Coping and Multiple Sclerosis: Individuals with Multiple Sclerosis and their Significant Others

A Qualitative Exploration

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Abstract

Multiple Sclerosis (MS) is a degenerative condition which affects everyone differently as regards emergence of symptoms. The illness uncertainty associated with MS has ramifications for how those with the condition and those close to them cope with the illness, with each other and with the effect it has on their lives. Health professionals acknowledge that those with MS need to be seen in the context of their families. The perspective of significant others (SOs) need to be acknowledged. However there is a lack of knowledge about what to expect about how people cope as a dyad.

This study used Interpretative Phenomenological Analysis (IPA) to explore how those with MS and their SOs cope with this illness in their lives. Seven couples were recruited using purposive sampling through the MS society. Each person in the couple was interviewed separately using a semi-structured interview schedule. The interviews were transcribed and analysed using the principles of IPA to produce overarching themes and sub themes. Peer coding by two supervisors helped to enrich the analysis and contributed to the trustworthiness of the findings.

Three overarching themes emerged from the data, two overarching themes with four sub themes and one overarching theme with 3 sub themes. These overarching themes are labelled: Resources and Barriers to Coping, Coping Together: "Peaks and T roughs" and Coping over the Long Haul. Two integrative themes emerged, which were called Faith in Self and Faith in Each Other, encapsulating the participants’ identified primary resources which enabled them to cope.
The results of this study will assist health professionals to better comprehend how those with MS cope in an interconnected way with those with whom they share their lives. This research has highlighted the individual preferences about coping style and choice of coping strategies from the perspective of both the person with MS and their significant other. In addition, the nature of the relationship between couples, and the impact this relationship has on their ability to cope, needs to be understood and acknowledged by health professionals. The results of this study indicated that the relationship can be a powerful resource for couples during times of illness related stress. This study adds to the small but growing body of literature about how couples with MS make sense of the disease and how they develop coping strategies relevant to their relationship.
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List of Abbreviations

CBT: Cognitive Behavioural Therapy
CG: Care-giver
CISS: Coping Inventory for Stressful Situations
COPE: Coping orientation for Problem Experiences
CR: Care-Receiver
HRQOL: Health Related Quality of Life
ICF: International Classification of Functioning
IPQ: The Illness Perception Questionnaire
MDT: Multi-Disciplinary Team
MS: Multiple Sclerosis
PwMS: Person with MS
QOL: Quality of Life
RCT: Randomised Control Trial
RAG-M: Regional Advice Group for Maori
SF-36: Short Form Health Survey (36 Items)
SO: Significant Other
WOC: Ways of Coping
WOC-C: Ways of Coping Checklist
WOCC-R: Ways of Coping Checklist-Revised
WOCQ: Ways of Coping Questionnaire
Chapter One: Background

1.1 Overview

This chapter will introduce key aspects of this research project, including the primary features about people with Multiple Sclerosis (PwMS), as well as the importance and relevance of the results. I will describe MS and explain what is meant by the terms coping and significant other (SO). My professional background will be detailed while explaining the path which led me to researching this topic in this way. I will also give an outline of the structure of this thesis.

1.2 Introduction to Research

This research will explore how PwMS and their significant others (SOs) cope with the changes MS causes in their lives. MS is one of the leading causes of neurological disability in adults, and almost 3000 people in New Zealand live with the condition (Taylor et al., 2010). Having MS or being a carer for someone with MS significantly increases the likelihood of developing depression or another mental health disorder (Siegert & Abernethy, 2005). Health professionals supporting couples where one has MS often come from a background of focusing on physical rehabilitation and they can be unprepared for the loss and coping issues that are present for both members of a couple (Somerset et al., 2001). There is a lack of understanding among health professionals about how couples cope in relation to each other (Koopman et al., 2006) and it was an aim of this research to explore this process. It is important to understand more about how those with MS and their families cope in order for health professionals to better support both these groups. The results from this research indicate that health professionals need to be sensitive to the individual coping strategies of both members of a couple where one has MS, as well as addressing the changing needs of their relationship. Many people in this study named their relationship as a valuable resource which supported them through times of stress. Therefore, developing ways to discuss, understand and support the relationship should be of interest to health professionals in order to encourage resilience for both members of a couple. Recommendations include suggestions for clinicians and policy developers to consider coping in relation to people with MS and those close to them, as well as indications for future research in this area. This study focused on couples, which is an example of a dyad, a term which refers to persons in an interactional situation.
1.3 Clinical Background

I am an occupational therapist who has worked in a variety of in-patient and community based services for people with neurological conditions since I first qualified ten years ago. MS can impact on all aspects of everyday life, and I have witnessed a wide range of different people coping with their symptoms which usually get worse over time. In turn, the ways in which my clients have coped with the presence of MS in their lives has intrigued and inspired me. There have been days when the coping strategies of either my client with MS or their SO made it very challenging to deliver occupational therapy intervention. Acknowledging the world people live in, including their family, is a vital part of occupational therapy philosophy (Bennett & Bennett, 2000), but it is an area I believed I had not taken time to understand in-depth. I had recognised the clinical need to understand how couples cope but never seemed to have the time to get to grips with the theory and research in this area. I had observed that how people coped, how (and if) they changed their coping strategies and how their care-givers coped appeared to have an impact on the way in which occupational therapy (or any other allied health intervention) could be implemented.

My initial motivation for embarking on this research was to explore the ways in which people cope and the effect their coping style might have on their ability to engage with occupational therapists and other health professionals. Indeed, prior to undertaking this study I had thought that by understanding coping better, I might be able to recommend the best way for people with MS and their SOs to cope so that occupational therapists and other allied health professionals could engage with them more effectively. The message from the participants of this research, however, is not about the best way to cope, rather it is an exploration of how they think about and make sense of the situation they have found themselves in. The recommendations from this research are less about what my clients should do and more about what health professionals need to consider when it comes to providing support for optimal coping for individuals and couples.
1.4 Justification for Study

In spite of health professionals being involved in supporting those with MS and their families all over New Zealand, there is a lack of research specific to New Zealand about the experience of coping for these groups (Gregory et al., 1996). Coping within a dyad is relatively unexplored, so I adopted an exploratory, inductive approach as it was more appropriate than a hypothetico-deductive one (McLeod, 1999). Fourteen participants were interviewed about their experience of coping with either having MS or being the SO of someone with MS. This kind of in-depth qualitative work in an area which has been under researched, and has been investigated primarily from a quantitative perspective, offered an opportunity to gather rich data on the complexity of how people cope together. This research will inform a more comprehensive approach to treatment for PwMS their families (Harkness Hodgson et al., 2004) and contribute to an increased understanding of how people with other chronic conditions and their caregivers cope (Ministry of Health, 2007).

1.5 Multiple Sclerosis

MS is a progressive neurological condition where the immune system attacks the myelin sheath of neurons, causing demyelination. The location of demyelination, and therefore the severity of symptoms, varies from person to person and changes with different rates of severity over time (Atchison & Dirette, 2007). While no two cases of MS are exactly alike, symptoms can include slurred speech, coordination problems, pain, impaired mobility, paralysis, fatigue, visual impairments, cognitive deterioration, dizziness, bladder and bowel dysfunction, sexual dysfunction and spasticity (McNulty, 2007). While there is no unanimous agreement on definitions for various clinical subtypes of MS (Lublin & Reingold 1996), there are four commonly accepted clinical courses. Relapse Remitting MS (RRMS) as the most common course, where people go through exacerbations and remissions of symptoms (Einarsson et al., 2006). Secondary Progressive MS (SPMS) occurs where people initially have RRMS but they stop having remissions and gradually and steadily experience more symptoms. Not all people with RRMS will develop SPMS and when the disease course changes will differ among individuals. People with Primary Progressive MS (PPMS) steadily lose function over time, without experiencing remission from symptoms (Thompson et al., 1991). Those with PPMS report higher perceived MS severity, more mental health problems
and lower physical functioning than those with RRMS (Lerdal et al., 2009). This study is concerned with people with RRMS, SPMS and PPMS as the fourth type of MS, known as benign MS, usually results in full recovery and normal functioning following a symptomatic period (Sayao et al, 2007), with no obvious disability. Please see the Glossary appended to this thesis for further detail on these terms.

1.6 Coping

Coping has been defined as the constantly changing cognitive and behavioural efforts a person undertakes to manage external and internal demands that they see as stressful (Lazarus & Folkman, 1984). Health professionals often identify what kind of coping strategy a person is using by looking at the ways they think and act in relation to a perceived stressful event or an idea related to illness. Psychological models typically identify two major dimensions of coping: dealing with the problem which is causing stress (Problem-Focused coping) and regulating the emotional reactions to the problem (Emotion-Focused coping) (Pakenham, 2001a). Coping theories detail different perspectives on how individuals appraise and adjust to challenging situations. How well individuals adjust to living with a chronic illness or living with someone who has a chronic illness will have a significant bearing on how they will interact with support services and rehabilitation (Lerdal et al., 2009; Schiaffino et al., 1998). The cognitive processes involved in coping with MS will be explored in Chapter 2.

1.7 Significant Others

People who care for individuals with MS often find that taking on this role affects their quality of life (Akkus, 2011) and significantly increases their levels of stress (Knight et al., 1993), even at the earlier stages of the disease when physical disability is less apparent (Elliott et al., 2001). It is vital to understand how they cope as individuals and as partners in a relationship with someone who has a chronic illness, in order to tailor support to this group (Finlayson et al., 2008; Knight et al., 1993). All SOs in this study were spouses of people with MS, however the original inclusion criteria for the study described SOs as someone the PwMS knew well, whose life was affected because of this person having MS, and they could be a spouse, family member, friend, neighbour or caregiver.
1.8 Structure of Thesis

This thesis is organised into six chapters. *Chapter One: Introduction* has covered my clinical background, as well as outlining key concepts involved in this study. *Chapter Two: Literature Review* describes the background literature relevant to this research, including models used to understand coping and research about how couples cope with MS. *Chapter Three: Methods* introduces and explains the methods, methodology and theoretical perspective used to analyse this research. *Chapter Four: Results* presents a description of the participants and outlines the results from this study, which are organised into themes, with supporting quotations from participants. *Chapter Five: Discussion* considers the results in the broader context of what is known about this topic and makes recommendations for future research as well as acknowledging limitations. *Chapter Six: Conclusion* summarises the significance of this research and emphasises the implications for clinical practice.
Chapter Two: Literature Review

2.1 Overview

PwMS have received an increasing amount of attention from researchers in the last 20 years. Less research has been conducted on the experience of the SOs of PwMS, although this has been expanding. This chapter will review the literature on mechanisms of coping identified in PwMS along with research relating to the coping patterns of the SOs for PwMS. The literature about how people cope with chronic conditions from an inter-relational point of view will also be explored. It is argued within this chapter that there is a lack of research looking at how the coping style of PwMS and the coping style of their SOs affect each other, making this study a timely and relevant piece of work.

2.2 Setting the Scene

2.2.1 Symptoms of MS

MS is a chronic neurological disease that is characterized by inflammation and demyelination within the central nervous system. The cause of MS is unclear and the pattern of disease is highly individualised and unpredictable (Koopman & Schweitzer, 1999). MS is thought to result from a complex interplay of genetic and environmental factors and is the result of an abnormal autoimmune response to either an infectious agent or environmental trigger in a genetically susceptible individual (McNulty, 2007). It is two times more common in people of Caucasian background than other ethnicities (Atchison & Dirette, 2007). When someone has MS, their immune system appears to attack the myelin sheath surrounding the axons of the central nervous system. The resulting plaques (often known as lesions) can affect all neurological function (Mohr & Cox, 2001). Almost two-thirds of PwMS have a diagnosable psychiatric disorder such as depression or anxiety (Siegert & Abernethy, 2005) and the risk of suicide for this group is 7.5 times higher than for the general population (Krupp & Rizvi, 2002). There are inconclusive reports that medication commonly used to treat RRMS, such as Beta-interferon, increase the likelihood of depression (Mohr et al., 1997).
While depression is a major psychological symptom of MS, it has yet to be determined whether depressive episodes are psychosocial reactions to the progressive nature of MS, or clinical manifestations of neurological impairment, or a combination of both (Siegert & Abernethy, 2005). The prevalence of major depression is elevated in PwMS relative to those without MS and those with other neurological conditions (Patten et al., 2003). MS is marked by a lack of clarity about prognosis and a fluctuating physical condition which can result in both the person with the illness and their partner experiencing ambiguous loss which can create a powerful block to coping (Boss & Couden, 2002).

2.2.2 MS and New Zealand

There are approximately 2,800 people living with MS in New Zealand, with women three times more likely to be affected than men (Taylor et al., 2010). The most recent nationwide cross-sectional study to identify all persons living with MS in New Zealand was carried out in 2006 and reported that there were 1,541 people with RRMS, 918 with SPMS and 458 with PPMS (Taylor et al., 2010). There was a latitudinal gradient in prevalence, increasing from north to south. MS is the third most common cause of neurological disability in adults aged 18-50 (Multiple Sclerosis Society of New Zealand, 2010). A survey investigating employment and PwMS in the Manawatu region found that most participants reported that having MS had caused the early cessation of their working life, and half of those who took part reported that they thought they could work if they had adequate support (Gregory et al., 1993).

2.3 Search Strategy

This review aimed to identify and synthesise literature relating to two areas: 1) the variables associated with coping for PwMS and their family carers or SOs and 2) evidence regarding theories and interventions to assess and facilitate optimal coping by people with MS and their family carers. This literature review was essentially narrative, as synthesising literature from both quantitative and qualitative studies is important, but can be complex to complete (Dixon-Woods et al., 2005). I accessed the following databases: Ovid - Medline (1980 - present), Cochrane Database of systematic reviews, Google Scholar, OTSeeker, PubMed, PsychInfo (1990 to 2009), AMED (1985 to July 2009), Embase (1947-Present), EBSCO database – CINAHL, RehabData, INNZ, and colleagues’ PhD reference lists.
The search strategy involved combining the term ‘multiple sclerosis’ (as a text word and as a MESH heading) with the following words and phrases: coping, stress, caregivers, psychological factors, rehabilitation, family, emotions, illness representations, appraisal, illness uncertainty, positive psychology, adaptation, chronic illness, resilience, illness narratives, self-efficacy and illness intrusiveness. Articles were restricted to those written in English and focused on research from the last 30 years. The reason for this timeline is that the majority of research into the most well-known coping theories (Folkman et al., 1986) and the caregivers’ perspective (McKeown et al., 2003) developed from 1980 onwards. After checking for duplicates across the databases 190 articles were found. I assessed the quality of relevant articles based on checklists developed for quantitative literature which addressed issues like randomisation, management of bias and blinding (Franche et al., 2005). Qualitative literature checklists were used which evaluated components of the studies such as reflexivity, theoretical orientation and transparent data collection and analysis (MacEachen et al., 2006). The decision to include an article in this review was based on relevance to the topic of coping with MS as well as methodological rigour, following use of appraisal checklists as mentioned. Following this critical appraisal process, 99 articles were selected for inclusion, with the most seminal works related to this area discussed in the text, and additional studies outlined in Table 1, 2, 3 and 4.

2.4 Coping Models

Coping styles play an important role in the adjustment to the challenges of having MS or becoming a carer for someone with MS. Chan, da Silva and Chronister (2009) referred to coping style as one of three primary mediators of adjustment to chronic illness and disability. The other two mediators are social support and family adaptation, which will be dealt with later in this chapter when I present the evidence around how families and couples cope with illness and stress. The next two sections, however, outline the theory and research behind two models of coping which draw on social-cognitive theories: Stress and Coping Model and Self-Regulation Model. I will also describe how qualitative studies have added to the understanding of how PwMS cope. I will begin by describing the models themselves before identifying studies where they have been used in relation to people with MS.
2.4.1 Stress and Coping Theory

Most of the research articles into coping with MS has been guided by Lazarus and Folkman’s (1984) Stress and Coping Model, with both cross sectional and longitudinal studies supporting the use of this model in explaining adjustment to MS (McNulty, 2007). This model focuses on the cognitive processes involved with coping with MS (Pakenham et al., 1997) and defines coping as an attempt to correct the imbalance between the demands on a person and their available resources (Lazarus & Folkman, 1984). This model is known as transactional as it holds that the variables involved with coping are not stable and are influenced by person-environment transactions. This speaks to the possibility of influencing these variables to promote positive coping for those in stressful situations. The importance of acknowledging coping resources (such as family) is inherent in this model, and its development has incorporated a greater emphasis on emotion as the focal point of adaptation (Lazarus, 1997).

According to the Stress and Coping Model, potentially stressful events are appraised by individuals with MS in terms of threat, challenge and controllability (McNulty, 2007). Following appraisal, the coping strategies an individual employs are categorised as either Problem-Focused or Emotion-Focused (Pakenham et al., 1997). Problem-Focused strategies are directed at altering the source of the stress, for example, if the stress is related to difficulties getting in and out of a house, improving the access by building a ramp is a Problem-Focused coping strategy. Emotion-Focused strategies, on the other hand, are directed at reducing the emotional distress prompted by the problematic situation and can include seeking emotional respite, avoidance of the stressor or wishful thinking. Emotion-Focused strategies also include acceptance of a disease process and its consequences. In general, Emotion-Focused strategies are associated with higher levels of depression and marital discord (See Table 1 and 2). Lazarus (1997) contended that both forms of coping influence each other during a stressful encounter, and that they each can facilitate and impede the other.

The stressors associated with MS can be broadly categorised as physical or psychosocial. The type of demands presented by physical and psychosocial problems are likely to differ, and so a variety of coping strategies may be employed simultaneously (Chalk, 2007). The extent to which physical symptoms can be relieved is limited; therefore, acceptance of some symptoms
may be more adaptive than relying on Problem-Focused strategies in this area. However, with psychosocial issues, such as familial stress, a Problem-Focused approach may be more effective (Pakenham et al., 1997). Both adjusting to MS and becoming a caregiver are cyclical processes, involving continual re-appraisal, from the initial diagnosis to understanding and assimilating the consequences of the disease into one’s life. For people with MS, poorer psychological adjustment is strongly associated with adopting a wishful thinking coping style (an Emotion-Focused coping strategy), as well as a lack of Problem-Focused coping or failing to seek social support (McCabe et al., 2004).

2.4.2 Illness Representation Theory

Though less researched than the Stress and Coping Model, the evidence base is developing for Leventhal’s theory of illness representation in relation to chronic illness. Illness representation is a core concept in the Self Regulation Model (SRM) (Leventhal et al., 1997), which proposes that perceptions about an illness develop as information is derived from symptoms and social messages and then compared to existing beliefs about health. According to the SRM, a person’s cognitive representation of their illness plays an important role in influencing their coping strategies and their emotional response. The components of these representations include: identity (the label attributed to the illness and the symptoms associated with it), timeline (the expected duration and course of illness), consequences (the short and long term effects of the illness), cause (the factors which led to the development of the disease) and cure/controllability (what the individual believes they or the medical professionals can do to control the disease or bring about recovery). For example, having a strong illness identity with a chronic time-line is believed to decrease an individual’s sense of control over the disease process. PwMS who exhibit a belief that they have low control over their symptoms have lower levels of self-esteem (Vaughan et al., 2003).

There is increasing interest in how illness representation has an impact on an individual’s ability to cope (Harman & Clare, 2006; Jopson & Moss-Morris, 2003; Lerdal et al., 2009; Neter et al., 2009; Schiaffino et al., 1998) and articles relating this model to MS are outlined in Table 3. A meta-analytic review of illness representation research suggested that perceptions that an illness is curable or controllable are positively related to adaptive
outcomes of psychological well-being (Hagger & Orbell, 2003). Hagger & Orbell (2003) reported that the perception of a strong illness identity was positively related to the use of avoidance coping strategies. Their analysis provided evidence for theoretically predictable relations between illness cognitions, coping and outcomes across the studies.

2.4.3 Communal Coping
Lewis, McBride & Pollak et al. (2006) proposed an integrated model, based on interdependence theory and communal coping perspectives. They suggested that a couple’s interdependence can transform motivation from doing what is in the best interest of the individual (person-centred) to actions that are best for the continuation of the relationship (relationship-centred). They recognised that being in a committed relationship impacts positively on health for both members of a couple compared to those not in a relationship. However few, if any, models of health behaviour exist that view a couple as a unit. Lewis et al., (2006), therefore set out to establish a clearer view of intra-couple mechanisms that lead to better health behaviour, informed by dyad-level theories from relationship science, and theories about interdependence and systems. Dyadic analysis is the examination of the themes emerging from each couple’s narratives (Eisikovits & Koren, 2010). This theory is depicted in Figure 1.
Lewis et al.’s (2006) model emphasises that communal coping may operate in the context of couples coping with a health threat such as receiving a diagnosis of MS and it is an alternative view to those which view coping from the perspective of the individual only (Lewis et al., 2006). Communal coping refers to “couple members holding a shared assessment of a health threat and a shared vision about managing the event” (Lewis et al., 2006, p. 1374). The authors hypothesise that if both couple members prefer to work together to make health behaviour changes, motivation will be higher than if only one of them is interested in change. While this model is not tailored specifically to health threats like chronic illness or MS it offers a rare framework to understand the potentially transformative nature of couple relationships and how couples cope communally.
2.5 Coping with MS

MS is a chronic condition and all those with chronic conditions are considered to be vulnerable people who deserve attention both in research and in clinical practice (Heijmans & De Ridder, 1998; Ministry of Health, 2007). This sentiment is fuelling momentum for researchers and clinicians to explore how to better understand and support this group. Charmaz (1993) speaks of the “progressive gains, plummeting losses and plateaus” (p. 1) inherent in chronic illness, which can challenge the coping ability of PwMS and the ability of their health professionals to engage with them successfully. The term chronic condition encompasses a wide array of illnesses and there is debate about whether coping with a chronic condition is best studied as a whole or in disease specific contexts. In Heijmans & De Ridder’s (1998) study, the perceptions of 1305 patients from ten chronic disease categories were compared with respect to important stressors. While they recorded differences in the amount and type of stressors experienced, these differences could not solely be explained by type of disease. Of more importance than the disease type were personal characteristics such as age, sex, education level, living situation, and illness duration, when determining the degree and type of stress experienced. The authors argued that if common stressors across chronic conditions can be identified, the potential for providing effective education and support programs is greatly increased. This comprehensive study indicates that researching coping in one chronic condition, (in the case of this research, for those with MS), is likely to provide valuable information for those coping with other chronic conditions.

One of the earliest works looking at emotional adjustment in relation to MS was a mixed methods study carried out by Brooks & Matson (1982). These authors sent a questionnaire to people diagnosed with MS, who were in the middle and late stages of the illness in 1974 and again in 1981. They then purposively selected 11 participants for in-depth interviewing. They also sent the questionnaire to a population of people without MS, who were matched for age and sex, at both time points. The primary measure was a questionnaire about self-concept which the authors developed themselves. Self-concept was defined as the image one holds in one’s mind’s eye of oneself (Brooks & Matson, 1982). The authors did not report how many questionnaires were sent out initially but they did report that they had a 60% response rate and that 103 questionnaires were analysed at the second time point in 1981.
(1982) reported that females were more likely than males to show positive adjustment over time at statistically significant levels. The number of MS exacerbations in the previous seven years was the strongest predictor of a negative change in adjustment indicating that exacerbations challenge adjustment. The participants who said they coped through acceptance of the disease showed improvements in self concept while those who identified religion or family as major coping strategies had decreasing self concept.

More recently, Pakenham et al. (1997) tested the Stress and Coping Model to evaluate the role of appraisal and coping strategies in the adjustment to illness-related stressors in PwMS. They interviewed 134 PwMS who also completed self-administered scales on how they appraised their situation (as a threat, as a controllable condition or as a challenge), disability, mood and coping. They used the Ways of Coping Checklist-Revised (WOCC-R) as the primary outcome measure which is based on the Stress and Coping Model. Their findings supported the hypotheses that threat appraisals and Emotion-Focused coping were related to poorer adjustment than Problem-Focused coping. In particular, avoidance (an Emotion-Focused coping strategy) was related to poorer outcomes across all dimensions of adjustment. This study supports the application of the Stress and Coping Model of adaptation to PwMS.

On the other hand, there is dispute about whether a transactional model of stress, where coping is seen as an attempt to correct the imbalance between demands and resources, can truly be applied to those with chronic conditions. Many studies researching coping with chronic illness contain the assumption, sometimes implicit, that Problem-Focused coping styles are generally associated with successful adaptation. This is despite the fact that leading theorists, such as Lazarus (1984), emphasise that there is no one right way to cope. Chronister, Johnson & Lin (2009) reviewed the evidence base for coping models and concluded that no single coping style is all good or all bad.

Generalizations about good adaptation, and the right way to cope with chronic illness, can be worrying in that they often take on a moral tone. King, Caroll, Newton and Dornan (2002) cautioned against this, noting that: “the good adapter could be characterized as the person who carries on with life cheerfully and uncomplaining while managing his or her condition efficiently and in obedience to medical instructions” (p. 331). It is tempting, if one were to
take this point of view, to judge many people as coping well if they agree with everything their health professional suggests and this is a one dimensional and a value laden way to address such a situation. It is therefore more important to understand successful and unsuccessful coping from the point of view of those who are dealing with illness or with becoming a caregiver as well as the effect their coping is having on their ability to engage with healthcare providers.

2.5.1 Quantitative Studies
The studies outlined in Tables 1, 2 and 3 represent three main bodies of quantitative literature in relation to coping with MS, and are part of a narrative review of research that has investigated what it is like for individuals to cope with having MS. The studies are organised chronologically and in three groups: 1) cross-sectional studies using the Stress and Coping Model to investigate coping, 2) longitudinal studies using the Stress and Coping Model and 3) studies investigating illness perceptions and coping for PwMS. There are a large number of studies using the Stress and Coping Model to investigate coping, so they have been categorised by study design (cross-sectional and longitudinal) for ease of reading.
Table 1 Cross-sectional Studies using the Stress and Coping Model to investigate coping for people with MS

<table>
<thead>
<tr>
<th>Reference</th>
<th>Focus of Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality Appraisal *</th>
</tr>
</thead>
<tbody>
<tr>
<td>O’Brien (1993)</td>
<td>To examine the relationships between self-esteem, social support, and coping behaviour of people with MS</td>
<td>Assessed coping using the Ways of Coping Questionnaire (WOCQ) along with measures of self-concept, social support and functional ability</td>
<td>101 people diagnosed with MS for at least one year</td>
<td>Self-esteem was positively related to Problem-Focused coping. A combination of Emotion-Focused and Problem-Focused coping strategies are likely to be the most useful</td>
<td>Strengths: Inclusion and Exclusion criteria well described; Clearly focused question, used appropriate methods to test theory. Limitations: Varying lengths of time since diagnosis making a heterogeneous group; All significant correlations were low.</td>
</tr>
<tr>
<td>Mohr, Goodkin, Gatto, &amp; Van Der Wende (1997)</td>
<td>To investigate the relationship between coping and depression in people with MS</td>
<td>Mail out questionnaires asking about disability and mood with Ways of Coping Index (WCI) as primary outcome measure</td>
<td>101 people recruited through MS centres</td>
<td>Problem-Focused strategies associated with lower levels of depression than Emotion-Focused strategies</td>
<td>Strengths: Response rate of 46%. Limitations: The different characteristics of responders and non-responders is not known, so it is not clear how representative the sample is; No information reported about population’s cognitive status.</td>
</tr>
<tr>
<td>Mohr, Dick, Russo, Pinn, Boudewyn &amp; Likosky (1999)</td>
<td>To examine the psycho-social impact of how individuals with MS cope with the disease</td>
<td>2 Stages 1 Telephone contact using open ended questioning to develop 67 statements about coping with MS 2 WOCQ administered along with measures of mood, cognition and physical function and a five point Likert scales with 67 statements from Phase 1</td>
<td>50 were selected for interview over the telephone; 94 people completed the mail out questionnaires</td>
<td>Three themes emerged: Demoralisation, Deteriorated Relationships and Benefit-finding. Benefit finding was the only one related to positive re-appraisal, BUT was also related to higher levels of anxiety and anger</td>
<td>Strengths: Mixed methods to capture as closely as possible stresses associated living with MS; Methodology allowed for discovery while being clear and reproducible; Appropriate measures used for domains of interest. Limitations: Phase 1 statement list was created by the authors and may not represent all the stresses in participants’ lives; No alpha correlation was used.</td>
</tr>
</tbody>
</table>

* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable.

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<tbody>
<tr>
<td>Beatty, Hames, Blanco, Williamson, Wilbanks &amp; Olson (1998)</td>
<td>Correlates of coping styles in patients with MS</td>
<td>Ways of Coping Checklist (WOC-C) was administered in relation to a vignette describing a stressful social situation, along with measures of psychological distress, cognition and mobility</td>
<td>43 people with MS</td>
<td>Patients with higher level of psychological distress are more likely to use Emotion-Focused coping strategies</td>
<td>Strengths: Clearly detailed inclusion and exclusion criteria A single standard stressor (as opposed to all MS patients reporting on coping with different stressors) enhanced the generality of the data Limitations: Methodology cannot determine a causal relationship between psychological distress and Emotion-Focused coping The vignettes were hypothetical</td>
</tr>
<tr>
<td>de Ridder, Schreurs &amp; Bensing (2000)</td>
<td>Optimism as a coping resource in MS and Parkinson’s Disease</td>
<td>Assessment using Life Orientation test (optimism) and Coping Inventory for Stressful Situations (CISS), mood and quality of life. Interested in relationship between optimism on coping and adjustment</td>
<td>96 people with MS and 70 with Parkinson’s disease</td>
<td>MS group benefitted more from optimism than group with Parkinson’s disease. A high level of optimism encourages avoidant coping but hinders other Emotion-Focused coping. A moderate (rather than high) level of optimism may be most adaptive</td>
<td>Strengths: Strong reported psychometric properties for coping measure Limitations: Self-referral may have resulted in a selection bias Cross-sectional design cannot establish causal relationships between variables Small sample size</td>
</tr>
<tr>
<td>Lynch, Kroencke &amp; Denney (2001)</td>
<td>Replicated a study by Mohr et al. (1997)</td>
<td>Ways of Coping Questionnaire (WOCQ) administered along with measures of illness uncertainty, hope, mood and disability</td>
<td>188 regular attendees of a MS clinic</td>
<td>Depression was correlated with greater disability and also with Emotion-Focused coping</td>
<td>Strengths: Collected details as participants attended clinic (where possible) to improve response rate Larger sample than original study (by almost twice) Limitations: Level of disability was rated by attending physician – no self rated health status measures</td>
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</table>

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<tbody>
<tr>
<td>McCabe, McKern &amp; McDonald (2004)</td>
<td>To investigate the relationship between coping and psychological adjustment among people with MS</td>
<td>Measured coping with the WOCQ, mood, along with illness duration, cognition, health related quality of life and severity via World Health Organization Quality of Life-100 Scale</td>
<td>381 people with MS and 291 healthy people in a control group recruited over the telephone</td>
<td>People with MS (particularly men) were less likely to adopt Problem-focused coping styles and had poorer levels of adjustment. Adopting a wishful thinking coping style (an Emotion-Focused coping strategy) and a lack of Problem-Focused coping increased likelihood for poorer adjustment</td>
<td>Strengths: Random selection from MS register Good response rate from MS population (60.5%) Limitations: While 60.5% of those with MS responded, only 28.8% responded from the general population No screening for cognitive status, though self-reported information on cognition was collected All measures were self-reported rather than objective which may have altered the results</td>
</tr>
<tr>
<td>Goretti, Portaccio, Zipoli, Hakiki, Siracusa &amp; Sorbi, (2009)</td>
<td>To study the impact of psychological variables on strategies and quality of life (QoL) for people with MS</td>
<td>Measured coping using the Coping orientation for Problem Experiences (COPE) with measures of disability, mood, personality questionnaire and a QoL measure for MS</td>
<td>104 people with MS</td>
<td>Participants were more likely to use avoidance type coping and less likely to use Problem-Focused coping. For those who did use Problem-Focused coping, this had a positive influence on QoL</td>
<td>Strengths: Clear inclusion/exclusion criteria MS specific QoL measure and novel use of personality trait questionnaire Limitations: Use of personality questionnaires can be controversial as they tend to measure traits rather than cognitive states (Nicholls et al., 1982)</td>
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* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable
Table 2 Longitudinal Studies using Stress and Coping Theory to investigate coping with people with MS

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<tr>
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<tbody>
<tr>
<td>Wineman, Schwetz, Zeller &amp; Cyphert (2003)</td>
<td>To examine the relationship between illness uncertainty, stress, coping, and emotional well being among people with MS at entry into a clinical drug trial</td>
<td>Two year study with a cross-sectional design at baseline. Used Jalowiec Coping Scale to assess coping, with measures of mood, disability and illness uncertainty and hope. Assessed one week into trial, at three months, 15 months and at 24 months (completion of trial)</td>
<td>59 people with MS in a two year randomised controlled trial (RCT) using metho-trexate for PPMS with (52 had complete longitudinal data sets)</td>
<td>Patients with more severe disability were less hopeful and more likely to have depression. Hope was positively correlated with coping and with better mood, suggesting that higher levels of hopefulness were associated with more effective coping. Relationships between variables remained consistent throughout trial.</td>
<td>Strengths: Only one person from 60 recruited to initial drug trial declined to take part in this auxiliary study on coping. Opportunistic study to examine coping while participants were engaged in a long term trial facilitated. Low loss to follow up (88% completed data sets). Limitations: All correlations were significant but modest and require further investigation.</td>
</tr>
<tr>
<td>Aikens, Fischer, Namey &amp; Rudick (1997)</td>
<td>A prospective investigation into life stress, coping and depressive symptoms in MS</td>
<td>Participants completed the WOCC along with measures of disability, cognitive status, depressive symptoms and negative life stress. Measures were repeated at two 6-month follow up intervals (so twice over 13 months).</td>
<td>27 people with MS taking part in a larger trial investigating spinal fluid predictors of disease progression. Five withdrew during the study, leaving 22 data sets at completion.</td>
<td>Life stress was positively correlated with current as well as future symptoms of depression. Escape avoidance (Emotion-Focused) was the only coping strategy that added to the prediction of future mood symptoms. Results suggested that MS-related depression are a function of prior disease-related impairment, life stress and escape avoidance coping.</td>
<td>Strengths: No detectable differences between drop-outs and those who completed the study. Participants were screened for cognitive ability using a basic screen. Limitations: Small sample size. No measure of appraisal or perceived social support. Sample was overly representative of people with higher educational attainment and milder physical disability. Only basic cognitive information gathered (from screening).</td>
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* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable.
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<tbody>
<tr>
<td>Pakenham (2006)</td>
<td>To investigate coping antecedents to positive outcomes and distress in people with MS</td>
<td>Coping with MS scale (CMSS) (developed by Pakenham (2001b) administered at two times three months apart, along with measures of illness severity, appraisal, cognition, mood &amp; benefit finding</td>
<td>502 people with MS completed first questionnaire and 404 completed second three months later</td>
<td>Coping strategies which predicted positive outcome at follow up were emotional release, personal health control and physical assistance Avoidance predicted distress</td>
<td>Strengths Large sample size, random selection of 1000 sent questionnaires initially Used both positive outcomes and distress, one of few to include a measure of benefit finding Limitations Relatively short time period (3 months) Reliance on self-report data All members of the MS society</td>
</tr>
<tr>
<td>Moreau, Schmidt, Joyeux, Bungener, &amp; Souvignet (2009)</td>
<td>To examine coping strategies and anxiety evolution in MS patients initiating Beta-Interferon treatment</td>
<td>Assessed people using the Coping Inventory for Stressful Situations (CISS) and measures for anxiety and depression at the start of first treatment round of Beta-Interferon. Monthly assessments for 3 months Multi-centre study in 65 centres</td>
<td>225 people with relapse-remitting MS initiating Beta-Interferon treatment were assessed monthly for three months</td>
<td>Most participants used problem solving (a Problem-Focused strategy) as their main coping strategy. Those who used more Emotion-Focused strategies were more anxious and more depressed than the two other coping groups During the first three months, anxiety levels slightly decreased</td>
<td>Strengths Multi-centre trial (65 centres) Comprehensive data at inclusion (taken from admitting data to start Beta-Interferon) Limitations Used a validated coping measure not common to other studies so a little more difficult to compare, though authors do compare their results favourably to other studies Short time for follow up – specific to treatment time with Beta-Interferon</td>
</tr>
<tr>
<td>Lode, Bru, Klevan, Myhr, Nyland &amp; Larsen (2010)</td>
<td>To examine how coping styles among people with MS change over time</td>
<td>Assessment of coping using Coping Orientation for Problem Experiences (COPE) scale, disability, mood and cognition at baseline and again after 5 years</td>
<td>76 people with MS and 94 healthy controls</td>
<td>People with MS were more likely to use Emotion-Focused coping strategies and this tendency increased over time</td>
<td>Strengths Longest study assessing coping with MS over time Groups matched for age and gender Limitations Controls only registered at baseline Response rate from controls was low (47.2%) and drop-out rate of 10.8% in follow up MS group</td>
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* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable
Table 3 Studies using Illness Representation Theory to investigate coping with people with MS

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<th>Participants</th>
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<th>Quality Appraisal*</th>
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</table>
| Jopson & Moss-Morris, (2003)  | To explore the role of illness severity and illness representations in adjustment to MS | Assessed patients’ illness representations (measured using the Illness Perceptions Questionnaire-Revised measure) as well as measures of mood, disability, fatigue and self-esteem while controlling for severity | 168 people with MS from Auckland based MS societies (invitation sent to all 420 members) | Illness representations showed strong associations with adjustment, particularly in relation to low control. This occurred even though severity variables were controlled for | Strengths: Low drop-out rate (10 people out of 168) Home based assessment of mobility as well as questionnaires for 91 people Rare study looking at illness representation for PwMS where illness severity is controlled  
Limitations: Marginally higher rate of women to men than would be expected  
All were recruited through a support group                                                                                     |
| Vaughan, Morrison & Miller, (2003) | To explore the illness representations of people with MS in relation to outcome | The Illness Perception Questionnaire (IPQ) was used in conjunction with measures of illness intrusiveness, activities of daily living, mood and self-esteem | 99 people with MS invited from past referrals to the Health Psychology Department | Higher levels of depression were associated with participants having perceptions of a stronger illness identity, perceived serious consequences and perceptions of low control over the illness process | Strengths: Comparing the final sample with those initially invited to take part demonstrated similarity in age and gender  
Good psychometric properties of IPQ (main outcome measure) from other studies  
Limitations: Cross sectional design cannot assume causal links  
The majority of sample had received some psychological input previously                                                                                                      |

* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable
<table>
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<tbody>
<tr>
<td>Spain, Tubridy, Kilpatrick, Adams &amp; Holmes, (2007)</td>
<td>To investigate the illness representation of people with MS in relation to health related quality of life (HRQoL)</td>
<td>Cross sectional correlation design measuring illness representation with the IPQ and measures of cognition, mood and HRQoL, using the 36 item Short Form Health Survey (SF-36) and disability</td>
<td>687 people recruited through MS society, public and private neurology clinics, all types of MS included</td>
<td>Illness representation had an effect on HRQoL in PwMS. Those with multiple neurological symptoms report worse HRQoL when compared with those with less generalized illness, even if the underlying physical disability is equivalent</td>
<td><strong>Strengths</strong>&lt;br&gt;Large sample, first of its kind in Australia, recruiting through a range of services&lt;br&gt;Checked MS diagnosis at inclusion met criteria&lt;br&gt;<strong>Limitations</strong>&lt;br&gt;SF-36 has been criticized for lacking sensitivity for the severely disabled, but appeared better matched to the theoretical underpinnings of illness perception than other HRQoL measures&lt;br&gt;Population biased towards those with better mobility</td>
</tr>
<tr>
<td>Lerdal, Celius &amp; Moum, (2009)</td>
<td>To examine the extent to which socio-economic variables, clinical variables and health related quality of life (HRQoL) are related to perceptions of disease severity</td>
<td>Questionnaires mailed 12 months apart measuring HRQoL and perceived illness severity, using the Illness Perception Questionnaire as well as subjective health status and disability</td>
<td>303 responded from an initial mail out to a potential 502 recipients</td>
<td>Having PPMS and longer time since disease onset was correlated with higher perceived MS severity. Changes in perception of disease severity over the year were related to changes in social functioning</td>
<td><strong>Strengths</strong>&lt;br&gt;62.4% response rate&lt;br&gt;Rigorous check on inclusion criteria and time since onset through MS registry&lt;br&gt;Well described population demographics&lt;br&gt;<strong>Limitations</strong>&lt;br&gt;Patients with PPMS were older and reported higher disease severity at both times&lt;br&gt;No report on the cognitive status of the participants</td>
</tr>
</tbody>
</table>

* All between-group comparisons are statistically significant findings, with a p > .05, and a response rate of <40%, where applicable
As is evident from Tables 1 and 2, for studies using measures related to the Stress and Coping Model, there is a significant support for the correlation between Emotion-Focused coping and poorer outcomes such as depression and decreased quality of life. However, this assertion was challenged by Chalk (2007), who examined the role of cognitive and behavioural variables in predicting psychosocial adjustment for those with MS. She used the Coping with Multiple Sclerosis Scale (Pakenham, 2001b) with 329 MS patients, along with measures of disability, appraisal of health, social support, satisfaction with life and mental health scales. The results indicated that using Problem-Focused coping strategies, challenge appraisals and acceptance were associated with positive psychological adjustment. Acceptance is categorised as an Emotion-Focused coping strategy and is therefore often associated with poorer outcomes. Nevertheless, for disease related variables, acceptance may be a more adaptive response than using a Problem-Focused strategy (Pakenham, 2001a, 2006). There may be benefit in accepting the symptoms of MS, in order to seek help, and thus alleviate stresses associated with the symptoms.

PwMS and their families who seek and receive social support tend to have better health outcomes than those who do not (Wethington & Kessler, 1986). However, seeking social support can include both Emotion-Focused and Problem-Focused coping strategies (Pakenham, 2001a). So Problem-Focused and Emotion-Focused domains of coping can potentially capture helpful and unhelpful strategies. This suggests that for people with MS, the Stress and Coping Model is only partially able to offer suggestions for measurement and intervention as regards coping.

2.5.2 Qualitative Studies

While most research in the coping literature relating to MS has taken a quantitative approach, there are some notable studies exploring coping with MS from using a qualitative perspective. Some of these studies are summarised in Table 4, in order of year of publication, with others described later in this section.
<table>
<thead>
<tr>
<th>Author</th>
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</table>
| Reynolds & Prior (2003)   | Exploring women’s strategies for negotiating acceptable quality of life with MS | Participants were interviewed and their transcripts were analysed using Interpretative Phenomenological Analysis (IPA) | 27 women with MS recruited through MS society | Participants revealed a wide array of positive enabling strategies to achieve a life they regarded as of good quality, including valuing roles and occupations (previously under-acknowledged in coping literature). They reported ‘day to day’ flexibility is required for living well with MS and positive and negative attitudes towards the disease co-exist simultaneously | Strengths  
Homogenous groups – all well educated with a partner providing financial assistance  
Thorough description of how IPA was used to analyse data  
Limitations  
Speculation that volunteers from MS society may have been more positive than those who chose to attend society  
All diagnosed 5 years+, so may represent a more positive group |
| Barker-Collo, Cartwright & Read (2006) | Two main areas of interest for the researchers were the experience of living with MS and the experience of receiving a diagnosis of MS | Interviews completed in participants’ homes  
Narratives were analysed using thematic analysis | 16 people with MS, half with RRMS and half with PPMS. Half had received their diagnosis less than five years ago and half more than 15 years ago | Themes which relate to receiving a diagnosis were: 1) The Diagnostic Process, 2) Symptoms Experienced before Diagnosis and 3) Emotions and Thoughts that followed Diagnosis | Strengths  
Strong emphasis on maintaining the participant’s voice in the results section  
Limitations  
Thematic analysis means interpretation may lack depth  
Lack of consistency between developing themes and keeping data in relation to lived experience of MS and free of named themes  
Results focused on diagnosis though there were two aims |

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<tr>
<td>Malcolmson, Lowe-Strong &amp; Dunwoody (2007)</td>
<td>Exploration of the personal accounts of individuals with MS and the self-management strategies that they find most effective on a day to day basis</td>
<td>Thematic analysis was used to analyse data from two focus groups</td>
<td>Thirteen people who attended two groups (seven in one and six in the other)</td>
<td>Key themes were identified as: 1) Something is wrong, 2) Getting a name, 3) Getting help, 4) Consequences to lifestyle, 5) Getting on with day to day life, 6) Advice to others with MS and 7) Advice for health professionals</td>
<td>Strengths: A second experienced researcher read and analysed all group transcripts as well as primary researcher. Focus group stopped after the second one as no new themes were emerging. The credibility of themes was checked by posting them to all participants and 12 of them provided further feedback. Limitations: Inclusion criteria targeted individuals with self-management skills in relation to MS, limiting the findings.</td>
</tr>
<tr>
<td>Kirkpatrick-Pinson, Ottens &amp; Fisher (2008)</td>
<td>Exploration of why some women with PPMS cope successfully in spite of disease progression</td>
<td>Interviewed using a protocol incorporating a psychotherapeutic model of change. A then-post rating system was designed with women rating a precursor’s intensity at diagnosis (then) and its intensity now (post)</td>
<td>Ten women who self-reported as coping successfully with PPMS</td>
<td>Three precursors of change, in particular, were potent in creating favourable conditions for individuals to cope successfully with MS: 1) Confronting the problem, 2) Effort towards change and 3) Awareness</td>
<td>Strengths: Screened for depression and self-efficacy to ensure participants were psychologically adjusted and therefore were therefore relatively similar in this regard. Limitations: Phenomenology is mentioned as the methodology but lack of detail as to how this could be implemented along with the structured interview incorporating model.</td>
</tr>
<tr>
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| Irvine, Davidson, Hoy & Lowe-Strong (2009) | To explore the lived experience of MS with regard to effective day to day self-management strategies | IPA was used to analyse two separate focus groups where 13 people in total participated | 13 people in two separate focus groups (six in one group and seven in the other) recruited through the MS society | Most salient finding was that there is a need for a formal approach to the management of psychosocial issues associated with MS Diagnosis was met with negative reactions however most reported that over time there were positive changes in terms of their outlook. Uncertainty seemed to be ameliorated by an increased appreciation for life, spirituality and identity re-definition | **Strengths**  
Well described methods a focus group set up – provided an opportunity for exchange between participants to enrich data  
Two researchers involved in focus groups – one taking notes and field notes were recorded by both after each focus group  
**Limitations**  
Large age range and time since diagnosis makes this a relatively heterogeneous group  
Lack of research validating use of IPA with focus groups |
| Lohne, Aasgaard, Caspari & Slettebo (2010) | To understand how persons with MS experience and understand dignity and violation in the context of a rehabilitation ward | A phenomenological-hermeneutic approach was used to analyse interview transcripts | 14 people with MS who had been admitted to one of two rehabilitation wards in the last | Key themes were: 1) Invisibly captured in fatigue, 2) ‘Fighters’ law: one who does not ask will not receive and 3) Dignity is humanity  
The invisible nature of MS was an issue for almost all participants. The importance of dignity in the lives of those with MS was emphasised with the theme Dignity is humanity | **Strengths**  
Specific question about dignity in relation to rehabilitation ward spread to include this group’s perception of maintaining dignity in general  
Well described data collection, analysis and presentation of results  
**Limitations**  
Very open inclusion criteria with a group of people very personally motivated to speak about this issue |
<table>
<thead>
<tr>
<th>Author</th>
<th>Focus of Study</th>
<th>Methods</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality Appraisal</th>
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<tr>
<td>Olsson, Skar &amp; Soderberg (2010)</td>
<td>To describe meanings of ‘feeling well’ for women with MS.</td>
<td>Interviews were conducted with women with MS using phenomenological hermeneutic interpretation to analyse the data</td>
<td>15 interviews with women with SPMS</td>
<td>One major theme ‘Find a place where daily life goes on’ encapsulated 5 sub-themes: 1) Having the power to do the ordinary, 2) Feeling Contented, 3) Feeling Peace and Harmony, 4) Feeling Needed, and 5) Feeling Understood</td>
<td>Strengths Good description of methodology and good fit between question and methodology choice Explicit acknowledgement of the role of the researcher in the interpretation process</td>
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From Table 4, it appears that the time between first experiencing symptoms of MS and receiving a diagnosis is under-acknowledged as a difficult time, with most attention given to the needs of those who have received a diagnosis (Barker-Collo et al., 2006; Edwards et al., 2008). The impact of receiving a diagnosis of MS can be stressful (Janssens et al., 2003) but that there can also be relief in receiving the diagnosis (Netleton, 2006). Janssens et al. (2003) evaluated the emotional burden and quality of life of recently diagnosed MS patients and their partners. They used data collected on the HRQoL, mood and disease related distress of 101 patients and their 78 partners. Participants demonstrated high levels of anxiety and distress in the early period after being diagnosed, which the authors believed indicated careful attention by health care professionals to identify those who may benefit from psychological support.

The journey of MS involves learning how to live with uncertainty. Finlay (2003) completed a phenomenological analysis of one PwMS. She interviewed the participant using an in-depth non-directive approach on two consecutive days. Intense idiographic analysis of the transcripts along with highly reflexive commentary produced an evocative account of one person’s experience of living and coping with RRMS. The participant described her experience of living with uncertainty as the “the Sword of Damocles. There’s a feeling of inevitability that something will at some stage happen again” (Finlay, 2003, p. 165). Other themes included feeling that having MS posed a threat to the participant’s sense of identity, to her plans and to her relationships with others. Finlay (2003) noted that exploring carers’ life-worlds is under-researched and that this is an area that should be developed, in part of an aim of this current study.

The perception of risk to self is something that goes hand in hand with living with the uncertainty of MS. Boeije & Janssens (2004) conducted a mixed methods study to examine the perception of PwMS with regard to their likelihood of using a wheelchair in the next two years, ten years and over their lifetime. These perceptions were assessed using visual analogue scales and semi-structured interviews with 85 people. The qualitative findings confirmed the results from the quantitative section, where patients’ symptom reporting was strongly associated with perception of two-year risk of wheelchair dependence.
2.6 Coping with Caring for a PwMS

The coping styles and illness representation of SOs has received scant attention in the literature (McKeown et al., 2003; Pakenham, 2005a), particularly with regard to carers’ coping ability compared to those being cared for (Blank & Finlayson, 2007; Pakenham, 1998). There are increasing calls for research which takes into account the interaction between the different perspectives of carers and those with chronic conditions they care for (Cheung & Hocking, 2004). Being a carer for someone with MS can be distressing and carers can be fearful of the future (Bogosian et al., 2009). Their quality of life tends to reduce as their partner’s disease progresses (Akkus, 2011), and is more marked when the PwMS develops cognitive difficulties than when they develop physical impairments (Figved et al., 2007).

The role of the family in the context of illness representation and coping with a chronic illness is manifold: family members are sources of information that may influence the patient’s illness representations (Leventhal et al., 2004; Salewski, 2003). This current study aimed to add to the body of literature about the interaction of coping strategies between PwMS and the coping strategies of their families. The role of hope for people with MS and their families in relation to coping and adjustment remains much debated in the literature (Snyder et al., 2006). In a recent qualitative meta-synthesis by Duggleby et al. (2010), describing the hope experience of family caregivers of persons with chronic illness, the 14 studies that met their inclusion criteria indicated that hope assisted people to live with uncertainty and that they could re-focus from a difficult present to a more positive future.

In order to better understand the experiences of carers of PwMS, McKeown et al. (2003) conducted a systematic review of studies related to this area. They found that the majority of the 24 studies that met their criteria were descriptive in nature and covered a broad range of topics, which made it difficult to synthesise the findings. What they could infer is that health care professionals should be aware that all areas of caregivers’ lives are seriously affected as a result of providing care for a person with MS and that their needs should be regularly and routinely assessed.
Chipchase & Lincoln (2001) investigated the factors associated with carer strain in 68 carers of PwMS. Data was collected using a postal questionnaire about carer strain along with questions about the cognitive function, disability and health of the PwMS. Results indicated that problems with memory and activities of daily living were found to be associated with carer strain. When the PwMS had increasing difficulty in these areas, the carer was less likely to get time to themselves, which in turn increased their reported strain.

Another study to examine the carer’s perspective when their partner has advanced MS was conducted by Boeije et al. (2003). They purposefully selected 17 couples and, using constant comparative analysis from grounded theory (Strauss & Corbin, 1998), identified three common themes: 1) MS is inevitable; 2) MS is a misfortune which leads some couples to develop a strong feeling of shared disadvantage, and 3) avoidance of nursing home admission. Three conditions appeared to account for the findings: 1) conjugal ethics, 2) arbitrariness of disease implying that either member of the couple could have had the illness and 3) the anticipation of guilt or failure if a partner enters a nursing home. A further study by Boeije et al. (2003) explored how men and women giving care to spouses with MS interpret their role in relation to fulfilling a sense of duty, with women much more likely to identify with caregiving in relation to a sense of duty than men.

In a study specifically investigating carer strain, Knight et al. (1993) studied 55 spousal caregivers of PwMS and asked them to complete a questionnaire assessing the stress associated with care-giving. They reported that problems with movement, mood changes, incontinence and pain in their partners were the things which upset them most. Overall, female caregivers had higher care burden scores than male caregivers. According to the Stress and Coping Model it was hypothesised that individual differences in burden would be accounted for primarily by the carers' appraisal of the symptoms, perceived social support, and satisfaction with coping (Knight et al., 1993). Regression analyses supported the importance of satisfaction with coping and social support as predictors of perceived burden, emphasising the need for healthcare professionals and researchers to consider the coping styles and needs of carers.
The ability of a family caregiver to employ problem-solving strategies is of importance when it comes to adjusting to changes brought on by their partner having MS. Elliott et al. (2003) examined the relationship of social problem-solving abilities to trajectories of adjustment of family caregivers in the initial year of their care-giving role. Measures of problem-solving ability, depression, anxiety and health were completed by participants who had recently assumed the caregiver role for a family member with a spinal cord injury (11 men and 55 women). Measures were completed while their partner attended in-patient program and at three other times in the year. The findings concluded that viewing a problem in negative terms rather than as a challenge or as a controllable condition explained significant variation in the rates of change in caregiver depressive behaviour, anxiety and health problems. The caregivers adopting a negative approach to problems associated with care-giving were at a significantly higher risk of developing psychological and health problems over the year.

Partners of people with MS are at a similar risk of burnout to those whose partners’ have cancer (Ybema et al., 2002). Ybema et al. (2002) studied partners of both cancer patients and PwMS, taking their subjective burden of care as a measure of burnout (as opposed to their objective burden of care, which could be measure in care hours and level of assistance). They concluded that both groups were at relatively high risk of experiencing burnout when they feel that they do not benefit enough from their time with their partner. Perceptions of equity or balance in the relationship between PwMS and their partners are important for preventing caregiver burnout and for enhancing positive caregiver experiences. The next section will deal specifically with how couple cope, in terms of their relationship, when one of them has MS.

2.7 Coping with MS as a Couple

There is no doubt that MS has the capacity to increase marital stress and dissatisfaction, with the frequency of divorce among couples where one partner has MS approximately twice that of the general population (Gold-Spink et al., 2000). The interaction of coping styles between the caregiver and care-recipient may be more important than the coping strategies of either person alone (Pakenham, 2005b), though this phenomenon has received little attention, which highlights the timeliness and relevance of this current study. This is also an area which has been significantly under-researched from the perspective of couples dealing with the disease
as a unit (Esmail et al., 2007). Much research in the arena of coping has been more concerned with the impact of various stressors on physical and mental ill health, and less on what actually happens between couples as they jointly attempt to cope with illness (Badr et al., 2007). However, the general relationship research literature has increased our understanding of how life events such as illness affect close relationships (D Ardenne, 2004). As Shovelar & Perkel (1990) stated, “All physical illnesses, particularly life threatening and chronic ones, profoundly affect the family life of the patient, and the changed family circumstances in turn have an impact on the physically ill patient” (p. 363). Taking an approach which includes the perspective of both members of the couple to better understand their communal coping is a primary aim of this research project.

Literature on relationships and chronic illness began increasing in the 1980s. Unfortunately, this literature tended, (and still tends), to neglect the perspectives of the partner without disability on the relationship (Acitelli, 1997). Franzoi et al (Franzoi et al., 1985) collected information from undergraduates in monogamous heterosexual relationships using a private self-consciousness scale and interpersonal reactivity index. He concluded that both an awareness of oneself (private self-consciousness) and an awareness of the other (perspective taking) were necessary for couple satisfaction. The findings from this study has relevance for couples where one has MS, as chronic illness poses a threat to the ability of each member of the couple to be aware of both themselves and their partner (Ybema et al., 2002).

A partner’s illness affects relationship rules in a powerful way. Couples must meet the challenge of maintaining a balanced mutual relationship while assuming, or preparing to assume, role changes as one becomes less able and the other becomes a care-giver (Rolland, 1994). Rolland (1994) developed a Family Systems-Illness Model based on the concept that systematic interaction between an illness and a family evolves over time. Like other challenges in life, illness presents the opportunity for a relationship to either develop or deteriorate. Rolland’s narrative review of the literature on couples coping with a chronic condition highlighted the challenge of intimacy in the face of loss, difficulties with communication, and the need to establish healthy boundaries. Whether couples view the
illness one of them has as ‘my’ versus ‘our’ problem” (Rolland, 1994, p. 329) will influence the extent to which they both identify with the need to resolve issues related to the illness.

Rolland et al. (1994) suggested that intimacy requires each partner to be able to maintain autonomy with clear boundaries while at the same time have the capacity to bring the self into the relationship. One of the ways that those who provide assistance to their partner cope is to set up mutually understood rules and boundaries around the care-giving relationship. Coeling et al. (2003) used qualitative methods to explore the ways in which caregivers (CGs) and care receivers (CRs) negotiated the dyadic rules that influenced how the care experience fitted into their lives. Sixty care dyads, where one member had a chronic condition, were interviewed separately by different researchers over four years and content analysis was used to analyse the data. The results indicated that a mutually agreed-upon care dyadic identity was developed when both negotiated a set of rules about their conduct. Failure to agree on these rules, or not following them strained the relationship. Three archetypes of dyadic relationships emerged from this study: 1) complete and mutually accepted immersion of identity, 2) some retention of personal identities while also accepting the care-giving process, and 3) rejection of the roles by one or both parties.

In order to establish boundaries and rules around the change in routine necessitated by one partner needing care, care-giving couples need to be able to communicate effectively. Badr & Actelli (2005) studied the effectiveness of talking about the relationship when one has a chronic illness with 182 couples, 90 where both were healthy and 92 where one member of the couple had a chronic illness. Results of multi-level modelling analyses showed that the association between relationship talk and dyadic adjustment was stronger for women than for men and also stronger for couples where one spouse was ill. This research emphasised the importance of seeing illness in interpersonal terms and states that “few have examined the strategies couples use to sustain their marriage during chronic illnesses” (Badr & Acitelli, 2005, p. 465). A limitation of this study was that they investigated the quantity of relationship talk, rather than the quality, quality being difficult to measure. The authors also caution that as gender roles are culturally specific, talking about the relationship is only effective in reducing stress if both spouses identify with a norm that values relationship talk.
Finding aspects of the relationship to be thankful about may mediate disease related stressors. Harkness-Hodgson et al. (2004) conducted a phenomenological investigation with ten couples where one member had Parkinson’s disease. Five themes emerged from this data: 1) relationship and disease history, 2) the couple’s relationship, 3) the impact of the disease on the self and others, 4) their connection with resources and 5) strategies for survival. They used phenomenology as a methodology, with an emphasis on the importance of the bias statement produced by the two researchers, by way of recognising and removing bias somewhat. They discussed in detail the concept of thankfulness which made up one of the core strategies for survival. This related to both people in the couple finding things to be thankful about as a way of coping, including each other’s presence, despite disease-related stressors.

There is evidence to suggest that couple identity mediates the stress experienced by caregiving spouses. Badr et al. (2007) investigated primary stressors (stemming directly from the needs of the patient) which caregivers experience and secondary stressors (related to the burden of care-giving). They explored whether seeing oneself as part of a couple, and incorporating one’s relationship into one’s self-concept (couple identity), mediated the negative effects’ of both stressor types. The sample was made up of 92 healthy spouses who had been caregivers for their partner with chronic illness for an average of 5.9 years. The results suggested that couple identity partially mediated the effects of both negative primary stressors (overload and relational deprivation) and secondary stressors (captivity and loss of self esteem). Couple identity fully mediated the effects of positive secondary role stressors (competence and caregiver self esteem).

The experiences of uncertainty in illness and optimism are relevant to both members of a couple where one has MS. Gold-Spink et al.(2000) examined relationships between uncertainty and illness, optimism, symptom severity, and depression in 18 PwMS and their partners. Uncertainty regarding the illness had a very strong positive correlation between those with MS and their partners, but there were differences between paired respondents when comparing levels of depression with uncertainty.
Sexual activity is usually an intimate and private phenomenon often involving two people in a close relationship (Speziale, 1997). Very little research has been carried out in the area of couples’ experience of MS in the context of their sexual relationship with one notable exception. Esmail et al. (2007) completed six interviews with heterosexual couples where the woman had MS and was at a pre-disability stage of the condition. The author produced five themes for each group of women and men, having interviewed them separately and analysed the data in gender specific groups. Participants in both groups identified that communication was key when it came to coping with the effect MS had on their sexual life. The women with MS experienced doubts about their worthiness, attractiveness, and identity, while the male partners of these women with MS perceived little impact on the women’s sexuality. This was possibly because the women made a significant effort to maintain their customary roles, and played down the effects of the illness for their own sake, in addition to concerns about how it may affect their partner.

The relationship between how couples cope together and the effect this has on their psychological distress was investigated by Pakenham (1998). He used mixed methods to examine the relationship between coping congruency and the levels of carer and care receiver psychological distress. Two interviews were administered with 45 couples with a 12 month interval. They also administered the Ways of Coping questionnaire (WOCQ), as well as completing semi-structured interviews with couples. The author concluded that coping skills training is effective in fostering adjustment and that training should be levelled at carers and care-receivers.

MS related stress will cause most couples to re-evaluate how they cope and continue this re-evaluation process as the disease progresses and their coping strategies may need to change. Blank & Finlayson (2007) conducted a small qualitative study interviewing three couples individually, and then separately, to explore the impact of MS on their lives and their related coping strategies. They identified two major themes: 1) increasing change and 2) how coping strategies were used over time. This study suggested that coping with MS is a dynamic process in which strategies used vary depending on personal needs and readiness to acknowledge the gradual changes brought on by MS.
In an effort to explore characteristics specific to relationships which indicate resilience in couples where one has MS, Starks et al. (2010) set out to examine, using mixed methods, how couples adapt to the challenges of MS and to identify possible risk factors for relational stress. Semi-structured interviews were conducted with eight couples to explore how they defined and identified the strengths and challenges in their relationship, negotiated role changes and received external support. The authors used a conceptual framework on family adaptation to chronic illness, based on Rolland’s Five Factor model (Rolland, 1994) as a diagnostic tool for assessing the demands of illness and the resources of the family. They characterised couples as in-sync or out-of-sync. Couples who were in-sync had a member with relapse-remitting MS, which proceeded at a pace that enabled both partners to maintain their social role and a collaborative problem solving style. Out-of-sync couples were characterised by one having a rapid progression of their MS, loss of employment before retirement age, differences in personal style that shifted from being complementary to oppositional in the face of increased demands, and struggles parenting adolescent children. The authors concluded that health professionals could use these indicators to assess relational strain in couples with MS and identify families who might benefit from referrals to family therapy or relational support.

Reciprocity may be a mediating factor when it comes to managing relational stress due to MS. Kleiboer et al. (Kleiboer et al., 2006) used a novel approach to explore the effects of daily support exchanges in couples facing MS. Sixty-one people with MS and their partners filled out questionnaires with demographic details and completed computerized daily diaries for 14 days. This diary included data on their end of day mood, self-esteem, emotional and instrumental received and provided, as well as information about MS related stressors. Two primary issues were highlighted: 1) the imbalance between received and provided support and 2) the extent to which reciprocal exchanges of received and provided support are associated with end-of-day well-being. They noted that reciprocity in domestic tasks (where each had a role to play) was associated with higher levels of self-esteem among both PwMS and their partners. However, they also noted that the well-being of those with MS was related to providing emotional support and instrumental support, whereas partners’ well-being was primarily related to receiving emotional support from their partner with MS. This gives a picture of partners not expecting their significant other with MS to provide instrumental
support and accepting this, however the availability of emotional support from their partner was still perceived as vital to their well-being. In the next section I will expand on how the research reviewed thus far on how PwMS cope and their SO’s cope, along with how couples cope, can be related to the rehabilitation and support provided by health care professionals.

2.8 Couples Coping with MS and Rehabilitation

Understanding how PwMS are coping is important for successful rehabilitation programs (Brooks & Matson, 1982; Lerdal et al., 2009; Schiaffino et al., 1998). Someone who is struggling to cope with MS may be amenable to change if a clinician can select an appropriate intervention strategy to teach efficient coping skills (Antonak & Livneh, 1995). Cognitive coping strategies such as reframing, information gathering, planning, and goal setting have been associated with better adaptation to MS (Kirkpatrick-Pinson et al., 2008; Mohr et al., 2002; Pakenham, 2001b). The evidence for how health professionals address the coping needs for both individuals in a couple when one has MS is discussed in more detail in this section.

While many adults with MS and their families have involvement with rehabilitation services, the evidence to support the efficacy of current practice with this group is sparse. Khan et al. (2008) completed a Cochrane review of multi-disciplinary team (MDT) rehabilitation for adults with MS. They reviewed eight trials which met their inclusion criteria, seven randomised control trials (RCTs) and one case controlled trial. The authors concluded that, despite no change in impairment level, MDT rehabilitation can improve the experience of PwMS in terms of activity and participation. The authors advocated the use of complementary research methods, in addition to RCTs, to build a rounded evidence-base in this area. This current study goes some way to providing complementary research around the experience of coping for PwMS and their partners, which can incorporate the perspective of the person with MS and “participation issues relevant to MS” (Khan et al., 2008, p. 31). Another Cochrane review, which dealt specifically with RCTs evaluating psychological interventions for PwMS, was conducted by Thomas et al. (2006). Sixteen studies were extracted by one author and independently compared by four others to set criteria. They concluded that the diversity of ways psychological interventions were applied in the studies made it difficult to make definitive recommendations. However, the authors cautiously reported that cognitive
behavioural therapy (CBT) can help people adjust to and cope with having MS. CBT is strongly informed by the Stress and Coping Model (McNulty et al., 2004), adding to research from earlier sections that this model has applicability for understanding and improving the coping ability for PwMS.

The literature points to the limitations of research and interventions conducted with the patient or caregiver in isolation from each other. Both live within the context of a relationship that clearly has a strong effect on their mutual well-being. This speaks to the need to develop dyadic or family interventions that treat not only the individuals, but also the relationships that form the primary context for their lives (Brannen & Petite, 2008). Rehabilitation prospects will be limited if the PwMS or their SO are coping poorly with disease related stressors. It is essential to better inform rehabilitation providers about how individuals with MS and their significant other’s may influence each other’s coping (Chalk, 2007; Natterlund et al., 2000).

As Rolland (1994) reported, “couples need to be forewarned that having intense and seemingly irrational emotions is natural in situations of illness and disability…clinicians can help re-direct the couple’s anger from each other to the illness” (p. 329). Most couples appreciate clear guidance, which health professionals can provide, as to which aspects of care can be realistically carried out by the PwMS, which require their SO’s involvement and which need professional assistance. For PwMS embarking on drug treatments for MS-related symptoms, assessing their coping ability could be useful to determine if they may require extra support during treatment. Those at risk for depression and anxiety can be monitored closely, or receive intervention to improve their coping strategies before a problem arises, which may influence vital drug treatment (Moreau et al., 2009; Wineman et al., 2003). Monitoring from health care professionals at times such as diagnosis and during relapses is particularly useful in helping to identify those who may be struggling to cope and to suggest interventions where appropriate (Janssens et al., 2003).

Just as communication is a key element to ensuring a couple can cope when one partner is unwell, the communication style adopted by healthcare providers can make a difference to the rehabilitation experience. Thorne et al. (2004) employed an interpretative descriptive design to
explore how people with MS describe helpful and unhelpful communication from their healthcare providers in Canada. They outlined three distinct transition points in the MS trajectory: 1) Managing fear, 2) Taking charge, and 3) Crafting a life. Different communication styles from healthcare professionals seemed to suit different phases. For example, supporting clients to interpret the initial onslaught of information available at diagnosis could give way to collaborative partnerships where clients receive support to understand what services are available and are empowered to manage their own health and disability needs. The authors recommended a basic communication competence that could include all health professionals.

In designing an occupational therapy based program to support caregivers of people with MS, Finlayson et al. (2008) conducted a three phase project. Phase 1 involved interviewing 302 caregivers by telephone to identify the challenges they experienced in relation to care-giving. The four most prevalent challenges were 1) finding and using formal support services, 2) managing the emotional aspects of care-giving, 3) doing the physical aspects of care-giving, and 4) dealing with informal supports. Following a comprehensive literature review in Phase 2 to identify existing caregiver programmes the authors reported that none in existence met all of the challenges identified in Phase 1. A five-session educational group programme entitled was developed in Phase 3. This programme is now in its pilot phase and will require further evaluation, but the design does offer a pragmatic route to selecting interventions that are specific to the needs of caregivers of PwMS.

For PwMS using Emotion-Focused coping strategies there is some tentative evidence that psychological group therapy may be effective. Tesar et al. (2003) conducted a non-randomised quasi-experimental pilot study looking at the efficacy of a seven week group addressing coping issues. Attendees came from an MS clinic, with the first consenting 14 patients assigned to the seven-week psychological therapy group, and the next 15 forming a control group. All participants completed a series of measures looking at depression, anxiety, coping, and body image prior to the intervention, at completion, and two months after the intervention had ceased. The active group showed a statistically significant reduction in Emotion-Focused coping at two months, although there was no significant reduction in the
levels of depression reported. Schwartz (1999) also reported on a RCT of two groups of PwMS. One group received telephone peer support (n=68) and the other group attended a coping skills group (n=64). The authors concluded that those who attended the coping skills group made more improvements in psychosocial role performance and coping behaviour.

Somerset et al. (2001) completed a mail survey asking PwMS in Britain about which services they accessed most frequently and their satisfaction with these services. They sent the questionnaire to 471 people and had a response rate of 68% (318 people). This group met with an MS specialist nurse most often and they tended to request information about both conventional and unconventional management of their symptoms, tailored advice and access to appropriately skilled professionals. As this sample was equally divided about whether or not they found their last interaction with the health service helpful, this study highlighted the value of involving people with MS in the identification of their preferences around treatment, which is part of the rationale for this current study. Health professionals tend to be more concerned about the physical manifestations of disease and associated impairments, whereas PwMS are more interested in issues such as mental health and vitality (Rothwell et al., 1997). Rehabilitation does not always improve impairments for PwMS but it does have proven benefits for reducing disability (Freeman et al., 1997; O'Hara et al., 2000) and improving quality of life (Patti et al., 2002). By completing this current study, the complexity of coping for couples where one member has MS will become clearer, as will the understanding of what these couples need from a rehabilitation or support service.
2.9 Summary

MS is a condition with a “bewildering array of symptoms” (Toombs, 1995, p. 7) which challenge both the PwMS and those closest to them. Research concerned with coping and MS has primarily used quantitative methods and has isolated either the PwMS or the caregiver for investigation. While quantitative methods have generally indicated that Problem Focused coping is more adaptive for PwMS and for their SOs, there is increasing debate about taking a ‘one size fits all approach’ to studying coping. That is to say, different coping styles may be more appropriate at different times. Of the studies that analysed couples as dyads the following factors appear to be influential on coping: 1) reciprocity, 2) couple identity, 3) communication about changing roles and boundaries and 4) the strength of ‘we-ness’ or how ‘in-sync’ a couple are in relation to the challenges MS brings. While PwMS regularly interact with rehabilitation services, it appears that these services rarely address issues to do with their relationships or their choices about coping or consider different styles of communication to suit different coping strategies. This study described in this thesis thus adds value and depth to an area which has been acknowledged as under-developed, that is the coping experience of a couple where one member has MS. Research is required which explores the SO’s experience in a direct and equal fashion to the PwMS (Malcolmson et al., 2007). Qualitative research methods, and in particular IPA, are well placed to allow researchers access to the rich and complex experience of coping as a couple. In the following chapter I will explain how IPA was used in this research and further discuss the value and complexities of analysing how a couple copes with chronic conditions as a dyad.
Chapter Three: Methods

3.1 Overview

This research project set out to explore the experience of how PwMS and their SOs cope as a dyad by analysing data gathered during semi-structured interviews. This study used a qualitative approach, employing IPA as a methodological framework. This chapter will explore the theoretical assumptions underpinning this qualitative approach before outlining how and why IPA was used in this instance. I will describe the research design and recruitment procedure which was used, and address issues relevant to the analysis process and ethical considerations.

3.2 Theoretical Background

3.2.1 Rationale behind Choice of Epistemology

As discussed in Chapter Two, understanding how PwMS and those close to them cope has largely been informed by attempts to measure the phenomenon. MS is an auto-immune disease resulting in central nervous system dysfunction and those with MS have received much attention from researchers operating from a quantitative paradigm seeking to quantify the mechanisms of the disease. However Toombs (2005), a PwMS who has written extensively about living with MS, has stated;

...a mechanistic description (based as it is on a biomedical model of disease) captures little, if anything, of my actual experience of bodily disorder. I do not experience the lesion(s) in my brain. Indeed, for me and others with similar disorders, illness is not even experienced as a matter of abnormal reflexes. Rather, my illness is the impossibility of taking a walk around the block or of carrying a cup of coffee from the kitchen to the den (p. 10).

Toombs is an example of someone who wants her story to be heard in the context of her life, without superimposing medically derived models and expectations on how one with illness perceives themselves and their world. I have worked with PwMS as an occupational therapist and have been part of the healthcare system which frequently seeks to label those with neurological conditions and their families. I have heard stories like Toombs’ many times. Realising the lack of research exploring coping in a qualitative, interpersonal way has
encouraged me to take the theoretical and practical direction which will be described in this chapter. The person-centred perspective provided through qualitative investigation will allow future research and theory to be more representative of and responsive to, the experiences of PwMS and those close to them (Gehart et al., 2001). The nature of data analysis and how the researcher views their position while using IPA (Finlay & Ballinger, 2006), will be explored in this chapter.

3.2.2 Epistemology

Epistemology relates to the theory of knowledge and the role of science. In research terms, the epistemology a researcher chooses defines how they conceptualise the nature of their research, and dictates the manner in which social principles can be known and how knowledge can be demonstrated (Mason, 2002). Madill et al. (2000) outlined that there are three broad epistemological strands identified within qualitative research, these being: realist, contextual constructionist and radical constructionist. This research project is aligned with contextual constructivism, where all knowledge is seen as local, provisional and situation dependent. Constructivism posits that truth comes into existence in our engagement with the realities of our world. This approach holds that meaning is not discovered (in contrast to positivism) but is constructed by different people in different ways (Crotty, 1998).

Contextual constructivism acknowledges the merits of triangulation (multiple researchers reading, analysing, and comparing analyses of the data), however, the aim of this process is to provide consensus rather than absolute clarity (Madill et al., 2000). Multiple researchers were involved in the analysis of the data in this project, with the aim of providing crystallisation of ideas rather than technical agreement on points of difference. The interpretivist perspective, which will be expanded on in the next section, is embedded in the concept of idealism, where knowledge is viewed as socially constructed (Ajjawi & Higgs, 2007). This is in contrast to the notion of realism, which fits with the positivist paradigm and states that scientific method can tap true representations of the world (Madill et al., 2000).
3.2.3 Theoretical Perspective

Our theoretical perspective is represented by the intrinsic beliefs we have about what kinds of knowledge we deem are possible and how we ensure their authenticity. This is a fundamental element which influences a researcher when developing a research proposal (Crotty, 1998). Essentially, our theoretical perspective asks us how we know what we know. It is a central concern for those who practice and write about science to describe how something is known (Cutcliffe & McKenna, 2002). While there are some who believe that the link between theoretical perspective and methods is overstated (Mays & Pope, 2000), the general consensus is that it is vital to make clear the philosophical underpinnings of a piece of research in order to understand how the data is being viewed.

Finlay & Ballinger (2006) reported that one way of identifying the aim of research is to ask if it falls into either the positivist or interpretivist tradition. Positivist theories argue that the goal of research is objective knowledge gained by an impartial observer (the researcher). However the stance taken during this research project is interpretivist, which draws attention to the ways our perceptions are culturally and socially produced. The interpretivist stance argues that it is impossible to be truly objective and that “understandings gained from research remain provisional, partial and entirely dependent on context” (Finlay & Ballinger, 2006, p. 19). This current research is driven by interpretivist principles, where the person being researched and the researcher co-construct the outcome with each other. Interpretivism takes an inductive approach which stimulates data that is rich in detail and specific to the person and their experience (Bernard, 2000). Most research conducted to understand coping has been from a positivist, deductive perspective, with some exceptions (Clare, 2002; King et al., 2002).

3.2.4 Methodology

The route from theoretical perspective and epistemology should be coherent, illustrating a natural fit between ideas as the rationale moves from the theoretical to the practical application (Finlay & Ballinger, 2006). IPA fits well with the epistemological and theoretical concepts outlined thus far as it adopts three guiding principles with strong interpretivist leanings: phenomenology, hermeneutics and idiography.
Phenomenology is a philosophical approach to the study of experience and it is a core principle of IPA. Research coming from this perspective is interested in experience which is of particular significance to the person in question. Smith et al. (2009) take the view that pure experience is never accessible. Both researcher and participant reflecting on their experience are witnessing the experience after the event has occurred. The meaning bestowed by a participant on an experience as a sense-making creature is at the core of how IPA uses phenomenology to explore the lived experience of others.

Hermeneutics is the theory of interpretation. Smith et al. (2009) proposed that hermeneutics is the key between the essentialist and the discursive, in that it makes it explicit that one is “trying to make sense of the words and the person who has said those words” (p. 28). The hermeneutic cycle views the parts in relation to the whole: one cannot exist or be analysed without the other. In this way, working within the hermeneutic cycle is similar to the complex issues inherent in understanding dyads, which is a core part of this research. Smith et al. (2004) suggested that researchers engage in a double hermeneutic in which the researcher has the ability to empathize with the participant (known as an empathic hermeneutic) as well as make sense of their sense-making process (a questioning hermeneutic). IPA holds that the research exercise is a dynamic process with an acknowledgement that both participant and researcher have pivotal roles to play when making sense of the phenomena under investigation (Smith et al., 2009). There are phenomenological researchers who align their stance with research with more of a focus on the description of phenomena rather than interpretation, most notably Dr. Amadeo Giorgi, who has been a vigorous critic of IPA (Giorgi, 1992).

The third philosophical pillar of IPA is idiography. This relates to focusing on the particular nuances of a person’s lived experience. This concept is in contrast to most psychological research which is nomothetic and is concerned with making claims at the group or population level and establishing laws about human behaviour (Smith et al., 2009). MS, with its variety of symptoms and differing rates of degeneration, is well suited as a condition to be studied on a case by case basis. As Finlay (2003) reported, following completion of a phenomenological study on one person with MS: “The disease of multiple sclerosis is so variable that it invites the use of an idiographic approach” (p. 174).
The aim of IPA is to explore the participants’ view of the world and to adopt, as far as possible, an insider’s perspective, recognizing that the research exercise is a dynamic process (Smith, 1996). IPA therefore requires the researcher to be attentive to, and conscious of their own perspective, as well as the perspective of participants (Chapman & Smith, 2002). Maggs-Rapport (2001) described interpretative phenomenology as an exploration of the meanings in phenomena, with the interpreter attempting to go beyond the data in order to draw out an explanation. In contrast to other qualitative approaches, such as Grounded Theory (Glaser & Strauss, 1977), which only implicitly theorise the role of cognition, IPA centres on the links between participants’ talk, cognition and behaviour (Smith, 1996). The aim of IPA is to explore how participants make sense of their experiences, so IPA attempts to engage with the meaning that experiences hold for participants (Chapman & Smith, 2002). IPA is therefore an appropriate approach to use to address this particular research question about the experience of coping. Some argue that IPA relies too heavily on the ability of participants to express themselves (Brocki & Weardon, 2005). Smith counters this, typically using a hermeneutic circle idea, saying: “When analyzing the language, I am also analyzing the person. My analysis of the person helps me make sense of my analysis of the language” (Smith, 2007, p. 4). Understanding both the person and the language they use complements the analysis process and is a fundamental aspect of IPA.

While IPA has not been used extensively with multiple perspectives (i.e. two groups coping with different phenomena, in the case of this current study), Reid et al. (2005), in their review on the use of IPA, reported that exploring multi-perspectives on phenomena can help an IPA analyst to develop a more detailed and multi-faceted account. IPA has been used effectively to explore the shared experience of couples where one has a chronic condition such as chronic obstructive pulmonary disease (Seamark et al., 2004), as well as dementia (Clare, 2002). While this methodology was first used in health psychology it is gaining increasing popularity in allied health and nursing arenas (Clarke, 2009; Cronin-Davis et al., 2009).
3.2.5 Method
Whereas methodology can be driven by philosophy and values, the methods researchers choose help them find out what they want to know (King, 1994). Methods are the procedures used to collect or generate data and are focused on the practical ways in which raw information is gathered for analysis. There are natural affinities between methods and methodologies (Finlay & Ballinger, 2006) and IPA is no exception. The majority of researchers who have used IPA have collected data via semi-structured interviews (Brocki & Weardon, 2005). Rostill-Brooks et al. (2010) completed one of the few IPA based studies looking at multiple perspectives on an experience. In their study exploring foster placement breakdown, they interviewed children from foster homes, foster parents and the social workers involved. Taking this approach enabled them to explore both the shared and distinct experiences of their participants. They acknowledged that concentrating on group level analysis brought with it the risk of losing some individual variation. However, they perceived that the benefits from working with groups rather than individuals experiencing something as complex as foster placement breakdown, was highly valuable from the point of view of understanding the ripple effect of the process. This is similar to the way I used IPA: to understand more about how coping occurs in the presence of a dyad when both their lives are changed in different ways.

3.3 Research Design

3.3.1 Overview
This study used IPA to analyse data from semi-structured interviews with both members of a couple where one member of the couple had MS. Purposive sampling (Sandelowski, 1995) was used to recruit 14 participants; seven couples where one had MS and the other did not. All participants provided written consent before engaging with the study. The interviews were centred on how each person coped with the presence of MS in their lives. Each PwMS and their SO were interviewed separately, using the same basic interview schedule. Demographic information about each participant was also collected and the interviews were audio-recorded and transcribed verbatim.
3.3.2 Participant Recruitment

Participants were recruited through branches of the MS society in two New Zealand cities. MS society field officers were consulted at an early stage about the study protocol and relevant committees for the society in both areas signed a locality assessment to support the study as part of the ethics application. The protocol was amended slightly during the study to expand the inclusion criteria to incorporate those who approached the researcher, having heard about the study through word of mouth. I presented at regional MS society meetings, to introduce myself and the research, as well as an area of interest to PwMS. This reciprocity of information sharing between researchers and participants is encouraged in constructivist methodologies. By offering something in return I acknowledged the time, energy and information participants contributed to this study (DiCicco-Bloom & Crabtree, 2006).

Potential participants were given a pack by their MS field officer with a cover letter (Appendix One), a consent form for both the PwMS and their SO (Appendix Two), and an information sheet (Appendix Three). The MS field officers obtained consent for me to make contact to discuss the research, after the participant had an opportunity to consider taking part. People were considered for inclusion if one member of the couple had a self-reported diagnosis of MS, had received their diagnosis at least two years prior, and if they could identify a SO. The rationale to include people at least two years since receiving diagnosis was twofold; that they would have had some time to experience symptoms and coping with symptoms and that they would be less likely to be grappling with the shock of receiving the diagnosis. A SO was defined as someone the PwMS knew well, whose life was affected because of this person having MS, and they could be a spouse, family member, friend, neighbour or caregiver. If either member of a couple was unable to follow multi-step instructions due to communicative or cognitive impairments, or could not speak English, they were ineligible to take part. If either member of a couple was known to me in a therapeutic capacity, they were also excluded¹. If there were emotional or social crises present for either or each member of the couple, they were excluded as it would have been unethical to discuss

¹ I had worked in New Zealand as an occupational therapist from 2004-2009, for participants who had known me in a therapeutic relationship, asking them to participate in research may have introduced confusion about boundaries and expectations
sensitive topics with such groups. The MS field officers assisted in screening for this possible ethical issue when they selected the participants to approach, whom they knew well.

Data collection was based on purposive sampling, where participants were selected once their experiences were deemed relevant to the research question, in an effort to form a reasonably homogenous group. The principle of purposive sampling is to select information-rich cases, as Patton (2002a) states: “cases from which one can learn a great deal about matters of importance and therefore worthy of in-depth study” (p. 242). Participants were selected (under guidance from the MS field officers) based on their ability to represent a perspective on the phenomenon (that of coping) and so varied in age, type of MS and time since diagnosis. However IPA strongly advocates selecting a reasonably homogenous group though this can be defined by individual studies. Homogeneity is important when using IPA in order to meet practical challenges to do with recruitment as well as interpretative issues: that too much variation between participants will make analysis of a phenomenon very difficult (Smith et al., 2009). There is no right answer to the question of sample size when using qualitative research in general (Sandelowski, 1995), and IPA in particular. Smith et al. (2009) reported that sample size is dependent on the intended level of analysis, the richness of the individual cases and the practical constraints one is operating under. IPA encourages deep analysis with smaller numbers of participants, given its dedication to idiographic detail. Analysing 14 interviews, as I did, ran the risk of losing some idiographic detail. However, I decided that this risk was offset by the opportunity to explore a more broad perspective on how couples cope (Merriam, 1998). Data collection and analysis occurred concurrently and the sample size was determined by the quality of the data. Due to this large potential data pool, an emergent opportunity sampling technique was used, which allowed flexibility to take advantage of new opportunities as they arose (Patton, 2002a).

3.3.3 Data Collection
Data was collected by audio-recording semi-structured interviews with PwMS and their SOs. Each participant was interviewed separately and each interview was kept confidential. All participants chose to have their interviews in their own home, with no order to which member of the couple was interviewed first. The decision regarding the order of the interviews was a pragmatic one, with the couple electing who would go first and this was often determined by
issues such as who happened to be ready to interview first. Interviews with the PwMS took nearly twice as long on average compared to the interviews with the SOs (56 minutes versus 26 minutes respectively), even though the interview schedule was almost identical in number and type of questions. The interview schedule evolved as interviews progressed, which is consistent with using an IPA approach (Smith et al., 2009). The schedules included in Appendix Four and Appendix Five are those used from the third set of interviews onwards, as no changes were made after these. Electronic versions of transcripts were assigned a password known only to me. Participants had access to the transcripts should they wish, and will receive a summary of the results, but they were not consulted as part of thematic analysis. The data will be kept for ten years in a locked cabinet at the university and then destroyed.

3.3.4 Interviewing couples
Portraying both couple members’ views simultaneously in qualitative studies is rare (as discussed in Chapter Two), so guidance on how best to conduct such research is scant. As stated by Acitelli (1997), a researcher well acquainted with studying dyads, “Hearing both sides of the story provides more insight into the story and the relationship between partners’ perspectives than could be gathered from hearing only one side” (p. 247). One of the first decisions to be made while developing the study protocol was whether to interview couples together or separately. I understood that the nature of the information could be different depending on which manner of interviewing I chose. Having carefully weighed up the pros and cons of each approach, I chose to interview people separately. This decision was taken to give each participant a safe space and allow equal emphasis for each person in the dyad to express themselves. I will now review the rationale behind that decision.

Social psychology theories often involve the interplay between two or more people, though most measurement tools are primarily interested in individuals only. A dyad is a special kind of group and analysing data from a dyad will have both similarities and differences with other groups (Kashy & Kenny, 2000). All dyads in this study were married couples. It has been established that information gathered from one partner differs from when information has been gathered from both members of a couple (Acitelli, 1997) and it has been recommended that more studies incorporate a dyadic design (Thoits, 1995; Wethington & Kessler, 1986). However, differing opinions exist as to whether qualitative data exploring dyads is best
collected through shared or separate interviews. From the research reviewed in Chapter Two, studies addressing both perspectives are split between researchers who interviewed their participants together (Eggenberger & Nelms, 2007; Harris et al., 2006) and those who interviewed them separately (Coeling et al., 2003; Esmail et al., 2007; Harkness Hodgson et al., 2004). Occasionally participants have been interviewed separately but with the other present (Prior & O'Dell, 2009), or have involved a mixture of interviewing people separately and together (Seamark et al., 2004). Starks et al. (2010) set out to interview people together and then separately, but abandoned this after the first two interviews as they found no discernible difference between the information gathered in both. They completed joint interviews for the remainder of the study.

Hertz (1995) made the case for interviewing couples separately, to better include unrepresented family voices. According to this author, interviewing spouses separately can provide valuable insights into how they operate as a couple. Interviewing couples separately disrupts their collective memory of events and challenges their usual roles in their joint storytelling process, forcing them to respond without the rehearsed routine. According to Hertz (1995), the challenge for the interviewer when interviewing couples separately is to make each feel comfortable in a potentially uncomfortable situation. It is not unusual for interviewees to feel as if they are being tested, and occasionally during the interviews for this study, couple members made reference to feeling anxious about whether they were portraying the same story as their SO. There is some concern about interviewing household members together as it can enable the researcher to accidentally expose tensions in a relationship and create an ethical dilemma. While reflecting on her experience of conducting research with multiple household members, Valentine (1999) concluded that: “interviewing couples apart is a more effective, ethical strategy for exploring household issues and the dynamic, negotiated and contested nature of household relationships” (p. 71). This further reinforced my decision to interview people separately as it was the dynamic nature of coping as a couple that I was interested in. Interviewing individuals separately made intuitive sense to me, to elicit potentially sensitive information (Esmail et al., 2007).
3.3.5 Development of the Interview Schedule

The interview schedule is important as it serves as a common thread between interviews even though each interview becomes a unique exchange with each new respondent (Hertz, 1995). The semi-structured interview gave me the opportunity to develop rapport (DiCicco-Bloom & Crabtree, 2006) and I was able to probe interesting areas which arose, using terminology volunteered by the interviewee wherever possible (Robinson et al., 2005). The interview schedules (Appendices Four and Five) were developed in conjunction with peers and supervisors. It was piloted on two colleagues who are therapists who have worked extensively with PwMS and their families. Issues such as double and leading questions were highlighted during this piloting process, as well as checking the language I was using, the order of questions and tone of my voice. I followed recommendations set out by McLeod et al. (1999), which included brainstorming topics and organising questions into logical groups, in this case related to the timeline of the MS disease process. I had a few broad questions at the start to establish ease, leading to more probing ones as the interview progressed. I introduced myself and the research and told participants what to expect before recording began. Participant rights were re-iterated prior to starting each interview and I considered how to close the interview and what would need to be discussed after the interview.

3.4 Data Analysis

3.4.1 Layered Interpretation

Analysis was based on IPA principles, starting with a content analysis and then continuing on to refine themes using an idiographic approach to examine and interpret the data (Smith et al., 2009). This involved a layered analysis and allowed for the emergence of commonalities and differences across participants and between groups. Rather than conceptualising analysis as a discrete stage of the research process, qualitative analysis begins with the first interview and evolves in multiple stages throughout the research process (Kvale, 1996). Analysis began while going through the interview preparation with participants, when thoughts and judgments about their coping started to surface in my awareness. These thoughts were noted at the end of interviews and discussed with a supervisor after particularly intense interviews. This debriefing process maintained my position in relation to the participants and their experience. I undertook all of the transcription myself, which allowed me to be immersed in the data.
While IPA avoids being prescriptive about how data analysis is performed, the following principles apply: 1) rigorous immersion in the data, 2) staying aware of the hermeneutic cycle of interpretation and 3) maintaining attention to the idiographic nature of the analysis (Smith et al., 2009). Table 5 outlines how analysis occurred and highlights the movement between description and interpretation, as well as the interplay between idiography and understanding commonalities and divergences within and between cases.

Table 5 Stages of Analysis used during this Study

<table>
<thead>
<tr>
<th>Stage</th>
<th>Action</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recording my reactions before, during, and after each interview</td>
<td>To enable clearer understanding of my pre-conceptions as they arose</td>
</tr>
<tr>
<td>2</td>
<td>Immersion in the data while transcribing and completing line by line analysis</td>
<td>To delve into the idiographic and highly descriptive nature of coping for each individual interviewed.</td>
</tr>
<tr>
<td>3</td>
<td>Noting possible trends and divergence of themes within and between cases</td>
<td>To begin to interpret and develop themes</td>
</tr>
<tr>
<td>4</td>
<td>Two other researchers independently read and coded the transcripts</td>
<td>To allow for comparison with coding and compare their notes with existing emergent themes</td>
</tr>
<tr>
<td>5</td>
<td>Re-read the transcripts</td>
<td>To return to the description given by participants, clustering some themes and eliminating others</td>
</tr>
<tr>
<td>6</td>
<td>Cluster the most prominent sub-themes into three overarching themes</td>
<td>To interpret with increased confidence and awareness around how the themes have evolved</td>
</tr>
<tr>
<td>7</td>
<td>Development of two integrative themes that appeared to be embedded within two of the overarching themes</td>
<td>To use these integrative themes to illustrate a deeper layer of understanding about the experience of coping for this group</td>
</tr>
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Analysis started by my noting my responses and pre-suppositions as they made themselves known to me, often while going through the preparation for the interview with participants, when judgments about the participants’ coping started to surface. Gut instinct reactions, such as noticing irritation and increased interest, were recorded immediately after interviews. This helped me to be more aware of my pre-conceptions (Smith et al., 2009) and is represented as Stage One in Table 5.
Stage Two occurred when I immersed myself in the data while transcribing each interview. I continued to reflect on my reactions and style of questioning and interaction during the interview (Mulveen & Hepworth, 2006). Thereafter line-by-line analysis was completed during a thorough reading of each transcript (Patton, 2002a). I moved between noting references from my reflexive diary, while highlighting potential key phrases and metaphors from the participants’ accounts (Chapman & Smith, 2002). At this stage of data immersion one of my supervisors conducted coding of transcripts independently from me. I conducted the initial layer of analysis in partnership with my supervisor. This phase is indicative of the highly idiographic and descriptive nature of IPA and was conducted using paper and pen.

Next (Stage Three in Table 5), I noted differences and similarities within and between interviews, tentatively drawing together ideas for sub-themes. The emphasis here was on remaining open to possibilities while looking for threads of information which may link together and explain the phenomenon under investigation, that of coping. During this phase I used QSR International’s NVivo 8 (2008), a software product designed to manage qualitative data. Software programs do not analyse data but they can be an organisational aid when managing and analysing data (DiCicco-Bloom & Crabtree, 2006). Using NVivo 8 enabled me to look for support and divergence for the numerous early sub-themes across all cases. Stage Three represented the beginning of rigorous interpretation, as I started to make decisions about which messages were coming through strongly from the transcripts. There was still an emphasis on checking data and ensuring that all possible avenues of understanding were explored.

At Stage Four, a second supervisor became involved with comparative coding for selected, rich narratives, to offer another perspective. The interpretative element was also becoming more relevant so I chose cases which were particularly detailed or expressive of the themes which were emerging. The perspective of an experienced qualitative researcher coding these interview transcripts provided me with confidence that no obvious interpretation had been omitted while analysing the data up to this point. Comments from my second supervisor were considered and incorporated into existing codes, or they were discarded based on other transcript analysis.
At Stage Five, I re-read the transcripts to ensure themes were arising from the words of participants. This illustrated a return to preliminary idiographic and descriptive analysis, ensuring that the themes are emerging in the first instance from the transcripts of the participants. The interweaving of description and interpretation is one of the key features of IPA (Bowen, 2008). Returning to the words of the participants helped me to validate the themes with examples and key quotes. Because quotes in qualitative research can illustrate ideas, evoke emotion and provide support for the claims of the research (Sandelowski, 1994), verbatim quotes were used to name themes wherever possible (Corden & Sainsbury, 2006).

Using NVivo again, at Stage Six, I gathered together the various sub-themes and weighed them again in terms of emphasis and relative importance, having re-read the transcripts in Stage Five. At this stage I started to cluster the most prominent sub-themes into broad overarching themes, collecting and collapsing themes as necessary during this interpretative phase (Smith et al., 2009). Codes were organised more hierarchically, so that the highest level codes represent broad themes and lower levels indexing more narrowly focused themes (King et al., 2002). While electronic software can be (and was) enormously helpful for organising the data, as Patton (2002b) points out: “the qualitative analyst doing content analysis must still decide what things go together to form a pattern, what constitutes a theme, what to name it, and what meanings to extract from case studies” (p. 227). With this in mind, I was aware that the software was a valuable but limited tool during my analysis, thus I primarily used it for organisation and management of my data. This process of sifting and revising resulted in three overarching themes becoming evident. Two of these overarching themes represented four sub-themes, while one represented three sub-themes. As a final layer of interpretation, I developed two integrative themes which were embedded in two (but not all three) of the overarching themes (Stage Seven). While this is not common in IPA studies, there have been some cases where integrative themes have arisen and been described in studies using IPA to explore the concept of coping (King et al., 2002). The integrative themes in this study represented a deeper sense of the ways people coped individually and together, thereby staying true to the layered style of interpretation which IPA encourages. All sub-themes, overarching themes and integrative themes will be discussed in Chapter Four.
3.4.2 Role of the Researcher

There is a balance which needs to be managed when using IPA between the emic (insider, phenomenological) and etic (outsider, interpretative) position (Reid et al., 2005). In the emic position, I began by hearing people's stories and prioritising their world view at the core of the account. In the etic position, I attempted to make sense of the participants' experiences and concerns, to illuminate these in a way that answered a particular research question. IPA required me to be attentive to, and conscious of, my own perspective, as well as the perspective of the participants (Chapman & Smith, 2002). To that end, I kept a diary reflecting on my own role and how interactions with participants might be affected by my particular communication style and my values. This diary was discussed as appropriate during supervision. This strategy helped to address the dual interpretive nature inherent in the analytic process with IPA, recognising that the researcher’s perspective and position shapes the research (Mulveen & Hepworth, 2006; Willig, 2001). Reliability and validity of the analytic process and the results of this study have been strengthened by documenting the stages of analysis with discussion between two researchers about data interpretation that had been previously analysed independently (Smith, 2004; Yardley, 2000).

Debriefing after interviews had the double benefit of me getting an opportunity to share the impact of hearing intimate, and often painful stories, with an experienced qualitative researcher, while also examining my immediate reactions and possible bias (Harkness Hodgson et al., 2004). Researchers can try to bracket, or acknowledge their pre-conceptions, prior to embarking on qualitative exploration (Elo & Kyngas, 2008; Finlay, 2008). However, pre-conceptions were only uncovered as I encountered the participants’ life-view during interviews and analysis of transcripts (Smith, 2007). It is for this reason that reflective supervision and using a journal were essential parts of the analysis process. Smith (2009) calls for a more enlivened form of bracketing, describing it as a cyclical process and something which can only ever be partially achieved. While it may be helpful to produce a bias statement prior to starting out to assist with reflection during analysis, one will most likely not be aware of all one’s preconceptions in advance of engaging with the data. Ahern (1999) talked about how important it is for qualitative researchers to identify their interests and own experience prior to beginning interviews, relevant to the stories which my participants may divulge. This
uncovering included issues such as the motivation for completing the research as related to attaining a tertiary qualification. Following Ahern’s other recommendations, I made a mental note to recognise when anxiety, annoyance or enjoyment arise during interviews and during analysis. Revisiting these feelings using a reflective diary was enormously helpful for me to gain insight into what I was bringing to the interpretative cycle.

3.4.3 Assessing the Quality of Qualitative Research

It is difficult to establish criteria to assess qualitative research due to the novelty and diversity of the field (Smith et al., 2009). Yardley (2000) described principles which can be used as a guide to assess the quality of a qualitative study, where the essence of qualitative research is often to be open-ended and flexible. She suggested the four following areas to consider when assessing the rigour of qualitative data, and I will address each one in relation to this current study:

1) Sensitivity to Context: This was achieved by conducting a thorough literature search including both quantitative and qualitative research. This process highlighted the gaps present in this field and ensured that as much issue specific planning as possible had been completed before embarking on the study. The socio-cultural setting had been well considered and the ethical issues were address in an ethics application to a Regional Ethics Committee prior to initial participant recruitment and data collection (Appendix Six), 2) Commitment and Rigour: The issues and sensitivity to interpretation and ethical concerns were considered in an in-depth way, from initial planning through to analysis, and presentation of data. My methodological competence has been supervised closely by two experienced researchers, through peer coding and debriefing meetings, 3) Transparency and Coherence: The epistemological stance, methodological choice and use of methods and reflexivity have been clearly outlined in this chapter to show the fit between theory and method. The steps outlined in Table 5 would enable a third party auditing my research trail to see evidence of each stage of my research process, as would supporting documents such as the transcripts, reflective journal and minutes from supervision meetings. Extracts from the interviews were included when writing up the results in Chapter Four, which further demonstrated transparency that the themes have emerged from the participants’ experience and 4) Impact and Importance: A strong argument has been presented in Chapter Two about the lack of research viewing people with chronic
illness and caregivers in inter-relational terms. The results of this study will help to illuminate this area and will enrich theories about communal coping, which are currently in their infancy.

Brocki et al. (2005) completed a review on the application of IPA across 52 studies. They expressed concern about variability in the way that papers deal with the interpretative facet of this approach and they recommended a greater acknowledgement of how this process occurs, which I have done in Table 5 and the analysis section of this chapter. Larkin et al. (2006) seasoned IPA researchers, warned against the growing body of IPA literature which stops at first order analysis, where participants’ views are summarised, but the analysis does not go deeper to the interpretative level. By illustrating the layered process which I went through to arrive at the overarching themes, sub-themes and integrative themes, I have illustrated depth to my interpretative process, given that I was working with a relatively large sample size.

3.5 Ethical Considerations and Risk Management

An application was made to a Regional Ethics Committee and their feedback was incorporated into the study protocol (Appendix Six). This committee granted ethical approval for this study prior to any participant being recruited to join the study.

3.5.1 Emotional Risk

Given the sensitive nature of the topic of this study, any emotional risks to either PwMS or their SOs were considered while designing the research protocol. The PwMS and their SOs had the right to nominate a whanau member or a support person to be present during the interviews. There was ongoing liaison with the local MS field officers, and referral to other community support services was offered if that was appropriate following the interview. Research which focuses on sensitive issues, such as coping with relationship changes due to illness, may stir up emotions of such intensity that failure to provide an opportunity for the respondent to talk would be unethical (Alty & Rodham, 1998). I expected that it was highly likely that sensitive issues would arise during interviews and maintaining the emotional safety of the participants remained foremost in my mind. DiCicco-Bloom & Crabtree (2006) outlined some issues to consider when one is using qualitative interviews to collect data, which I found extremely useful. These included the following aims: 1) Reducing the risk of unanticipated harm: By its very nature this is difficult to predict. Given that this research area is sensitive, it
was possible that the participants might find the interview itself emotionally harmful. This risk was managed by reminding participants about access to the MS field officer or other counsellors. The participants were reassured that they could turn the audio-recorder off at any time for a break, or permanently should they wish, and one participant did request the audio-recorder to be turned off on two occasions when she became upset during the interview, 2) Protecting the interviewee’s information: In order to maximise participants’ anonymity, each was given an alphanumeric code, which was used in all transcripts, instead of their name. In a study reviewing how participants in qualitative research felt about having been assigned pseudonyms, strong feelings were expressed that names were distracting because they raised connotations in readers’ minds, and the associations made might create negative stereotypes. This applied whether names used were the real names of the speakers or pseudonyms (Corden & Sainsbury, 2005). All identifying details (such as names of places, people or organisations) were removed or replaced with collective nouns, 3) Effectively informing interviewees about the nature of the research: Potential participants had ample opportunity to discuss the research with the MS field officer and myself. They were given an information sheet using layperson’s language to describe the study and any possible risks associated with it. Participants were reminded that they had the right to withdraw from the study at any time, 4) Reducing the risk of exploitation: The MS society supported recruitment and completed a locality assessment for ethics approval, which they could withdraw at any stage if they were concerned about how the research was progressing. I was bound by a code of ethics, in my capacity as a registered occupational therapist and infringing this code by consciously exploiting participants would result in my being struck off. Both thesis supervisors provided a monitoring role regarding the risk of participant exploitation. I was appreciative in all interactions with participants for their time, interest and energy.

3.5.2 Physical Risk Management
The interviews took place at a venue convenient and accessible for participants. Safety of the researcher and participants was achieved by following good research practice principles such as informing work colleagues of the interview venue, recording an expected time for returning to the office, and carrying a mobile phone. No adverse events occurred during this study, but should they have, they would have been recorded on a reporting form (Appendix Seven).
3.5.3 Cultural Safety

A submission to the Ngai Tahu Consultation Committee was completed and their suggestions were considered as part of the research protocol. They encouraged that ethnicity data be collected during study and this was completed as per ethnicity data protocols for the health and disability sector (Ministry of Health, 2004). Self identification of ethnicity has been established as best practice in New Zealand and, as a result, knowledge about health and the incidence and prevalence of certain conditions is improving (McPherson et al., 2003). Ethnicity information was gathered using a demographic data collection tool (Appendix Eight). Local consultation took place with the Research Advisory Group for Māori (RAG-M) in Wellington, and their feedback was incorporated into the study protocol (Appendix Nine). This group requested that I consult with the Whanau Care Centre in the planning stages and gain their support, which I did (See Appendix Ten). None of the participants in this study identified as Māori, which is not surprising given that there is a relatively low incidence of MS in Māori compared to New Zealand Europeans (Taylor et al., 2010).

3.5.4 Confidentiality

Confidentiality is a vital, but difficult, area to manage in qualitative research which involves dyads (Hertz, 1995; Valentine, 1999). Tolich (2004) argued that enlisting members of support groups for qualitative research limits the traditional idea of confidentiality, as the participants’ relationship to each other can lead to diminished autonomy. He stated that:

Internal confidentiality is distinct from external confidentiality, which assures protection against identification by those who were not subjects of the research...external confidentiality is the traditional notion of confidentiality where the researcher acknowledges they know what the person said, but they promise to not identify them in written reports (p. 101).

Internal confidentiality in this study was complicated by the fact that most participants (12 out of 14) were recruited through the MS society. When compiling material from interviews with people who are connected, I have been mindful of possible connections between participants as well as between members of each couple. I tried to recognize and assume responsibility for this impaired autonomy, which involved taking the time to learn from insiders what information is potentially damaging, and going to all reasonable lengths to alter information in reports to conceal the identity of the participants (Tolich, 2004).
3.6 Summary

This chapter has outlined why IPA was the most suitable methodology to explore the phenomenon of coping for PwMS and their SOs, and how this methodology has been applied to this research. I have shown that IPA has been linked to an interpretive epistemology, within a constructivist paradigm. This approach to research is a shift from a traditional research paradigm that privileges the researcher's distinctions by representing therapy participants solely on their objective performance on researcher-defined measures (Gehart et al., 2001). IPA emphasises the importance of lived experience, in this case of coping with living with MS or with being an SO for someone who has MS, as well as the responsibility and involvement of the researcher’s role in interpreting another’s experience. The steps taken to remain true to both the descriptive and interpretative stance of IPA have been described in Table 5. This chapter presented the epistemological and methodological considerations relevant to analysing the data, and Chapter Four will discuss these findings following analysis.
Chapter Four: Results

4.1 Overview

This chapter will provide an interpretative account of the themes that emerged following analysis using IPA. The pertinent details of the population under exploration will be described, including the rationale for decisions about terminology use. The experience these couples cope with will be outlined, particularly with regard to the losses they have endured as a result of one of them having MS. An overview of the themes and their inter-relationship will be presented, before giving details of the sub-themes, with supporting quotes from the participants. The three overarching themes are: 1) Resources and Barriers to Coping, 2) Coping Together: “Peaks and Troughs” and 3) Coping Over the Long Haul. Two further integrative themes emerged which were: 1) Faith in Self and 2) Faith in Each Other, which relate primarily to Coping Together: “Peaks and Troughs” and Coping over the Long Haul.

4.2 Participant Description

4.2.1 Participant Characteristics

Fourteen people were interviewed: seven couples, all of whom were legally married. Six couples identified as European New Zealanders and one couple identified as British. This ethnic make-up is as one would expect given that MS in New Zealand predominantly affects those from a European background (Taylor et al., 2010). Three couples lived in a rural setting and four were urban dwellers. Of the seven PwMS who were interviewed, three were men and four were women, which means that there was an over representation of men as women are nearly three times more likely than men to have MS (Rosati, 2001). Six couples heard about the study via the MS field officers while one couple approached me after they heard about the study via word of mouth. Though 11 couples were approached and indicated their interest over the duration of the study, as a pragmatic approach was taken to recruitment, the first seven couples who met the inclusion criteria were interviewed. Further details about participants’ characteristics are provided in Table 6 and Table 7.
### Table 6 Characteristics of People with MS

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>4 women, 3 men</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>6 New Zealand Europeans, 1 British</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Median: 53; Inter-quartile Range: 53 - 70; Range: 35 - 75</td>
</tr>
<tr>
<td>Type of MS</td>
<td>3 with PPMS, 3 with RRMS, 1 with SPMS</td>
</tr>
<tr>
<td>Employment situation</td>
<td>3 unable to work due to MS, 1 stay at home mother, 1 retired, 2 working full-time</td>
</tr>
<tr>
<td>Mobility</td>
<td>4 full-time wheelchair users, 1 walked with a walking stick, 2 walked unaided</td>
</tr>
<tr>
<td>Length of time since receiving diagnosis of MS (years)</td>
<td>Median: 10; Inter-quartile range: 6 - 17; Range: 2 - 27</td>
</tr>
<tr>
<td>Length of time in a relationship with SO (years)</td>
<td>Median: 29; Inter-quartile Range: 12 - 46; Range: 6 - 53</td>
</tr>
</tbody>
</table>

### Table 7 Characteristics of Significant Others

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>3 women, 4 men</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>6 New Zealand Europeans, 1 British</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Median: 58; Inter-quartile Range: 51 - 66; Range: 43 – 74</td>
</tr>
<tr>
<td>Employment situation</td>
<td>3 SOs were unable to work due to care-giving commitments for spouse for 23 years, 5 years and 4 years respectively. Of the other 4 SOs, 1 was retired, 1 was semi-retired and 2 were working full-time.</td>
</tr>
<tr>
<td>Nature of care-giving within relationship</td>
<td>3 spouses provided daily assistance for personal care tasks, 3 provided daily assistance with domestic tasks, 1 provided occasional assistance with domestic tasks</td>
</tr>
</tbody>
</table>
4.2.2 Care Situation
Three couples, where the SO was a full-time caregiver, received substantial support from care agencies providing personal care assistance (daily or twice daily formal care). The PwMS in each of these couples accessed residential respite care on a regular basis. None of the other four couples were receiving formal household or personal care assistance.

One challenge associated with this study was coming up with a collective noun to describe the support people who were nominated by PwMS. Initially, I wanted to keep the possible relationship between PwMS and their SO as open as possible (i.e. siblings, partners, friends, children). There had been no objection to the descriptive term ‘significant other’ from participants, but neither did anyone in the study spontaneously use it. Participants either identified (sometimes strongly) as carers (if they provided a lot of physical assistance to their partner) or did not associate themselves with the word ‘carer’ at all (if they didn’t have a hands on role), so the terms carer or caregiver did not seem appropriate to use as a collective noun to describe the whole group of SOs in this study. However, all those interviewed clearly identified as each other’s ‘spouse’ or ‘partner’, so when describing the results of this study the abbreviation SO and the terms spouse and partner have been used interchangeably to refer to the person without MS.

4.2.3 Medical Situation
Three of those with RRMS were taking medication intended to alleviate symptoms of MS and prevent relapse (typically Beta-Interferon) and all three and their SOs expressed relief that it appeared to be working well for them. One participant with RRMS was no longer taking Beta-Interferon, but was taking medication aimed at reducing urinary incontinence, and managing pain related to MS. Those with PPMS perceived that there was no medication for their type of MS and they did not report taking any specific medication.
4.3 Introduction to Themes

Three overarching themes emerged during the analysis, which described how these couples coped with the challenges of MS. These were:

Theme One: *Resources and Barriers to Coping*

Theme Two: *Coping Together: “Peaks and Troughs”*

Theme Three: *Coping Over the Long Haul*

Theme One related to how people interacted with perceived barriers and resources to coping, which were external to the couple relationship. Theme Two identified information about the couple’s experience, in relation to each other, of what helped them to cope and what got in the way of coping effectively. Theme Three reported on what the couples expected for themselves and their coping in the future. During layered analysis using IPA it became evident that theme two and three are underpinned by concepts about participants finding strength and comfort in their own sense of self and self-determination, as well as the importance they place on having their spouses present through the ups and downs of the illness. These integrative themes are named *Faith in Self* and *Faith in Each Other*. All overarching themes, along with the sub-themes and the integrative themes are illustrated in Table 8. Where themes have titles which include words in quotation marks, those words were directly from the participants. Appendix Eleven outlines the key to the transcription conventions.
Table 8 Summary of Themes

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Resources and Barriers to Coping</th>
<th>Coping Together: “Peaks and Troughs”</th>
<th>Coping Over the Long Haul</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub themes</td>
<td>• Right Information at the Right Time</td>
<td>• Different Strokes for Different Folks</td>
<td>• “Just Get on With It”</td>
</tr>
<tr>
<td></td>
<td>• Knowledge of Others with Disability</td>
<td>• How to Support Each Other and What Gets in The Way</td>
<td>• Relief Gives Way to Realisations</td>
</tr>
<tr>
<td></td>
<td>• Relationships are tested: “Swings and Roundabouts”</td>
<td>• Intertwined Lives: “Journeying Together”</td>
<td>• Looking for Positives and The Role of Hope</td>
</tr>
<tr>
<td></td>
<td>• Relationship with Health Professionals: A Mixed Bag</td>
<td></td>
<td>• Immediate Future Only</td>
</tr>
</tbody>
</table>

Integrative Themes
- Faith in Self
- Faith in Each Other

4.4 Participants’ Life-world View

While it was not the focus of this research to explore the difficulties related to having MS, or caring for someone with MS, all participants spoke a lot about the challenges they faced. This section is intended as an overview of the nature of these challenges. It will set the scene for what the participants coped with, before discussing the themes which relate to how they coped.
4.4.1 What did PwMS and their Spouses Cope With?

Loss, illness uncertainty and associated grief issues dominated the interviews as the primary challenges for participants. Ambiguous loss and fluctuating health status meant that life with MS involved a lot of fear about worsening symptoms. The fluctuating health status of the PwMS influenced the fluctuating nature of coping for both the person with MS and their SO. Along with the tangible losses associated with oneself or one’s partner having reduced physical function, participants spoke about the emotional impact of one of them having a disease with such an uncertain future. The difficulties dealing with the uncertainty of MS are illustrated in Table 9.

Table 9 Emotional Impact of Illness Uncertainty

<table>
<thead>
<tr>
<th>Loss</th>
<th>Illustration of loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of Hope</td>
<td>There’s…the very nature of the illness is that there is no cure or, or (pause). You can’t get back any degree of recovery …yeah it’s just the ongoing nature of it that makes it quite difficult SO 2</td>
</tr>
<tr>
<td>Ambiguous Loss</td>
<td>And because it’s a disease that they can’t tell you you’re going to be like this in 5 years or 10 years or whatever. You sort of think, ‘well where the hell are we going from here? SO 5</td>
</tr>
<tr>
<td></td>
<td>With the MS, it just seems to, it goes away and then it comes back and you can actually almost forget about it, but then suddenly you’re hit back SO 5</td>
</tr>
<tr>
<td></td>
<td>But yeah, a mixture of emotions, just not knowing and still it’s like…., the way it’s progressing it’s certainly having a big effect, but you just don’t know. I guess there is a path it seems to be going down…. PwMS 7</td>
</tr>
<tr>
<td>Loss of a potential shared future</td>
<td>You know, I finally find someone who is the love of my life and [now] the permanency of that is tentative SO 7</td>
</tr>
</tbody>
</table>
Most PwMS and their spouses could at times forget about the disease, that it appeared to go away. When her symptoms returned, this participant thought that her MS was fighting with her:

Yeah, the MS rears its head every so often, every so often it just stirs round the body and you know that things are going on and you can’t describe them but you just know that things are happening...with the MS, it goes away and then it comes back and you can actually almost forget about it but then suddenly you’re hit back PwMS 5

This PwMS had to deal with shock and disappointment when they were reminded the MS had not gone away. The nature of the illness was such that the grieving process occurred in waves, often coinciding with a relapse or noticeable loss in function. This quote captures the on-going process of grieving which MS necessitates every time there is a downward turn:

You think you’ve grieved about the MS, but every time something new happens it brings it all back up again. You think you’ve cried all you can, but then even more tears come along PwMS 2

Participants mentioned social stigma, when others seemed to treat MS as if it was contagious. Often work colleagues or friends of either member of the couple withdrew either at the time of diagnosis, or when the PwMS began to exhibit symptoms. Some talked about their shock at receiving the diagnosis, but these were primarily participants who had not spent a period of time having tests, and wondering what was wrong. The possibility of becoming unwell was new to these people, as opposed to those who had had some time to think about the possibilities.

For SOs who were providing daily assistance for their partners’ personal care, there were references to feeling forgotten and having their lives restricted. They said that their sacrifice was less apparent than that of the PwMS, and that they had to take a back seat. This may go some way to explaining why the SO’ interviews were shorter than their spouses; they may have genuinely had less to say about their coping or they may be in the habit of accepting that their issues were less relevant and so, were less to the forefront of their thinking. There also appeared to be an emotional pendulum swing to deal with, for SOs in particular. They went from feeling frustrated by their spouses’ diminished abilities to feeling guilt for that frustration. The next section outlines the resources and barriers to coping with loss and change, which both groups experienced.
4.5 Theme One: Resources and Barriers to Coping

This overarching theme captures thoughts and beliefs from participants about what supports and barriers they encountered, external to their relationship.

4.5.1 Right Information at the Right Time

The thoughts about timing and usefulness of information about MS and the myriad of possible ways it can progress appeared to be mixed across the participants. However, all couples had a sense of whether or not learning more about the condition was important to them, and whether their interest in MS related information had changed over time. This sub-theme describes how participants related to the information about MS available to them. Most participants had initially been quite interested in increasing their understanding about MS and its implications. Some sought this information out actively while others were more hesitant or downright avoided information. For some, information meant power and understanding, for others, it meant pessimism. For example, this participant felt that taking on information about MS involved hard work but ultimately was useful in the early stages:

> It meant a steep learning curve on what MS was, because we didn’t, I had a vague idea, but yeah, it was a jump in the deep end [to] try to figure out what we could do about it. That was how I coped with it. Try to get my head around what the problem was SO1

Others were glad that the MS society was available to dispense information to them. They found that as the information from the MS society was accessible and understandable to them, it was also helpful when it came to explaining their situation to others around them:

> …the MS society got a field officer to come and visit me, explain what MS was. It was pretty frightening, but talking to the MS field officer really helped PwMS 2

This PwMS found it helpful to use the information leaflets supplied by the MS field officer to explain to friends what was happening to her. This enabled her to educate others and feel confident to answer their questions, which she really valued. Another PwMS acknowledged that having more information alleviated their fears in some ways, but it was a double edged sword in that more information could introduce new fears and knowing more may not necessarily improve things:

> I think ignorance is a big, you know, the fear of what could be can be a really horrible thing, so just to know, have a bit more knowledge about stuff is good, although you know
it may not necessarily help in some ways to know, it may not make it any better, put it that way, it just helps you in your mind, I think PwMS 7

This participant’s SO had even more ambiguous feelings regarding whether finding out more information was helpful for her or not. She revealed that she experienced a real tension about how much information was useful for her coping:

I’m torn between wanting to know too much and not wanting to know anything SO7

In contrast to those who found it useful to embrace information at the time of diagnosis and during the illness, there were two male SOs who said MS-related information was something that they either avoided, or did not see as necessary for them to know about. They were also sceptical about some of the sources of information that their spouses had turned to when researching their MS:

For me personally, it’s so easy to just overdose on written material, written by all sorts of different authors…and the internet, but you can just get completely befuddled by the amount of good and bad information SO 5

Rather than read too much information from sources they did not trust, these SOs adopted an attitude of ignoring information that did not seem immediately relevant. Taking this perspective seemed to enable them to focus more easily on what was happening on a day to day basis. Others described situations where their attitude to accumulating information about MS had changed over time. They were initially keen after receiving their diagnosis to find out a lot about it, but over time they had decided (or taken advice) to limit the information that they were gathering. As one PwMS put it:

Find out as much as you can, then put the books away and get on with living PwMS 6

The decision to avoid, or stop looking, at information is of interest as regards choices around coping. It seemed possible that people decided that it was in their best interests to switch off the information onslaught, with its gloomy future possibilities, in favour of a decision to focus on their present lives (see later sub-theme “Just Get on With It”). It seemed that gathering information at the time of diagnosis was important for most participants, (but not all), and that the need to seek out MS-related information lost its urgency as time went on.
4.5.2 Knowledge of Others with a Disability

This sub-theme related to whether or not the participants thought familiarity with others with a disability was useful to their ability to cope. The other person with a disability was sometimes a friend or family member or at other times the participants referred to people they had met through the MS society. Most people thought those they had met through the MS group were inspirational and offered support and practical advice about living with disability. The perception of the MS society as a safety net, something that provided comfort and knowledge, was an image described by one SO:

That’s your safety net [MS group], and you’ve got to have that safety net, you can’t just keep bungling your way through each day without knowing that there is somebody out there who may have the answer to your problems SO 6

This idea that the MS society was supportive contrasted with the beliefs of others that attending the MS society deepened their sense of foreboding. Within couples, there was sometimes dissent about whether going along to the MS society was something that helped or hindered their ability to cope with their situation. The following remark was made by a SO whose spouse found attending the MS society helpful, but she did not:

I said to [spouse] ‘the reality of watching some of the severe ones there, that doesn’t help me to cope.’ It’s not about the people; it’s about watching the process SO 7

This illustrated the realisation of fears that occurred when participants were brought literally face to face with the ways in which MS could manifest itself, and ties in with the sub-theme Relief Gives Way to Realisations. Meeting people with MS with more obvious symptoms could represent a moment of realisation which could be very difficult to cope with:

I tried to encourage [spouse] to go to [MS soc related] stuff, he’s not comfortable in groups and I think, you go to a room and you see wheelchairs and things that that’s just the worst case scenario. But I’ve met some amazing people through the MS society in wheelchairs and things PwMS 5

When her husband declined to attend the group, she understood and respected his decision. Seeing others with MS made her more appreciative of the abilities she still had, rather than scared about losing these abilities in the future. Similar to the sub-theme Right Information at the Right Time, this sub-theme highlights that there are differing appraisals of whether involvement with others with a disability is useful to coping.
4.5.3 Personal Relationships are Tested: “Swings and Roundabouts”

Friendships and working relationships were reconsidered and many participants changed their perceptions about their friends or work colleagues for better or worse. It was a testing time for many friendships when the participants first disclosed that they had MS. Some found that they deliberately avoided telling a wide group of people. Those who remained friends through that time and who were still supportive were highly valued, while there was disillusionment about the friends who had fallen away:

The friends you thought were friends dropped off. And yeah, there’s only, they always say that you only have a few friends in a life time, the rest are acquaintances, well you learn that pretty quick **SO 6**

The belief that it is important to know who your friends are, in order to cope, was continued when this SO talked about his need for trusted friends. He shared fears about the consequences for both he and his spouse if their burden is not shared:

Make sure you know who your friends are. Because unless the burden is able to be shared amongst friends and family, both the person with MS and their partner can relapse at an equally alarming rate **SO 2**

The idea that both will relapse without support highlights how much the SO is affected when the PwMS experienced a relapse, to the extent that their lives somehow mirrored their spouses’ relapse. This idea also related to the sub-theme Intertwined Lives: “Journeying Together”. Not all friends were supportive when they were told about the diagnosis. One PwMS had been shocked when she received the diagnosis, having had almost no symptoms prior to her first relapse. She had talked at length in the interview about her shock and she was still trying to work out what it all meant for her when she told her friend what had occurred:

She lost the plot, the first thing was ‘yeah, yeah, you’re going to be a wheelchair case’, it was, like, she went straight to the worst case scenario **PwMS 5**

This participant found her friend’s reaction unhelpful in that she jumped to the most negative possible future when the PwMS was still processing for herself what the diagnosis of MS meant. In this case, the PwMS supported her friend to deal with her shock and panic, rather than receiving support from her friend. For one SO, his wife’s personality had altered before they knew she had MS. This unexplained change in character had alienated them from some
of their friends. While receiving the diagnosis made it a little easier for both the PwMS and her spouse to understand why this had occurred, not all of their friends were as accepting:

It’s hard, because [spouse] she was scaring away some of our friends and we didn’t understand why she was being so rude to our friends. Off the wall comments and sarcasm. So when we did find out about it, [received the diagnosis], I suppose we lost 3 or 4 or our close friends…but we’ve picked some new ones up along the way, so swings and roundabouts SO 1

This SO talked about a benefit which evolved from his spouse having MS. They both met new people and created alliances which were more supportive than previous friendships had proved to be. This process of re-evaluating personal connections was highlighted from a different angle by this PwMS, who recalled her partner (previous to her SO who took part in this study) reacted in an offhand way to hearing her diagnosis:

I was seeing someone at the time [of diagnosis] and I rung him and told him and his reaction was ‘oh well I’d better go, I have friends coming around’. That’s not the response you want from a significant other PwMS 2

For this PwMS, her previous partner’s reaction proved to be the beginning of the end of their relationship. The same participant valued her close friends and how they had not changed in their approach to her:

She just treated me the way that she used to treat me, there was nothing different and that is something I really appreciated PwMS 2

All SOs identified having time with their friends as enormously helpful to their ability to cope. Given the re-shuffle to many friendships brought on by their partner having MS, the friendships which had endured that process were ones that SOs felt they could rely on and were a vital resource for them:

I make sure I get time out, not from him, just I make sure that I keep contact with my girlfriends, you know, I go out and do stuff that I want to do SO 7

This sub-theme highlighted the importance of friends and the influence that friends’ reactions can have on the coping ability of PwMS and their SOs. There was a strong sense that relationships are re-evaluated when the diagnosis is received and when the disease makes its presence felt over time.
4.5.4 Relationships with Health Professionals: A Mixed Bag

Most participants gave some example of feeling like they had battled an individual or the health service in general. The health professionals they had encountered were viewed either as a resource or a barrier to their coping. All PwMS had first been involved with a neurologist when they received their diagnosis. Many described this experience as traumatic and they thought that it could have been handled better:

When I was first diagnosed with MS my neurologist said to me ‘We think you’ve got MS’ and booked me in for steroids. And that was it, nothing else was said. Maybe they need to explain, sit there and think, okay, you’ve just changed this person’s life by giving them this diagnosis  

This PwMS was not alone in believing that the neurologists they had dealt with lacked empathy, or at the very least, the communication skills that the participants perceived were vital for their role. Six of the seven couples interviewed had spent time wondering what was happening to them, as their symptoms grew, or waxed and waned. They reported that the PwMS was not always believed by the health professionals. This appeared to have been quite distressing at what was already a stressful time:

If [you] know what’s wrong you can deal with it. But it’s when this silly lady [GP] was telling me ‘get over it, there’s nothing wrong’, that I was basically mental  

Those who held the perception that they were not believed carried painful memories of this time. They also recognised that once they had received a diagnosis they felt in a better position to deal with the symptoms. SOs found that it was important to be included in consultations when their partner was being tested and diagnosed. Having access to the same information at the same time about what was happening and what might happen for their spouse supported their coping process:

I’ve sat in on all the appointments he [husband] has had with the neurologist and she’s been open with me as she has with him and so I’ve been thankful for that  

For some couples, when they both attended the PwMS’s medical appointments, there could be tension about what each was prepared to disclose:

I think he [husband] dreads me coming along. He answers their questions; I actually tell them what’s going on
This SO was concerned that her spouse minimised his MS-related difficulties when he met with health professionals. She had a firm opinion that his approach would disadvantage both of them. She explained her partner’s behaviour, in part, by his desire to not be bothersome, as well as his avoidance of thinking about his worsening physical state. There were some participants who believed that their health professionals had not been upfront about health-related information and this had resulted in a lack of trust in them:

My GP knew about 6 months before I went and asked her that I probably had MS, so I was pretty pissed off with my GP PwMS 1

In contrast to this PwMS, most participants had some positive experiences with health professionals. Those with mobility issues (six PwMS) had interacted with allied health professionals, some having had a variety of different people work with them over the years. While most were remembered as useful some PwMS had found that their allied health professionals: “varied, very, very much” PwMS 6.

4.6 Theme Two: Coping Together: “Peaks and Troughs”

This theme and its associated sub-themes relates to how the participants coped on a day-to-day basis. MS affected their lives in different ways but for all participants it had a powerful impact on their personal choices, emotional and cognitive processes, and their relationship. As one SO put it:

Like a lot of things, it’s all peaks and troughs. Most of the time it’s mostly manageable, other times it’s a lot to deal with…the nature of her illness is that no one day is the same as the next SO 2

This SO has described the essence of this theme. Her illness causes both of their routines to vary and fluctuate. The ability to cope with the ups and downs of MS describes the glue that holds people together as they share their hopes, fears and frustrations.
4.6.1 Different Strokes for Different Folks

Most participants could easily identify whether they and their spouse employed similar or differing coping strategies, and whether their individual coping styles were complementary or oppositional. If their coping styles were oppositional, there appeared to be an increased likelihood of conflict or frustration:

I get much more frustrated than [spouse]; he’s more patient than I am. But because I’m several steps ahead of him I’m trying to anticipate what he’s going to need… I don’t know if he’s choosing not to look at it, [the effects of MS] but he’s coping with the everyday SO 7

Often the differences in coping related to the extent to which one or the other wanted to talk about their stress. It is not known which spouse experienced more stress, but it was apparent that each had a strong perception of whether or not the other was comfortable to talk about it. For example, this PwMS noticed that she preferred to talk about her worries to help her cope; whereas she perceived that her spouse coped better by doing the opposite:

When I get stressed and worried I sort of want to bring it up in conversation and try and talk about it. Whereas he [husband] is quite content to sit back PwMS 2

While this PwMS was concerned as she wanted to be able to talk openly with her partner, for others, the difference in their coping style was something that was acknowledged without any sense of frustration. Many seemed to accept that they had always dealt with stresses differently and that when one of them had MS this was no different to other times of stress in their relationship. This PwMS had been with his spouse for 53 years, which may have contributed to his resignation to their different coping styles, when he said:

She [wife] is a worrier, and whilst I won’t profess that I don’t worry, she will find something to worry about where there isn’t anything to worry about PwMS 4

Often, how people chose to cope with MS-related challenges related to whether they saw information as a barrier or a resource, as discussed in the theme Resources and Barriers to Coping. Receiving MS-related information represented a threat to any coping style which involved trying to avoid the possible realities that come with the illness, so it is understandable that one would avoid information related to it. This SO acknowledged his choice to avoid information about MS, whereas his partner is interested in finding out as much as she can:
Well a lot of my coping strategies, I just shut it out of my mind and think, well if I don’t think about it it’s not happening… whereas she [spouse] would be much more interested in researching it as much as she could SO 5

As each member of this couple was content to let the other deal with seeking out information as they saw fit, the difference in coping styles did not cause friction. Another couple differed in how they coped with feeling housebound. While the PwMS had a significant level of physical disability, she craved the opportunity to leave the house and this would lift her mood. Her SO’s assistance was vital for her to leave the house:

It’s good to get out of the house as she [spouse] often feels imprisoned here. Quite often I’m happy to be at home, she wants to get out SO 2

The difference in coping with mobility difficulties for this PwMS (which had a significant impact on both their social lives) illustrated the potential for conflict when a coping mechanism which was once complimentary becomes oppositional. Before her MS affected her mobility she could go out as often as she liked and he could stay home; but now, their choices about whether or not to leave the house affected each other much more.

4.6.2 How to Support Each Other and What Gets in the Way

This sub-theme concentrates on how people support each other and what they believe challenges their ability to cope as individuals, and as a couple. Many PwMS received support from their spouse for physical tasks which is not detailed here as the focus is on the emotional and cognitive aspects of coping. Shared responsibility around domestic life seemed to normalise their situation and gave both concerned something constructive to focus on. This SO found that sharing a life together and having a common purpose helped him to cope with the bad days:

What helps [is] living together and bringing up our son SO 2

How both people in this couple felt about their ability to manage their routine was an important factor in whether they perceived themselves as coping well or not. When their routine was not working, one or the other was usually not coping as well as they would have liked. When couples had worked out a routine which they thought worked for them both, as with this PwMS, there was a sense of pride in maintaining this routine:
We’ve learnt how to cope with it ourselves. We’ve worked out sort of routines and systems between us; we’ve got a good set up PwMS 6

The uncertainty around the illness, often when the symptoms were pronounced, could result in a lack of routine, which was perilous to the coping ability of each member of the couple. When their routine became haphazard, the overarching theme of *Coping Together: “Peaks and Troughs”* became even more pertinent as changes happened on a daily or weekly basis.

SO 1 implied that the nature of “her” illness dictated that they can’t have a routine:

> We don't really have a routine. The nature of her illness is that no day is the same as the next SO 1

There was no apparent distress in the case of this spouse as he appeared to accept the lack of routine at this stage. However, others found the difficulty planning and maintaining a routine stressful. The unexpected tended to catch them off guard and it was in those moments that this spouse felt isolated:

> We have some pretty good friends but it’s not easy to find someone to assist because most of the time when you do need help it’s at fairly short notice SO 2

In addition to the value couples placed on sharing a routine, the belief that the PwMS was taking some active part in their shared lives was important to most couples. This SO had asked her very physically disabled husband to choose recipes from a cook-book, which she would then cook, so that she could feel he was taking part in some way in their routine:

> I like him to take part, I said to him, ‘I can’t do this on my own, you have got to have some input,’ I just need him to take part in our lives SO 6

Likewise for PwMS, being supported to take part in the household routine was valued highly. Having support, or in some cases, permission, to complete domestic tasks meant that the PwMS felt that they were still contributing to the household:

> He [husband] puts up with a commode in the bedroom…he allows me to put washing up all over the front room…panties and bras, so I can still feel useful by doing the washing PwMS1

The spouse of this PwMS realised the importance for his wife of being involved in household tasks, and so he was willing to let her do things, even though it took her longer than it would
have taken him and sometimes she seemed unsafe. He recognised her need to be involved and respected her for it, saying:

She is still willing to have a go at things like vacuum cleaning. It’s a worry (laugh) but she sits there on the ground and shuffles around. For the last couple of months she has been doing the dishes, though she does tend to smash a few things because, what’s it called, the shakes SO1

SOs acknowledged that their partner may become upset at having things done for them even when they were struggling with tasks. Knowing where to help, and when to pull back from helping, appeared to be a tension experienced by most of those giving assistance to their spouse. This SO emphasised the importance of constantly negotiating changes in task allocation with each other, so that neither would resent the other:

We talk about this, I pace myself as far as when I pick up something that he has had to give up…we’ve worked through that process that, you know, he will ask me when he really wants me to do something SO 7

Most SOs valued the coping style and perspective of their spouse and found their resilience admirable. One SO described her spouse as “brave” (SO 7), and another explained that his wife “wasn’t going to lie down and die” (SO 3). The PwMS often admired and was grateful for all that their spouse had done for them, one describing her husband as a “hero”, (PwMS 1). The SOs, on the other hand, could find qualities about their spouse that they admired or valued in spite of, (or sometimes highlighted by), their deteriorating physical condition. Recognising these qualities helped most SOs to cope when they were feeling stressed, for example:

She [wife] has got a pretty good outlook on life and that hasn’t gone away, that hasn’t changed, it makes dealing with it a lot easier SO 1

All PwMS expressed gratefulness for the support their SO gave them. One PwMS in particular had reflected on the importance of remembering to be grateful and considerate to her SO:

I’m constantly trying to remember things like he has a name and say please and thank you, because I do forget that occasionally PwMS 2

Maintaining a joint routine, as well as being able to negotiate and divide household tasks, was important to both PwMS and their spouses. Recognising personality traits that each admired
and appreciated in the other person also came through as an important aspect of coping as a couple on a day-to-day basis.

4.6.3 Intertwined Lives: “Journeying Together”
This sub-theme describes how participants perceived themselves to be part of a unit with their spouse, and that this sense of togetherness gave them comfort and a sense of purpose when their emotional stability became threatened. This sub-theme relates to how couples found that being committed to each other or in love with each other were pivotal factors in why they remained involved in what could, at times, be a very stressful situation. As one SO put it:

I just want to be included because he’s part of me and vice versa SO 7

Participants perceived themselves intertwined with, and essential to, each others’ lives and well-being despite the fact that one had an illness that would adversely affect both their lives. The stress was worth it in spite of the real and possible threats to their emotional well-being. The extent to which participants’ beliefs about love and togetherness were paramount to them continuing to cope is described by this PwMS, who was asked about what he thought made their situation work:

Love. Simple as that. I can’t answer any better. We’re sort of telepathic to an extent PwMS 6

One SO articulated that the most supportive element for him at the time when his spouse was diagnosed was the love he had for her. He said that trying to understand what she was going through, taking her perspective, helped him to make sense and deal with the initial diagnosis. In response to a question about what helped him to cope when his spouse first received her diagnosis, he had this to say:

My love for her [wife]. Understanding, trying to understand what she was going through, the difficulties she was having SO 1

Some couples acknowledged a mutual need for each other which encouraged them to believe that this would cause their stresses to balance out. There was a belief that no matter what adversity they faced, they would be stronger and more able to cope together than if they were separated:

I think really we both need each other, so we do the best we can for each other SO4
Participants were honest that acknowledging this strong sense of togetherness did not necessarily mean that the relationship was always smooth, but believing that they were better off together than separate seemed get them through the hard days:

We do annoy the tits off each other a lot of the time, but we’d be hopeless without each other PwMS 5

Realising that the other person knew them well was comforting for many. This PwMS reported that her spouse would often notice symptoms of her MS manifest in her before she noticed herself, but that he would not talk about them until she noticed so as to not upset her:

He knows me better than I know myself sometimes PwMS 2

For PwMS, knowing that their SO was getting time for themselves was important for those whose spouses had a lot of involvement in their care. One PwMS viewed her formal care package as something that was vital for her husband and his well-being. As well as feeling relieved that he would have a break and their relationship would feel more equal, she also benefited from the arrangement by having her guilt alleviated:

I feel quite guilty that he doesn’t get as much time to himself as he should…in a way the care-giving [formal carers] that I’ve got is as much a subsidising of his [pursuing his hobby] and yep, I would like him to have more time to spend on that, as and when needed PwMS 1

Along with the feeling that the “essence” (SO 7) of their spouse remained intact as the disease progressed, there were common bonds that didn’t diminish which helped couples to feel connected to each other. These bonds were important to both, whether it was working on a farm together or bringing up a child, and provided an avenue for couples to experience togetherness. One SO explained how she and her spouse shared a religious faith which supported them and their relationship:

Well the fact that we share our faith, that’s really helpful. If that was a personal journey I would feel excluded and it’s definitely not, it’s a very common bond we have SO7

Couples who were strongly linked to each other found comfort in the things they continued to admire in each other and in maintaining links to their mutual life goals. Both members of a couple remaining committed to joint goals helped to manage illness-related stress.
4.7 Theme Three: Coping Over the Long Haul

This theme encompasses four sub-themes relating to how couples considered their future, including how they planned to cope as time went on.

4.7.1 “Just Get on With It”

Almost everyone interviewed for this research spoke of just getting on with it. Participants didn’t see that continuing on with life was something complicated or difficult to explain, and they appeared quite matter of fact about this reasoning. Participants normalised the presence of MS by accepting it and trying to not make too big a deal about it:

You’ve got to do one of two things, you either get yourself in a mess, or you go along and meet it half way, and get on with it. PwMS 4

This speaks to the idea that participants could see two ways they could cope and most people tried to adopt the way that caused them least anguish on a day to day basis. Some participants talked about the inevitability of time passing, intimating that they were going to stay alive despite the MS. They had to keep going; they did not seem to consider any alternative. One PwMS found the idea that she was going to wake up tomorrow comforting when she became anxious about what may go wrong in the future:

I’m going to wake up breathing again tomorrow. You’ve just got to keep on keeping on. PwMS 5

Carrying on without “panicking” (SO3) came up for both those with MS and SOs. For some the idea that they needed to just get on with things had come after a period of denying the presence of the illness:

Some of the times I might have chose to ignore it, but it’s there, it’s happened so we’ve got to get on with it. Get on with life. SO5

Others were driven by wanting to not be self-pitying, as there were worse things that could happen. This stoic PwMS took pride in her belief that she wasn’t going to let MS get her down:

Shit happens and life goes on. What happens, happens. You can’t sit down and go ‘oh woe is me’. MS isn’t going to kill you. PwMS 3
Some participants found some solace in the fact that their condition could have been something worse than MS. Their MS, or their SO’s MS, was not something to get upset about when compared with other life threatening conditions. This SO, who had lost some friends to cancer, discussed how he felt about receiving the diagnosis of MS about his wife:

> It might be more devastating if you had cancer, or stuff like that. But as far as MS, it’s not even in the same street as cancer SO3

For some, there appeared to be a conscious awareness of their own thinking leading them towards distressing thoughts, at which point they employed techniques to halt the direction of their thinking, redirecting themselves back to the present:

> I have to stop myself and think ‘whatever is going to happen, is going to happen, worrying about it is not going to help PwMS 2

This PwMS was grateful to the counsellor she had attended who had encouraged her to develop ways of dealing with distressing thoughts related to having MS. She held a belief, as did many other participants, that stress could bring on MS symptoms, a belief which provided further motivation to minimise the distress that stressful thoughts could cause.

### 4.7.2 Relief Gives Way to Realisations

This theme relates to how people’s perception of their illness, or their spouse’s illness, changed as symptoms either presented themselves or did not. Many had found the road to receiving a diagnosis fraught with tests and the fear of the unknown. Because the stress of the unknown passed once the PwMS received their diagnosis, there was a relief in being able to put a name to what was going on in their body. It freed them from fears which may have been developing about their mental health as the journey to a diagnosis was marked by suggestions (implicit or explicit) that their symptoms may be a product of their imagination and have no neurological basis. This PwMS suggests that she found receiving the diagnosis validating:

> It was a feeling of relief, to know that I’m not going nutty. That there is actually a word to put to this thing, which is happening to my body. Ahm, and then it’s trying to get to grips with it all PwMS 2

For this PwMS, and for many others, receiving the diagnosis was the beginning point of learning about MS. For some, there was initially a presumption that receiving a diagnosis meant that a cure existed. However, as time wore on, people had moments where they realised...
that the illness was treatable, but not curable. One PwMS went so far as to say that she was pleased to be diagnosed, but that the full reality of the lack of treatment for MS did not occur to her for some time afterwards:

I was quite pleased to be diagnosed, but at that stage I didn’t know that MS just kept on getting worse, and kind of thought that there would be a pill that you could pop and everything would be fine again PwMS 1

For couples where the PwMS had PPMS, which is essentially not treatable, realising the lack of medical intervention available to them challenged their beliefs about doctors and the power of medicine to cure illness. As one PwMS put it:

Usually when you go to a doctor you go along and he diagnoses the problem and then he says ‘this is what you need to do’. Basically what they said is ‘this is the problem, sorry about that, see you’ PwMS 7

As with the sub-theme “Just Get on With It”, some participants were heartened by receiving their diagnosis because it wasn’t a condition that they had been more afraid of. For one PwMS, whose MS was in remission at the time of her interview, she described relief at receiving her diagnosis because she thought that MS was a disease she could live with:

It was relief. Absolute relief. It wasn’t fatal; you can learn to live with things like this. It didn’t mean to say that I’d be in a wheelchair, but I’m probably going to PwMS 3

This PwMS took the view that the worst case scenario for her, that of needing a wheelchair, may or may not happen. Rather than consider a possible negative future, she accepted that she may end up using a wheelchair, but she chose to think that it may not happen for a long time.

4.7.3 Immediate Future Only

This theme relates to the changes in how couples imagined their future. Receiving the diagnosis of MS had brought about a re-evaluation of what they expected from their separate and shared lives. Almost all participants had a strong sense of needing to live in the present moment therefore it was challenging for them to think about the future. The tendency to stay in the present is illustrated by this SO saying:

I don’t think about it crippling her [wife]…I sort of think (laugh) that tomorrow will be like today… I take it day by day SO 5
While this SO knew that his partner’s MS will most likely cause deterioration in her health and functional ability, he chose to imagine their future as similar to the way they existed at that moment. For another SO, he tried to keep negative consequences about his spouse having MS out of his mind:

I try to put it on the back-burner. Now and again, particularly if he [husband] is having a bad day, that’s when it crowds in on you SO 4

Thinking about the future seemed like unnecessary stress and somewhat futile for many as the illness uncertainty associated with MS meant that there was no way of predicting or planning how it may unfold. One SO said he had given up trying to plan things because his partner’s condition could change so quickly and unexpectedly:

Immediate future only I’ve learnt. Because she can change so much from one week to the next, from one month to the next that you don’t try and make too long a plan SO1

While this SO found taking it one day at a time the most practical way of dealing with the uncertainty, for others, thinking about the future brought on fear and sadness. It is understandable that dwelling on a possible negative future was something that most sought to avoid in order to get on with living day to day. The sadness experienced by losing the imagined life they could have had together was described by this SO:

So while I do plan for the future I don’t try and live there, cause that’s, the thoughts of what will happen to him [husband] and what have you, are horrible. So yeah, live in the here and now but be real about the future SO 7

This SO struck a balance between planning for the future in a practical sense (housing alterations, care arrangements) without dwelling too much on the ways in which both their lives may be altered by the progression of his MS.

4.7.4 Looking for Positives and the Role of Hope

Participants found some positive aspects, often indirectly, of one of them having MS. One PwMS, who was a devout Christian, was comforted by thinking that he had MS so that God could make him more aware of others with disabilities. Having MS showed him aspects of life he may not have known otherwise, particularly about having empathy for others:

Well I guess learning about myself, perhaps through the MS; it’s made me a lot more aware PwMS 7
The same PwMS had adopted an attitude towards his MS where he tried to accept it rather than fear it. He looked for the positive things it had brought into his life. Taking this approach enabled him to find things to be grateful for and reduced the times when he despaired about it:

Make friends with it [the MS], try and think of the good things about it PwMS 7

Similar sentiments were echoed by a participant who reported that knowing he had a degenerative condition meant that he was more grateful for his health and abilities while they were still relatively intact. He had a slowly progressing form of MS and had developed symptoms relatively later in life (in his 50s) and so he was appreciative that he had enjoyed his health for so long:

I think you have got to treasure your health whilst you’ve got it PwMS 4

For participants with RRMS, many had experienced symptoms that had come and then gone again. This left them with a sense of urgency to make the most of the time their MS symptoms were in remission. This PwMS decided to book a holiday in the South Island so she could watch the trees change colour in autumn. She had wanted to go for years but had not got around to it. When her last relapse occurred, it affected her vision and she thought of a trip which she had always put off:

I mean when my eyes went silly and I couldn’t see and it was really frightening cause I thought ‘what do I do if I don’t come out of this?’ So I thought, ‘no, I want to see the sunsets while I can, and the change of the trees as it is happening’ PwMS 5

Hope was a factor which helped to maintain optimism for many SOs and PwMs. They tended to be hopeful that their spouse would not get too unwell too quickly rather than hopeful for a cure, although two PwMS were indeed hopeful that medical advances would cure them in time. The relevance of hope also ties into the sub-theme Just Get on With It, where couples have appraised their present situation as something that they can live with as long as they can believe it won’t deteriorate too quickly:

‘Well it’s happened, it’s hopefully not going to get any worse, and we can live with it like this’ SO5
For others, health professionals had been instrumental in giving support to make the most of hard situations. Acknowledgement of meeting useful health professionals came up, where one SO found the hospice nurse supportive when he and his spouse were having a difficult time:

At that stage she [wife] was only given a few weeks to live, and the hospice nurse, she was quite inspirational. She helped teach us about how to appreciate the time we had SO1

Through knowing this nurse, he and his spouse had found a way of dealing with a stressful situation in a way that was somewhat comforting for them both. Finding things to be positive about the fluctuating nature of MS was most difficult when a new symptom emerged. Participants thought they could cope with things until there was another sign of deterioration:

I’m pretty positive. I’m alright until another symptom happens PwMS 2

This PwMS prided herself on staying positive, explaining that she had “strength of spirit” (PwMS2). Discovering this aspect of her character occurred directly as a result of having MS at a young age. Every time a new symptom appeared she had to rely on her strength of spirit to continue to stay positive.

4.8 Integrative Themes

There were two integrative themes which arose from the data following close analysis of two of the main themes: *Coping Together: “Peaks and Troughs”* and *Coping Over the Long Haul*. These two integrative themes evolved from analysis of the data while I was trying to understand where both the PwMS and their spouse found strength to carry on. It became apparent that having a strong belief in their own ability to cope, as well as a belief that their relationship was solid and worthwhile, enhanced their ability to manage their situation. These two integrative themes are named *Faith in Self* and *Faith in Each Other*.

4.8.1 Faith in Self

This integrative theme illustrates that participants found their own character a resource. One PwMS who was “determined to be about” (PwMS 6) considered his resilient outlook directly related to his childhood when he had lost both of his parents at an early age and been raised by a grandmother:

When this [MS] happened to me, okay, so right, it’s happened, you’ve got to stand on your own two feet, you’ve got to sort it out … Live with it. Deal with it PwMS 6
Others perceived themselves and their spouses to be resilient, and trusted that they had found ways to deal with adversity in the past, and would find ways to cope with whatever the future held. The participants held a view of themselves where they believed they would cope, even if there were days when they would get upset:

I probably consider myself quite a brave person, even if I cry; I still think I’m quite a brave person SO 7

With the lack of ability to predict how and when MS may present itself, many thought that they had to “learn to trust their own body” (PwMS 3) rather than look to medical professionals for advice.

4.8.2 Faith in Each Other

Couples believed that they loved each other, had a mutual interest in each others’ well-being, and admiration for each other. This was despite some significant role changes and personal challenges as a result of the presence of MS. As this SO understood it, she and her spouse were on a journey which included him having MS and her becoming a caregiver, but she had an overall sense that being on the journey together made it worth the hard times:

…we were still journeying the journey together even though his part was different to my part. And, um, I just think it’s worth the journey. Why wouldn’t I want to be on it with him? SO 7

Being able to recognise each others’ qualities, and feeling like they were a team rather than isolated from each other, was important to most couples; also an appreciation of each other and the things that they still brought to each other’s lives to make this “journey” (SO 7) worthwhile and bearable. The freedom to be able to show vulnerability and fear when it arose appeared valuable to participants, and intrinsic to their ability to cope. The belief that the other person could and would deal with these moments was vital to feeling free enough to express oneself fully and thereby feel heard and acknowledged. When this SO was asked about what made the situation tolerable, he reported that his partner’s outlook made it easier to cope. When asked to expand on this further he said:

Yeah, a good sense of humour, a good laugh as well as a cry SO 1

This SO also referred to the freedom to be light hearted, as well as realistic, about the challenges each member of the couple faced. The ability to admire and respect the other
person appeared to be a significant factor in maintaining personal and communal resilience in the face of MS-related adversity. This is illustrated by the following PwMS:

Make sure you are married to a hero. I can’t get over how he [husband] has been so…patient and, um, I can’t think of anything that I could say to anybody else to advise them on how to better to live life with MS PwMS 1

4.9 Summary

This chapter has discussed three primary themes (Resources and Barriers to Coping, Coping Together: “Peaks and Troughs” and Coping Over the Long Haul) and related sub-themes which arose from the interview data. Along with these main themes, each with four sub-themes, there were two integrative themes which permeated the themes Coping Together: “Peaks and Troughs” and Coping Over the Long Haul, namely Faith in Self and Faith in Each Other. These two themes as well as the two integrative themes, relate specifically to the experience of a couple coping together when one of them has MS. In Chapter Five, the results of this research will be placed in the context of previous research about how couples cope with MS.
Chapter Five: Discussion

5.1 Overview

This chapter will reflect on how the information obtained during this study contributes to knowledge on coping with MS and coping with being a SO of someone with MS and how such a dyad copes together. The characteristics of the study and of the results will be discussed, with reference to current literature relating to couples and coping with chronic conditions. The strengths and limitations of this research will be analysed and recommendations for future research will be outlined. This chapter includes a summary of how the findings fit with what is already known about how couples cope when one member has a chronic condition and reiterates both theoretical and practical considerations arising from this study.

This research did not set out to make a judgement on whether or not the participants were coping successfully with what MS meant for their lives, whether they were someone diagnosed with the disease or a SO. This is in contrast with the dominant focus in research on stress and coping (McNulty, 2007). Sharpe & Curran (2006) argued that coping is a process that begins at the presentation of symptoms and continues throughout the course of an illness, responding to changes as they arise. These authors go on to state that while facilitating a person to cope and adjust to illness should be a priority for healthcare professionals, the starting point is to understand the processes by which a group is able to cope, and in some cases, find positive meaning in their lives as a result of having an illness. This occurs in spite of the illness and the psychological challenges that come with MS, and it is from this perspective on coping that this discussion is based.

Three overarching themes were identified: Resources and Barriers to Coping, Coping Together: “Peaks and Troughs” and Coping over the Long Haul. This discussion will focus primarily on the latter two themes, along with their sub-themes, in addition to the two integrative themes: that of Faith in Self and Faith in Each Other. The reason for taking this direction is that these two overarching themes best illustrate the issues at the core of a couple coping with the presence of MS in their lives, the primary focus of this research. I will return
to discussing the theme *Resources and Barriers to Coping* when I address the clinical implications of this research, as there are some important messages from this theme for health professionals about what PwMS and their spouses experience. The experience of loss and uncertainty for both members of a couple arose many times during the interviews. Coping with loss is a key developmental task in the crisis phase of illness (Rolland, 1994), as is dealing with ambiguous loss (Boss & Couden, 2002), which may develop into chronic sorrow (Hainsworth, 1994). However, as discussed in Chapter Four, while it is acknowledged that the losses associated with MS can be powerful, the focus of this discussion will be on the results which described how the participants coped with their changed world.

### 5.2 Models of Coping

While using pre-existing models cannot structure the phenomenological life world of participants (Smith et al., 2009), it is useful to place the results of this study in light of the substantial research which has been carried out on stress and coping. Two of the most relevant models (Stress and Coping Model and Illness Representations Model), which theorise the psychological processes involved in coping, will be explored in relation to the results of this study. I have included a less well known model which explores communal coping (Lewis et al., 2006), as this concept related strongly to the themes which emerged from this study. Thereafter, the focus will shift to understanding what the experience of coping as a couple has meant for the participants.

#### 5.2.1 Stress and Coping Model

Most research which investigates coping uses the Stress and Coping Model as its theoretical basis (McNulty, 2007), and this model has been discussed extensively in Chapter Two. These studies have taken a quantitative approach to investigating the relationship between two of the main coping strategies described in the Stress and Coping Model (Problem-Focused and Emotion-Focused) to outcomes such as mood and disability, and its use underpins many psychological measures and interventions (Chalk, 2007). Pakenham (2001a) asserted that, in general, coping research has failed to examine the influence of illness-related stressors on coping, particularly in relation to MS. In an attempt to remedy this situation, he used the Stress and Coping Model to evaluate the role of appraisal and coping strategies in the adjustment to illness-related stressors for PwMS and their care-givers. Eighty nine PwMS and
their caregivers completed self-administered scales measuring depression, global distress, subjective health status and the impact of care-giving. All participants also completed the Ways of Coping Checklist (Revised) and three scales evaluating threat appraisals on seven seven-point scales, both of which are based on the Stress and Coping Model. The measures were administered 12 months apart, with 51 couples completing the second round of assessment. The findings from Pakenham’s study supported the hypothesis that threat appraisals and Emotion-Focused coping were related to poorer adjustment and that Problem-Focused coping was associated with better adjustment. This research supports the hypothesis that the Stress and Coping Model can be used to explain how PwMS and their caregivers cope. This study noted that wishful thinking as regards physical problems was related to better subjective health status. *Looking for Positives and the Role of Hope* can be seen as wishful thinking, depending on what it is people are hoping for. Pakenham’s study and this study concur, in that certain styles of wishful thinking may help PwMS and their SOs to re-frame their physical problems more optimistically, thereby promoting a positive sense of self (Pakenham, 2001a).

This research project did not attempt to superimpose a model to predict or evaluate how people were coping: nevertheless, some of the themes which emerged were suggestive of either Problem-Focused or Emotion-Focused coping. For example, wishful thinking is defined as an Emotion-Focused coping strategy in the Stress and Coping Model and Emotion Focused coping strategies are often linked with poorer outcomes in terms of adjustment and depression for PwMS (Chalk, 2007). Chalk (2007) explored variables that affected adjustment in MS patients, in order to suggest interventions specifically for this population. According to the Stress and Coping Model, people who employ Problem-Focused coping strategies experience better outcomes than those who use Emotion-Focused coping strategies. Chalk (2007) argued that while Emotion-Focused coping has been associated with increased emotional distress and decreased quality of life, several Emotion-Focused strategies (such as seeking emotional respite and acceptance of physical symptoms) have been associated with positive outcomes for people with MS (Brooks & Matson, 1982). Chalk (2007) studied the relationship between coping behaviour, cognitive appraisal, social support and adjustment with 329 PwMS. The study sample was representative of the MS population with respect to
gender, ethnicity, type of MS and employment status. The results indicated that females, and those with the primary progressive form of the disease, were significantly more likely to report negative outcomes, even after controlling for health status. The level of physical disability experienced by this population was not significantly related to psychological adjustment, suggesting that psychological adjustment may be more closely related to controllable cognitive and behavioural factors than to the unpredictable physical effects of MS. The findings from Chalk’s study parallel some of the themes which emerged from this research. There was a wide range of physical ability and deterioration experienced by all participants with MS, yet the theme to “Just Get on With It” was almost universal among PwMS and spouses alike. This highlighted that being able to find coping strategies that are effective for the individual outweigh some of the psychological risks posed by a deteriorating functional state.

The sub-theme of “Just Get on With It” has many possible interpretations. It may be that the couples interviewed had accepted the diagnosis, and the presence of MS in their lives, and were now normalising it, adapting to its challenges and accepting increased uncertainty about their future. It can be argued that this group had already taken a Problem-Focused approach, and that they were now in a phase where acceptance and minimisation of the condition in their daily life was seen as the most adaptive response. However, there is the possibility that this sub-theme also represents elements of denial, whereby the participants are ignoring the presence of MS because it is something they do not want to, or believe that they cannot, deal with. Denial is an emotional response to illness, according the Stress and Coping Model, and it is associated with poorer outcomes than taking a Problem-Focused approach (Folkman & Greer, 2000; Folkman et al., 1986). Denying the effects of an illness such as MS can lead to the avoidance of services which could prove supportive to both members of a couple. It can also lead to unexpressed fears and frustration between the couple members if one is denying the effects of the illness and the other is not.

The overarching theme Coping Over the Long Haul captured ideas about how adaptive coping was sustained over time for each member of the couple. Lode et al. (2010) completed a prospective longitudinal study investigating how the coping styles of people with MS changed
over time. Of the limited longitudinal studies which have investigated how PwMS cope over time, this was the longest one completed. A questionnaire assessing coping (the COPE scale) was administered with 76 people with MS, along with measures of disability, mood and cognition. The COPE scale is an adaptation of the Ways of Coping Scale which was developed by Lazarus and Folkman (1984), so the investigators were interested in measuring coping as it is understood through the Stress and Coping Model. They concluded that compared to healthy controls, people with MS were more likely to use Emotion-Focused coping strategies when coping with stress. The tendency for PwMS to use Emotion-Focused coping (including avoidance) became more pronounced over time. These authors reported that, according to the Stress and Coping Model, PwMS were frequently employing coping styles that may be inadequate, and that this becomes more of an issue over time. While there is less clear judgment when using qualitative research methods about what constitutes an adequate coping style, the theme of Coping Over the Long Haul indicated that the participants were feeling like they were “Just Getting on With It” and Looking for Positives and finding a Role for Hope. This is in contrast to Lode et al.’s (2010) conclusions, where results indicated significantly increasing use of avoidance coping strategies, which the authors described as a “passive” (p. 336) way of dealing with disease-related situations. While this implied that avoidance constitutes ineffective coping, the participants in this study avoided focusing on worst case scenarios, failing health and lost function, and did so because it seemed sensible to them to minimise the presence of the illness in their lives and their plans.

Studies have shown that the stress experienced by care receivers and caregivers is highly correlated (Bogosian et al., 2009; Northouse et al., 1995). The Stress and Coping Model has rarely been extended beyond analysing individuals to analysing dyads or groups. One of the few studies to examine couples coping together, Pakenham (1998) examined how coping congruence between couples where one has MS was related to adjustment in care receiver-caregiver dyads. Although his findings indicated that coping congruence was related to both collective and individual adjustment, it was not clear from the results whether this meant couples who coped in a similar way did better than those who coped in a different way to each other. With the themes Different Strokes for Different Folks and How to Support Each Other and What Gets in the Way, there is a suggestion in this study acknowledging that individuals
cope in different ways and participants often identified that they had differing needs to be met. Both members of most couples appeared comfortable with their different approaches to coping, which arose in all areas of their shared lives. The results of this study adds further information to how participants perceive their own coping, where they do not categorise their appraisal style or know if they are using a Problem-Focused or Emotion-Focused coping strategy. The view from the Stress and Coping Model that wishful thinking and avoidance are less optimal coping strategies than Problem-Focused strategies was challenged in this study, by how participants chose to use Emotion-Focused strategies. Most participants perceived that Looking for Positives and The Role of Hope and Just Getting on With It (potentially avoidance coping strategies) were useful and effective for them.

5.2.2 Self-Regulation Model (SRM)
This theory posits that how people represent (or perceive) their illness will have a bearing on how they cope with the illness and argues that how people represent their illness will be affected by factors such as their social roles and self-identity. There is evidence that beliefs about identity, consequences, control, timeline and causes of illness are important in determining health behaviours and emotional well-being (Sharpe & Curran, 2006; Vaughan et al., 2003). Following completion of a narrative review on adjustment to chronic illness, Sharpe & Curran (2006) reported that those with chronic illness who perceive their illness as more serious, longer term and less controllable have poorer health outcomes. Another review of studies using the SRM, by Hagger (2003), this time a meta-analysis of 45 studies across a range of disorders, confirmed theoretically derived relationships between participants’ illness perceptions and adjustment. The study of illness perceptions influencing coping is less commonly related to couples, though there is research that stronger health threat perceptions in spouses is associated with their partners’ health behaviour (Lewis et al., 2006).

The SRM has received almost no analysis from the perspective of dyads. However, certain core principles of this model do seem to have a bearing on the results of this research project. The overarching theme Coping Over the Long Haul, and in particular, the sub-themes of “Just Get on With It” and Immediate Future Only tells us something about how the participants in this study perceive their type of MS (or their spouse’s type of MS) in the context of their lives. Namely, they appeared to have taken an approach with their thinking whereby the timelines,
causes, control and consequences of the illness were uncertain, therefore there was “no point worrying about it until it happens” (PwMS 2).

Lerdal et al. (2009) tested whether there was a link between perceived illness severity, HRQoL, and physical function with 313 people with different types of MS. While physical function was shown to be the most statistically significant contributor to HRQoL, change in social function during the year this study was conducted was the only predictor related to patients’ perception of change in MS severity. The authors hypothesised that PwMS may adapt more easily to a worsening of physical function than to a worsening of social function. While the relationship between physical function and social function remained undefined in this study, the results have highlighted that maintaining a social role may outweigh some of the losses experienced due to physical deterioration. Examples in this study included couples who stated that maintaining a shared routine and getting out into the community were activities that were helpful in the sub-theme How to Support Each Other and What Gets in The Way. But when one person in the couple was unable, physically or emotionally, to engage in their previously shared routine, this was brought up as something that got in the way of coping.

Vaughan et al. (2003) conducted a cross-sectional study measuring illness representations, along with mood, disability and self-esteem for 99 people with MS. Participants in this study indicated that they held the perceptions of a strong illness identity, chronic time-line with no particular cause and no cure. Higher levels of depression were associated with participants who had perceptions of a stronger illness identity, more serious consequences, an acute time-line and lower control. Consistent with the SRM, when an individual’s illness and self-schema become enmeshed the person was more likely to define themselves by the negative aspects of the illness, and had an increased risk of depression (Sharpe & Curran, 2006). For the most part, the participants in this study still held their self-schema separate to the illness, which is illustrated in the integrative theme Faith in Self. They would refer to perceiving themselves as “determined” (PwMS 6) or “sure it [MS] wouldn’t beat me” (PwMS 2). Indeed, it was the ability of the PwMS to hold their sense of self as separate or superior to the illness that inspired and gave comfort to their spouses as highlighted by the theme Coping Together:
“Peaks and Troughs” as well as the integrative theme *Faith in Each Other*. Spouses admired and respected their partners’ ability to hold their sense of self separately to the illness, so that they didn’t lose the “essence” (SO 7) of the person they were married to.

In diseases such as MS, where an illness is not controllable, Sharpe & Curran (2006) contended that beliefs about controllability are unhelpful. This assertion was supported by Fournier et al. (2002) when they investigated the role of optimism in three illnesses that varied with regard to controllability: diabetes (largely controllable), rheumatoid arthritis (partly controllable) and MS (uncontrollable). Among these three groups, the controllability of the illness positively moderated the effect of optimism on depression and physical functioning. It is possible that the sub-themes of “*Just Get on With It*” and *Looking for Positives and the Role of Hope* indicated that participants desired their illness to be more controllable than it actually was. Some participants specifically spoke about their hopes of cure in relation to medications that do not yet exist and of following controversial diets. Re-focusing on an aspect of life that is controllable, such as one’s physical environment, can aid adjustment by decreasing stress associated with the illness (Janoff-Bulman & Frantz, 1997). For the participants who have selected controllable aspects of their lives when they “*Just Get on With It*”, this may well be a sensible path to take.

**5.2.3 Interdependence and Communal Coping Approach**

Neither the SRM or the Stress and Coping Model have been well researched with regards to how pairs of individuals cope together. Lewis et al. (2006) set out to develop a model which acknowledged the health benefits of being in a close relationship and to integrate constructs from interpersonal dyad-level theories to enable better understanding of dyadic interaction in relation to health behaviour. Dyad-level models account for both interpersonal (couple level) as well as intra-personal (individual level) coping and behaviour change. While this model deals more with health related behaviour change rather than focusing on coping with chronic illness, this theory represents a significant shift in the literature towards understanding how couples cope and adjust their behaviour to better manage their health when the health of one member of the couple is threatened, rather than examining how individuals cope with health threats in isolation.
Understanding communal coping was at the heart of Lewis et al.'s (2006) model described in Chapter Two, and was also intrinsic to this study. The overarching theme *Coping Together: “Peaks and Troughs”*, as well as the integrative theme *Faith in Each Other*, speaks strongly of the dynamic nature of making the relationship work in the face of uncertainty. The sense-making process which participants spoke of when desiring to still be “on the journey together” (SO 7) indicated that they had interpreted the health threat of MS as meaningful for both of them and they had responded accordingly. Through strategies alluded to in “*Just Get on With It*”, there appeared to have been a resolution from one or the other of the partners to accept the situation and set their thinking to positive outcomes (*Looking for Positives and The Role of Hope*). The theme *Intertwined Lives: “Journeying Together”*, with its focus on how people view themselves, their coping behaviours and emotions as strongly inter-linked, re-emphasised the need for further development of models taking a communal coping approach.

Sharpe & Curran (2006) argued that, despite the different models which have been developed to explain aspects of adjustment to chronic illness such as MS, an integrative approach is needed which describes how the process of adjustment evolves. This research answers that call by operating outside restrictions of super-imposing a model of coping, or testing a theory about coping, and therefore is well placed to inform future models which may develop about the process of coping for this population. This current study provides evidence of the importance and complexity of understanding couples coping at a theoretical level, which is lacking in theories which describe coping from an individual’s perspective. How this research fits with other studies examining coping for couples will be outlined in the next section.

### 5.3 Couples coping with MS

The sub-theme *Looking For Positives and the Role of Hope*, comes with a message from participants that they still have hope, be it for a long remission or a cure, and that they place importance on having hope. This finding is in line with a study by Harkness-Hodgson et al. (2004) whose thematic analysis revealed that couples where one has a chronic illness find hope essential for their survival. In contrast, clinicians often view hope as detrimental to the well-being of someone who will not generally recover or be cured of their condition (Harkness Hodgson et al., 2004).
Whether or not hope is adaptive is contested in the literature. Differences in what members of a couple hope for (i.e. one may hope for things to get no worse, while the other hopes for improvement), could have a detrimental effect on the relationship. Some participants in this study hoped for a slower rate of progression, which indicated a level of acceptance that the illness will progress and an appraisal that it will be manageable for longer if it is slower. The Stress and Coping Model associates hoping for a cure with wishful thinking, which is an Emotion-Focused coping strategy and is correlated with poorer acceptance and increased caregiver stress (Knight et al., 1993). Conversely, in a study for caregivers of people with chronic conditions, hope represented different strategies which they employed to maintain psychological well-being in the face of an uncertain future for themselves and their family member. Duggleby et al. (2010) identified four themes from 14 qualitative studies which met their criteria for a meta-synthesis. These themes were: 1) transitional refocusing from a difficult present to a positive future, 2) dynamic possibilities within uncertainty, 3) pathways of hope and 4) hope outcomes. The authors concluded that hope was “transitional dynamic possibilities within uncertainty” (p 148). By this, they acknowledged that uncertainty could provide a precondition for hope, as hope was about possibilities. For the SOs of PwMS, uncertainty was something that was acknowledged, as illustrated in the overarching theme Coping Over the Long Haul. For both PwMS and their SOs, Looking for Positives and the Role of Hope, as well as Immediate Future Only, told us something about how they chose to deal with uncertain futures. They chose to focus on possible positive outcomes and they tried to not plan too far ahead.

The sub-theme Immediate Future Only speaks to the challenge couples face when one visualised a future that is significantly worse than their present. This was another consistent theme, where some participants had learnt to deal with life in this manner as they had tried planning further ahead in the past and the MS had “reared its head” (PwMS 5). For other participants, they had had a clear vision about how their joint future would look before one of them was diagnosed with MS, and they dealt with the disappointment of having to alter this imagined future (often associated with retirement or financial independence) by avoiding making long term plans again. The sub-theme Immediate Future Only indicated that it was necessary to avoid making plans and that this avoidance seemed like a sensible way of coping
in the face of uncertainty. Participants had an increased sense of not knowing what might happen next, compared to how they used to view their future before they knew that one of them had MS.

Related to the idea of not planning too far ahead, Boeije & Janssens (2004) developed themes from their mixed methods study investigating how PwMS explained their perception of prognostic risk, which supports the overarching theme *Coping Over the Long Haul*, and particularly the sub-theme *Immediate Future Only*. The authors examined 85 participants’ own prognoses on whether they would need to use a wheelchair in the next two years, ten years, or in their lifetime. The risk of wheelchair dependence was chosen as it is generally perceived as a serious outcome because of its limitations on all aspects of life. Participants cited their current functional state, the course of their MS, recent disease progression and medication as factors which guided their perception of risk of wheelchair use (Boeije & Janssens, 2004). However, psychological factors such as hope and fear were also considered important when it came to developing their own risk prediction. Physical and psychosocial factors were at play for participants in this current study, when they described why they planned for the *Immediate Future Only*. Boeijie & Janssens (2004) asserted that heuristic reasoning was used by participants to perform their personal risk analysis. Heuristic principles refer to short-cut strategies that reduce complex judgment tasks into simpler ones. Thinking patterns that were verbalised in “*Just Get on With It*” were examples of heuristic reasoning. The risks associated with the information available about possible futures for each member of the couple had been appraised by each PwMS and their spouse, and for most, the implicit decision was taken that the best way to move forward is to “*Just Get on With It*”.

The couples interviewed in this study described their understanding of MS, and how they noticed it manifesting, when they considered their future. They seemed to make decisions about how they imagined their future playing out based on their hopes (that they or their spouse would stay well, get better or not get unwell too quickly) rather than their fears (that they or their spouse would get worse). This mode of thinking is represented by the sub-theme *Looking for Positives and the Role of Hope*. In the face of uncertainty, there is research to
suggest that taking an optimistic view may be a buffer against depression and may allow individuals and couples to adjust to the illness (Gold-Spink et al., 2000).

“Just Get on With It” and Immediate Future Only emerged as sub-themes under the overarching theme Coping Over the Long Haul. These two sub-themes appeared linked to the need to deal with the present in a concrete way and to either avoid thinking about, or accept, the losses that had occurred and the uncertainties that remained. These sub-themes suggested that it was important to the emotional survival of participants to concentrate on the present, rather than visualising a gloomier future. Both sub-themes are suggestive of the need to seek areas that one can control. It was important for both people in the couple to see the current situation in as positive a light as possible (Looking for Positives and the Role of Hope) if they were to think of the future at all.

In her paper outlining what couples need to consider when one of them has an illness that they must both face together, D’Ardenne (2004) described the pressures and risks of unilateral dependency which may arise at the time of initial diagnosis or as the disease progresses. D’Ardenne reviewed literature relating to maintaining sexual intimacy for couples, where one has a chronic illness. The aim of the review was to suggest strategies to support a couple to maintain their well-being and their sense of togetherness, including: 1) support from family and friends, 2) support from hospitals and healthcare organisations, 3) community support for the couple, 4) checking and revising support and strategies over time and 5) using a couple therapist as required. Based on the study completed here, these suggestions appear to be particularly important factors for a couple to cope well. While D’Ardenne’s focus was on maintaining sexual intimacy when one partner has a chronic illness, her literature review encompassed a wide range of studies addressing the power and importance of intimacy as a support to successful coping. She described that the relationship where one partner has MS was: “like the illness, [it] becomes a rollercoaster of hope and despair” (D’Ardenne, 2004, p. 303). This is similar to descriptions given by couples in this study when they discussed their routine in the overarching theme Coping Together: “Peaks and Troughs”. One partner had a good day when the other had a good day and likewise for the bad days. Most participants
spoke of the times when they could almost imagine the MS had gone away, before being “hit back” (PwMS 5).

McKeown et al. (2003) concluded, following their systematic review of 24 studies looking at the experience of being a caregiver for someone with MS, that physical and psychological well-being, social life, finances and quality of life, were the areas most commonly affected. While the physical health concerns of caregivers did not arise during thematic analysis of this study, psychological well-being, reduced social life, finances and general quality of life were highlighted through the sub-themes How to Support Each Other and What Gets in The Way. Finding a way to maintain their routine, as captured by the sub-theme Intertwined Lives: “Journeying Together”, is a notion which has been emphasised by the small body of research addressing the couple’s experience of coping with MS. D’Ardenne (2004) recommended: “open communication, encouraging expression of anger and frustration and working with couples to maintain equity” (p 305), so that each member of the couple can find something to gain from their altered life situation.

These ideas were echoed in a study by Coeling et al. (2003), where the researchers interviewed both a caregiver and a care-receiver in their own homes, who were in a relationship with each other. Following qualitative content analysis, the authors surmised that a dyadic care identity developed when both parties negotiated a set of rules about their roles and expectations in the care relationship. Re-negotiating the boundaries of this care relationship could be difficult and couples were likely to require external support at such times. Failure to agree on these dyadic rules resulted in strain on the care process, and this may be why the routine appears so important to couples where one is unwell. Couples who described themselves as being completely immersed in the care relationship found this approach was ultimately detrimental to their personal and shared well-being. While purely descriptive in nature, Coeling et al.’s (2003) study indicated that the negotiation process was vital for enabling both members of the couple to know their role and the limits of their role, including negotiated time off for the caregiver.
As this study illustrated, planning for deterioration for the PwMS can be challenging for one or both members of the couple (*Immediate Future Only*). The sub-theme *Relief Gives Way to Realisations* gives an indication of the times of potential re-negotiation of roles and boundaries within the couple. The couples involved in this study also spoke of the need to let the other do as much as they could do, while they could do it (*How to Support Each Other and What Gets in the Way*) which related to how they negotiated the care relationship on a day to day basis. Olsson et al. (2010) identified themes titled *Feeling Needed* and *Feeling Understood* in their qualitative study exploring the meanings of feeling well for women with MS, which appear to have parallels in the themes that arose around *How to Support Each Other and What Gets in the Way*.

Along with open communication and clearly negotiated boundaries, the ability to be in-sync with each other is vital to the well-being of the relationship for a couple where one has a chronic illness (Starks et al., 2010). Starks et al. (2010) conducted semi-structured interviews with eight couples, using a conceptual framework on how families adapt to chronic illness to guide analysis. These authors identified two patterns of adaptation to MS, where couples were either in-sync with each other or they were out-of-sync. The experience of being in-sync was described as being “analogous to a three-legged race in which [couples] must coordinate their efforts to achieve their goals” (Starks et al., 2010, p. 198). This analogy relates well to the sub-themes in *Coping Together: “Peaks and Troughs”*, particularly *Intertwined Lives: “Journeying Together”*. Also, the integrative theme *Faith in Each Other* relates to the idea of being in-sync, which is described as a couple being able to re-calibrate and continue to do things that were meaningful for them and the ability to adjust their dreams and expectations to meet their new reality. If one member of the couple loses employment or retires early due to themselves or their SO having MS, this was likely to have made it more likely that they would be ‘out-of-sync’ (Starks et al., 2010). Five of the seven couples had experienced changes where one or the other stopped work because of the MS, however the theme about having *Faith in Each Other* still emerged, which can be likened to being ‘in-sync’. Being in-sync demonstrates a couple coping effectively and is a similar concept to being able to negotiate the care-giving experience effectively (Coeling et al., 2003).
As with the sub-theme *How to Support Each Other and What Gets in the Way*, all couples
deemed to be in-sync had the advantage of being able to retain a level of independence and
sense of individual identity, whether they had the illness or not. Being out-of sync, on the
other hand was exemplified by couples who were together due to their sense of commitment,
but it seemed that the additional strains brought on by the illness were close to overwhelming
them. Where the disease had progressed faster than expected, where the PwMS had left work
prematurely, or where the strategies that had worked in the past were no longer effective,
couples reported greater conflict in their relationship.

As D’Ardenne (2004) reported, open communication is likely to be key in supporting both
members of a couple to cope, and indeed this was illustrated on a number of occasions when
participants discussed issues related to *How to Support Each Other and What Gets in the Way*.
Conversely, participants also acknowledged that one or the other struggled to discuss the
relationship or aspects of the disease. This came across in this study with the sub-theme
*Different Strokes for Different Folks*. Badr & Acitelli (2005) interviewed 182 married couples,
92 where one had a chronic illness and 90 where both were healthy. They were interested in
whether relationship talk (which involved talking about one’s relationship as a specific entity
or talking in relational terms) had an impact on dyadic adjustment (the extent to which a
couple reported feeling adjusted to changes in their relationship). They used multi-level
modelling to illustrate that relationship talk and dyadic adjustment was stronger for women
than for men and stronger for couples where one spouse was ill. Their findings reinforce the
importance of taking a relationship perspective when trying to understand the coping
strategies of a couple and ties in strongly with messages inherent in the theme *Coping
Together: “Peaks and Troughs”* as well as the integrative theme describing positive
appraisals of the couple’s identity, *Faith in Each Other*.

In another study looking at couple identity and chronic illness, Badr et al (2007) completed a
cross-sectional study focusing on how couples cope when one has a chronic condition. The
authors investigated whether the nature of the couple’s shared identity mediated the stress
experienced by care-giving spouses. Becoming and remaining a spouse who gives care to their
partner is well known to be a potentially stressful experience (Knight et al., 1993), and Badr et
al.’s (2007) question about whether, and how, a couple’s identity will mediate that stress is in line with the interest of this research. A couple’s identity was described as an extension of the individual’s self-schemata, a cognitive generalization about the self that organises and guides the processing of self-related information. Badr et al. (2007) proposed that having a greater sense of ‘we-ness’ (p 212), or seeing the relationship as an entity which is a part of the self, may serve as a cognitive resource in times of stress. Badr et al. (2007) was interested in both the primary stressor (stemming directly from the needs of the patient) and secondary stressor (the subjective burden of caring for another). Their results showed that couple identity partially mediated primary stressors and secondary stressors and fully mediated the effects of positive secondary role stressors (i.e. caregiver self-esteem). There was a range of illnesses experienced by the spouses of the 92 caregivers interviewed, so the authors recommended that future investigations take the type of illness into consideration when analysing their results (Badr et al., 2007), which has happened in this study.

For the couples who took part in this study, there was a strong sense of couple identity that alleviated the stress of the care-giving relationship, where the participants identified as caregivers. The overarching theme Coping Together: “Peaks and Troughs”, and particularly the integrative theme Faith in Each Other captured how couples absorbed the changes and fears that MS brought into their relationship because the relationship was seen as worth the adversity. The sub-theme Intertwined Lives: “Journeying Together” and the integrative theme Faith in Each Other depicted how many of the participants had difficulty imagining their lives without the other person, illustrating how they had aligned their personal identity so closely to their couple identity that it was hard to imagine separating the two. When trying to identify predictors of couple identity, Badr et al (2007) suggested that pre-illness communal relationships were likely to characterize behaviours of both partners that were responsive to each other’s needs. In highly communal relationships, partners were able to recognise and respond to each other, whereas in less communal relationships this was more difficult for one or the other. Some couples in this study acknowledged that they had paused to consider their relationship when the diagnosis of MS was received, but all had thought that their relationship at that point was valuable enough for them to be able to deal with the challenges as they arose. This thinking led to the feelings behind the sub-theme “Just Get on With It”. This suggests
that these couples had the ability to revise intimacy to include rather than avoid issues of
disability and threatened loss, which can be seen as a positive coping strategy for couples
(Rolland, 1994).

Rolland (1994) completed a review of literature examining the impact of illness on couples’
relationships. His discussion drew on the Family Systems-Illness Model he had developed
over the preceding ten years, which is based on the idea that there is a systemic interaction
between an illness and a family which evolves over time. Some of the challenges he
highlighted from the literature included: 1) whether a couple defined the illness related issues
as ‘mine’ or ‘ours’, 2) the need for communication that supports the well-being of both
members of the couple and 3) the difficulty of maintaining intimacy. The concept of the
challenges that come with MS being ‘mine’, ‘his’ or ‘hers’ or ‘ours’ is linked to the
overarching theme Coping Together: “Peaks and Troughs”. The peaks seemed to represent
challenges that could be borne together, whereas the troughs were often times when one or the
other member of the couple felt isolated, guilty or resentful because they were experiencing
stress that could not be shared or understood by the other person. The connectedness and
sense that each had access to the resource that was the relationship is represented by the
integrative theme Faith in Each Other.

The results of this study have been placed in context with other relevant research into how
couples cope, as well as in relation to theories about coping. The role of staying hopeful has
been shown to be perceived as useful to these couples, as has keeping their plans grounded in
the present and trying to minimise the presence of the illness in their routine. The strategies
used by couples to manage relationship changes effectively related to clear communication
and explication of boundaries in their relationship and routine as they dealt with each new
symptom of MS. Having a strong sense of togetherness or faith in their relationship was
highlighted by participants as a valuable resource to their coping. The next section will outline
what implications these findings have for health professionals dealing with these couples.
5.4 Clinical Implications for Health Professionals

There are some important messages from this research for health professionals. Health professionals need to understand and acknowledge the needs of each person in the dyad as well as the needs of the couple. Understanding the process by which individuals cope with illness and adjust to becoming a caregiver will enhance interventions to support psychological adjustment (Sharpe & Curran, 2006). Understanding the patient and the family’s perception of the illness is vital to developing patient-centred intervention (Lerdal et al., 2009). As stated by Brooks & Matson (1982): “There is a tendency for rehabilitation programmes to overlook issues intrinsic to the client and their family, such as coping, in favour of daily functioning skills, which oversimplifies the adjustment task for many clients” (p 2130).

The sub-theme Immediate Future Only presents a challenge to health professionals who see their role as preparing couples for a future when one of them will become more physically and cognitively dependent on the other. There is some weight to the argument that deteriorating cognitive function (which some studies rate as occurring in as many as 50% of PwMS (Chiaravalloti & DeLuca, 2008)) may have limited some participants’ ability to imagine their future. However, it is more likely that difficulties imagining a future self arise from a person’s choice of coping strategy, as well as the effect of deteriorating cognitive abilities. The strength of this sub-theme suggested that this is something commonly experienced by couples where one has MS, and as such it should be noted as an issue that is likely to be viewed differently between those living with MS and health professionals working with them. There is also a potential source of conflict here, where if health professionals do not acknowledge that the sub-theme of Immediate Future Only can be a positive coping strategy for couples, they will be challenging a concept that clients perceive is important for their emotional well-being.

Involving PwMS and their spouses when it comes to designing and tailoring services to their needs has been highlighted in the literature (Patti et al., 2002; Somerset et al., 2001). In this regard, health professionals need to be aware of how difficult both the PwMS and their SO find planning for their future needs. Health professionals could re-frame this planning process, particularly around housing and specialist equipment provision, as one that will ultimately give both members of the couple more control in the long run. If health professionals can
support couples to re-frame aspects of their future as controllable rather than threatening, this may decrease the stress experienced by both and promote Problem-Focused coping strategies. Health professionals have an in-depth understanding of the system they work in, with waiting lists and funding demands, which couples with MS are not usually aware of until they need something in an emergency, often at a time of remission or deterioration. Health professionals and the couples involved need to find a balance between planning for the future, which may seem gloomy, while remaining focused on the positives. The sub-theme “Just Get on With It” could be used as a focus point to ‘get on with’ understanding the health service and how it works before a crisis develops, so that the health and support services are viewed as helpful rather than unhelpful at the time when couples feel they most need support (Somerset et al., 2001). In turn, improving responsiveness for the need for specialist equipment and advice from health services will enable health professionals to be ready to act quickly when the PwMS is ready to accept that they need increased physical or emotional support.

Benedict et al. (2005) measured health related quality of life (HRQoL) in 120 PwMS and 44 healthy people as control. When all clinical domains of disease characteristics, physical disability, fatigue, cognitive function, personality traits, mood disorder, and behavioural dysfunction were accounted for, depression most strongly predicted self-reported indices of HRQoL. Given the elevated risk of depression among those with MS (Sieger & Abernethy, 2005), taking a HRQoL perspective when measuring the success of intervention may be one way to ensure that personal factors and mood issues have been taken into account during intervention. In addition to measurement of quality of life in PwMS, the findings from this research have emphasised the need to measure caregiver strain in order to give a true picture of what each person in the dyad is dealing with. The participants valued the “essence” (SO 7) of their partner and feared deterioration in physical function less than they feared personality changes, which is consistent with other studies looking at caregiver strain (Buhse, 2008). Regularly administering a measure of caregiver burden, such as the Caregiver Distress Scale (Knight et al., 1993), could help clinicians to identify and predict likely times of stress, as described in Coping Together: “Peaks and Troughs”. Increased support could then be planned, including reviewing the nature of support to account for relationship changes.
To understand both individuals in the dyad where one has MS, clinicians must look at both members of a couple interacting together, as well as their separate needs as illustrated by sub-themes *Intertwined Lives: “Journeying Together”* and *Faith in Each Other*. Measures of dyadic coping such as the Dyadic Adjustment Scale (Starks et al., 2010) could assist health professionals in understanding and discussing this phenomenon. When interventions include both the PwMS and their SO, either in a group setting or individually, such a scale would support understanding of these interventions on how the couple is coping. The sub-theme *How to Support Each Other and What Gets in the Way* tended to acknowledge that each person in the relationship will find different things helpful. This theme addressed what it was about the couples’ relationship, or their SO, which helped them to cope.

Both people in a relationship tended to notice that the other had a different coping style. These differences in coping were sometimes admired, as discussed in the integrative theme *Faith in Others*, but they could also become a source of tension. Encouraging open communication about differences in coping is something that can decrease stress (Rolland, 1994). A health professional facilitating such a conversation could also discuss the merits of an individual’s style of coping, which would increase awareness of how the couple cope together and would support them to support each other. Feeling like each member of the couple was supporting the other, and finding things to admire about each other, have been strongly emphasised in this study as coping resources.

The *Intertwined Lives: “Journeying Together”* sub-theme illustrated how these couples saw themselves as a unit that needed to be maintained, while also having separate and different needs. This relates to studies looking at couple identity (Badr et al., 2007). Just as the bio-psycho-social model (Engel, 1980) stated that different areas of health cannot be viewed in isolation, couples with a strong sense of themselves as a unit or a system need the same kind of holistic and inclusive focus. Catering for the needs of both members of the couple, as well as the relationship’s needs, almost as a separate third entity, will ensure that health professionals have understood the individual and systemic challenges that come with MS (Kouzoupis et al., 2010).
The reasoning by which the participants decided to “Just Get on With It” needs to be acknowledged by clinicians. There were instances when taking this attitude was helpful to normalise their situation, avoid undue stress about an uncertain future and minimise focusing on the negative aspect the condition, allowing couples to enjoy the present moment. However, there were also instances when sticking to this coping strategy too rigidly encouraged a member of the couple to deny that the disease is progressing and that communication and re-negotiation of roles and routines are required (Coeling et al., 2003). It is particularly important if health professionals are involved during these times of re-negotiation, that they understand where each person is coming from, and why they feel that they need to “Just Get on With It”, rather than perhaps dwell on clinical issues that the health professionals believe to be important at that point in time.

The different approaches to coping that exist at the individual level, and the support and stress that these approaches bring to a relationship, need to be acknowledged in order to enable both members of the couple to take each other’s perspective; a factor which positively influences how satisfied couples feel with their relationship (Franzoi et al., 1985). The ability to support couples where one has MS to talk about how they cope and how their coping affects each other (known as coping congruence) should be skills that are nurtured and emphasised by the health professionals with whom they are involved (Pakenham, 1998; Starks et al., 2010). Sharpe & Curran (2006) reported that few rehabilitation programmes targeted the abstraction of positive meaning, which was an issue for many participants, in the sub-theme Looking For Positives and the Role of Hope. The most recent review of rehabilitation for PwMS noted that the role of personal factors has not received enough research (Khan et al., 2008). This was echoed by a group developing the ICF to identify preliminary comprehensive and brief core sets for MS (Khan & Pallant, 2007). Better understanding of the role of benefit-finding while having MS, or being a SO or becoming a caregiver of someone who has MS, would open up an avenue for strengths-based intervention that is currently underdeveloped (Pakenham, 2005b, 2007).
The sub-theme *Relief Gives Way to Realisations* relates to the impact of receiving a diagnosis of MS on both the person diagnosed and their SO, as well as the sense of a growing realisation of what the illness will mean for them both. This realisation occurred over time. Receiving a diagnosis or “name for what is happening to your body” (*PwMS 2*) was perceived as validating and somewhat comforting, and this perception is one that has come across in other research (Edwards et al., 2008; Malcolmson et al., 2007). This underscores the importance of timing the dispersal of disease-related information (*Right Information at the Right Time*), as the readiness to receive, understand and process information will vary from person to person. The tendency for health services to distribute information in abundance at the time of diagnosis is useful for many (Lode et al, 2007), but the true relevance of information will only be known as the disease makes its individual mark on each person in these couple’s lives at the moments of realisation.

With regard to the overarching theme, *Resources and Barriers to Coping*, the sub-theme *Relationships with Health Professionals – A Mixed Bag* came up for all participants. There were many instances where health professionals they had met were supportive and knowledgeable. However, almost everyone reported feeling dismissed or unsupported by a health professional, and these relationship break-downs warrant more research in their own right. While direct and timely information is often cited as important to couples where one has MS, how the information is delivered is equally as important (Thorne et al., 2004). After information has been provided, particularly if it difficult to understand, a range of follow up services need to be offered, from telephone contact to visits and support groups. While rehabilitation services make little difference at the impairment level of function for people with MS, health and support services have the potential to reduce activity limitations and participation restrictions (Khan et al., 2008).

Designing services and evaluating them around the suggestions made here could ensure that services are concentrating on the areas they can change, and measuring their efficacy in these areas accordingly. Health professionals tend to be more concerned with the manifestations of the disease, whereas PwMS and their families are more concerned with their vitality and mental health (Rothwell et al., 1997). Interventions such as CBT are not routinely offered to...
PwMS or their families (Thoits, 1995). However, this therapeutic modality has proven benefits with supporting people to be aware of the coping strategies available to them (Van Kessel et al., 2008). One way to ensure that support services are targeted where they are most needed is to specifically consult with consumers of a service and their families. The emergence of the integrated themes of Faith in Self and Faith in Each Other indicated that PwMS and their partners identify as being strongly intertwined. This is encouraging from a health care provider’s point of view, in that successful intervention with one member of the couple is likely to have a positive effect on the other.

Finding ways to plan with couples whose coping is reliant on focusing primarily on the present challenges current healthcare practice, as does the notion of treating both people in a couple as part of dynamic unit. The potential areas for improvement for allied health professionals are to concentrate on supporting couples to view their relationship as a resource by facilitating communication and the re-definition of boundaries as the disease progresses. Taking a relationship-based and consumer-driven approach to service design, as well as finding ways for health professionals from traditional physically focused backgrounds to use CBT principles, offer potential ways to meet these challenges (Harding & Williams, 1995).

5.5 Recommendations for Future Research

This study remained open to most definitions of significant other, leaving it up to participants to select who their significant other would be. That they all chose someone who was also their legal spouse was not surprising, but this had not been a specific aim of this study. There may be merit to researching less traditional or conventional relationships, to see if such a study could further inform nuances, similarities and differences in how couples in different contexts cope. It is also advisable to consider this research in terms of those not in a relationship (perhaps living alone), to see if their experience of coping is affected by their relationship status. While Lewis et al. (2006) contended that marital related relationships and same-sex relationships are likely to arrange their communal coping in a similar way to traditional married couples, this has not been fully explored in relation to couples where one has MS. Rather, as Acitelli (2007) noted in her research looking at relationship awareness, information from population samples that only consist of married heterosexual couples (as was the case in
this thesis) will have limited applicability to other styles of relationship structure, such as those who are divorced, living together or in same-sex relationships. The experience shared and interpreted here is idiographic to the individuals, as well as to people engaged in this style of relationship. Indeed, Rolland et al. (1994) speculated that gay and lesbian couples facing chronic conditions must deal with issues related to social stigma, in addition to all the same issues facing heterosexual couples, which may influence how they cope.

This research attempted to place no external judgement on what constituted a good or bad coping style from the point of view of someone outside of the relationship. However, my clinical intuition tells me that there may be a lack of congruence between what couples consider effective coping and what health care providers consider effective coping. There remains much to be researched on this potential source of conflict between those providing a healthcare service and those receiving it, on what is considered the best kind of coping from both perspectives. The *Relationship with Health Professionals: A Mixed Bag* experience of interactions with health professionals needs to be addressed in further studies. As half as many PwMS are satisfied with their last health professional appointment as not (Somerset et al., 2001), much more research needs to focus on where the breakdowns in communication or understanding occurs between what health services provide, and what PwMS and their families need (Kouzoupis et al., 2010). Future research could include addressing the different perspectives taken by PwMS, SOs and health professionals on how each prioritises how to plan for the future, and how to incorporate *Looking for Positives and the Role of Hope* into rehabilitation intervention. Studies could include the PwMS, their spouse and their key health professional completing measures related to HRQoL to see if they agree about this vital area. Alternatively, experimental studies could be conducted to test the effectiveness of training health professionals to enhance their methods of communication with PwMS and their SOs.

It was noted that research on how best to support couples where one has MS is scant (Chalk, 2007; D’Ardenne, 2004; Heiskanen & Pietila, 2009), as is the research around the optimal timing of such intervention (Starks et al., 2010). A full understanding of the mechanisms by which both members of a couple adapt together would facilitate health care professionals’ ability to provide greater assistance to people with MS and their families. Future research
could use the results of this study as a basis to establish the issues at the heart of a couple coping with a chronic degenerative illness, to better devise and investigate the effectiveness of intervention aimed at supporting spouses and carers for people with MS. SOs interviewed in this study echoed the sentiment from many other carer-focused research studies (Chipchase & Lincoln, 2001; Corry & While, 2009), that there is very little available in the way of services and formal support for them. More interventions aimed at the couple rather than just the person who is unwell may go some way to remedying this imbalance. While acknowledging this group more comprehensively will have implications for health-related funding, informal caregiver services are valued at US$306 billion a year (Buhse, 2008). By comparison, half that amount is spent on homecare and institutional care. Better support for informal carers with carer specific support packages and options around tailored information and education will ultimately save money in the formal care arena.

5.6 Strengths and Limitations

While there are considerable advantages to researching couples where one has MS using qualitative methodology, there are some limitations of analysing this population in this way. It is important to acknowledge that the purposive sampling strategy was skewed towards people who consider themselves, and were considered by the MS field officers, to be managing reasonably well and able to talk about their coping without it being too traumatic. While this is useful to understand how people process the challenges that MS brings to find successful ways of coping, it does not acknowledge that many couples’ coping strategies are less successful for them. In other words, these participants were a self-selected, reasonably resilient group, with the communication skills and self-awareness to be able to discuss sensitive issues. Having conducted separate interviews with each member of each couple is strength, and a limitation, of this research. The strength is that interviewing each member separately ensures that both perspectives are given an equal voice and can be analysed separately (Coeling et al., 2003). However, there was also the risk that one or either person in the couples may have felt more comfortable being interviewed together, which would mean that the interviews were not set up to maximise ease of conversation flow for certain participants. It is likely that the information on how these couples perceive their coping would have been presented differently if they had been interviewed together.
Due to the nature of qualitative sampling and interviewing, participants were not screened for cognitive impairments. I sensed that two or three of those interviewees with MS had some difficulties with concrete thinking, and that they were challenged by abstract concept formulation. For two of these participants their SO commented on the presence of cognitive impairment. Their ability to be self-aware, and able to recognise how they are coping and how their relationship with their SO was affected by them having MS, may have been somewhat impaired. This remains an unknown influence across the interviews completed with PwMS and therefore the degree to which it affected the development of interview data is uncertain. It is a challenge when investigating coping with MS over time, as the likelihood of increasing cognitive impairment will have a bearing on how individuals cope (Lode et al., 2010).

However, it can also be argued that including the perspective of people who potentially have cognitive impairments is a strength in this study, as this group is often excluded from research which limits the capacity for knowledge about this subgroup.

Concentrating on a more homogenous group in terms of MS type, for example, just RRMS or PPMS, or level of disability would further enhance the use of methodology such as IPA which emphasises the importance of homogeneity (Smith et al, 2009). This was challenged somewhat in this study, which included people with a range of different types of MS, largely due to taking a pragmatic approach to recruitment. Also, the intention was to select participants who had rich and detailed stories to tell about how they coped together and separately. As people with PPMS are more likely to have negative outcomes than those with RRMS (Chalk, 2007), exploring the coping of couples where one has PPMS may give significantly different results, particularly around issues to do with control and future planning because the degeneration speed is more certain, and often more pronounced, for this group.

People with RRMS tend to be younger, less disabled and have greater prevalence than those with PPMS (Goretti et al., 2009). Exploring coping with groups with the same type of MS and level of disability would create more homogeneity among the sample than time since illness, as the rate of disability can be so varied over time that such a group could still all be experiencing very different functional challenges.
Adjustment to MS as regards depression and social function appears to improve over (Pakenham, 2001a), which may go some way to explaining the generally well-adjusted population studied here, as they had all received the diagnosis of MS at least two years ago. Studying couples at times closer to receiving the diagnosis and further along the disease progression may produce different results. Gender has been acknowledged as affecting how individuals cope and, therefore, how people of different genders cope together (Badr, 2004; Lewis et al., 2006). This study had a mix of gender as regards the PwMS (four women and three men had MS), whereas a study where only the male or female member of a couple had MS may produce different results. Variations within themes were present and this was not surprising given the different types of MS, the different length of time since diagnosis and the different ages and time spent together of the couples involved.

There was only one researcher conducting all interviews, which had the advantage that I could adjust the interview schedule as time went on. However, having multiple interviewers may have increased the trustworthiness of the data (Yardley, 2000). Multiple researchers were involved in the data analysis, increasing the breadth of the interpretative process. Given that it has been acknowledged that increased care-giving increases the strain on a relationship, concentrating on couples where the PwMS needs more or less care may prove worthwhile. Decreased cognitive abilities (Chipchase & Lincoln, 2001) or diminished physical ability (Janssens et al., 2003) are likely to increase stress. Harkness-Hodgson et al. (2004) acknowledged that ways in which couples cope with these demands, are likely to change as the PwMS deteriorates, stating that: “Chronic illness changes the relational landscape. As the caregiver demands increase, it is highly likely that the energy needed to maintain and nurture an emotionally intimate relationship and marriage also increase” (p 102).

That the sample size in this study is larger than is generally recommended for a student research project using IPA (Smith et al., 2009), is both a strength and a limitation in this study. While practically, the analysis of each case cannot be so detailed with larger participant numbers, in this case, the emphasis shifted to analysing what were the key emergent themes for the whole group. Smith et al. (2009) recommended measuring recurrence of themes across
cases as particularly important when one is dealing with larger numbers, as well as constant negotiation between convergence and divergence, commonality and individuality.

5.7 Personal Reflections

Throughout this research I kept a reflective diary, to note and analyse my preconceptions about the topics under discussion as these pre-conceptions became clear to me through completing interviews and analysis. This practice is encouraged when using IPA and proved to be a useful way of tracking the research project as well as my own realisations about my prejudices and assumptions. This section will give a summary of what I have learnt through using this diary as part of a methodological requirement, as well as recording a personal journey into my thoughts and realisations which arose during the research process.

Coming from a clinical background as an occupational therapist working with people with chronic neurological conditions, the idea of asking strangers in-depth questions about how they are coping with the challenges in their lives did not seem daunting. This was the stuff of my everyday working life and these participants were typical of the clients I had worked with for nine years. However, I have been humbled to listen to and analyse their stories using IPA, and feel that I have truly heard and considered their life-worlds and the importance of finding ways to cope that work for both the individual and the couple. I have heard what they said about the health system without feeling defensive or allied to that service. I have been able to listen without the agenda that accompanies health professionals working within a system which quantifies peoples’ issues, and defines the specifics of intervention along a linear path. Being able to listen without trying to fix and quantify the issues that arose has been a shift in the way I engage with people and one I am wholeheartedly grateful to have had.

I have been surprised and saddened by how seldom participants, either PwMS or their spouse, spontaneously mentioned their health professionals as a resource to their coping. I have been struck by how much people look within themselves, to their own personal resources, and to their intimate relationships, to find ways to make sense of having MS and to continue to live and try to be happy. Witnessing the magnitude of the process the participants have gone through strengthens my belief that to understand the part (the effects of disease, the coping mechanism and the change of life role) you must look to the whole of their lives.
5.8 Summary

This chapter has examined in detail how two of the three overarching themes, *Coping Together: “Peaks and Troughs”* and *Coping Over the Long Haul* relate to current research on how individuals and couples cope when one has MS. These overarching themes, along with the integrative themes of *Faith in Self* and *Faith in Each Other* fit well with theories that consider couples where one has a chronic illness as capable of finding the best coping strategy to suit their situation. Models which suggest ways of viewing couples and individuals have been reviewed in relation to the findings of this study. The practical considerations of these results for health care professionals have been discussed, with recommendations to assess and provide interventions for both members of a couple while considering the relationship. The strengths and limitations of qualitative research with this population have been outlined and recommendations have been made for future research, primarily around developing models and interventions which acknowledge the complexity of communal coping.

5.9 Conclusion

MS affects approximately 3000 people in New Zealand, challenging those that have the condition and the coping abilities of those closest to them. It challenges every physical and cognitive capability and introduces an uncertainty to the lives of those with it and those close to them. These health and social challenges require the careful consideration and exploration that has taken place in this research to produce information about how these couples cope that is truly reflective of their experience. This research adds to the small but growing body of evidence that those with MS and those they live with need to be seen as intrinsically linked. Services cannot plan for one without considering and consulting the other. The message that both members of these couples find *Faith in Self* and *Faith in Each Other* vital to their successful coping is one that needs to be acknowledged and incorporated by the services that aim to support both of these individuals. It is valuable to see chronic and degenerative diseases like MS in interpersonal terms (Badr, 2004) as the complex interplay of emotions and coping strategies between those that have a disease and those that live close to them cannot be truly understood by reductionist methods whereby one or the other is isolated for the purposes of research (Lewis et al., 2006).
Glossary of Terms

Acceptance: A cognitive processes that enables a person to appraise their illness stressors more positively and integrate them into their lifestyle (Pakenham, 2006).

Adjustment: A process that begins at the presentation of symptoms and continues during the course of an illness, responding to changes as they arise. In psychology, adjustment often refers to a desirable state or endpoint. It can be viewed as the process to maintain a positive view of the self and the world in the face of a health problem (Sharpe & Curran, 2006).

Appraisal: A cognitive evaluative process that reflects the person’s subjective interpretation of an event.

Benign MS: Covers a range of presentations of MS where full recovery is usually achieved after a symptomatic period, with the disease generally achieving a state of stability with nil or very mild disability (Sayao et al., 2007). Occasionally this form of MS will develop into a secondary progressive course with more noticeable disability.

Beta Interferon: An immune-modulating drug, which systematically regulates immune activation and is used to treat RRMS. It has proven benefits in reducing the incidence of relapses in MS and in reducing the rate of cognitive impairment (Clanet et al., 2002). The therapy is given via daily injections and must be continued indefinitely to maintain the effect. It is expensive and its availability in New Zealand is limited to MS patients with frequent relapses and significant residual disability (Multiple Sclerosis Society of New Zealand, 2010). Its effectiveness is limited for people with PPMS or SPMS, and people with these types of MS usually do not receive this treatment.

Chronic: Of long duration, not acute; a term often used to describe a disease showing gradual worsening over months or years.

Dyad: Two people who live together or interact together regularly.
**Exacerbation:** The appearance of new symptoms of MS or the aggravation of old ones, lasting at least 24 hours, usually associated with inflammation and demyelination of the brain or spinal cord (Multiple Sclerosis Society of New Zealand, 2010).

**International Classification of Function (ICF):** A theoretical framework developed by the World Health Organisation which promotes a bio-psycho-social model of health and describes the multi-dimensional consequences of a health condition (World Health Organization, 2001).

**Multiple Sclerosis Society of New Zealand:** A non-profit organisation formed to provide ongoing support, education and advocacy for people with MS and their support networks. It also aims to educate the general public, employers and health professionals about MS and actively funds key research into the condition (Multiple Sclerosis Society of New Zealand, 2010).

**MS field officer:** Professionals, usually from a health or social work background, who are trained to give advice on a range of matters concerning MS, as well as arranging groups, exercise classes and support meetings (Multiple Sclerosis Society of New Zealand, 2010).

**Multiple Sclerosis:** A chronic disease affecting the central nervous system which is mediated by the immune system. The cause is unknown and symptoms present with differing frequency and severity for each person who has the condition (McNulty, 2007).

**Primary Progressive MS (PPMS):** A type of MS affecting approximately 10% of PwMS, where a progressive loss of functional ability is experienced, at varying rates of deterioration, with no remission. PPMS has little proven treatment (Leary & Thompson, 2005).

**Relapse Remitting MS (RRMS):** A type of MS affecting 65-70% of people with MS, where symptoms intensify suddenly and then subside at varying rates. This group is often, but not always, left with no residual deficit after the exacerbation (McNulty, 2007). Treatment options for RRMS have broadened with the development of Beta Interferon (Clanet et al., 2002).
Rehabilitation: A process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and social functional levels, thus providing them with the tools to change their lives towards a higher level of independence (World Health Organization, 2001).

Secondary Progressive MS (SPMS): A type of MS where an individual has relapse remitting type MS but after a period of time, (often years), they stop having remissions and enter a period of progressive loss of functional activities (Thompson et al., 1991).
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Appendix One: Cover Letter

Dear Sir/Madam,

You have been invited to potentially participate in a study being completed by Pauline Boland, a Master’s student with the School of Medicine in Wellington.

This study is interested in how people with MS and their significant others cope with the everyday experience of having MS in their lives.

Please take some time to read through the information sheet provided, and do not hesitate to contact me with any enquiries.

Kind Regards,

___________________________
Pauline Boland
NZROT, BSc (Hons) OT, PGDip Rehab
Appendix Two: Consent From

Coping and MS – individuals and significant others

This is a qualitative study exploring how individuals and their significant others cope with multiple sclerosis. We do not have funding to provide interpreters in this small study.

☐ I have read and I understand the information sheet dated _________________ for volunteers taking part in this study.

☐ I have had the opportunity to discuss this study with family members, whanau, friends or other support and the study researcher. I am satisfied with the answers I have been given.

☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.

☐ I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

☐ I have had time to consider whether to take part

☐ I understand that my GP will be contacted should the research appear to be harmful to me in any way. The researcher will discuss this GP referral with me first

☐ I know who to contact if I have any questions about the study.

☐ I consent to being part of an interview which will be recorded, and transcribed.

☐ I wish to receive a copy of the results YES/NO

I ___________________ (full name) hereby consent to take part in this study.

Date ____________________

Signature __________________

Full names of Researchers: Pauline Boland NZROT BSc (Hons) OT
Phone: 04 385 5541 ext 6564 E-mail: paulineboland79@gmail.com

Research Supervisor William Levack
Phone: (04) 385 5999 ext 6279 Email: william.levack@otago.ac.nz
A copy of the consent form is to be retained by the participant.
Appendix Three: Participant Information Sheet

Coping with Multiple Sclerosis – Individuals and their significant others

Invitation
You are invited to take part in a study to explore how individuals and their significant others cope with multiple sclerosis. The purpose of this information sheet is to give you the information you need to be able to decide whether or not to take part in this research study. Please take it away with you to read and consider before making up your mind. You can contact Pauline Boland at any time by phone or e-mail to discuss the information or to arrange a meeting.

Please remember that:
Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will in no way affect your future health care.
If you do agree to take part you are free to withdraw at any time, without having to give a reason. This will in no way affect your future health care. The study is being carried out by a researcher undertaking a Masters in Health Science through the University of Otago. This information sheet will explain the research study. Please feel free to ask about anything you do not understand or if you have questions at anytime.

What is the purpose of the study?
This study is trying to establish an understanding of how people with MS and their significant others cope with multiple sclerosis.

How are people chosen to be asked to be part of the study?
People are being asked to take part if they are identified as meeting all the following criteria:
1 Have had a diagnosis of MS for at least 3 years,
2 Live the Lower North Island,
3 Are able to take part in an interview about how they feel they cope with multiple sclerosis
4 Can nominate a significant other who will also be interviewed by the researcher
5 Both the person with MS and their significant other are able to communicate with the researchers.

Who is a “significant other”?
For the purposes of this research a significant other is someone whom you may nominate who knows you well, and whose life is therefore also affected by the fact that you have multiple sclerosis. This may be a spouse, family member, friend, neighbour or caregiver.

What happens in the interview?
The aim of this research is to find out how people cope with and make sense of multiple sclerosis, and how the significant others in their lives cope with and make sense of it. If you agree to take part, you will be interviewed and so will your significant other. You will be interviewed separately, unless you specifically want to be interviewed together. Each interview will take from 40-50 minutes to complete. The interviews will take place at a time and place which is convenient to you and your significant other. Interviews will take place between March and July 2010.

What are the risks of this study?
There should not be any risk to you from this study. You may find the interview process tiring. We will try to help with this: You may ask for a break at any time, and the researcher will go at your pace.
How will this study help?
The information from this study will help us to form a better understanding of how people with MS cope with this illness, and also how the significant others in their lives cope. It may also identify ways of improving care for patients with MS.

What are the costs of taking part in this study?
There will not be any cost to you except your time.

How will my privacy be protected?
All information you give will be kept confidential and your name will not be known to anyone but the researchers. We will keep the information locked in a cabinet. No material that could personally identify you will be used in any reports on this study. If the researcher you are working with thinks it would help in your case to talk with anyone else about issues that arise, they will ask you first.

Compensation
No harm is likely to happen to you from taking part in this study. However, in the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention, Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office.

What will happen with the results?
The results of this study will be used to inform health care professionals and government policy makers about how individuals and their significant others cope with MS.

Will I be able to have a copy of the results?
If you would like a summary of the results it will be sent to you at the end of the study. There may be quite a delay between collecting information and letting people know about the results.

If you have any concerns or questions?
If you have any questions please feel free to contact Pauline Boland or one of the supervisors on this project:

Pauline Boland
Tel: 385 5541 ext 6564
Mob: 021 0648032
E-mail: paulineboland79@gmail.com

Dr. William Levack
Phone: (04) 385 5999 ext 6279
Email: william.levack@otago.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone 0800-555-050.

Statement of Ethical Approval
This study has received ethical approval from the Central Regional Ethics Committee. If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate. Free phone 0800 377 766 or free fax 0800 2787 7678.
Appendix Four: Interview Schedule for People with MS

I’m going to ask you a little about yourself
Will you tell me a bit about yourself?
- What do you like doing?
- Are you studying, working, retired?

I’m going to ask you a little about how the MS has affected you?
How did you first experience MS?
- What was it like?
- What did you think was happening?
- Will you tell me about the feelings that stood out for you after you heard the diagnosis?
- What were the reactions of those around you?
- What was it like telling people?
- What did you learn from the early stages?
- What helped you to cope at this early stage?
- What do you think got in the way of dealing with things/ did anything make this time more difficult than perhaps it needed to be?

I’m going to ask you about how you deal with the MS at the moment
How do you deal with the multiple sclerosis on a day to day basis?
How are things for you this week?
How do you cope with thoughts about the future?

I’m going to ask you about how you think your SO copes with you having MS
What was their reaction when they first heard about the MS?
How did they act?
What do you think they think about it now?
What do they do that is helpful/not helpful for you?
How do you see the support relationship working or not working at present?

If you were giving advice to someone who has multiple sclerosis/ the husband/sibling/daughter/friend what would it be?
What do you think the role of health professionals is for you/ will you say some more about the different health professional and how they were involved
Is there anything else you'd like to tell me about any of this?

Conclusion.
Thank you for that, the interview is finished. Again, I really do appreciate your helping me with this study. I’m going to turn the recorder off now
Appendix Five: Interview Schedule for Significant Others

I’m going to ask you a little about yourself
Will you tell me a bit about yourself?
- What do you like doing?
- Are you studying, working, retired?

I’m going to ask you a little about how the MS has affected you?
How did ------ first experience MS
- What was it like?
- What did you think was happening?
- Will you tell me about the feelings that stood out for you after you heard the diagnosis?
- What were the reactions of those around you?
- What was it like telling people?
- What did you learn from the early stages?
- What helped you to cope at this early stage?
- What do you think got in the way of dealing with things/ did anything make this time more difficult than perhaps it needed to be?

I’m going to ask you about how you deal with your spouse having MS at the moment
How do you deal with the multiple sclerosis on a day to day basis?
How are things for you this week?
How do you cope with thoughts about the future?

I’m going to ask you about how you think your spouse copes with their MS
What was their reaction when they first heard about the MS?
How did they act?
What do you think they think about it now?
What do they do that is helpful/not helpful for you?
How do you see the support relationship working or not working at present?
If you were giving advice to someone whose partner has multiple sclerosis what would it be?
What do you think the role of health professionals is for you/ will you say some more about the different health professional and how they were involved?
Is there anything else you'd like to tell me about any of this?

Conclusion.
Thank you for that, the interview is finished. Again, I really do appreciate your helping me with this study. I’m going to turn the recorder off now
Appendix Six: Ethics Approval

Ms Pauline Boland
Rehabilitation Teaching and Research Unit
University of Otago
PO Box 7343
Wellington

Dear Ms Pauline Boland

Ethics ref: CEN/09/10/079
Study title: Coping with Multiple Sclerosis: an Interpretive Phenomenological Analysis of the Experience of Individuals with MS and their Significant Others
Investigators: Ms Pauline Boland
The above study has been given ethical approval by the Central Regional Ethics Committee.

Approved Documents:
- Consent Form, Version 2, dated 16 November 2009
- Participant Information Sheet, Version 2, dated 16 November 2009
- Serious Adverse Events Form, dated 16 November 2009

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until 31 December 2010. A final report is required at the end of the study. The report form is available on http://www.ethicscommittees.health.govt.nz and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments
It is also a condition of approval that the Committee is advised if the study does not commence, or is altered, including documentation e.g. advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.
Yours sincerely
**Sonia Scott**  
*Administrator*  
**Central Regional Ethics Committee**  
Email: sonia_scott@moh.govt.nz

Sonia Scott  
Ethics Committee Administrator  
Ethics Committees  
Health & Disability Services Policy Group  
Population Health Directorate  
Ministry of Health  
DDI: 04 8162405  
Fax: 04 496 2191

http://www.ethicscommittees.health.govt.nz  
mmailto:Sonia_Scott@moh.govt.nz
Appendix Seven: Serious Adverse Events Form

Participant information

Participant Name / ID
____________________________

Date of birth:
____________________________

Gender: □ male □ female

Date of Serious Event: ________________________

Outcome attributed to the Serious Adverse Event. Tick one box.

Death ☐
Life threatening illness ☐
Hospitalisation ☐
Serious disability ☐
Required intervention to prevent permanent impairment ☐
(Include referral to relevant health care providers)
Other event considered serious ☐

Describe the Serious Event
Events pre-ceding event
___________________________________________________________________________
___________________________________________________________________________

What exactly happened?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

What happened directly after the serious event?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Signature of person completing this form
____________________________
Printed Name
____________________________
Date
____________________________

Please attach any medical reports relating to this incident
### Appendix Eight: Demographic Data Collection Tool

**Coping with Multiple Sclerosis – Individuals and their significant others**

<table>
<thead>
<tr>
<th>Individual with MS</th>
<th>Significant Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

**Date of Birth**

- ________ / ________ / ________
  - (day)
  - (month)
  - (year)

**Sex**

- Male □
- Female □

**Which ethnicity do you identify with?**

- NZ European □
- Maori □
- Samoan □
- Cook Islands Maori □
- Tongan □
- Niuean □
- Chinese □
- Indian □
- Other (Please state) □
  - (Please state): _______________
  - (tick as many as apply)

**When did you first receive your (significant other’s) diagnosis of MS/?**

- ______________
  - (year)

**How long have you known (person with MS/significant other)?**

- ______________
  - (years)

**How would you define your relationship with person with MS/significant other?**

- Spouse / Friend / Mother / Father / Son / Daughter / Neighbour / Other relative
- Partner (Circle one)
Appendix Nine: Regional Advice Group for Maori Approval

9 September 2010
Pauline Kent
Rehabilitation Teaching & Research Unit
University of Otago
Wellington

RAG-M 2009/76(2) — Letter of Endorsement

Dear Ms Boland

Tena koe

On behalf of the Research Advisory Group (Maori) I write in relation to your study entitled "Coping and Multiple Sclerosis — individuals and their significant others: an interpretive phenomenological exploration". You have supplied a RAG M overview sheet and a copy of the study protocol. We understand you have not yet received ethical approval.

Our review of your proposal characterises the research as:

- a small qualitative study involving about 20 participants, few if any may be Maori, particularly given the lower rates of MS in Maori.

We note that:

- you will seek approval from the relevant Health and Disability Ethics Committee;
- you will advise the Research Committee of the CCDHB of the conduct of this research.

Our assessment of this research is that it poses a low risk in Maori terms. Given the possibility of Maori MS patients as participants, we would expect that:

- you would ensure that any Maori who participates is well informed and supported, including their whanau as appropriate;
- you would recognise any cultural expectations and seek to meet these expectations responsibility.
Whanau Care Services (WCS): You will be aware that WCS operate within the Wellington Regional Hospital. WCS have a responsibility to both patients of the hospital and staff. We acknowledge your support agreement with WCS.

RAG-M are satisfied that you have read and understood the expectations outlined in this letter and therefore are happy to endorse this research project.

We recognise that this very interesting study may have implications for Maori and Maori health and thank you for consulting with RAGM. We wish you well in your study.

Naku noa na

Jack Rikihana
Chair RAG-M
Appendix Ten: Support Letter from Whanau Care Centre

15 March 2010

Pauline Boland
Rehabilitation Teaching and Research Unit,
University of Otago,
Wellington

Tena Koe Pauline

#75 - Coping and Multiple Sclerosis - individuals and their significant others: an interpretative phenomenological exploration

Thank you for your email, requesting support from Whanau Care Services for any Maori participants who may be recruited for this study including appropriate support for themselves and their whanau.

We are happy to be able to support this request; if you require brochures for Whanau Care Services or have any further queries please do not hesitate to contact me.

Naku noa, na

PP. Gaylene Te Rauna

Coordinator
Whanau Care Services
CCDH
04 3855056
wcs@ccdhbr.org.nz

CC: Vanessa Mill
RAG-M Secretary
Appendix Eleven: Key to Transcription Conventions

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses (…) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Rounded brackets ( ) were used to indicate where nonverbal sounds such as laughter occurred on tape. En Dashes (-) were used in the place of handing phrases resulting in an incomplete sentence, interruption by another speaker, or where the speaker made a meaningful pause.