was further developments out there and not to lose sight and that things are happening
- I was having an MRI later on that day and so she phoned later on that day because we had the results of the MRI and when I said to her it's MS she said "oh thank God, because there is a lot worse that it could have been, and I have got many patients with it and I hardly ever see them" so she was really positive too, she said all the right things so that was wonderful.
- He has actually said quite off handily at some stage that your MS is not that bad, so that's sort of nice to hear. So he has reassured me and that sort off hand comment.
- He turned to me and said "it could be worse" and he said "in ten years they will find a cure and don't worry about it" so he was great

Tangible

Provided technically competent medical care

- Absolutely, one look and straight away he knew that there was something terribly wrong, he didn't know what was wrong but he knew there was something terribly wrong and it had to be dealt with straight away
- Just I suppose in the first year or two if I went there with something, some compliant unrelated in my head unrelated to MS or something, say I have got a sore throat or something and it just went away. So he will have a look and he would say "we need to check these things just in case related to MS"
- He knows, he doesn't take things at face value and he always takes what I say as serious and that's really helpful because other GP's who say well why is that a problem, oh and yes I might only have a numb finger and it might be a finger that I don't use much but I want to know if it means something else
- She instructed me, she was there in her office and she talked me through giving myself my first injection. She didn't do it, I did it but she sat there and she talked me through that, so that is probably the most helpful thing, because I got medication injection prescribed to me from the neurologist and he said to me I am not really sure how this works so just contact the MS society
- Switching neurologists because at the time I didn't like the neurologist that he had assigned because he had just gotten it out of the book and he switched me to somebody else.

- He is a very good GP we found him about two years ago and he is excellent. He is a great support all the way around with my father and me and he answers questions directly and if he doesn't know he will say so, he is great person and you can ask him anything under the sun no matter how stupid.
- My doctor down there was really great he knew that sometimes getting around was hard for me or getting to the surgery was hard, so he would come out to my place. And when I had an MS attack instead of going into the hospital if I knew it was one that I could manage at home, he would bring the nurse out and set the drip at home and allow me to stay at home. Once I have had the first drip I am up walking so he would arrange to come out to the house and help put the drip and then he would come out after closing his surgery and make sure I was alright and I had his home number. And then the nurse would come out every day and help with the drip and come and take it down
- So I mean I think I was grateful that he wasn't one of these GP's that sent me away with a script for something, which you do get. I am really grateful that he knew and he was aware and he checked me out because well I would have found out eventually but other than that I can't think of anything else
- He is interested in my MS. He is always there for me and he makes time for me because you have to book two weeks in advanced, but he makes time for me during his lunch break. He has said to me that if you ever get stuck ring me up and I will fit you in some how
- They will do things like if they are running late they will give me a call and say that they are running late or if something happens, one time... oh even the chemist they work with the doctor and one time my injection didn't arrive well they rang the doctor and got all my information, they all worked it out and they stayed back late and the chemist stayed back for the courier and got the injection to me.

Unhelpful – GP Support

Emotional/esteem

No instances

Informational

Provided insufficient information

- Just lack of knowledge, he just didn't know, he still doesn't know
- But it annoys me when I know more about MS than what she does

- Yes, he is very basic and unless we sort of say to him that we really need you to let us know so we can be referred to somebody else because he can't give those prescriptions somebody else more qualified has to. If he could just prompt it rather than us have to go to our neurologist and pump him for information and the longer you stay there the dollar ticks. Whereas the GP is bulk billed and standardised item numbers. All the GP knows is who to refer you to and then next please.
- But in the past yes I have had some GP's who are unhelpful because of their attitudes because a lot of them don't know about MS and they really don't know. You know that you are fighting all the time trying to explain to them about MS. It would be nice if they had more knowledge particularly if they are dealing with someone with this
- I virtually tell her what I want. She probably knows all the answers but I don't find her particularly helpful.
- Um, from these up here the lack of knowledge and not knowing anything about MS. And of course he has heard of MS but I would like that he would at least have a base knowledge of what it is. I take this into the surgery (frame) and he say "what do you need that for?" and I say "if I stand up I will fall over" and he would say "oh what do you mean?" and I was thinking why do I have to tell and explain this to a doctor. So I only go if I need scripts or something until I find another doctor that I don't have to explain about MS to.
- Lack of knowledge and I think the biggest worry if you do have a problem they just think it's because of the MS, they don't investigate.
- Um, when I went back to him and said I need a different neurologist because I mean you think you have got cancer sort of thing and I said can you refer me to someone else and then he looked at my back x ray and that's when he said "I think it could be MS" while it was helpful, I then came home that night and was just shocked that he had thrown it out there as a possibility and really hadn't given any more information and then I had to take that home with me and didn't really have enough knowledge about it and didn't know that that was really it and had to try to get back into to the neurologist so had this time between to think about it and worry. That was very unhelpful and I mean, he has been my GP for quite a few years and he did it with the best of intentions and was trying to give me an answer but to throw it out there and then not have an explanation and still not be sure that that's what it was, but of course then you have got it. And then not to even explain a little bit about MS and provide with some reassurance. I think he probably shouldn't have put it out there really at all because he just didn't have enough information and it wasn't his call to make.
- Yes, they ask you about MS, like when I have had trouble breathing they would say to me "well do you think it's the MS?" and I would be like I don't know you're the doctor.

Tangible

Incompetent medical care

- It's the lack of support completely, complete lack of support. Time, information everything it's all lacking there is just not enough doctors.

Helpful – Neurologist Support

Emotional/esteem

No instances

Informational

Provided useful information and advice

- Probably the best thing is that he has made himself very available for information and advice, he has even given me his home phone number and his mobile and everything like that
- He said “just stop it, put it away, don’t look at it and leave it alone” and I really thought about that and really took that in my head and thought about what he was really saying to me was just to stop that kind of stuff and just flow with it and let it go. And I did from that day, I stopped doing it
- He said even if you are diagnosed with MS... his biggest advice to me was make decisions in your life how you would’ve if you hadn’t been diagnosed and then make plans around it, rather than he said “you are going to regret it if you start to make decision as an ill person” and he said “later on you will regret it”
- I think I got fair help to decide which immunotherapy to choose, I think that was fair. I went to him with the sole determination to come out of there with a script to one of these different drugs, but I had no idea which one. And I think that he gave me... he didn’t choose for me, he didn’t tell me which one to choose, but he gave me information, very helpful
- Early on when I was first diagnosed you get all the reading matter and you start reading and I went to see him once and I said “what about this and what about that” and he said “MS is such a thing that these things may not ever happen to you” so he made me realise that maybe this is what it says there but I may never have to deal with that set of criteria. And I think that has been helpful
- Well he explained everything; he even got the coat hanger out and showed me inside the coat hanger that was like the myelin going over my nerves. Yes because I was really panicky so he was a really good neurologist
- It’s really the time she took to take me through not only the MS but all the test results and that reassurance about where you are at and worse case and best case, and what the tests involved, so it was that time I think was the important thing
- But he just gives me his opinion and I often say to him “if I was your wife” and he plays with that and he tells me what he thinks and what he feels. He has got a lady who has had MS for 20 years and she is a bit like me, she has not had episodes for a long time and so he will share that with me and I know that he is really up to date with it

because he goes to all the seminars and he is really involved and up to date with anything new going on in the field. And I trust him and that's a big thing

- What the most helpful is that every time I have seen something on a current affair or 60 minutes I will always ask him and he always has an answer for me.
- And he is very good, he will listen to me, he will tell me what the problems are and what can be done, he is very helpful.
- Yes, I do a lot of positive reinforcement and things like that and I use to talk to her about it and she would say keep doing it because it's working.
- My neurologist at St Vincent's private suggesting the injections to me because he said that I was working 12-14 hour per days and he said he didn't have another MS patient who worked as hard as I did and if anyone deserved it I did. So getting me onto the injections.
- I'd say the new neurologist that I see, he is only a young guy, he is very supportive as in the sense that if I say to him, like "I really want to lose weight but I don't know how to" and he will say "go and see the MS society and here is this phone number" or there is usually a nurse in with him and then she will give me the details, like "here there is an exercise program on the website".

Optimistic about prognosis of patient's ability to successfully live with MS

- Probably the most helpful thing was to say that it is not the end of the world, that has helped me a lot because I know mum and everyone gets very emotional about things and everything like that and he was always saying you know we can deal with this, we have battled through worse than this, we know just to get on with things
- So when he told me I had MS I said "so what will I be doing in 10 years time" and he said "exactly what you want to be doing" and so he was really wonderful.
- The one in Mittagong I use to go and see her twice a year for a check up and she always use to say to me "I don't know what you going but keep on doing it", she would say that to me all the time.
- He has been good in that he was very much like just go on with your life and that's the best thing that they can give you. That about not dwelling on it and getting on with your life.
- He looked at me and said "you amaze me, I tell people that they are going to suffer from migraines for the rest of their life and they burst into tears and I tell people who have brain tumours that they are going to die and I can't operate and they are completely fine, the same way you are handling it" and that was great that he said that. And it could have been worse I could have a brain tumour.

- He wasn't not at all, he had a very positive outlook about it and I remember going for my first visit, just after being diagnosed I hadn't even been out of hospital and I had to go and see him and I had a stick with me, I could walk but I was really slow. And he was looking at this stick and he said "what the hell have you got" and he came over and grabbed the stick and threw it to the wall and said "you don't need that bloody thing, get rid of it" and it was very positive a really good attitude

Tangible

Provided technically competent medical care

- So you know he doesn't muck about, he says this is what's happening and we need to get you fixed up
- And ages ago there was something about botoxs and he said there is a doctor that does it down in Westmead and he sent me there and it was been unbelievable. My leg straightens out and this botoxs is able to bend it and it's not as bad, so what the botox has done has been incredible.
- He is always going away to seminars and learning about all the new stuff and he is just very spot on with his notes and when you go back to him he knows exactly what you told him the last time you left him.
- The last one in Penrith and this one both take time and they both listen and they both say have you lost strength and I say yes, and they test my hand and they say it still feels pretty strong to me but you should be the one to notice. I say yeah well I have because I pick things up and my hand shakes. And they will listen and say yes if you think that's the case than that's the case and I find that very gratifying to have someone believe me because I say it and everyone else disregards it and as I said they say "well you look fine so you are fine"
- I think it's just being able to keep track, my doctor was able to keep track of how I was with the MRI's and things like that

Unhelpful – Neurologist Support

Emotional/esteem

Expressed little concern, empathy or affection

- He was very clinical and probably was the one that at times upset me because he was very factual. But where he did upset me, it probably made me better able to deal with things later on, which I didn't like, he made me confront certain things that I needed to but at the time I wasn't probably in the frame of mind for confronting

Rude and inappropriate

- The first one I saw he hurt, I walked into the door and he told me to hop on the bed and he said you have got to do this and pushed on my hand and he really pushed and really broke my feet and as soon as he done with those tests and was like OK see you, so he was very rude. He was very very rude; I didn't like him at all

Informational

Acting as a poor role model

- You have no idea what the journey is going to be so you want them to or you to feel that they have an idea of where you're heading with it, even if they don't. Like you still want to have hope that you are going to get better and things, and you put all that positive energy into that and see what happens

Provided insufficient information

- That's the last thing we need when someone says I'm not sure and can't advise you on what is going on, we want them to be 100% sure, there's no ifs or buts. So that's really the only thing
- I was in hospital the second time and I was on the intravenous cortisone and I wasn't really improving at that time and he said "I just don't know what's going to happen, and I am not sure what we are going to do here and I am concerned because you're just not getting better and we are just not getting a response and I am not understanding" and I just thought, you know you always want your doctor to be the one that is certain and can tell you what is going on, to be stone and to be the rock and that sort of just unmoved me a little bit
- He didn't seem to prompt anything, he didn't know medicines
- I just don't want it, you have got to be a bit open with me because I am asking you questions and I need the information and even if you don't have it just tell me you don't have it
- Putting off not telling me about the diagnosis
- That the most unhelpful thing is that she didn't know about certain things and lacked information that really she should know.
- You want him to tell you all about it and what is going to happen. He did the scans and said "I am sorry to tell you that you have got MS" and I said "what is MS" and he just explained briefly and then said "there's a book to read" and that's when I got in contact with the MS society

- And I had a lot going through my head and I was thinking he wants me to read a book about it and I needed someone to sit down and talk to me about it. I was thinking worse case scenario, and that was going through my head.
- “Isn’t it lucky you don’t have pain?” That lack of knowledge and no idea.

Minimised the impact of MS

- Well the fellow in Westmead just kept telling me it was stress and I kept saying I am not a stressful person, and he would continue to say it was stress. That annoyed me the fact that I wasn’t believed and I suppose because of the symptoms of MS and the weirdness of MS, people don’t believe you because they are such strange things.
- When I was diagnosed by the neurologist that diagnosed me, who had the bedside manner of oh I don’t know. And he just told me it wasn’t that bad and I didn’t have to end up in a wheelchair it’s only one in five and then he gave me a few brochures by the MS society and he sent me away

Tangible

Incompetent medical care

- She lost my records, that annoyed me a little bit because of all the things I went through and she had them all. That was disappointing that I had to start again. That was my scans that I lost, it was all gone, but you can’t change that. So that stressed me out especially when work asked for them
- You wonder if other neurologists had given the medication earlier on, we may have not reached this stage, but you never know. But you still have to think that if there is something for it why is it not offered and let me have the decision
- That lack of understanding and not listening to what you are telling them. Not modifying their approach to suit you

Helpful –Acquaintances Support

Emotional/esteem

Physical presence (just being there)

- Just the support, like they say call me anytime if you want to talk

Understanding the nature of MS and its emotional impact

- Um, the big manager I had at the time was very understanding and supportive of me just you know I obviously I needed to have the time off work
- But I did sit down and explain to him and he said “what can we do, how can we help?” and I said “Bruce, one thing that I do want is that I just want you to understand that I will give you 100% but if I am not here it’s because I can’t give you that 100%” and that really helped to reinforce that position so he knows that at the end of day I can work at home from the laptop

Expressing concern, empathy or affection

- I couple of people at my husbands work would ask “how is your wife going, how is her MS?”
- That they have asked me what to do if something happens to me, that they have asked about it and that they want to know what it is and how they can deal with it if something happens
- But just those passing comments and I know that if I needed anything she would be here within 10 minutes, because she near by and she would go out of her way to do anything at all and I would do the same for her. It’s helpful to know because she is close.

Kind and pleasant

- I guess the most helpful thing an acquaintance has done is that she got her husband to crave me the most beautiful walking stick, absolutely lovely it has got birds, that was a very nice gesture. And that was a lady who had to use a walking stick because she had arthritis and he had craved one for her. And when I told her I had MS, I don’t use the stick very often but she thought that it was unfair for young people to have to use horrible walking sticks, so he craved me a beautiful walking stick and they were acquaintances.

- I suppose the biggest thing is not to look at me like there is something wrong or not to straight away think that there was something wrong or not to make me feel as though something is wrong. That they talk to me and not to whatever I am using, I don't know why that is but it is helpful.
- There is a situation when I was in Coogee, I had only been out of hospital for a few days and I had a stick with me and my sister and I were walking to a café on the beach, on Coogee beach. I was very slow, I was walking very tentatively with the walking stick. And we looked over and there was this guy who was just about to leave and he was packing up and the table was going to become available and this stranger, this guy, he waited, he knew what was going on, he must of just figured it out and waited until we had come all the way over which must have taken forever because I was walking at a snails pace. The minute we got there he got up and actually said "oh I saw you and I knew you wanted the table so I waited for you to walk over" and I thought that's fantastic and it was a good ten minutes and he was aware which was nice
- There is an acquaintance and she asked me if I wouldn't mind coming to lunch with her one day because her sister in law had just been diagnosed and she said "because I would really like to talk to you about it, would you mind?" and I said "no not all" and I thought that was good, because she didn't say lets have lunch and then when we got there suddenly mention it.

Calmly accepted

- But people who may know someone who has MS are usually better able to talk to you about it. Probably the most helpful is just, for those people who might have a background maybe filing it in their mind but not making judgements
- Well when we first moved in here, I had 'Mr Sharp' service come to pick my injections. The neighbours would have thought I was a drug addict so I went to their houses and told them I had MS. They were all like "what's that?" and then I had to explain to them about the coat hanger thing, and then it was like nothing was said anymore
- And as I said to you on the phone I am really lucky with my boss, I have had a few chats with him about it and he has talked to me about it and he will sit down and ask about how I am going and if I have a day or two off ill and tell him it was because of my legs or the migraines that I get and the next day he will come in and see how I am going and things like that. It's not like "why were you not here?" it's like "How are you going?" so that for him on that side I think that that's as good as it can get with support and similarly our HR has the same sort of support and our OH&S nurse they are all that similar

- They accept me the way I am no matter if I have got MS, if I can still do my job than they don't see me as any different to anyone else.

Informational

No instances

Tangible

Provided practical assistance

- I met people who can help and they help you know, in the same way that you and I may if we see a really old person with a walking stick you would try to move out of the way and open the door for them and I met people who kind of do that, so it's only small things and it's kind of cool. And I don't have to explain to them what is going on, they just do it
- I had to go up one of those escalators things with a full trolley and I was thinking at the bottom and this woman was there and she said "can I help you with the trolley" and I thought she was going up too "I said well if you did I would really appreciate it because it would mean that I wouldn't feel guilty if my trolley rolled back on top of you". She helped me push it up, she pushed it up for me but when she got to the top she reversed and came back down, she didn't need to come up she came up just to bring the trolley
- People like the neighbours daughter is going to come this afternoon to help me, because my homecare lady left without bringing the washing in because it was wet. So I have friends and neighbours that cook for me because I am too fatigued at the end of the night so they'll bring me left over stuff
- Giving you that assistance, helping you get out of the car or in the car, or opening the door, those little things. They have identified that you can't do it so they have stepped in to help.
- Um, take me from point A to point B
- He is quite happy that anytime that I need a specialist appointment I take time off, the school is fantastic they have never had a problem with me going to a specialist appointment. Whether or not it takes all day, I try to do the best by them as well, but they are very understanding and supportive.
- There have been instances like once I was on an escalator and I started to fall and this man from down the ground had seen me going and raced up the escalator in the wrong way and grabbed me just before my face hit the escalator. That practical support and it actually happened recently where at RTA a person saw me falling and ran and grabbed me before I fell.

- I think people I have meet when they find out I have got MS, they say “I don’t know a lot about it but if you need help with anything just give me call”. So that practical support that if I need a hand just to let them know. That’s the best thing that I have had
- And when I couldn’t walk a few years ago and when I started walking again I came in on crutches and staff was incredibly supportive with helping me around.

Unhelpful – Acquaintances Support

Emotional/esteem

Expressed little concern, empathy or affection

- And this boss is a lot better than the other boss because the old boss would say “we are going to fire you if you have more time off” regardless if I was sick
- I love the beach but I have trouble with standing in the sand and I went one day on my own and asked this lady if she could just walk me in a little further. And she was really offended by it, she was horrible and I thought well I won’t do that again. And to get back in I had to drag myself on my belly even though it was very shallow and then pull myself up on the hand rail. And of course every one was looking at this mad women who wasn’t just standing up and walking and I thought well that’s the end of that I can’t do that again. It’s terrible no one helped me, and that lady was so put off by my asking her, I told her I have MS and I am having trouble keeping my balance and I am a good swimmer I just need to get in a bit deeper so I can swim and she just went “no” and I thought I won’t try that again.
- It was worse in 1996 when I was first diagnosed I worked at Toyota for 16 years and I left my job because...I didn’t think to hide it because I thought they were all my friends. They started to treat me like I had AIDS I just couldn’t bear it and I had to keep telling people that it wasn’t contagious
- Yeah, like here she goes again, like I am a whinger or look she gets very emotional very quickly and I don’t mean to cry all the time. I don’t like crying in front of my bosses but I just get that why, because you just get so worked up that you can’t let it out.

Too much worry or pessimism

- Some of the young teachers on the staff when we have a sports day she came across and said “you sit down, you haven’t been sitting down for ages” and I said “no I will let you know if I want to sit down”.

- “Are you right?”, well friends say that too, “are you right?” has become...aaww, oh don’t tell me that, people have to ask you every six seconds if you’re right and that really annoys me, so even if you stay at someone’s house, or friends or whatever or someone will visit and they will be like are you right, are you right, are you right, are you right, are you right and that becomes annoying, like if I need help I will call out and ask

Rude and inappropriate

- Yes, the work factor because I don’t work anymore, I can’t work I find that very annoying when people start throwing the 20 questions at you and I know it’s human nature when people first met you, “what’s your name and what do you do?” and then when you say I don’t do anything you get this look of saying well why not
- Then my direct boss at the time, well he diagnosed me before even the specialist had diagnosed me. He sort of said well it is MS, and he had been telling people at work, he oh well it sounds like and I am sure she will be diagnosed with MS
- Probably back to that thing of my husband not working, it comes up all the time um and also because it comes up for me too, you meet lots of people and usually there’s the question of “what do you do?”, and like I had a career and I was actually on maternity leave when I got sick and I actually got terminated as being totally and permanently disabled so I didn’t have a choice to go back to work although I had full intentions of going back to work, um and now being classified as permanently disabled
- I once wasn’t admitted into the cinema because I wasn’t wearing shoes, I was experiencing symptoms for a period of time and I had balance and combination issues with really bad sensation in my legs and in my feet like pins and needles and it was so bad that I had to walk bear foot, because when I walked bear foot and I had direct contact with the ground I could feel where I walked and it was so much easier
- People who are too busy in what they are doing and they will just push past you and it’s like give me a break I can’t walk as fast as you.
- Anyway I went to have an ultrasound and the young fellow who looked about your age he said to me “is there anything any longstanding chronic illness that maybe affecting your health” and I said “well I have got MS” and he just looked at me and said “but you walked in here, you are mobile” and I thought oh my God, I can’t believe he said that and I thought if I had just recently been diagnosed and he said that I would probably burst into tears
- They won’t be that helpful with the wheelchair, actually it’s funny people think that you are dumb when you are in a wheelchair, it’s one of the issues like a pat on the head “are you right?” like you’re dumb, it’s a funny thing but

people do have that attitude some times, you can't blame everyone but sometimes they do, the ignorance behind that.

- I found it irritating one day when I parked in the disabled spot and I stuck my thing on the window and because I wasn't in a wheelchair and didn't have a walking stick or anything, this lady said "are you aware that you are parking in the disabled peoples spot" and I said "yes thank you I have my sticker in the window" and I suppose because of the weird symptoms again people aren't aware that you have a problem and people look at you as though you are committing a heinous crime if you park in the disabled spots and I don't unless there are not other spots. But just that fact you don't look sick.
- A couple of times I have bumped into people with this (frame) and they have become a bit testy about that. And it's just my clumsiness I have bumped into them and they have got a bit jerky about it.
- When I was working at the architect I was bullied by two women and they were well aware of the MS and I put up with a lot of abuse, swearing, name calling and I found it hard to come to terms with the fact that knowing that you were alone and you really had no support and you were working to support yourself and had an illness like this, that they would behave in that way.
- And being cut off to get into disabled parking spots by able bodied people, I put my blinker on to go into the disabled spot and this woman in this big Mercedes cut me off and drove into the spot.
- People think that you are drunk all the time. I remember one time when I went out to dinner this was before the walking stick days, I got up at this restaurant and this man said loudly "oh she has had a bit too much to drink" and I turned around and she "excuse me I have had nothing to drink but water, I have MS" and he was like "oh sorry I am so sorry" and I said "well maybe you will think twice before you make an announcement like that again".
- I really find that upsetting when he announces things in front of kids and he mentions things and I know that he means well. Like the other day he was telling me about a talk that was on the ABC radio between these patients, it was great information but I felt a bit embarrassed that he actually said it with students around, I would prefer no one was aware of it and my personal business and he is very indiscrete and I don't think he realises and I have actually said that I haven't told too many people. The principal and the vice principal of course know. So the essential people know and that's all that needs to know, and I don't like that he is not very private about it.
- I was still kind of funny on my feet and I had massive balance issues because I was still a bit numb and tingly and stuff, and I was meant to go to Fiji and I was planning in a couple of months time to go to Fiji. And one of them turned around and said to me "well you wont be going anywhere if you keep walking like that" and I said "well that's what happens when you have got an incurable disease"

- I was half asleep as I said I was sleeping 20 hours a day and she was saying something like “don’t take your drip into the toilet” and she was really rude and she seem to be having a go at me and she seem to pick on me and I don’t know why but because I was ill because normally I would have a real argument with her but when you are ill you are just not in the mood. And she was really awful and she was just a stranger in the room but she just a real bitch and I don’t know what her problem was.

Avoided social contact

- It’s not helpful when you hear about people trying to disregard you because of the MS. When the ladies from the play ground did not invite me to the outing because they didn’t think I would cope when they hadn’t seen me in a long time and didn’t even know how I doing. So making assumptions about how I was going. They hadn’t seen me for a while so they didn’t know where I was at with it and I had been diagnosed while I hadn’t seen them, so I guess they didn’t know and my friend said “oh no she is fine”. When I saw them we didn’t even mention it, so I knew that it would have been discussed behind my back later do you know what I mean.

Informational

Minimising the impact of MS

- My boss at the time came to my house, he didn’t even call, knocked on my door and basically told me that I should be back at work, he said just moaning around here is not going to do you any good. I didn’t take that well, not at all because again he was not even accepting that there was a problem or issue and I agree that it probably would be good to be back at work but I will tell you when I am ready and I am not ready now. And for him to come out and do that, it really fired my up because I thought how dare you

Tangible

No instance

APPENDIX 4

STUDY 2 QUESTIONNAIRE PACKAGE



Dear XXXXXX

My name is Gabrielle Berea and I am contacting you to invite you to participate in a study being conducted by researchers at the University of Wollongong. This research is being conducted with the assistance from the MS society of NSW who are fully support of this research. The purpose of the research is to investigate if people with MS experience particular phases as they adjust to the condition. Furthermore to investigate the characteristics associated with these phases and the helpfulness of social support. Participation involves the completion and return (via mail in envelope provided) of the questionnaire package which has been included with this letter. It is anticipated that completion of the questionnaire will take approximately 90 minutes.

Once I have received the completed questionnaire package, I may contact you via mail with a letter inviting you to participate in a face to face interview with myself. This interview will centre around your experiences with adjusting to MS. You are by no means obligated to participate in this interview as you may wish to only complete the questionnaires.

In order for this research to be successful in helping us understand how health professions can more effectively assist people with MS in terms of adjusting, we require your assistance and a small amount of your time. Attached is a participant information sheet which further explains the background and benefits of the research as well as more information about what participation entails.

If you are interested in participating in this highly valuable research please complete and return via mail in the provided envelope the questionnaire package. If you have any questions please do not hesitate to contact me on

Phone – 0414 66 7902 or (02) 9832 7902

Email – gb799@uow.edu.au

Your participation and assistance with this research would be greatly appreciated.

Kind Regards,

Gabrielle Berea



PARTICIPATION INFORMATION SHEET

TITLE: Adjustment to Multiple Sclerosis: Application of the Fennell Four Phase Model and Identification of Effective Social Support

PURPOSE OF THE RESEARCH

This is an invitation to participate in a study conducted by researchers at the University of Wollongong. The purpose of the research is to explore whether people with MS go through stages of thoughts and feelings as they adjust to the condition. The aim is to explore these stages and the experiences within the stages, in addition the type of social support which may be helpful depending on the stage.

INVESTIGATORS

Gabrielle Berea
School of Psychology
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gb799@uow.edu.au

Dr Nadia Crittenden
School of Psychology
4221 4515
n_crittenden@uow.edu.au

METHOD AND DEMANDS ON PARTICIPANTS

If you choose to be included, you will need to complete the questionnaire package which has been sent to you and return this via mail in the provided envelope. It is anticipated that the questionnaire package will take about an hour to complete. You are encouraged to take breaks if you prefer, rather than complete the questionnaire in one sitting. It may be beneficial to have a support person present with you while you complete the questionnaires to help you identify if you are fatigued and can no longer continue. You are under no obligation to continue or return this questionnaire. These are some examples of the types of questions in the questionnaire package: "I think of my illness all of the time", "I hoped for a miracle", "I am satisfied with my life".

Once the questionnaire package has been received you may be contacted by mail through the MS society requesting for your participation in a face to face interview with me which is expected to take about an hour. However, you are not at all obligated to participate further after completing the questionnaires if you do not wish to do so.

RISKS, INCONVENIENCES AND DISCOMFORTS

Apart from the hour of your time for the completion of the questionnaire we can foresee no risks for you. Your involvement in the study is voluntary and you may withdraw your participation from the study at any time and withdraw any data that you have provided to that point.

POSSIBLE BENEFITS OF THE RESEARCH

This research will provide an understanding of how people cope and adjust to MS and the personal struggles which they may experience. As the majority of people are unaware of what living with a long term chronic illness entails, the journey is often unknown and misunderstood by others. By understanding the phases of MS adjustment, interventions can be tailored to meet these needs and health professionals will be more effective in assisting individuals. Confidentiality is assured, and you or any of the information provided will not be identified in any part of the research.

ETHICS REVIEW

This study has been reviewed by the Human Research Ethics Committee (Social Science, Humanities and Behavioural Science) of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UOW Ethics Officer on (02) 4221 4457.

Below is the contact information for several counselling services if you feel that you are in need of assistance.

MS Connect

1800 042 138 (free call)

A support and referral service, which enables you to speak to one of a team of health professionals about MS, its symptoms and a range of lifestyle considerations.

Monday – Friday (9am – 4.30pm)

Lifeline Australia

24-hour telephone counselling and referral service

13 11 14

Lifeline Sydney

For face-to face counselling services

9951 5577

Centre for NSW Mental Health

24-hour contact numbers for NSW Area Mental Health Services

Northern Sydney/Central Coast

Northern Sydney area: 1300 302 980

Central Coast area: 02 4320 3500

South Eastern Sydney/Illawarra

South Eastern Sydney area: 1300 300 180

Illawarra area: 1300 552 289

Sydney South West

Central Sydney area: 1800 636 825

South Western Sydney area: 1300 787 799

Sydney West

Western Sydney area: 02 9840 3047

Wentworth area: 1800 650 749

Thank you for your interest in this study



CONSENT FORM FOR PARTICIPANTS

ADJUSTMENT TO MULTIPLE SCLEROSIS: Application of the Fennell Four Phase Model and Identification of Effective Social Support

GABRIELLE BEREÄ
DR NADIA CRITTENDEN

I have read the participation information sheet and have had the opportunity to ask the researcher any further questions I may have had. I understand that I am able to contact Gabrielle Berea the primary researcher who is conducting this research as part of a Doctorate in Clinical Psychology supervised by Dr Nadia Crittenden from the department of Psychology at the University of Wollongong. If I am having difficulty understanding this form I am aware that I am able to contact Gabrielle Berea for assistance or may seek help from a support person.

I understand that my participation in this research is voluntary, I am free to refuse to participate and I am free to withdraw from the research at any time. My refusal to participate or withdrawal of consent will not affect me in any adverse manner.

I have been advised of the potential risks and burdens associated with this research, which may include some emotional upset and have had an opportunity to ask Gabrielle Berea any questions I may have about the research and my participation.

If I have any enquiries about the research, I can contact Gabrielle Berea 0414 66 7902 or 02 9832 7902 *and* Dr Nadia Crittenden 4221 4515 or if I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

By signing below I am indicating my consent to

- Completing a questionnaire package
- Possibly being contacted by mail to request my further participation in an interview which I can freely decline from participating in by not responding to the invitation letter

I understand that the data collected from my participation will be used for purpose of a thesis and possibly a journal publication, and I consent for it to be used in that manner.

Signed

Date

.....
Name (please print)

...../...../.....

.....

Demographics Questionnaire

What is your gender? (Please circle appropriate answer): **Female** **Male**

What is your date of birth? _____

What is your marital status? (Please circle appropriate answer/s)

Married

Single

Divorced

Defacto

Other: _____

What is your current living situation? (Please circle appropriate answer)

I live with my partner/spouse and children

I live with my partner/spouse

I live with my children

I live alone

Other: _____

Do you have children? (Please circle appropriate answer) YES NO

If so, how many? _____

What is your employment status? (Please circle appropriate answer)

Unemployed

Working part time

Retired

Working full time

Other: _____

Do you attend MS support group meetings? (Please circle appropriate answer)

Yes, I regularly attend

I am an irregular support group member and may attend on the odd occasion

In the past I regularly attended support groups but I no longer do

I have never attended a support group

What form of MS do you have? (Please circle appropriate answer)

Relapsing – remitting Multiple Sclerosis

Secondary progressive Multiple Sclerosis

Primary progressive Multiple Sclerosis

Not sure

If relapsing remitting....

When was your last acute episode? _____

How would you rate the severity of your last acute episode? (Please circle appropriate answer)

| | | | | | | | | | |
|------------------|----------|-------------|----------|----------------|----------|----------|---------------|----------|--------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Very mild | | mild | | average | | | severe | | Very Severe |

What is your current symptom state? (Please circle appropriate answer)

| | | | | |
|------------------|-------------|----------------|-------------|------------------|
| Excellent | Good | Average | Poor | Very poor |
|------------------|-------------|----------------|-------------|------------------|

How would you identify yourself at this time in relation to the following questions (please circle)?

1. I am feeling anxious

| | | | | | | | | | |
|------------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|
| <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> | <u>6</u> | <u>7</u> | <u>8</u> | <u>9</u> | <u>10</u> |
| Not at all | | | | Somewhat | | | | | Very much |

2. I am feeling very moody

| | | | | | | | | | |
|------------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|
| <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> | <u>6</u> | <u>7</u> | <u>8</u> | <u>9</u> | <u>10</u> |
| Not at all | | | | Somewhat | | | | | Very much |

3. I am coping well at this time

| | | | | | | | | | |
|------------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|
| <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> | <u>6</u> | <u>7</u> | <u>8</u> | <u>9</u> | <u>10</u> |
| Not at all | | | | Somewhat | | | | | Very much |

4. I have quality of life

| | | | | | | | | | |
|------------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|
| <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> | <u>6</u> | <u>7</u> | <u>8</u> | <u>9</u> | <u>10</u> |
| Not at all | | | | Somewhat | | | | | Very much |

Fennell Phase Inventory Scale

Please respond to these statements by entering the number that best describes how you are feeling.

1 = Definitely do not agree

2 = Do not agree

3 = Somewhat agree

4 = Agree

5 = Very strongly agree

- _____ 1. I feel like I am falling apart
- _____ 2. I am just beginning to recognise when and how my symptoms occur
- _____ 3. I am beginning to accept the fact that I will never be completely like I was before the illness and that I will need to become a new person
- _____ 4. I now have learned that living with the illness involves getting sicker, at times, and improving, at times
- _____ 5. The primary way for me to improve is if my physician finds me the right treatment
- _____ 6. I am beginning to seek support and information from others who have or who know about the illness
- _____ 7. I am in the early process of creating meaning about my illness experience
- _____ 8. I have gained a sense of myself that is blended – a combination of my life before and after I first got sick
- _____ 9. I need to know with certainty when and if I am going to get better
- _____ 10. I just starting to feel like I have some control over my life
- _____ 11. I am beginning to learn how to live with the unknown or chronic nature of my illness
- _____ 12. I have better and more satisfying relationships with people I care about since I first became sick
- _____ 13. It is my fault I got sick
- _____ 14. I am just starting to realise that there may be things I can do to help myself feel better
- _____ 15. I am starting to see my illness experience as having some value
- _____ 16. I am proud of myself for living with this illness
- _____ 17. I think about my illness all of the time
- _____ 18. I am just beginning to stabilise (i.e., feeling a bit less confused and a bit more ordered)
- _____ 19. For the first time, I am beginning to have compassion and love for myself and for what I have endured
- _____ 20. I am a better and wiser person since I first got sick

Ways of Coping Questionnaire

Shorten Version

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. As this research is focused on Multiple Sclerosis please keep in mind having a chronic illness as the stressful situation. When responding to the questions think about how you have coped with the MS in the past few weeks or months. We are interested in your recent coping strategies not ones you may have used years ago; it may be helpful to keep in mind the past 6-12 months and the strategies you used during this time.

As you respond to each of the statements, please keep MS in mind as the stressful situation.

Read each statement carefully and indicate, by circling 0, 1, 2 or 3, to what extent you used it in the situation.

| | | |
|-------------|---------------------------------------|------------------------------|
| Key: | 0 = Does not apply or not used | 1 = Used somewhat |
| | 2 = Used quite a bit | 3 = Used a great deal |

Please try to respond to every question.

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I tried to analyze the problem in order to understand it better. **0 1 2 3**
2. I felt that time would have made a difference –
the only thing was to wait..... **0 1 2 3**
3. I talked to someone to find out more about the situation..... **0 1 2 3**
4. I hoped for a miracle..... **0 1 2 3**
5. I went along with fate; sometimes I just have bad luck..... **0 1 2 3**
6. I went on as if nothing had happened. **0 1 2 3**
7. I looked for the silver lining, so to speak;
I tried to look on the bright side of things..... **0 1 2 3**
8. I accepted sympathy and understanding from someone..... **0 1 2 3**
9. I was inspired to do something creative about the problem..... **0 1 2 3**
10. I tried to forget the whole thing. **0 1 2 3**
11. I changed or grew as a person. **0 1 2 3**
12. I waited to see what would happen before doing anything. **0 1 2 3**
13. I made a plan of action and followed it. **0 1 2 3**
14. I let my feelings out somehow. **0 1 2 3**
15. I tried not to act too hastily or follow my first hunch. **0 1 2 3**
16. I rediscovered what is important in life. **0 1 2 3**
17. I changed something so things would turn out all right..... **0 1 2 3**
18. I asked advice from a relative or friend I respected..... **0 1 2 3**
19. I talked to someone about how I was feeling..... **0 1 2 3**
20. I drew on my past experiences; I was in a similar situation before..... **0 1 2 3**
21. I knew what had to be done, so I doubled my efforts
to make things work..... **0 1 2 3**

Go on to next page

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

22. I came up with a couple of different solutions to the problem..... **0 1 2 3**
23. I accepted the situation, since nothing could be done..... **0 1 2 3**
24. I tried to keep my feeling about the problem from interfering
with other things..... **0 1 2 3**
25. I wished that I could change what had happened or how I felt..... **0 1 2 3**
26. I daydreamed or imagined a better time or place
than the one I was in..... **0 1 2 3**
27. I wished that the situation would go away or somehow
be over with..... **0 1 2 3**
28. I had fantasies or wishes about how things might turn out. **0 1 2 3**
29. I went over in my mind what I would say or do. **0 1 2 3**
30. I tried to see things from the other person's point of view..... **0 1 2 3**

Satisfaction with Life Scale

Below are five statements with which you may agree or disagree with. Using the 1 to 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

- 1= strongly disagree
- 2= disagree
- 3= slightly disagree
- 4= neither agree nor disagree
- 5= slightly agree
- 6= agree
- 7= strongly agree

- ___ 1. In most ways my life is close to my ideal.
- ___ 2. The conditions of my life are excellent.
- ___ 3. I am satisfied with my life.
- ___ 4. So far I have gotten the important things I want in life.
- ___ 5. If I could live my life over, I would change almost nothing.

DASS₂₁

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

| | | | | | |
|----|--|---|---|---|---|
| 1 | I found it hard to wind down | 0 | 1 | 2 | 3 |
| 2 | I was aware of dryness of my mouth | 0 | 1 | 2 | 3 |
| 3 | I couldn't seem to experience any positive feeling at all | 0 | 1 | 2 | 3 |
| 4 | I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 5 | I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |
| 6 | I tended to over-react to situations | 0 | 1 | 2 | 3 |
| 7 | I experienced trembling (eg, in the hands) | 0 | 1 | 2 | 3 |
| 8 | I felt that I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| 9 | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 10 | I felt that I had nothing to look forward to | 0 | 1 | 2 | 3 |
| 11 | I found myself getting agitated | 0 | 1 | 2 | 3 |
| 12 | I found it difficult to relax | 0 | 1 | 2 | 3 |
| 13 | I felt down-hearted and blue | 0 | 1 | 2 | 3 |
| 14 | I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| 15 | I felt I was close to panic | 0 | 1 | 2 | 3 |
| 16 | I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| 17 | I felt I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| 18 | I felt that I was rather touchy | 0 | 1 | 2 | 3 |
| 19 | I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 20 | I felt scared without any good reason | 0 | 1 | 2 | 3 |
| 21 | I felt that life was meaningless | 0 | 1 | 2 | 3 |

SOCIAL SUPPORT QUESTIONNAIRE

This questionnaire has been constructed based on interviews with people with Multiple Sclerosis. It explores the value of different types of social support for various social support providers (spouse, other family members, friends, health professionals etc).

Please indicate in the boxes for the questions how relevant each type of social support for each support provider is for you.

When responding to these questions please think of what you find most helpful/unhelpful at this time in your life with MS. We are interested in learning about what you currently feel is supportive and unsupportive for you in your current situation not in the past.

1 = Most relevant to me at this time

2 = Second most relevant to me at this time

3 = Least relevant to me at this time

An example of a possible response is as follows:

It is very important that my **neurologist** provide me with support with my MS by providing:

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☒ 3

Helpful tangible support such as providing me with technically competent medical care (appropriate monitoring of my health, appropriate referrals etc) ☒ 2

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☒ 1

*1) It is very important for my **spouse/partner** to help me with my MS by providing me with (if you don't have a spouse/partner could you answer in the context of how you anticipate you would feel if you did have one):*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with practical assistance with daily activities such as cleaning, cooking etc..... ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

GO TO NEXT PAGE

1 = Most relevant to me at this time 2 = Second most relevant to me at this time 3 = Least relevant to me at this time

2) *It is most unhelpful/hurtful/unsupportive if my **spouse/partner** provides me with inadequate support with my MS by providing me with (if you don't have a spouse/partner could you answer in the context of how you anticipate you would feel if you did have one):*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate..... ☐

Unhelpful tangible support such as providing unwanted practical assistance..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

3) *It is very important for my **friends** to provide me with support with my MS by providing:*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with practical assistance with daily activities such as cleaning, cooking etc..... ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

4) *It is most unhelpful/hurtful/unsupportive if my **friends** provide me with inadequate support with my MS by providing:*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate. ☐

Unhelpful tangible support such as providing unwanted practical assistance..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

1 = Most relevant to me at this time 2 = Second most relevant to me at this time 3 = Least relevant to me at this time

5) *It is very important for my **other family members** (parents, sibling, children, etc) to provide me with support with my MS by providing:*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with practical assistance with daily activities such as cleaning, cooking etc..... ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

6) *It is most unhelpful/hurtful/unsupportive if my **other family members** (parents, siblings, children, etc) provide me with inadequate support with my MS by providing:*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate..... ☐

Unhelpful tangible support such as providing unwanted practical assistance..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

7) *It is very important that **other people with MS** that I may know, provide me support with my MS by providing (if you do not know another person with MS could you answer in the context of how you anticipate you would feel if you did know someone with MS):*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with practical assistance with daily activities such as cleaning, cooking etc..... ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

1 = Most relevant to me at this time 2 = Second most relevant to me at this time 3 = Least relevant to me at this time

8) *It is most unhelpful/hurtful/supportive if **other people with MS** that I may know provide me with inadequate support with my MS by providing (if you do not know another person with MS could you answer in the context of how you anticipate you would feel if you did know someone with MS):*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate. ☐

Unhelpful tangible support such as providing unwanted practical assistance..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

9) *It is very important that my **GP** provide me with support with my MS by providing:*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with technically competent medical care (appropriate monitoring of my health, appropriate referrals etc) ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

10) *It is most unhelpful/hurtful/unsupportive if my **GP** provides me with inadequate support with my MS by providing:*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate. ☐

Unhelpful tangible support such as providing technically incompetent medical care (not monitoring my health, not making appropriate referrals etc)..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

1 = Most relevant to me at this time 2 = Second most relevant to me at this time 3 = Least relevant to me at this time

11) *It is very important that my **neurologist** provide me with support with my MS by providing:*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with technically competent medical care (appropriate monitoring of my health, appropriate referrals etc) ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

12) *It is most unhelpful/hurtful/unsupportive if my **neurologist** provides me with inadequate support with my MS by providing:*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate. ☐

Unhelpful tangible support such as providing technically incompetent medical care (not monitoring my health, not making appropriate referrals etc)..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

13) *It is very important that **acquaintances/strangers** (this may include complete strangers or acquaintances such as work colleagues) provide me with support with my MS by providing:*

Helpful emotional support such as being physically there for me, calmly accepting my MS and carrying on with life, expressing concern, empathy and affection and understanding the impact of my MS on me as an individual..... ☐

Helpful tangible support such as providing me with practical assistance with activities such as helping me with the shopping trolley, providing a seat in public etc..... ☐

Helpful informational support such as providing me with useful information and advice about MS, being optimistic about my MS and acting as a positive role model..... ☐

1 = Most relevant to me at this time 2 = Second most relevant to me at this time 3 = Least relevant to me at this time

*14) It is most unhelpful/hurtful/unsupportive if **acquaintances/strangers** (this may include complete strangers or acquaintances such as work colleagues) provide me with inadequate support with my MS by providing:*

Unhelpful emotional support such as expressing too much worry or pessimism, expressing little concern empathy or affection, avoiding social contact with me, or being rude and inappropriate. ☐

Unhelpful tangible support such as providing unwanted practical assistance..... ☐

Unhelpful informational support such as providing insufficient information or advice about MS, being critical to my response to MS and minimising its impact..... ☐

STOP HERE

Thank you for your time and assistance

APPENDIX 5

STUDY 2 CHAT ROOM ADVERTISEMENT

Chat room announcement

My name is Gabrielle Berea and I wish to invite you to participate in a study being conducted as part of my doctoral studies at the University of Wollongong. The purpose of the research is to explore what happens to people with MS as they adjust to their condition. This includes how they feel and think as they adjust, and also the helpfulness (or not) of social support. As this research is focused on adjustment issues we require the participation of a wide range of individuals with MS from people who are newly diagnosed through to people who have lived with MS for many years. We need your assistance in order for this research to be successful. Participation involves completion of a questionnaire package which takes about one hour to complete.

If you are interested in participating or have any questions please contact me via email or phone on:

Phone: 0414 66 7902 or (02) 9832 7902

Email: gb799@uow.edu.au

I will then post you the questionnaire package with a return envelope.

Your interest and assistance is greatly appreciated.

APPENDIX 6

COMPLETE STATISTICAL RESULTS FOR UNLIMITED FACTOR ANALYSIS

An unlimited factor analysis was performed and five factor solution (with Eigenvalues exceeding 1) was identified as underlying the 19 questionnaire items. Factor loadings ($>.45$) for each of these factors are presented in Table 12. In total these five factors accounted for 60.77% of the variance in the questionnaire data. The Bartlett's test of sphericity was $<.000$ and the Kaiser-Meyer-Olkin measure was .814, both tests indicating the suitability of the data for the factor analysis. Cronbach's alpha was computed on the five factors and the values were within the moderate range for all factors with the exception of factor five (Factor 1, .85; Factor 2, .71; Factor 3, .64; Factor 4, .61; Factor 5, .37).

Table 12

Varimax Rotated Component Loading for Initial Unlimited Factor Analysis

| Item | Factors | | | | |
|---|---------|-----|-----|-----|-----|
| | 1 | 2 | 3 | 4 | 5 |
| I have gained a sense of myself that is blended | .66 | ... | ... | ... | ... |
| I have better more satisfying relationships with people | .70 | ... | ... | ... | ... |
| My illness experience has some value | .74 | ... | ... | ... | ... |
| I am proud of myself for living with this illness | .75 | ... | ... | ... | ... |
| I am beginning to have compassion for myself | .66 | ... | ... | ... | ... |
| I am a better and wiser person since I first got sick | .83 | ... | ... | ... | ... |
| I will need to become a new person | ... | .69 | ... | ... | ... |
| Starting to feeling like I have some control of my life | ... | .68 | ... | ... | ... |
| I am beginning to learn how to live with the unknown | ... | .57 | ... | ... | ... |
| There may be things I can do to help myself feel better | ... | .52 | ... | ... | ... |

| | | | | | |
|--|-------|-------|-------|-------|------|
| Beginning to recognise when/how my symptoms occur | ... | ... | .70 | ... | ... |
| Beginning to seek support and information from others | ... | ... | .62 | ... | ... |
| I am in the early process of creating meaning | ... | ... | .61 | ... | ... |
| I am just beginning to stabilise | ... | ... | .51 | ... | ... |
| I feel like I am falling apart | ... | ... | ... | .57 | ... |
| I need to know with certainty when/if I am going to get better | ... | ... | ... | .80 | ... |
| I think about my illness all of the time | ... | ... | ... | .58 | ... |
| My physician must find me the right treatment | ... | ... | ... | .58 | .54 |
| Illness involves getting sicker, at times, and improving, at times | ... | ... | ... | ... | .74 |
| % of variance | 20.68 | 11.50 | 11.05 | 10.73 | 6.82 |

Note: Values <.45 have been suppressed

APPENDIX 7

COMPLETE STATISTICAL RESULTS FOR PERCEIVED HELPFUL AND UNHELPFUL SUPPORT QUESTIONNAIRE

Helpful Support from the Spouse

A Friedman two way ANOVA indicated that the rankings of helpful types of support from the spouse varied significantly, $\chi^2 = 61.79$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that helpful emotional support from the spouse (*Mean Rank* = 1.31) was perceived as significantly more valuable than tangible support (*Mean Rank* = 2.12), $T = 517$, $z = -5.01$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.58$.

The difference between helpful emotional support and informational support (*Mean Rank* = 2.57) was also significant, with emotional support being perceived as more important from the spouse, $T = 226.50$, $z = -6.53$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “large”, $r = 0.75$.

Informational and tangible support were also found to significantly differ, with tangible support being perceived as significantly more helpful than informational support, $T = 856.50$, $z = -3.24$ (corrected for ties), $N - \text{Ties} = 75$, $p = .001$. This effect can be described as “medium”, $r = 0.37$.

Unhelpful Support from the Spouse

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from the spouse varied significantly, $\chi^2 = 40.46$ (corrected for ties), $df = 2$, $N - \text{Ties} = 74$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that hurtful or inadequate emotional support from

the spouse (*Mean Rank* = 1.42) was perceived as significantly more unsupportive than inadequate or unwanted tangible assistance (*Mean Rank* = 2.15), $T = 575.50$, $z = -4.64$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can be described as “large”, $r = 0.54$.

The difference between unhelpful emotional support and unhelpful informational support (*Mean Rank* = 2.43) was also significant. Results indicated that participants perceived inadequate or unhelpful emotional support as more hurtful and obstructive $T = 420$, $z = -5.39$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can also be described as “large”, $r = 0.63$. No significant differences were found between unhelpful informational and tangible support ($p = .073$, $r = .20$).

Helpful Support from Other Family Members

A Friedman two way ANOVA indicated that rankings of helpful types of support from other family members varied significantly, $\chi^2 = 54.51$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 demonstrated that the emotional support from other family members (*Mean Rank* = 1.33) was perceived as significantly more essential than tangible assistance (*Mean Rank* = 2.15), $T = 508.50$, $z = -5.05$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.58$.

Helpful emotional support was found to be perceived as significantly more valuable than helpful informational support (*Mean Rank* = 2.51) from other family members, $T = 247$, $z = -6.43$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “large”, $r = 0.74$. Finally, no significant differences were found

between helpful informational and tangible support from other family members ($p = .024$, $r = .26$).

Unhelpful Support from Other Family Members

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from other family members varied significantly, $\chi^2 = 47.04$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the unhelpful or inadequate emotional support from other family members (*Mean Rank* = 1.36) was perceived as significantly more detrimental than unwanted tangible assistance (*Mean Rank* = 2.24), $T = 467$, $z = -5.26$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.61$.

Inadequate or negative emotional support was found to be viewed as significantly more unsupportive than unhelpful informational support (*Mean Rank* = 2.40) from other family members, $T = 439.50$, $z = -5.37$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “large”, $r = 0.62$. No significant differences were found between unhelpful informational and tangible support from other family members ($p = .023$, $r = .14$).

Helpful Support from Friends

A Friedman two way ANOVA indicated that rankings of helpful types of support from friends varied significantly, $\chi^2 = 71.70$ (corrected for ties), $df = 2$, $N - \text{Ties} = 74$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the emotional support from friends (*Mean Rank* = 1.20) was perceived as significantly more valuable than tangible support (*Mean Rank* = 2.31), $T = 248.50$, $z = -6.37$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can be described as “large”, $r = 0.74$.

The difference between helpful emotional support and helpful informational support (*Mean Rank* = 2.49) from friends was also significant, with emotional support being perceived as more important, $T = 188$, $z = -6.67$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can also be described as “large”, $r = 0.78$. No significant differences were found between helpful informational and tangible support from friends ($p = .193$, $r = .15$).

Unhelpful Support from Friends

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from friends varied significantly, $\chi^2 = 44.03$ (corrected for ties), $df = 2$, $N - \text{Ties} = 74$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the unhelpful or inadequate emotional support from friends (*Mean Rank* = 1.39) was perceived as significantly more hurtful and unsupportive than unwanted tangible assistance (*Mean Rank* = 2.16), $T = 543$, $z = -4.78$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can be described as “large”, $r = 0.56$.

The difference between unhelpful emotional support and unhelpful informational support (*Mean Rank* = 2.40) from friends was also significant, with unhelpful emotional

support being perceived as more obstructive, $T = 460.50$, $z = -5.17$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can also be described as “large”, $r = 0.60$. Differences between unhelpful informational and tangible support from friends was found to be non significant ($p = .038$, $r = .24$).

Helpful Support from Other PwMS

A Friedman two way ANOVA indicated that rankings of helpful types of support from other PwMS varied significantly, $\chi^2 = 44.24$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 demonstrated that the emotional support from other PwMS ($\text{Mean Rank} = 1.67$) was considered significantly more essential than tangible support ($\text{Mean Rank} = 2.63$), $T = 355.50$, $z = -5.92$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.68$.

Informational support ($\text{Mean Rank} = 1.71$) was found to be significantly more valuable than tangible assistance from other PwMS, $T = 2407$, $z = -5.37$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “large”, $r = 0.62$. No significant difference was found between helpful informational and emotional support from other PwMS ($p = .733$, $r = .04$), indicating that other PwMS are equally valued for both emotional and informational support.

Unhelpful Support from Other PwMS

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from other PwMS varied significantly, $\chi^2 = 20.67$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the unhelpful or inadequate emotional support from other PwMS (*Mean Rank* = 1.60) was perceived as significantly more unsupportive than unwanted tangible assistance (*Mean Rank* = 2.33), $T = 588$, $z = -4.64$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.54$.

Unhelpful emotional support was also found to significantly differ from unhelpful informational support (*Mean Rank* = 2.07) from other PwMS, with unhelpful emotional support being perceived as more unsupportive, $T = 924$, $z = -2.75$ (corrected for ties), $N - \text{Ties} = 75$, $p = .006$. This effect can also be described as “medium”, $r = 0.32$. No significant differences were found between unhelpful informational and tangible support from other PwMS ($p = .102$, $r = .19$).

Helpful Support from the GP

A Friedman two way ANOVA indicated that rankings of helpful types of support from the GP varied significantly, $\chi^2 = 18.71$ (corrected for ties), $df = 2$, $N - \text{Ties} = 76$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the tangible support in the form of competent medical care (*Mean Rank* = 1.88) was perceived as significantly more valuable than emotional support from the GP (*Mean Rank* = 2.39), $T = 2192$, $z = -3.90$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “medium”, $r = 0.45$.

Informational support (*Mean Rank* = 1.72) from the GP was also viewed as significantly more essential than emotional assistance, $T = 2054$, $z = -3.22$ (corrected for

ties), $N - \text{Ties} = 76$, $p = .000$. This effect can also be described as “medium”, $r = 0.37$. No significant differences were found between helpful informational and tangible (competent medical care) support from the GP ($p = .370$, $r = .10$), indicating that the GP was similarly valued for providing both competent medical care and MS related information.

Unhelpful Support from the GP

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from the GP varied significantly, $\chi^2 = 21.84$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the unhelpful or inadequate tangible support in form of incompetent medical care from the GP (*Mean Rank* = 1.60) was perceived as significantly more unhelpful than inadequate emotional support (*Mean Rank* = 2.36), $T = 2240$, $z = -4.46$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.52$.

The difference between unhelpful tangible support (incompetent medical care) and unhelpful informational support (*Mean Rank* = 2.04) from the GP was also significant, with unhelpful tangible support being perceived as more obstructive, $T = 937.50$, $z = -2.70$ (corrected for ties), $N - \text{Ties} = 75$, $p = .007$. This effect can also be described as “medium”, $r = 0.31$. No significant differences were found between unhelpful emotional and informational support from the GP ($p = .056$, $r = .22$).

Helpful Support from the Neurologist

A Friedman two way ANOVA indicated that rankings of helpful types of support from the neurologist varied significantly, $\chi^2 = 42.87$ (corrected for ties), $df = 2$, $N - \text{Ties} = 76$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the tangible support in the form of competent medical care from the neurologist (*Mean Rank* = 1.57) was viewed by participants as significantly more valuable than emotional support (*Mean Rank* = 2.59), $T = 2535.50$, $z = -5.73$ (corrected for ties), $N - \text{Ties} = 76$, $p = .000$. This effect can be described as “large”, $r = 0.66$.

Results also indicate that informational support (*Mean Rank* = 1.72) was perceived as significantly more valuable than emotional support, $T = 2306$, $z = -4.60$ (corrected for ties), $N - \text{Ties} = 76$, $p = .000$. This effect can also be described as “large”, $r = 0.53$. No significant difference was found between helpful informational and tangible (competent medical care) support from the neurologist ($p = .081$, $r = .20$).

Unhelpful Support from the Neurologist

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from the neurologist varied significantly, $\chi^2 = 27.63$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 demonstrated that the unhelpful or inadequate tangible support in form of incompetent medical care from the neurologist (*Mean Rank* = 1.87) was perceived as significantly more unsupportive than inadequate emotional assistance

(*Mean Rank* = 2.48), $T = 2254.50$, $z = -4.52$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$.

This effect can be described as “large”, $r = 0.52$.

Inadequate informational support (*Mean Rank* = 1.65) from the neurologist was perceived as significantly more unhelpful than inadequate or misguided emotional support, $T = 2077.50$, $z = -3.60$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “medium”, $r = 0.42$. No significant differences were found between unhelpful tangible and informational support ($p = .147$, $r = .17$).

Helpful Support from Acquaintances

A Friedman two way ANOVA indicated that rankings of helpful types of support from acquaintances varied significantly, $\chi^2 = 30.48$ (corrected for ties), $df = 2$, $N - \text{Ties} = 75$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the emotional support from acquaintances (*Mean Rank* = 1.76) was perceived as significantly more helpful than informational support (*Mean Rank* = 2.52), $T = 592.50$, $z = -4.62$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can be described as “large”, $r = 0.53$.

Tangible assistance (*Mean Rank* = 1.72) was found to be significantly more valued by participants than helpful informational support (*Mean Rank* = 2.52) from acquaintances, $T = 564$, $z = -4.70$ (corrected for ties), $N - \text{Ties} = 75$, $p = .000$. This effect can also be described as “large”, $r = 0.54$. No significant differences were found between helpful emotional and tangible support from acquaintances ($p = .940$, $r = .01$).

Unhelpful Support from Acquaintances

A Friedman two way ANOVA indicated that rankings of unhelpful types of support from acquaintances varied significantly, $\chi^2 = 24.41$ (corrected for ties), $df = 2$, $N - \text{Ties} = 74$, $p = .000$.

Follow-up pairwise comparisons with the Wilcoxon Signed Rank test with a Bonferroni adjusted α of .017 indicated that the unhelpful or inadequate emotional support from acquaintances (*Mean Rank* = 1.61) was perceived as significantly more unsupportive than unwanted tangible assistance (*Mean Rank* = 1.97), $T = 969$, $z = -2.38$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can be described as “medium”, $r = 0.28$.

Unhelpful emotional support was also perceived as significantly more detrimental than unhelpful informational support (*Mean Rank* = 2.42) from acquaintances, $T = 587.50$, $z = -4.46$ (corrected for ties), $N - \text{Ties} = 74$, $p = .000$. This effect can also be described as “large”, $r = 0.52$.

A significant difference was also found between unhelpful informational and tangible support, unwanted tangible assistance was perceived as more unhelpful than inadequate informational support, $T = 898$, $z = -2.77$ (corrected for ties), $N - \text{Ties} = 74$, $p = .006$. This effect can also be described as “medium”, $r = 0.32$.