IMPACT OF MULTIPLE SCLEROSIS ON COMMITTED CARING RELATIONSHIPS: THE EXPERIENCE OF TWELVE SPOUSAL CAREPARTNERS DEALING WITH THIS “UNINVITED GUEST”

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Abstract

This research study explores the perceived impact of multiple sclerosis on “carepartners” in committed caring relationships as the spousal roles change over time. Both quantitative and qualitative methods were used in this study of persons with MS and their spousal carers residing in Australia during ten months of recruitment. Varied recruitment methods were used including the internet. 263 expressions of interest were received, and 203 survey packets were returned with usable data (77%). The demographic instrument and 4 scales measuring mood, reciprocity, life satisfaction and functional wellness were subjected to descriptive statistical analysis. Results from the quantitative phase of the study supported many international epidemiological findings related to gender, age of onset, difficulty in obtaining a diagnosis in the light of vague early symptoms of MS, and high levels of depression in the study sample. The preliminary analysis suggested that these data should be analysed further in dyadic terms (a person with MS and their identified carer). Further inferential statistical analysis examined the data sub-set of ‘pairs only’ which helped to inform formation of a pool of couples in caring relationships from which was selected a sub-sample of 12 spousal dyads residing in Victoria for interview in the second phase of the study.

Emerging themes from narrative analysis (n=24 persons) revealed pressing concerns, personal strengths and coping strategies of interviewees. Two themes of special interest relating to (1) differing perceptions by ‘carepartners’ of the importance of cognitive changes to the dyadic relationship, and (2) expectations of health professionals are explored. Most respondents agreed that their expectations left much to be desired, suggesting that improvements could be made in the area of health care delivery to persons with MS, their carers and their families. There are implications for the development of a multidisciplinary, ongoing assessment, educational and support program for these persons. Further research is needed to define and expand the proposed role of a specialized key contact person to be a valuable ‘advocate’ in the delivery of timely health care resources throughout the disease trajectory.
Declaration of Authorship

This is to certify that:

(i) The thesis comprises only my original work towards the PhD except where indicated on the Acknowledgments page indicating the contributions of others, and work carried out prior to PhD candidature enrolment.

(ii) Due acknowledgment has been made in the text to all other material used.

(iii) The thesis is less than 100,000 words in length exclusive of tables, charts, maps, figures, bibliographies and appendices.

Signed: _______________________________ (B. H. Zuluaga)

Date: ____________________________
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Glossary of Terms:
Acronyms, Abbreviations and Explanatory Notes

Aggregate: In this study, an aggregate is a group of two or more people who have something in common and are the subject of assessment, which becomes the ‘entity’. Thus, in this study, the entity that is being studied consists of Carepartners (See below and also Chapter One, Figure 1.2)

Caregiver Reciprocity: Reciprocity is defined as: “the collective affective and behavioural expression of exchanges given and received between a caregiver and a care receiver and among family members (Carruth 1996)”. In this study care recipient and care giver are seen as co-carers or ‘carepartners’ (see Reciprocity below).

Carepartners: (A term coined by Holland, 1997). Care recipient and care giver are seen as co-carers, in which each member of the spousal dyad contributes to the affective and behavioural exchanges that are valued in their relationship (Holland and Sarnoff 1997).

Carer: For the purpose of this study, a carer or main support person, is the one identified by the person with multiple sclerosis who fulfils this role. (See Chapter Two on care, caring, and carers). Also called a ‘caregiver’.

Chronic Sorrow: This term is examined in several research studies by Hainsworth (1993;1994;1996;1997) and Burke and Hainsworth (1992). Chronic sorrow is described as ‘a pervasive sadness that is permanent, periodic and progressive, and differs from the sadness of acute grief’. Hainsworth (1993) believes it may be a normal component of chronic illness and disability. In a later study exploring the experience of living with multiple sclerosis, Hainsworth (1993), reported that 80% of spouse-caregivers of persons with MS exhibit ‘chronic sorrow’. Hainsworth (1994) examined the roles of nurses and other caring professionals and determined that empathic presence helped these carers the most with inner feelings of chronic sorrow (Hainsworth 1994). Chronic sorrow is often applied to multiple losses of ability (sensory, motor, intellectual, sexual or reproductive functioning). Hewson (1997) suggests an Episodic Stress Response Model (ESRM) be offered in place of the grief model in common use by professionals. Hewson’s model is
non-prescriptive and recognizes the varying responses of individuals to stressors without ascribing any time limit or hint of pathology if agreed time limits are exceeded by some (Hewson 1997).

**Clinically Isolated Syndrome (CIS):** This term is used to describe a person who has had one episode of suspected multiple sclerosis. If this is not followed by any further attacks, or significant disabling symptoms, it is sometimes denoted as “benign MS” (See ‘Types of MS’ below).

**Codependency:** Beattie (1987) defined codependency in lay terms saying “a codependent person is one who has let another person’s behaviours affect him/her and who is obsessed with controlling that person’s behaviour (Beattie, 1987 p.36)”. She notes that the expression has often been used as ‘alcohol treatment center jargon’ and ‘professional slang’, and admits that the term, as it is used, has a ‘fuzzy definition’.

http://family.jrank.org/pages/270/Codependency-Codependency-Popular

**Coding (e.g., 2ax) of interviewees in multi-tiered analysis of transcriptions:** Phase Two of the study (see Chapter Six). Interview transcriptions were coded alphanumerically and reviewed sequentially for analysis from different perspectives as illustrated in Figure 6.1. Coding of interview transcriptions identified the following:

ID number for dyadic pair (1-12)

- a = PwMS
- b = Carer
- x = female
- y = male

Thus, 2ax indicates a female person with MS from dyad #2; 11ay is a male with MS from dyad #11; 1by is the male carer in dyad #1.

**Cognitive Appraisal:** an evaluative process that reflects the person’s subjective interpretation of an event. Events are appraised in terms of threat, challenge and controllability (Lazarus and Folkman 1984).

**Committed caring relationships:** in the context of this study, this phrase represents a heterosexual couple living in a spousal (married or de facto) relationship where each has expressed long term commitment to the relationship over a period of years.
Coping: The cognitive and behavioural efforts used to manage the internal and external demands of situations that are appraised as stressful (Lazarus and Folkman 1984).

Caregiver Reciprocity Scale II (CRS II): This scale was designed to measure the perceived level of reciprocity between care giver and care recipient. The scale was modified by Carruth in 1997 from the original CRS developed in 1996, and relates to spousal caregivers.

Dyadic coping: is described as the interplay between the stress signals of one partner and the coping reaction of the other (Revenson et al 2005)

Expanded Disability Status Scale (EDSS): (Kurtzke 1983), is a scale developed by Kurtzke to measure the functional disability level of persons diagnosed with MS. This scale is commonly used by neurologists in the assessment of persons with MS. The scale has undergone revisions and further psychometric analysis and has proved to have very good reliability and validity in measuring the functional levels of persons with multiple sclerosis.

Epidemiology: “The study of the distribution of states of health and of the determinants of deviations from health in human populations (Valanis 1999)”

Incidence: “The frequency of newly occurring cases of a disease in a specified population during a given time period (Valanis 1999, p. 46)”.

Prevalence: “Measures the number of cases of a given disease in a specified population at a designated time, usually a rate measurement at a point in time. Also called “point prevalence (Valanis 1999, p.47)”.

Hermeneutics: The study of interpretive understanding of meaning in narratives. A theoretical approach that can inform qualitative inquiry and help put other theoretical orientations in perspective. According to Patton (1990) hermeneutic philosophy asks ‘what are the conditions under which a human act took place that makes it possible to interpret its meanings?’ (Patton 1990). To place any qualitative study in hermeneutic context it is necessary to know the researcher as well as the researched. Both voices are heard in the narrative analysis.
Heuristic Inquiry: (from ‘heuristics’ – to find or discover). A method of inquiry that can be subsumed under the broad philosophical position of phenomenology (Munhall 1994). Heuristic inquiry asks: “what is my experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely? The researcher comes to understand the meaning of the phenomenon through shared reflections with the researched (Douglas and Moustakas 1984, p.42, in Patton 1990, p.71-72)”.

Immunomodulatory drugs: Four injectable drugs are approved for the treatment of multiple sclerosis at the time of writing. As their name suggests, their effect is to modulate or alter the effects of the immune system’s response to the threat of MS by suppressing T-cell activation and limiting the ability and access of activated T-cells to cross the blood-brain barrier (BBB) that normally protects the brain from these damaging invaders. Avonex, Betaseron and Rebif are ‘beta interferons’. The fourth drug, Copaxone, has a different function, reducing inflammation and producing cells that are thought to be beneficial, rather than damaging (Antel, J.P. & Bar-Or, 2004). A fifth drug, Tysabri (Natalizumab), formerly known as Antegren, was briefly approved but was taken off the market in 2005 after several serious adverse effects were recorded, suggesting that further research was needed before its use could be resumed. This drug has been resumed for use since 2006, and is being closely monitored for adverse effects.

Life Satisfaction and Quality of Life: Terms often used interchangeably in the literature. This study prefers and uses the former since its measurement is by a self-report scale which is one of the key values maintained throughout the study. See discussion in Chapter Three (Methodology and Methods).

Lived experience: The term ‘lived experience’ is commonly used in phenomenological research and represents the first hand personal account of day to day living with a particular condition, event or situation by a person (or persons) experiencing the phenomenon of interest that is being studied by the researcher (i.e. stroke or other disabling condition, surviving a disaster, etc.). This research study explores the first hand reports of persons living with multiple sclerosis or caring for such a person in a committed spousal relationship.
According to Van Manen (2002), phenomenological inquiry cannot be formalized into a series of technical procedures. A variety of activities may be included that fall into two types: empirical and reflective methods. Empirical inquiry activities aim to explore the range and variety of pre-reflective experiential material that is appropriate for the phenomenon under study. In this study this involved interviewing persons actually experiencing the phenomenon (http://phenomenologyonline.com) accessed June 4, 2009.

**Magnetic Resonance Imaging (MRI):** a test currently used to confirm the diagnosis and progression of multiple sclerosis (MS) by visualizing plaque-like lesions in the brain or spinal chord that are diagnostic of MS.

**Multiple Sclerosis Societies:** offering a variety of services have branches in every State in Australia as well as other countries of the world. (Note: Information stated below refers to Australia) Some of these maintain extensive libraries and internet access that is open to the public. Information packets are sent out to newly diagnosed persons with MS. Resources for persons with MS and their families include medical and neuropsychological assessment, counselling, education, access to mobility aids as required, limited long term care and respite care as available, interest-free loans for needed equipment such as air-conditioners, instruction and advice by nursing personnel in the use of injectable drugs, referral to physiotherapists, occupational therapists and social work services. Regular educational and group sessions are held by State MS Societies to assist PwMS and their families to manage the changes that MS brings about in their lives. Inservice education sessions are conducted periodically for health professionals as important new developments in the care and treatment of MS are discovered. Some limited forms of these services are available to persons living in regional or country areas. Outreach programs are very limited for persons living in rural or regional areas, or for those unable to attend the Centres for group classes, activities or meetings. Local hospitals, agencies and professional groups are actively involved in research studies related to new drug trials and the management of common problems experienced by People with MS. National and International MS websites provide updated information on conferences, recent research and matters of interest to families affected by MS. An annual MS Conference is held in Australian Capital cities with renowned international speakers bringing the latest information and research findings. However, persons residing outside the metropolitan area of Capital cities have limited access to these conferences. The
People with MS produce periodicals and newsletters for their members and support each other through social activities and internet chat rooms, forming a useful social network for many. Fund raisers such as the ‘MS Readathon’ increase public awareness of MS, and the Go for Gold scholarship offers recognition and encouragement for PwMS in a variety of areas of excellence. Local Councils provide some assistance with home help, gardening, maintenance work and personal care services according to need and availability.

**Ontological Security:** a stable mental state derived from a sense of continuity and order in relation to the events in one’s life. It is related to people’s ability to give meaning to their lives. Events which disrupt this sense of stability and continuity threaten a person’s ontological security, which involves having a positive view of self, the world and the future (Bilton 1996).

**Person/people with Multiple Sclerosis (PwMS):** This is the preferred term to be used when referring to persons diagnosed with multiple sclerosis, and is used throughout this paper. It is preferred to the terms ‘patient’ or ‘sufferer’.

**Perceived Disability Index (PDI):** a measurement scale designed by the researcher and used in this study. It is derived from items in two of the other scales used in the study to measure depression and functional wellness. Scores on the scale range from 0-1 = little or no perceived disability to 6 = severe disability perceived (See Chapter..)

**Pharmaceutical Benefits Scheme (PBS):** A Government Body in Australia that sets criteria for reimbursement or subsidy of all pharmaceutical drugs authorised for use in the country.

**Phenomenology:** A theoretical perspective that attempts to understand social phenomena from the actors’ own perspective. The important reality is what people perceive it to be. Phenomenological inquiry uses qualitative and naturalistic approaches to inductively and holistically understand human experience in context-specific settings (Patton 1990; Seidman 1998).

**Reciprocity:** The mutual ‘give and take’ that exists in a relationship and is valued by each. Carruth, (1997) identified four constructs of reciprocity in the development of a measurement scale for adult children, carers of elderly parents (the Caregiver Reciprocity
Scale). These constructs are: warmth and regard, intrinsic reward of giving, love and affection and balance within family caregiving. The scale has only been used and tested with carers. In this current study, the scale was administered to both carepartners, and was analysed using triangulation of quantitative and qualitative methods. Results suggest that further research is needed in the scoring of this scale if it is to be used with both carepartners in chronic illness.

**Relationship:** The meaning ascribed by two or more individuals to their connectedness, which determines a negotiator’s position in relation to the other person (Greenhalgh and Chapman 1995). Individuals are seen as social decision-makers, focused on decisions, rules, behaviours, interactions and self-awareness.

**Self Perception:** How individual persons see themselves to be; how they see their situation or identify their needs. This is accepted to be unique to each individual and may not necessarily agree with the view of an observer or health professional (Patton 1990). The researcher is admonished to always try to understand someone from his or her situation, from the way he/she experiences the situation (Van Maanen 1994). Self-perception is a **key value** in this study.

**Social Capital Theory:** ‘The core of this theory is that social networks have value. Just as a screwdriver (physical capital) and higher education (human capital) can increase productivity (both individual and collective), so too social contacts affect the productivity of individuals and groups (Putnam, 2000, p.19)’. The concept of social capital, in this study, is related to reciprocity at the individual level, where two persons in a relationship perceive that they receive mutual benefit from their relationship (carepartnership), and includes valued social networks. Reciprocal relationships can be supported and enhanced by wider social networks, both formal and informal.

**Technical and Further Education (TAFE):** A branch of the Australian Education system established and funded in the 1970’s, separate from the university system. The structure of TAFE Institutions have developed and evolved in close relationship with the economic, geographic and demographic characteristics and needs of each Australian State and Territory (Goozee, 1993)
**Triangulation:** Triangulation has many definitions and applications in research. The term is originally drawn from maritime science and refers to the use of several different markers or sources of information to determine the position of a vessel in the open ocean. At first this may seem to have little relevance to research but in fact, use of a variety of methods to examine a phenomenon from a variety of perspectives may illuminate the findings in a manner that use of one method alone could not. Denzin and Lincoln (1984) speak of qualitative research as ‘bricoleur’, or, having a variety of facets, colours or textures. In this study, triangulation of methods (quantitative and qualitative) is used to examine the variable of ‘reciprocity’.

**Types of Multiple Sclerosis:** The commonly accepted categories or types of multiple sclerosis at the time of writing include: (1) Relapsing-Remitting MS, (RRMS), which is characterized by periods of clinical symptoms of MS and may be followed by partial or (rarely) total remission of these over time. This is the most common form of MS and accounts for 60-80% of cases. (2) Primary Progressive, (PPMS), in which there is no evidence of remission, and is characterized by a slow or rapid progression of disabling symptoms. Approximately 10-15% fall into this category.(3) Secondary Progressive (SPMS), sometimes called relapsing progressive (RPMS). Most cases of RRMS convert to this type, which is marked by a slow progression of loss of abilities. There are other types of MS recorded in the literature, but these are either rare or the terms are not in general use. There is still considerable variation in the classification of multiple sclerosis. An International Panel on MS Diagnosis recommended the following simplified terms be used after a thorough diagnostic evaluation for MS has been completed: “Multiple Sclerosis”, “Possible Multiple Sclerosis” (i.e. Those at risk of MS but for whom diagnostic evaluation is equivocal) and “Not MS” (McDonald, Compston, D, et al 2001).

**Zuluaga-Raysmith Model (Z-R Model):** for Assessment of Basic Human Needs across the Lifespan (Z-R Model) – This Model was designed by the researcher and is described fully in Chapter One (see Figure 2) An implementation study for this Model was published in Public Health Nursing (Zuluaga 2000), and has been selected as the conceptual framework for this study together with other theoretical underpinnings. Some abbreviations often used when discussing data analysis with this model are PH (Physical Health); MESSH (Mental, emotional, Social and Spiritual Health), and the subscales used to measure these needs in the Functional Wellness Inventory (FWI(ph) and FWI(messh)).
Prologue:
Positioning of the Researcher

Who is the researcher and what is the motivation for undertaking this research study?

I am a retired nurse educator with a background in public and community health nursing, gerontology, research and nursing education. I am the parent of a person with multiple sclerosis (PwMS), and I have a strong motivation to contribute to the knowledge base related to the experience of living with multiple sclerosis, its daily and unpredictable life challenges and its effects on caring relationships. The ideas for this study were conceived in one continent and explored in another.

I was not allowed access to the membership data base of the Multiple Sclerosis Society of Victoria, Australia, for reasons of confidentiality, although my proposed study was supported in principle by this organization. I needed to find other ways to find willing participants, including use of the web for recruitment. The study was originally planned as a small one, but the use of the web indicated worldwide interest, and brought expressions of interest from many corners of the globe, including Europe and North America. Considerations of design, time and cost required that I send out an amended call for participants limiting the study to residents of Australia. I wanted to know the characteristics of the nationwide (Australia) population of people with MS, and draw from it a sub-sample for interview to better understand the lived experience of couples where one partner had been diagnosed with MS. Thus, my original ideas have evolved as the research progressed and I became interested in exploring concepts of perceived strengths, needs, reciprocity and coping strategies in these dyads.
The study now focuses on the impact that MS is perceived to have on the dyadic spousal relationship; what it is like for the person with multiple sclerosis (PwMS); what it is like for the carer and how they cope as a couple. New directions have emerged from the findings that suggest further multidisciplinary research and potential changes to be made in health policy relating to the care and management of people with chronic illnesses and disabilities.

While there are extensive global research efforts currently in progress to find a cause and cure for this baffling, usually progressive and debilitating neurological condition, fewer efforts have been expended in exploring psychosocial aspects of coping with MS. I believe, together with Maslow (1968), Travis (1977), Kubler-Ross (1978), and others, that there is a potential for a higher level of wellness in the presence of disease, disability and even impending death (Maslow 1964;1968; Travis, 1977; Kubler-Ross 1978).

Another of my strong beliefs, supported by Patton (1990), is that a person’s perception of their needs is the best source of this information, and that as health care professionals we need to listen to the voices and stories of those experiencing a situation in order to divine their pressing needs and with them, develop the most effective and suitable assessment, education and support interventions needed to help people to move to a higher level of wellness throughout the uncertain disease trajectory.

The belief that there may be valuable clues about the disease embedded in the stories related by people with MS encourages active listening to the voices of those who are experiencing life with MS on a daily basis. These stories may also reveal patterns in the disease that have been formerly overlooked or taken for granted. These ‘clues’ may form the basis for new research that may help to uncover some of the mysteries of this condition. Metaphors and colorful descriptions used by PwMS and their carers in describing their experiences create strong images of their feelings and are worthy of exploration (Patton 1990), p.402).

An illustration of such a ‘clue’, resulting in important research was reported by Burks (2004) at the Melbourne MS Conference. He said that there has been a dramatic change in the approach to treatment of persons presenting with early symptoms of suspected multiple sclerosis as a response to global research. In Australia, as well as in many parts
of the world today, medical professionals have been reluctant to diagnose a person with multiple sclerosis until two separate acute attacks have been reported, separated by time, and confirmed by Magnetic Resonance Imaging (MRI). This approach was held in the belief that the disease was probably dormant in the intervening period between attacks and nothing much was changing physiologically. However, more recent studies conducted by Italian scientists (2005), building on the work of others, and using monthly MRI’s following the first suspicious event, revealed conclusively that the disease was far from inactive during these times. There were many lesions and plaque deposits present in the Central Nervous System although there were no clinical symptoms as yet to accompany these findings (Pestalozza, Pozzilli et al. 2005). Perhaps these scientists were listening to the very common “clue” reported by people with MS as they recounted their stories of presenting symptoms and losses of function. When asked if everything was restored to “normal” after an acute episode with a sudden loss of function, most PwMS will respond: “almost, but not quite”. Are there other “clues” embedded in the stories of people with MS that have not been recognized or studied? Although this study focuses on psychosocial issues, I believe all health care professionals need to be alert to the “total picture”, and work together as they seek further pieces to the “MS puzzle”.

An overview of multiple sclerosis is offered in Chapter One, but this baffling, usually progressive neurological disorder has been the subject of international research for many years. MS research in Australia has been admittedly under-funded, as reported at the Victorian MS Conference 2004, and some action has been taken to rectify this situation with the launching of “MS Research Australia” (MSRA) at the same Melbourne MS Conference. Available funds have been allocated on a priority basis in the past to research efforts that may shed light on “cause” and “cure”, while “care” has come low on the priority list. Until a cause is found and a successful cure is discovered, people with MS require support and understanding to enhance the quality of their lives and the lives of their families during the disease trajectory. It was anticipated that MS research funding would increase from the current expenditure of (AUD) $750,000 per annum, to over $3 million or more in the very near future.

New research developments keep adding ‘pieces’ to the MS puzzle. Some of these pieces do not seem to fit the picture and it is necessary to think ‘outside the square’ for further answers. So-called ‘facts’ that are available regarding MS, have often been disproved by
research. Burks (2004) advocates early, aggressive treatment with the available immunomodulatory drugs (see Glossary of Terms and Explanatory Notes) as this is now believed to be the best approach to lessening the progression of the disease and halting the damage that it causes to myelin, nerves and brain tissue, even when the disease is apparently in remission.

These drugs are not considered to be a cure, but extensive worldwide research supports the belief that they lessen the number and severity of exacerbations. They are also believed to comply with the Hippocratic dictum “primum non nocere” (first, do no harm), and to have few serious side effects. However, the views expressed by Burks (2004) regarding early, aggressive treatment have not been generally accepted or universally implemented at the time of writing.

Several methods have been used to answer the research questions in Chapter Seven. Triangulation of results and findings from the two phases of the study may reveal clues embedded in the interview transcriptions relating to the pressing concerns of PwMS and their care partners as the data unveils new insights in this descriptive, phenomenological and hermeneutic study. Analysis of surveys and interviews may form a basis for developing a comprehensive, ongoing assessment, education and support program for PwMS, their partners and families.

The potential for researcher bias is very real and must be acknowledged. I have taken several steps to reduce this potential bias by using multiple methods and triangulation of results from the quantitative statistical survey analysis and findings from the multi-tiered qualitative analysis of interview narratives. I pilot-tested demographic forms and measurement scales prior to use, and made regular presentations to faculty and peers as the research progressed, which have provided valuable insights and suggestions to enhance the rigor of the study. The interview guide was also pilot-tested with two interstate interviews (see Appendix B and C).

I propose to use the first person in the Prologue, Epilogue and where relevant in Phase Two (that is when interjecting my comments in the interview analysis or making comments about the quotations used). The use of third person in the literature review, methods and statistical analysis sections helps to emphasize that the study has two phases.
that are addressed differently—one from an objective and measurable stance and the other from a subjective and intuitive/interpretive stance. Hopefully this provides a semi-three-dimensional picture while allowing for the severe limitations and potential for bias in the findings and conclusions.
Chapter One

INTRODUCTION TO THE RESEARCH STUDY

This descriptive, phenomenological and hermeneutic research study in two phases, utilizes both quantitative and qualitative methods to explore the perceived impact of multiple sclerosis (MS) on spousal dyads (Carepartners) in committed caring relationships where one member of the dyad has been diagnosed with multiple sclerosis, a chronic neurological condition that is usually progressive.

Figure 1.1 below provides an overview of the study, including the Australian recruitment catchment area, expressions of interest received, phases of the study, percentage response rate, interview sub-sample and the primary research question addressed in the study.

Purpose and importance of the study

The purpose of the study has been to gain a broader and deeper understanding of this experience as reported by spousal “carepartners” at interview. MS is a disease that is appearing in greater numbers worldwide and is affecting increasing numbers of women (Burks 2004). In Australia, at 2005, it was noted that the incidence of MS was increasing at a rate of 8% per annum (MSRA website accessed 19 March, 2007. (www.msra.org.au). Until a cause and a cure can be found, it is important to study the lived experience of this puzzling disease so that effective ongoing interventions can be designed to assist affected persons, their partners and their families.
Figure 1.1. Overview of the study

Australia
Recruitment Catchment Area

Persons with Multiple Sclerosis and their
Main support person
Residing in Australia at
The time of the study
Estimated number of PwMS
N=15,000-18,000

263 Expressions of Interest

Persons with MS and their identified carers
Choosing to participate in the study
N=203=77% return rate
85 carepartners dyads identified
in National sample
23 of these in Victoria

PHASE 1:
Quantitative Analysis
Descriptive and Inferential Statistical Analysis

PHASE 2:
Qualitative Analysis of Interview Transcriptions
Multi-Tiered Narrative Analysis

12 Victorian spousal dyads interviewed

The Research Question

What is it like for me to live with MS at this point in time?
The Population and study sample

The study sample was derived from people living in Australia during the ten month recruitment period who responded to a call for participants and who met the criteria set out in the six different modalities used to disseminate information about the research study (see map schema, ‘Australia Recruitment Catchment Area’ Fig 1.1). The process and types of recruitment are described fully in Chapter Three – Methodology and Methods.

Phases of the study

The study was conducted in two phases. Phase One consisted of a demographic survey and four scales used to measure depression, reciprocity, life satisfaction and functional wellness as described in Chapter Three. (see Appendix A.5). Seventy seven percent of surveys posted were returned with usable data that were subjected to descriptive statistical analysis (n=203). Preliminary analysis of these data as reported in Chapter Four-Part A. Data Analysis, suggested that the phenomenon of interest would most likely be found in further inferential statistical analysis of a split data set labeled: ‘pairs only’. These results are reported in Chapter Five. Descriptive and Inferential Analysis of ‘Pairs only’ (n=85). Results obtained in Phase One of the study helped to inform selection of a sub-sample of pairs from which twelve spousal dyads residing in Victoria were selected for interview in Phase Two. A multi-tiered analysis of interview transcriptions provided information on common themes, concerns and coping strategies, offering compelling insights into the essence of the lived experience of MS for these persons with MS and their main carers.

Narrative analysis and triangulation; new questions arising from these data

Six males with MS and six females with MS and their respective partners were interviewed in their own homes. Interviews were tape-recorded and transcribed by the researcher and these narratives were subjected to a multi-tiered analysis according to a schema (see Chapter Six Figure 6.1). Emerging themes reflecting the pressing concerns of participants were identified, coping strategies were noted and the essence of each individual’s perception of their lived experience was gleaned, using the participants’ own words and the researcher’s observations in order to add another perspective to the data. A new question arose from this analysis related to ‘couple-coping’. Was this couple
functioning as a team or partnership or did each member of the dyad seem to have different goals and agendas?

**Concepts of interest measured in the study: (a) depression (b), reciprocity in caring relationships, (c) life satisfaction and (d) perceived functional wellness**

(a) Depression has been reported in the literature as being very common in persons with chronic illness and their partners (Silber 2004). Pozzili, Palmisano and others note that the moods and health of one partner clearly affect the other (Pozzilli, Palmisano et al. 2004).

(b) The issue of reciprocity in caring relationships is seen as a concept that is central to spousal and life satisfaction (Carruth 1996)

(c) Life satisfaction, as perceived by participants, is measured using the LSI-Z instrument.

(d) The Functional Wellness Inventory (Carter 1990) measures the perception of satisfaction with the ten basic needs of the Zuluaga-Raysmith (Z-R) Model (See Figure 1.2, p.21) and identifies key concerns, strengths and values of the entity (Zuluaga 2000).

The mixed methods selected for the study design made it possible to respond to the research questions from different perspectives and these were examined using ‘triangulation’ of data obtained in both phases seeking congruence or difference as reported in Chapter Seven. (See Figure 1.3) Insights will be discussed in Chapters Eight and Nine.
THE RESEARCH QUESTIONS

Primary question

1.0. What is the lived experience of couples (a PwMS and a Carer) when one partner has been diagnosed with multiple sclerosis?

Subordinate questions

1.1. What are the main concerns and fears expressed by interviewees?
1.2. What are the main strengths, coping skills and insights reported by interviewees since diagnosis with MS?
1.3. What needed resources are perceived by participants to be available, acceptable, and affordable?
1.4. What implications are there for healthcare professionals emerging from this study?

CONTENT OUTLINE OF THESIS CHAPTERS

Chapter One: offers an introduction to the study, describing the type, purpose and importance of the research and a brief outline of the population and study sample, and includes an introduction to the two phases of the study, the mixed methods used to answer the research questions, and the format used for analysis of all data. Chapter contents may guide the reader in this complex and iterative study. An overview of multiple sclerosis is considered essential as a backdrop to the study and is included in this chapter. Other concepts that drive the study are covered in Chapter Two together with the relevant literature review. The conceptual framework undergirding the study relates to the perception of basic human needs and is based on the seminal work of Maslow (1968) and others. A section is devoted to a description of the ‘Zuluaga-Raysmith (Z-R) Model for Assessment of Perceived Basic Human Needs Across the Lifespan’ (Zuluaga 2000). Other theoretical underpinnings are discussed in Chapter Two. Limitations and issues of potential bias in the study are referred to in this chapter which concludes with a Summary of Chapter One and an introduction to Chapter Two.

A Glossary of Terms, Acronyms, Abbreviations and Explanatory Notes has been compiled to provide information regarding abbreviations and acronyms that are commonly used in Australia, together with operational definitions for some terms that may be used with a particular meaning within the context of this study. Commonly used terms such as ‘caring’ and ‘carer’ may evoke widely different meanings depending on the reader’s ontology. The reader may benefit from reading the Glossary before starting the thesis review.
Chapter Two: Review of the Literature introduces and briefly discusses the relevant international literature relating to caring, reciprocity, disruptive life events such as chronic illness, ways of coping, dyadic caring relationships, couple coping, and other concepts briefly mentioned in Chapter One. Relevant literature on the research methods used and rationale for selection in this study are discussed more fully in Chapter Three.

Chapter Three: Methodology and Methods, discusses the methodology and outlines the methods used in the study, describing the survey and scales in some detail, together with the rationale for the selection of each., piloting of instruments and interview guide (Appendix B).

Chapter Four-A: Descriptive Statistical Analysis of Survey Data, presents a descriptive statistical analysis of survey data, together with emerging findings of interest. This descriptive analysis revealed that the phenomenon of interest was most likely to be found in ‘pairs’ or dyads and led to splitting of the original data file into a new data set labelled ‘pairs only’, as previously mentioned. The ‘pairs only’ data file was subjected to inferential statistical analysis including analysis of variance, multiple regressions, correlations and paired t-tests. These results are reported in Chapter Five.

Chapter Four-B: Thematic Analysis and Frequencies of Four Open-Ended Questions. Four open-ended questions were included at the end of the Functional Wellness Inventory (FWI), one of the scales used in the initial survey packet. This section identifies perceived needs, strengths and values of participants.

Chapter Five: Descriptive and Inferential statistical analysis of the ‘pairs only’ file. Preliminary analysis of the file revealed that nearly 90% of the care-giver/care-recipient pairs were spousal, and helped to inform selection of the interview pool for the second phase of the study.

Chapter Six: Multi-tiered Data Analysis of Interview Transcriptions provides a schema (see Figure 6.1) and discussion of findings of a multi-tiered analysis of interview transcriptions, illustrating some of the insights obtained during this process with direct quotes from the interviews. Themes, coping strategies and metaphors are identified and discussed. Interview transcriptions are analysed within the context of the Conceptual Framework to further support findings from other tiers.
Chapter Seven: Summary of Results and Findings from the Two Phases of the study: Response to the Research Questions. This chapter responds to the research questions in the light of findings from both phases of the study.

Chapter Eight: Discussion: What the study tells us: New Directions in working with Carepartners in MS. Salient insights emerging from the findings suggest a need for health care professionals to focus on the caring partnership as it changes under the impact of MS over time.

Chapter Nine: Conclusions and Recommendations. Conclusions derived from the results and findings of both phases of the study are included in this chapter and suggestions are made for further research.; for the education of PwMS and their families. Recommendations for continuing education for health care professionals, for revision of health policy relating to persons with chronic illnesses and disabilities and the development of a multidisciplinary comprehensive ongoing assessment education and support program for PwMS, their main support person and their families.

Epilogue. This section addresses the bidirectional impact of research on researcher.

MULTIPLE SCLEROSIS: AN OVERVIEW AS A NECESSARY BACKDROP TO THE STUDY

This overview of multiple sclerosis is not intended to be comprehensive or unduly technical. The information presented here represents current research at the time of writing and recognizes that what is considered ‘fact’ today may be disproved tomorrow as new findings emerge from the extensive ongoing international research on this baffling disease.

History. The history of the disease has been difficult to capture due to the varied presentations of multiple sclerosis and the different interpretations given to its clinical manifestations over the years. It has often been confused with other conditions, and the period of time from first symptoms to diagnosis has sometimes spanned months and even years in the past. Improved diagnostic methods have shortened this period of time during which patients experienced considerable anxiety as they feared that they were ‘going mad’. They reported that their symptoms were trivialized or attributed to being ‘uptight’
or even diagnosed by doctors as ‘hysteria’. Unnecessary surgical operations have been reported as a result of misdiagnoses in the past. Couple #6 in this research study reported a back operation following a neurosurgical diagnosis of ‘transverse myelitis’, which had no beneficial effect on the participant’s leg weakness.

Murray (2005) published an extensive historical text on Multiple Sclerosis (MS), where he asserted that most research on MS has taken place during the last quarter century, and it is difficult to place this research in a historical context. Murray (2005) suggests that this task remains for future medical historians to complete. He mentions at least 30 different names used in various countries to refer to what we would now call MS (Murray 2005). Even at recent MS Conferences, (Sydney 2003, Melbourne 2004) it has been suggested that what we now call MS may in fact be a cluster of different conditions with different causes, triggers and trajectories.

Murray’s (2005) work traces the contribution over the years of neurologists, scientists and researchers all over the world who have added to our knowledge of MS, which sadly, is still a work in progress and therefore incomplete. He identifies some landmark events, meetings, reviews, symposia and organizations that have advanced MS knowledge. He particularly mentions the formation of the National MS Society in the US in 1946 largely due to the untiring efforts of Sylvia Lawry, whose brother had MS. International MS Societies have now been formed all over the world.

Recently (2005) forty-one different MS Societies have amalgamated and their latest discussions, research work and findings can be accessed on the World of MS website. It is not the purpose of this study to review the extensive and sometimes confusing history of this baffling disease, but Murray presents its history in an interesting and well-researched manner, addressing the international origins of most of the commonly held beliefs about MS that have evolved to the beginning of the Twenty-first Century.

He provides early historical exemplar maps supporting current beliefs about the existence of a geographic gradient in the incidence and prevalence of MS in the US, Italy and worldwide. An updated version of a map has been included with permission from the Multiple Sclerosis Research Association (MSRA) from data obtained in an ongoing longitudinal study in Australia (2007) (See Figure 3.1). This map supports the widely held
belief in the existence of a geographic gradient that needs to be considered as a factor in the incidence and prevalence of multiple sclerosis. Murray (2005) also discusses many of the factors that have been mentioned over time as possible causes and triggers but admits that none of these have as yet been supported by convincing empirical research (Murray 2005).

**What is MS and who is likely to get it?** Multiple sclerosis is one of the more common diseases that affect the central nervous system (the brain, spinal cord and the optic nerves). Shapiro (2002) calls MS “A disease of people” (Shapiro 2002). It affects people of all ages around the world but usually strikes young people during their most productive years (McKeown, Porter-Armstrong et al. 2003). Wollin (1993) suggests that a realistic range for the onset of MS may be from 15-50 years rather than the generally quoted range of 20-45 (Wollin 1997). Geisser (2003) describes MS as both racist and sexist, affecting Caucasians predominantly and women more frequently than men with a ratio of 2:1 (Geisser 2003), Melbourne MS Conference 2003;(King 1998); (Barnett, Williams et al. 2003). Burks (2004) reports that the female/male ratio is approaching 3:1 (Burks 2004), Melbourne MS Conference 2004). Geisser (2003), at the same Conference, stated that MS is rare in Blacks and Asians unless there is Caucasian ancestry (Geisser 2003).

**Epidemiology.** As noted by Murray (2005) and as mentioned above, there appears to be a generally accepted geographic gradient for the incidence and prevalence of MS, with greater prevalence in temperate zones of the world, and in countries with a population predominantly of Northern European heritage such as the UK, Northern Europe, Canada, USA, Australia and New Zealand. Incidence and prevalence diminishes with proximity to the equator which suggests exposure to the sun may be protective for MS (Jelinek 2000);(Van derMei, Ponsonby et al. 2001). This geographic gradient has been noted in Australia, with the largest incidence and prevalence of MS to be found in Tasmania (see Figure 3.1). It has been estimated that there are one and a half million persons with MS worldwide, but this estimate is believed to be an under-representation of the true picture. A worldwide prevalence rate of 57.9 per 100,000 was reported by O’Brien (1996), by Aronson (2001), (O’Brien 1993; Aronson, Goldenberg et al. 1996). Prevalence in Canada is 100/100,000 or 1:1000, and this is believed to approach figures for Australia as reported by Kilpatrick at the MS Conference Melbourne 2004. Currently, the estimated
number of persons with MS in Australia is over 16,000, with over 4000 residing in Victoria. (Newsletter of the Multiple Sclerosis Research Association 2005 p.1).

Although not considered strictly a hereditary disease, there is an agreed genetic predisposition or susceptibility to MS. First degree relatives of persons with MS have a 2% chance of developing MS while identical twins have a 30% chance if one twin is affected (Kilpatrick, 2004 MS Conference, Melbourne). Ongoing research since the landmark international collaborative effort to complete the sequencing of the human genome is expected to shed more light on the susceptibility genes involved in MS (Ebers and Yee 2000; Lander, Linton et al. 2001).

**What kind of a disease is MS?** Despite extensive, ongoing international research efforts to find a cause and cure for this perplexing disease, the complete picture is yet to be unveiled. It has been classified among the autoimmune diseases in which the body mistakenly attacks its own cells and tissues as if they were threatening invaders that must be destroyed. In the case of multiple sclerosis the initial target for destruction is the myelin sheath surrounding nerves in the brain and spinal cord, thus disrupting or slowing nerve conduction. It does this seemingly erratically, accounting for the wide variety of symptoms reported by those eventually diagnosed with MS. Recent research (Burks 2004) suggests that not only myelin is affected but also axons (the nerves themselves) and brain cells. Burks concludes that the probable cause is the genetically determined predisposition mentioned above, coupled with some as yet undiscovered environmental trigger or triggers. Many of these suspected ‘triggers’ have been explored, such as severe stress preceding the first or subsequent attacks, a viral infection, or exposure to environmental toxins, but none of these has as yet been supported by convincing empirical research.

Every time a new piece of information is ‘discovered’ it is greeted with enthusiasm in the belief that science is closer to an explanation, and with the explanation a possible new approach to effective treatment, cure, eventual prevention or possible repair of tissues damaged by MS. However, many of these puzzle pieces do not seem to ‘fit’ and must be rejected. There is as yet no cure for MS, but there are several immunomodulatory drugs (see Glossary) commonly used to treat MS that are believed to lessen the number and severity of relapses.
**Diagnosis, signs and symptoms.** Diagnosis is made on the basis of one or more clinical symptoms of:

- optic neuritis (with partial or complete loss of vision that is often transitory), loss of muscular strength or coordination,
- vague sensations in different parts of the body and
- presentations that are not consistent with diagnostic criteria for other conditions.

Early signs can be a dramatic loss of function or vision requiring hospitalization and treatment with steroids. Further diagnostic tests may include the examination of the spinal fluid which may reveal the presence of certain cells typical of multiple sclerosis (oligoclonal bands). The advent of the MRI in the 1980’s has allowed the actual visualization of lesions in the brain called ‘plaque’, and this discovery has been a considerable aid to definitive diagnosis of MS (Noseworthy, Lucchinetti et al. 2000). Berger (2003) and his associates are currently conducting research to determine if a simple blood test can help identify persons at risk of developing MS following a Clinically Isolated Syndrome (CIS) (Berger and al 2003).

In order to receive a Pharmaceutical Benefits Scheme (PBS) (see Glossary) discount on the drugs used to treat MS in Australia, it is necessary for there to have been two independent episodes of presumed MS separated by time and confirmed by MRI and demonstrating the accepted changes recognized as MS. This regulation has resulted in the loss of much valuable time in initiating early treatment that might have slowed down the progression and severity of the disease and its attacks. This treatment protocol is currently under review.

**Fatigue.** The most common and most debilitating symptom of MS is fatigue (Shapiro 2002; Geisser 2003). This symptom affects every aspect of the person’s life at home and at work and is often reported to be more severe in hot or extremely cold weather. Family members often fail to understand the significant impact of fatigue on the ability of the PwMS to carry on their normal life and activity patterns. Life expectancy is not notably affected. As the disease progresses, there are other symptoms that may appear, including loss of libido and sexual dysfunction in both males and females, bowel and bladder
problems, spasticity, impaired mobility and the cognitive changes previously noted (Shapiro 2002).

Types of MS. Over the years, many attempts have been made to categorize MS into distinct ‘types’. An MS Conference in Montreal (1996) was devoted entirely to this task, but there is still a lack of general agreement about classification, and it is still not possible to place each individual case in a clear category. Some specialists in the field of neurology accept that there may be a ‘benign’ form of MS, characterized by one episode only (CIS), causing very limited long term effects or disruption to life plans and activities and perhaps showing mild or minor episodes of loss of strength or intermittent visual problems, Other specialists deny the existence of this category or include it in the ‘relapsing remitting’ type, which is the most common form of MS. Approximately 10% of cases meet the criteria for the disputed ‘benign MS’ category (McDonald, Compston et al. 2001; Hawkins and McDonald 1999).

The vast majority (80%) of persons diagnosed with MS fall into the relapsing-remitting category (RRMS), having demonstrated recurrent signs and symptoms that have been diagnosed as MS (Barnett, Williams et al. 2003). Burks (2004) challenges the accuracy of the descriptors for this category (RRMS) claiming that a disease which is in remission is inactive, but this in not apparently the case with RRMS, and research studies that followed persons having only a first episode of suspected MS with sequential monthly MRI studies (Pestalozza, Pozzilli et al. 2005) indicate that there are demonstrable changes in the brain on these sequential MRIs even in the absence of new clinical symptoms (Pestalozza, Pozzilli et al. 2005). As previously noted, attacks can be severe enough to require hospitalization and aggressive treatment with steroids, often followed by a period of rehabilitation. Symptoms usually recede, but often not completely, leaving some residual disability or weakness, loss of strength or function, partial loss of vision, and in many cases memory loss and lessened problem-solving abilities. It is estimated that cognitive and behavioural changes affect 50% or more of PwMS (Fraser and Stark 2003). It is impossible to predict the intervals between ‘bouts’ or attacks.

Burks (2004) believes that without treatment, about 80% of those diagnosed with Relapsing Remitting multiple sclerosis (RRMS) go on to the type called Secondary Progressive MS (SPMS), (or more recently named Progressive Relapsing MS). Primary
Progressive MS (PPMS) is, as its name implies, a steadily progressing type of MS with no obvious remission of symptoms or return to normal function. It is believed that 10-20% of persons diagnosed with MS can be placed in this category. PPMS can progress very slowly over the years or very rapidly, causing complete loss of function and mobility and requiring twenty four hour nursing care at home or in an institutional setting. Other forms of MS have been noted in the literature but they are rare and will not be covered in this thesis. At a recent International Neurological Conference it was recommended that the complicated categorization of MS into ‘types’ be abandoned in favour of a simple three-tiered nomenclature after extensive testing for MS had been completed. Either it was ‘MS’, ‘Possible MS’ (if tests were inconclusive), or ‘Not MS’.

When persons with MS become severely disabled and require nursing home care, they are usually much younger than other long term residents, and it is often seen as difficult to meet the very different needs of the young and the old in the same setting. Long term care facilities are very limited throughout Australia, and there is ongoing concern in the community about the shortage of suitable institutional services for younger persons with disabilities. One creative model for the care of disabled young people (between the ages of 18-50) called “Youngcare” is being developed currently in Queensland (O'Maley 2007) as reported at the MSNA Conference in Dunedin, N.Z., 2007.

Treatments. Current treatments for multiple sclerosis may include steroid therapy during acute episodes, as previously mentioned, or may include one of the several immunomodulatory drugs currently approved for treatment of some types of MS (see Glossary). There is at this time no cure for MS, but there is sufficient research to support the belief that use of these drugs can limit the severity of the disease and limit the number of recurrences as previously stated. Other drugs are used for relief of various symptoms as they arise, such as depression, anxiety, pain, spasticity, bowel and bladder problems. Additionally, some cytotoxic drugs, such a Mitoxantrone, have been used with limited success. Complementary and alternative therapies are used by some PwMS, but their effectiveness has not been supported by research and few specialists endorse any of these modalities at this time.
Geisser (2003 MS Conference) stated:

We can’t cure MS and we can’t stop it, but we can almost always do something for everyone to make them feel or function a little better. I think the most important part of treating persons with MS is to empower them to take charge of their own health needs and be proactive about managing their MS with their health care professionals (Geisser 2003).

This statement has strong implications for ongoing education and support programs for PwMS, in which the affected person is an active participant in the planning process for their care.

Hassad, at the same conference (2003), said that in the management of chronic illness it is necessary to attend to the whole person. Allopathic (traditional) health care can no longer afford to ignore holistic health. Burks (2004), in the light of new research findings about the dynamic nature of MS, recommends early diagnosis, aggressive treatment with the interferon drugs, developing a good support system and a health and wellness approach in the management of multiple sclerosis. It appears these recommendations are slow to be implemented (Burks 2004).

**Research.** Extensive international research efforts continue the quest to discover a cause and cure for multiple sclerosis, to explore the genetic and environmental triggers that start the disease process, to study and conduct trials of new drugs that may alter the course of the disease or repair its damage, including the potential effectiveness of stem cell transplantation (Perry and Anthony 1999; Fassas, Passweg et al. 2002). Psychosocial aspects of the disease and research into factors affecting adjustment, coping, life satisfaction and family relationships are also the topic of ongoing research in an effort to develop effective education, support and intervention programs to improve the level of wellness of affected families (MS Conferences 2003 and 2004, Melbourne and Sydney). Pakenham (2001) identified the need for development of a disease specific assessment instrument for multiple sclerosis and later developed such a measurement tool (Pakenham 2002).
THE CONCEPTUAL FRAMEWORK AND KEY CONCEPTS THAT DRIVE THE STUDY

The theoretical bases of this research study are drawn from multiple disciplines including psychology, sociology and the social sciences, medicine, psychiatry, pharmacology, nursing, medical anthropology and philosophy. These theoretical bases will be addressed further in Chapter Two. Chapter One introduces and discusses the Zuluaga-Raysmith (Z-R) Model which serves as a conceptual framework for this study. The model, developed by the researcher, building on the work of Raysmith (1972), is based on the accepted principles of basic human needs expounded by Maslow (1968). Its assumptions, based on self-perception of basic human needs and level of wellness, are carried as a thread throughout the study and included as a meta-analysis of the interview transcriptions (Zuluaga 2000) (see Figure 6.1).

The Z-R Model, (see Figure 1.2.) with its holistic focus, is used as a framework in discussing provision of services for individuals, carers and families with MS as well as in exploring the implications of the study for further research, education, practice and health policy issues in multiple sclerosis. The Functional Wellness Inventory (Carter 1995), relates to the ten basic needs of the Z-R Model. A modified version of Carter’s instrument was used as one of the four measurement instruments included in the survey packet posted to participants in Phase One of the study. All the instruments that were used in the study are described in Chapter Three, and a complete survey packet is included in Appendix A.5.

Initially, the study was designed to focus only on carers of persons with multiple sclerosis. The international literature review revealed many research studies that explored different psychosocial aspects of the caring role as well as various aspects of the problems encountered by persons with MS. However, none seemed to address the effects of this chronic illness on the caring partnership. It seemed logical to this researcher, that if one were to examine a phenomenon like caring (care giving) there must be another component, namely, a care recipient. It seemed difficult to explore one without the other. Studies of carers of disabled, elderly or chronically ill persons reveal that carers are usually spouses, with other female family members taking that role as well, if and when needed (Baines, Evans et al. 1991). Of course, since multiple sclerosis affects many more
women than men, the carer is most likely to be a male spouse who may not fit the
gendered view of a carer, as discussed by Watson (2003) in her study of men caring for a
spouse with MS (Watson 2003)

**Key Concepts: Caring and the carepartnership, Reciprocity, Coping
and couple-coping, Disruptive Life events and story-telling to create
meaning**

**Caring – Carepartners.** It would be reasonable to assume that the spousal type of
informal caring relationship would be unique, with strengths and limitations that may not
be present in a sibling caring relationship, or a parent/adult child or child/adult parent
relationship. It was necessary to examine the types of caring relationships reflected in the
total study sample and examine these ‘pairs only’ in greater depth using inferential
statistics (see Chapters Four, Part A and Chapter Five). The spousal carepartnership
would possess many interesting characteristics relating to the impact of multiple sclerosis
on the relationship as the level of dependency of the partner with MS changed over time.
Research studies published since 2000 recognize and examine this dyadic relationship,
and are discussed further in Chapter Two. Thus the focus of this research study is on the
lived experience of multiple sclerosis where one of the carepartners has been diagnosed
with this condition.

The design of the two-phase research study remained the same as the original proposal,
and included a survey of persons with MS residing in Australia. The first phase provided
a profile of the demographic characteristics of persons with MS who responded to the call
for participants and assisted in the creation of an interview pool from which a sub-sample
was selected for interview in Phase Two (see Figure 1.1). The two phases of the study
have allowed a greater breadth and depth of understanding of the impact of MS on
carepartners, which became the phenomenon of interest and the focus of the study. The
concept of caring and the relevant literature is discussed in greater detail in Chapter Two.

**Reciprocity.** The concept of reciprocity in caring relationships is explored together with
its possible impact on life and family satisfaction for the dyad. It may be possible to
reconceptualize the caring relationship in terms of reciprocity. Social Exchange Theory
(Becker 1986; Cook 1987) and the more recent work of Carruth (Carruth 1994; Carruth
1996; Carruth 1997) contribute to understanding the importance of reciprocity in committed caring relationships, and its impact on marital and family satisfaction.

**Coping.** How individuals and couples coped with a diagnosis of MS became a concept of interest that was explored in the study. Several coping theories and scales were examined for possible use in the study, including Jalowiec’s Coping Scale (Jalowiec, Murphy et al. 1984) and Lazarus and Folkman’s Ways of Coping (WOC) (Folkman and Lazarus 1980) and, although these typologies were somewhat disappointing in their application to carepartners with MS, some of the WOC items provided a useful guide for identifying the potential effectiveness of common coping strategies used by interviewees as they faced an unknown future with MS.

**Disruptive life events and story telling to create meaning.** Viewing illness as an event that disrupts the Western cultural expectation of continuity in life as described by Gail Becker (1997) was of value. Story telling, re-storying and the use of metaphors by interviewees in the second phase of the study unveiled feelings and ways of making meaning for participants as MS entered their lives and was perceived to remain as an intruder or ‘uninvited guest’ whose presence could not be ignored.

**THE ZULUAGA-RAYSMITH (Z-R) MODEL FOR ASSESSMENT OF PERCEIVED BASIC HUMAN NEEDS ACROSS THE LIFESPAN (FIGURE 1.2)**
The Zuluaga-Raysmith Model (Z-R Model), recognizes ten basic needs, and eliminates any hierarchical priority to the needs, which are numbered here for convenience only. These are:

1. Physical Health, (PH)
2. Mental, Emotional, Social and Spiritual Health, (MESSH),
3. Income,
4. Mobility,
5. Accommodation (Housing),
6. Safety/Security,
7. Knowledge,
8. Communication,
9. Opportunity for Development and
10. Opportunity to Make a Contribution or, need to perceive a purpose in life.

This model addresses the bio-psycho-social parameters of human life in its assessment of perceived needs and recognizes that needs are often inter-related. The model may be applied to individuals, families, aggregates or communities. An aggregate in this Model is any group of people that have one or more characteristics in common, such as ‘teenagers’, or ‘the homeless’. In this study ‘Carepartners’ are defined as a spousal dyad in which one partner has been diagnosed with MS and the other is the identified main support person or carer (see Glossary). The instrument used to measure the perception of the needs by Carepartners with MS is Carter’s (1990) modified Functional Wellness Inventory (FWI), which is described fully in Chapter Three.

The Z-R model is based on concepts developed by Maslow (1968) of the existence of basic human needs, which he placed in hierarchical order. However, this form of need prioritization is removed in the Z-R Model, as explained above, and it is argued that needs are inter-related and a perceived deficit in any of the basic needs impacts other needs and can cause distress that is sufficient to require assistance from sources outside immediate family or support group. There is evidence in the literature to support the removal of the hierarchy of needs, particularly in the work of Viktor Frankl (1967; 1984), who observed the phenomenon that human beings will often sacrifice their most basic needs for food and shelter, deferring to the needs of another person, thus placing love and esteem needs above the physiological ones (Frankl 1984). His work also validates the “Need (Opportunity) to Make a Contribution” of the Z-R Model, listed above. Frankl (1967) asserts that human beings can put up with apparently overwhelming adversity if they believe their life has purpose and meaning. These assumptions were explored during interviews with participants in the second phase of this study.
Raysmith (1972, p 13) proposes that:

Every man, woman and child has ten basic needs. To the extent that these needs are perceived to be satisfactorily met, the entity will function autonomously in the community without need of community services.

Conversely, a perceived deficit in any of the ten basic needs will influence satisfaction of other needs and will adversely affect progress of the entity on the wellness-illness continuum illustrated in Figure 1.2 and described by Travis (Raysmith 1972; Travis 1977).

Travis proposes that humans exist on a wellness-illness continuum, represented by a double pointed arrow (see Figure 1.2 below). At one end of this arrow is high level wellness, equivalent to Maslow’s ‘self-actualization’ and at the other extreme is preventable illness and premature death (such as heart disease, cancer, substance abuse, suicide). At the centre of the arrow is a hypothetical neutral point representing no discernible disease or disability. Travis maintains that traditional health care providers attend to persons presenting with signs and symptoms of illness, and are content to bring these clients to a midpoint, where the acute signs and symptoms are relieved or eliminated. However, little or no effort is made to suggest strategies that can move the client further along the arrow to a higher level of wellness and greater life satisfaction. He suggests this may be achieved through skilled interventions, educational programs, interdisciplinary referrals and judicious use of community resources. The high level wellness model focuses on four dimensions: physical activity; nutrition awareness; stress management and self-responsibility (Travis 1977). Use of the Z-R Model for assessment of perceived basic human needs has been successfully used in clinical practice of community health nursing to unveil areas of perceived need and to suggest strategies to assist clients to move to a higher level of wellness, despite the presence of disease, disability or even impending death (Zuluaga 2000).
In this research study, ‘the entity’ represents the dyad of a person with MS together with their identified carer or support person (see Glossary). The central figure in the model represents the entity to be assessed. Surrounding the figure are the ten basic needs. These can be viewed as an inter-related system where each need impacts others. The entity, which exists on the wellness-illness continuum, may move freely in the direction of greater health and self-actualization or toward illness and premature death. The reality of the client’s perception is acknowledged and validated by the assessor, who stresses the importance of client participation in any therapeutic plan that may be developed to improve health and well being. Pender (1983, 1988; 1996) agrees that there is a greater possibility of change in behaviour when a client perceives there is a problem appraised to threaten their health and well being. This can be the case when a chronic or disabling disease has been diagnosed (Becker, Radius et al. 1978; Pender 1996).
Becker’s Health Belief Model (1974) concurs that a threat to health and appraisal of serious harm to future well being and planned goals is often the motivation for action to change behaviours if these actions are seen to be within the power and control of the individual. Roden (2003), in revisiting Becker’s Health Belief Model, addressed issues of locus of control and self efficacy in reorienting the Model to health promotion and wellness (Bandura 1977; Becker, Radius et al. 1978; Roden 2004).

As described above, the Z-R Model has been successfully applied in a variety of settings to assess the basic needs of several populations including home health clients and their care givers (Zuluaga 2000); in completing community assessments related to research grant applications; in the education of nursing students and as an effective adjunct assessment instrument used by a Visiting Nurse Service in the USA (Zuluaga 2000).

**SOURCES OF POTENTIAL BIAS AND THREATS TO INTERNAL AND EXTERNAL VALIDITY OF THE STUDY: LIMITATIONS OF THE STUDY**

Every research study has limitations inherent in its design and implementation. It is important to identify these and to note and acknowledge efforts that have been made to limit their threats to the reliability, validity and trustworthiness of the findings (Brink and Wood 1988, chapter 10). Together with Frank (2005), who recognized the limitations of the one-off interview at a Melbourne Conference in 2005, it must be emphasized that the stories related in this study represent only a brief snapshot at a given point in time for the carepartners as they dealt with the uncertainties of multiple sclerosis and the ‘uninvited guest’, or ‘intruder’ in their lives. Some have described MS as ‘a third person’ in their marriage. Even though their stories are continuing, and do not represent the final word, many valuable insights have been gained, with implications for further research, education and practice of health professionals, support agencies and groups (Frank 2004). These implications are addressed in the final chapter of this thesis.

As noted by Folkman and Moskowitz (2004), studies that depend on self-report data are subject to distortion and bias based on memory problems and retrospective falsification. In the case of multiple sclerosis, cognitive changes and memory losses are additional potential sources of bias that may have occurred when participants were asked to “tell
your story since MS entered your life”. There was a ten to eighteen month time lag between the time of the survey and the interview, and many participants could not easily recall at the time of interview the responses they had given on their survey forms and several agreed that their situation had changed since the survey (Folkman and Moskowitz 2004).

Triangulation of results and findings from quantitative and qualitative methods sought congruence or dissonance in findings, and raised more questions for future research (see discussion on reciprocity tool, Chapter Seven, Finding 5). Other limitations of the study include the small sample size of the interview pool; limitation of the interviews to one State in Australia and the lack of randomization in selection of participants in Phase One. These persons were recruited from PwMS residing in all States in Australia using various methods of recruitment, including the internet (see Chapter Three). Recruitment methods failed to recruit representative sampling for each State in Australia as discussed in Chapter Three. Pilot interviews were conducted in two other Australian States to refine the interview guide, but these were not included in the data analysis, and have been placed as interesting vignettes in the Appendices (see C.1 and C.2). Any findings from these interviews would not be generalizable to other groups.

Recruiting on the internet provided many participants, but this may be a biased sample of persons in the higher socioeconomic and education groups. Participation by these recruits would need to assume computer literacy, a skill which continues to grow in the general population, but still excludes a large number of older or visually-impaired persons. One participant offered a critique of one of the scales in the survey where the statements were perceived to be too far from the response options, increasing the potential of error in recording their preferred response. Correction was not possible during the study since most surveys had already been distributed. Difficulty with mobility of some participants was overcome by offering a home based interview, thus enabling participation by several persons with mobility problems who would otherwise be unable to take part. Possible researcher bias has been mentioned and includes the fact that the researcher was the sole interviewer and transcriber of interviews. The strong personal interest of the researcher in the subject can be seen as a potential source of bias, but also as a strength that has helped to maintain interest and motivation over the long period of the study. Regular interaction
with an engaged supervisor provided valuable external ongoing critique that helped minimize bias.

The reciprocity scale (CRS-II) (Carruth 1994) was applied to both the care giver and care recipient in this study in the erroneous belief that others using the scale had also measured both members of the caring dyad. Recent conversations with the designer of the scale indicated that my application was the first reported time the scale had been used with both members of the dyad, thus presenting potential difficulty in scoring, interpreting or comparing results obtained for the scale in this study. It does, however, open fertile ground for further research on the use of this potentially very useful tool to measure the concept of perceived reciprocity in the caring relationship, which is seen to be a central construct in marital and life satisfaction. Triangulation of methods is used to overcome some of these measurement problems for this scale.

Figure 1.3 below illustrates triangulation using reciprocity as the exemplar depicting quantitative and qualitative methods to look at the same concept and allow the researcher to interpret the research findings more completely.
The study was conducted in only one country and interviewees were limited to one State within the Australian health care system. Availability and access to medical resources and support systems differ from those available in other countries, and often varies from State to State within the same country. Results are difficult to compare with other countries or health care systems.
SUMMARY OF CHAPTER ONE AND INTRODUCTION TO CHAPTER TWO

Chapter I has identified the type, importance, purpose and mixed method design of this two phase study, which uses surveys, observations and interviews to gain a deeper understanding of the lived experience of carepartners dealing with MS in their daily lives. Various methods of data analysis have been outlined, and the results and findings of these are used to respond to the research questions in Chapter Seven. Miles and Huberman (1994) remind us that qualitative data analysis often hides the complex nature of phenomenological research studies (Miles 1994). The researcher has positioned herself in a Prologue and recognizes the potential for researcher bias. Other limitations and potential bias issues have been addressed. Also recognized is the dynamic nature of life and the fact that each of the dyads interviewed were at a different point in both their life course and the disease trajectory, which cannot as yet clearly be defined or predicted. An overview of current information on MS has been given as a necessary backdrop to the study. The Conceptual Framework for the study has been included in Chapter One. Chapter Two will cover concepts of interest that drive the study including a review of the literature relevant to each of these, which include: caring, the notion of ‘carepartnerships’, reciprocity in caring relationships, individual coping and coping as a couple with disruptive life events, relationship issues in chronic illness and chronic sorrow. Further theoretical underpinnings of the study are also discussed.
Chapter Two: Literature Review

CARING AND THE CARING RELATIONSHIP; CARE GIVERS AND CARE RECIPIENTS: THE CONCEPT OF “CAREPARTNERSHIPS”

The subject of carers and their problems has aroused extensive interest in the literature of diverse disciplines over several decades (Cantor 1983; Cockerill and Warren 1990; Miller 1991; Vrabec 1991; Dewis and Niskala 1992; Winslow and O’Brien 1992; De Meneses and Burgess-Perry 1993; Lindgren 1993; Carruth 1994; Ricks 1995; Sato, Ricks et al. 1996; Carruth 1997). Caregiving has been explored from many perspectives with a variety of care recipients from elderly parents to developmentally delayed children and brain damaged teenagers; from frail elderly to those with the progressive dementia of Alzheimer’s Disease; from chronic conditions such as Motor Neurone Disease and Multiple Sclerosis to AIDS (Des Rosier, Catanzaro et al. 1992; Weinert and Long 1993; Carruth 1996; Gerder, Richards-Hall et al. 1996; Wolter 1998). Vrabec (1991) conducted a review of 50 studies over 15 years relating to social support and caregiver burden. Conclusions derived from Vrabec’s study suggested there were several problems with statistical validity and a lack of generalizability of the findings (Vrabec 1991). Graduate students in fields such as nursing and social work have found lay caregivers and their needs a fertile ground for their research efforts (Carruth 1994; Sachschaule 1994; Carter 1995; Ricks 1995; Burggraf 1998; Duncanson 1998; Velasquez 1998; Wolter 1998; Lopez 1999). There has been increasing recognition of the immense contribution that family caregivers/carers make to society and to the affected families (Dewis and Niskala 1992), and of the importance for healthcare professionals to identify their perceived needs (Ricks 1995; Sato, Ricks et al. 1996).

Hunt (2003) reviewed the caring literature to mid-2002, examining the bio-psycho-social effects, both negative and positive, associated with providing care for a relative or friend with a chronic illness. Findings of the study included reports of caregiver burden and
stress, strain and ‘hassles’. However, positive concepts were also reported, such as caregiver esteem, emotional ‘uplifts of caring’, caregiver satisfaction, and finding meaning in life through caring. A neutral view of the caring experience was also unveiled which was described as ‘appraisal’. ‘Hassles’ were described as minor inconveniences or stressors whose cumulative effects were not insignificant to the carers’ wellbeing (Hewson 2003; Hunt 2003). Hunt (2003) concluded that more attention should be given to gender and cultural differences in caring; to the development of flexible interventions and to the biophysical sequelae of caring (Hunt 2003).

Carers: terms, definitions and questions

The concepts of caring, caregivers (carers) and care recipients are complex and context-dependent. Definitions of caring and caregivers abound in the literature. The North American term for carer is ‘caregiver’, whereas the English and Australian commonly accepted term is ‘carer’. The latter term is preferred in this research study, but at times terms have been used interchangeably in deference to the terminology used in the international literature. It is important to frame any definition in the context of the role and after answering the following questions: Who is a carer and what is a carer? Is this an informal carer (unpaid partner, family member or friend) or a formal (paid) carer? Is this a professional person who accepts caring as an integral part of their work, for example, nurses, therapists and other health professionals? What are the parameters of caring?

These and other caring issues have been addressed in past decades by many authors and the debate continues (Dalley 1988; Baines, Evans et al. 1991; Edwards and Ribben 1998; Edwards 2001; Hunt 2003; Watson 2003; Sumner 2004). Does a carer give hands-on care to the care recipient with activities of daily living, instrumental activities of daily living or technical nursing procedures, or does the carer simply care about the care recipient and organize the provision of necessary care by others? Is a carer seen by the recipient as a ‘support person’ and not a ‘carer’? Does making this differentiation help the person with MS or other care recipient to believe that they are not ill enough to require a ‘carer’, and thus feel better about their situation? Is there a relationship being established between caregiver and care recipient and is this relationship seen to be reciprocal with each deriving valued benefits and personal satisfaction from their roles (Dalley 1988; Carruth 1997; Hunt 2003; Pozzilli, Palmisano et al. 2004)? What about gender and caring? Is this an
issue or do males and females view and fulfill the caring role in a similar manner? Watson believes that males fulfill the caring role in much the same manner as their female counterparts (Watson 2003). Earlier carer literature discusses caring as gendered, with females mostly undertaking this role and describing caring by females as a societal expectation (Dalley 1988; Baines, Evans et al. 1991; Hunt 2003). These issues are the focus of many studies and have been the subject of extensive research, that now recognizes the important role of males as carers (Archer 1993; Fisher 1994; Funnell 1998; Watson 2003). Anderson (2001) believes there is a cultural assumption that male caregivers are not capable of caring for someone with a chronic illness and therefore cannot be trusted with such responsibility. This assumption works to undermine men’s perceived capability to care for a vulnerable family member with a chronic illness or disability (Anderson. 2001).

**Caring: negative and positive views-dynamic nature of the caregiving phenomenon**

A review of the literature over past decades reveals a negative slant on caregiving that focuses mainly on caregiver burden, stress, chronic sorrow, depression and burnout (Cantor 1983; Lindgren 1993; O'Brien 1993; Wineman, Durand et al. 1994; Hainsworth 1996; Knight, Devereaux et al. 1997; Hughes, Giobbe-Hurder et al. 1999; Schwartz and Kraft 1999). However, a study by Boeije, et al (2003) used Lindgren’s (1993) concept of a caregiver career to note the dynamic nature of the caregiving phenomenon, recognized the dyadic and reciprocal nature of caregiving and applied many of the ‘caregiver career’ concepts to its study of carepartners with MS. Their findings support those of previous researchers suggesting that a continuation of caregiving is the result of an interchange between the partners. The commitment that is established can be expressed in terms of inevitability, shared misfortune, reciprocity and the desire to prevent nursing home placement (Lindgren 1993; Boeije, Duijnste et al. 2003). In the Boeije et al (2003) study, three aspects were identified which contributed to the creation of commitment in the relationship and continuation of caregiving, namely marital loyalty, the arbitrariness of the disease and its serious nature. The authors emphasize the need for health professionals to consider fostering negotiation skills between partners and an awareness of the impact of caregiving on their relationship (Boeije, Duijnste et al. 2003).
In more recent years a more positive view of caregiving has been explored (Aronson, Cleghorn et al. 1996; Carruth 1997; Helmich-Henson 1997; Pakenham 1998; Szabo and Strang 1999). Although many studies were found in the literature about carers and caregivers, and also many about the experiences of care recipients with varying diagnoses, none were found to address the care giver/care receiver dyad as a unit, although one Italian study (Pozzili et al 2000) reported on the relationship between emotional distress in caregivers and the health status of the care recipient with MS, making the case for therapeutic strategies focused on carers and their wellbeing (Pozzilli et al 2000). Few studies have sought to discover the perception that carers have of their own needs and the satisfaction that many report from their caring role. McKeown (2002) reviewed twenty four worldwide studies of the needs of carers of persons with MS, and concluded that providing care for these persons impacts all areas of a carer’s life, and recommended the development of a reliable and valid disease-specific caregiver assessment instrument (McKeown 2002, p.234; McKeown, Porter-Armstrong et al. 2003). Pakenham (2002) has developed such an instrument for MS, which is currently in use and continually being updated and refined (Pakenham 2002). Self-appraisal of needs by participants has been recommended by Patton (1990), who believes this to be the best source of information.

A research study by Good et al. (1995) explored gender differences in perceived social support of spousal caregivers of persons with multiple sclerosis. Good (1995) reported a positive relationship between caregiver-perceived social support and the ability of the mate to perform intimate functions. There was also a positive relationship between perceived social support and the carer’s level of commitment to the spousal relationship (Good, Bower et al. 1995).

Most studies of carers tend to view the multi-faceted activity or role from a negative or pathological perspective, emphasizing the ‘plight’ of the carer, or the strain, burden and ‘burnout’ resulting from caring over time (de Meneses 1993; McKeown et al 2002). The close relationship between care giver and care recipient is noted, where the health and wellbeing of one impacts on the other in terms of health status and depression (McKeown et al 2002, p.234). Hunt’s (2003) review of the family caregiving literature until 2002, also examined the negative and positive bio-psycho-social effects of caring for a relative or friend with a chronic illness.
No studies have been found that explore the symbiotic or reciprocal nature of the care recipient/caregiver relationship except in relation to the concept of co-dependency. When reciprocity in a relationship is interpreted in terms of co-dependency, a pathological slant emerges, hiding or submerging any positive perceptions or ‘uplifts’ of caring, such as those described by Kinney and Stephens (1995), who describe ‘uplifts’ as events that make a person feel good, make one joyful or make one glad or satisfied. Caregivers reported less distress in the Kinney study when uplifts outweighed ‘hassles’ (Kinney and Stephens 1995). One PwMS from New South Wales, wrote at the end of his completed survey: “At last, someone is recognizing the symbiotic nature of a caring relationship where both partners benefit (NSWay)” (See Glossary).

**Impact of MS on relationships?**

This thesis explores the concept of reciprocity and mutuality in spousal caring relationships and agrees with Carruth that there is a strong element of co-caring in these relationships (Carruth 1994; 1996; 1997). Thus the term ‘carepartners’ is used to explore this dyadic caring relationship (Holland 1996; Holland and Sarnoff 1997). Both negative and positive impacts have been reported on spousal relationships by dyads with MS in the literature. Although Mohr et al (1999) found that many people with MS reported deterioration in their relationships, many also reported psychosocial benefits such as a greater appreciation for life and an increased focus on spirituality. Mohr believes theirs is the first research study to identify a variable called ‘benefit finding from MS’ (Mohr, Dick et al. 1999, p.380).

**Strength in loss of ability?**

In the light of overwhelming negative reports on the care giving experience, it may seem absurd to contemplate a positive side to it, seeking strengths and positive reported outcomes. A strengths perspective is discussed at length by Saleeby (1997) as an effective approach for healthcare professionals dealing with persons who may see themselves as powerless and marginalized (Saleeby 1997). He asks: “Isn’t the strengths perspective just positive thinking in another guise?” But Saleeby (1999) answers his own question and argues that there is a difference, maintaining that the strengths perspective is not just a mindless repetition of uplifting mantras that may relieve pain and suffering, but is rather the work of helping clients and communities build something of lasting value from the
materials and social capital within and around them. He also suggests it is hard work. Saleeby (1997) discusses the unfortunate use of terms in our society that label people as ‘disabled’, implying that the person is ‘less than perfect’, lacks power and is therefore marginalized. Any suggestion that such a person may have strengths is therefore considered ludicrous. It is probable that persons so labeled take on the powerless, helpless and dependent mantle, partially explaining the phenomenon noted in my research study where the person with MS (the care recipient) had difficulty seeing him or herself as a ‘carepartner’ or co-carer of the well spouse.

The labels we ascribe to the chronically ill or disabled emphasize what the person cannot do rather than what they can do. Disabilities are given categories according to their increasing levels of severity, and services are allocated according to these, aggravating the feeling of helplessness, uselessness and powerlessness of the care recipient. Paolo Freire (1970), in his seminal work describing oppression, suggests that those who feel oppressed tend to view the world from the point of view of the oppressor, of those who are stronger and more powerful than they are. All they can see are their weaknesses as they focus on their losses of ability which in turn leads to low mood and loss of self esteem and self-efficacy. Saleeby suggests that viewing the care recipient from a strengths perspective can begin to turn this situation around (Saleeby 1997).

**Chronic illness, sadness, grief, losses and concept of chronic sorrow**

Losses are an integral part of chronic illness and disability. Chronic sorrow has been described in the chronically ill and their carers in response to continual losses (Lindgren, Burke et al. 1992). The term ‘chronic sorrow’ is examined in several studies throughout the 1990s by Hainsworth, Burke and others (Burke, Hainsworth et al. 1992; Hainsworth 1993; Hainsworth 1994; Hainsworth, Eakes et al. 1994; Hainsworth 1996). Chronic sorrow has been described as a pervasive sadness that is permanent, periodic and progressive, and differs from the sadness of acute grief (Hainsworth 1993)(See Glossary). Hainsworth believes it may be a normal component of chronic illness and disability.

In a later study exploring the experience of living with MS, Hainsworth reported that 80% of spouse/caregivers of persons with MS exhibit ‘chronic sorrow’. In another study (1994) Hainsworth examined the role of nurses and other caring professionals and determined that empathic presence helped these carers the most with inner feelings of
chronic sorrow (Hainsworth 1994). The concept of chronic sorrow is often applied to situations of multiple losses of ability, whether sensory, motor, intellectual sexual or reproductive functioning (Hewson 1997). This pervasive sadness, described by one participant in my study as ‘going down a lot (10 ax)’, and described as ‘low mood’, is evident as they recount the many losses they have experienced throughout their trajectory with MS. 2. This pervasive sadness appeared to be difficult for them to overcome despite their best efforts to appear bright and optimistic, and to cover their feelings of sadness with humour. One participant described a long list of her losses to MS and then added wryly “but we are happy (2ax)”

Depression has already been explored in the literature extensively in relation to women in the general population and in relation to depression and the chronically ill. It is generally agreed that in the general population, women are more depressed than men, although the reasons are not fully understood as yet. In this study sample, as will be discussed later, women were more depressed than men and persons with MS were more depressed than carers. (See data analysis Chapter Five).

**Negativity in the medical profession?**

Weil (1995), speaking from the Alternative and Complementary Therapy perspective, describes the profound negativity and pessimism displayed by the medical profession about the body’s desire and ability to transform, regenerate and even heal itself. However, even in the traditional Western medical discipline there are voices that speak for a holistic view of the human body and the human person (Hassan, Melbourne MS Conference 2004). There is a tendency in traditional Western medicine to over-specialize, thus losing sight of the broader picture that includes an awareness of the patient’s contribution to healing. Doctors convey these negative beliefs to patients in many ways, and examples were reported by several interviewees whose comments are presented in Chapter Six. The power of words, especially when used by doctors and specialists, has a significant impact on their patients, who often see the doctor as a person who knows everything and can ‘fix’ whatever is wrong with their bodies. Unrealistic though these assumptions may be, there is still a duty for the healthcare professional to carefully consider the words they use with clients, offering ongoing support when disclosing bad news to avoid destroying the

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2 For participant coding, see Glossary
essential element of ‘hope’ that is vital to a health and wellness perspective. Health professionals “need to explore the possibilities for reflecting power back in ways that influence health in a positive way rather than a negative manner; in ways that stimulate rather than retard healing (Saleeby 1997 p.6)”.

It is not the purpose of this study to explore in depth the different conceptions that exist about the caring role in society, nor to arrive at a definition that fits all situations, even if this were possible. Suffice it to say that caring is a complex concept covering a wide array of activities and levels of care. The role is not static but dynamic and ever-changing, varying with the level of dependency and desire for independence of the care recipient (Watson 2003).

Many questions have been raised in this literature review and discussion of caring, carers and care recipients. It is necessary to state a clear meaning of the terms used in any research study, consistent with the focus and direction of the study. The operational definition for ‘carer’ that has been chosen for this study is: “any person nominated by the person with multiple sclerosis as their main support person or care giver (carer)” (See Glossary). This definition is consistent with the value placed on self-perception throughout the study. Several interviewees denied that they needed a ‘carer’ but accepted that their spouse was their ‘main support person’. Thus, the terms ‘main support person’ and ‘carer’ are used interchangeably. No other criteria were set by the researcher and there was notable variability in the extent and level of care reported by the twelve dyads in the interview subset.

**Reciprocity and carepartners**

Concepts of mutuality and reciprocity have started to emerge in more recent studies, suggesting that there could be some benefits or uplifts derived mutually from the caring relationship as previously noted (Carruth 1996; Helmich-Henson 1997; Grant, Ramcharan et al. 1998; Folkman and Moskowitz 2000). First hand anecdotal stories of spousal carers emerged from periodicals devoted to persons with specific chronic illnesses who reported positive elements in their experiences (Heywood 1988; Duncanson 1998; Tofteland and Tofteland 1999). Carruth (1994) developed an instrument to measure caregiver reciprocity in adult children caring for elderly parents, and this instrument was later modified to include elderly spousal caregiver dyads (Carruth 1994; Carruth 1996). In both
studies, internal consistency and the coefficient of reliability were considered acceptable. In addition to the evidence presented by these quantitative studies, first-hand reports in the lay periodicals mentioned above and relating to the lived experience of care giver/ care recipient dyads expressed a sense of mutuality and partnership; of ‘being in this together’ (Holland and Sarnoff 1997). In other words, carers perceived that the care recipient was giving valuable affirmation and emotional support to the care giver (Tofteland and Tofteland 1999). The term “carepartners”, coined by Holland (1997), was selected for use in this study rather than the more commonly used term of caregiver or carer to more closely reflect the reciprocal aspects of the caring relationship.

**Caring: a dyadic focus**

The focus of this study is on the lived experience of ‘carepartners’, where one member of the dyad has been diagnosed with multiple sclerosis. The term ‘carepartners’ (Holland 1997) seems to imply that two people are caring for each other in a reciprocal manner, even though the benefits gained in this type of partnership may not be perceived to be equal by observers. It simply suggests that each receives a valued contribution from the other. This term reflects the growing emphasis in the literature that care recipient and care giver (carer) need to be considered as a unit when health professionals assess their pressing needs and concerns.

Although Lindgren (1993) explored the concept of a ‘caregiver career’, her study viewed caregiving from a very negative stance. The concept had merit from the standpoint that a ‘career’ is assumed to have a beginning, a middle and an end. A career involves a certain level of commitment and expected progression and personal growth. Application of this concept to carepartners in multiple sclerosis was viewed at first as useful, but was later rejected in favour of a more positive approach based on Carruth’s (1994) ideas of reciprocity in the caring relationship and a focus on the dyad rather than on the carer alone.

Of course, the negative impact of long-term caring on a carer’s physical and psychosocial and emotional health in chronic illness situations cannot be denied, but there is a positive side that can be supported by health care providers and agencies to lessen the negative impact of this challenging role, to enhance the spousal caring relationship, and to reinforce a health and wellness perspective for both. If the care recipient can appreciate
that they contribute valuable reciprocal benefits to their carepartner, including love, affection, esteem, appreciation and affirmation, there is potential benefit to both in the spousal relationship where each appreciates and reinforces the valued contribution of the other. The idea of reconceptualizing the caring relationship in terms of reciprocity has potential for development of helpful educational and support programs for carepartners (Gerder, Richards-Hall et al. 1996; Shaw 1999).

As has been previously noted, there has been a paucity of literature addressing the strong correlations between the health and well-being of care recipient and caregiver, and thus the need for health professionals to focus their attention and interventions on the dyad and its relationship. As mentioned before, one study was found (Pozzilli, Palmisano et al. 2004) examining the relationship between the health of the carer and the health and well-being of the care recipient and suggesting that the carer should be the focus of supportive interventions by health professionals. Often healthcare systems only fund care given to a ‘sick person’ and do not fund care or support of the carer. Although his research study dealt only with caregivers of persons with MS, findings reported in Pakenham’s (2001) paper draw attention to the need for a dyadic focus, citing many previous studies that suggest the levels of distress in chronic illness of care receivers and carers are highly correlated. Couples react to disease as a unit (Pakenham 2001).


Coeling et al (2003) agree that little attention has been paid to the ‘totality of the relationship between care recipient and caregiver’. These authors concur with Bodenmann (2001) that the literature has focused on the negative side of caring and on burden, stress and burnout, and that only recently has research focused on the benefits accrued by caregivers or to the contributions of care receivers (Coeling 2003). In their study, Coeling et al (2003) assumed that a certain amount of negotiation takes place between the dyad as the caring relationship changes over time. A spousal relationship
challenged by chronic illness is likely to change subtly over time as one partner changes from caring spouse to carer and the other changes from caring spouse to care recipient. These changes require ongoing support and negotiation for successful adaptation.

**Negotiation in changing roles**

The presence of some form of negotiation was observed during interviews with carepartners during the second, or interview, phase of the current research study. This negotiation related to changing roles; to the allocation of household tasks and activities; to the extent of help that was acceptable to the care recipient; to adjustment to cognitive changes, as well as to sexual and social expectations as the disease progressed. These negotiations were not always free from conflict as related by dyads struggling to adjust to changes brought about by MS, and often there was a level of frustration noted, especially in the caregiver, when fatigue, or cognitive obstacles in the partner made clear communication and decision-making difficult. Coeling et al (2003) concluded that negotiation was important in dyadic care relationships and suggested that healthcare professionals need to help both members of the dyad to develop negotiation skills. Negotiation recognizes the rights of both the care recipient and the care giver and introduces an element of choice which is empowering to both (Coeling et al 2003). It is argued that successful negotiation enhances adjustment to and coping with chronic illness.

**RECIPROCITY AND CARING RELATIONSHIPS**

**Committed caring relationships**

In the context of this study, this phrase represents a heterosexual couple living in a spousal (married or de facto) relationship where each has expressed long term commitment to the relationship over a period of years (See Glossary).

According to Carruth (1994), **reciprocity** is “the collective affective and behavioural expression of exchanges given and received between a caregiver and a care receiver and among family members”. Caregiver reciprocity was measured by Carruth (1994) using four subscales for the constructs of the Caregiver Reciprocity Scale (CRS) which estimate *warmth and regard, intrinsic rewards of giving, love and affection, and balance within family caregiving*. She suggests in this study that it may be useful to reconceptualize the caring relationship in terms of perceived reciprocity.
Although the CRS and later, the CRS II Scales have been used several times in research studies since their development (Carruth, 1994, 1996 and 1997), and have been used in different caring contexts, as previously mentioned, no studies to date have applied the measures to both care giver and care recipient. If this is a measure of “exchanges given and received”, it seemed logical as discussed earlier that each member of the dyad should be seen as a ‘co-carer’ or ‘carepartner’. It followed that each member of the dyad should have the opportunity to respond to the statements in the measurement scale. Thus, both were asked to respond independently to the CRS II, in this research, and scores were compared by the researcher seeking congruence or difference. The problems encountered in the use and interpretation of scores obtained on this scale and the measures taken to overcome these problems are discussed later in Chapter Eight.

Despite differences in the scores of carepartners, observable and verbalized expressions of love and affection and mutual regard from the interview narratives, may help to support the concept of reciprocity and suggest if the caring relationship could be reconceptualized in terms of reciprocity. Also, the absence of observable and verbalized expressions reflecting these constructs may suggest there are perceived deficits that can be addressed supportively by healthcare professionals. Thus the use of triangulation of quantitative and qualitative methods is used in this study to partially overcome this difficulty as discussed in Chapter Eight.

Becker, (1986), maintains that reciprocity is a moral virtue and a fundamental idea that has been the subject of ethnographic studies, experiments in developmental psychology, social anthropology and political theory. Becker’s work relates mainly to reciprocity in human interactions at the societal level, but many of the concepts of reciprocity are applicable between and among individuals in community, family and spousal relationships. Becker (Becker 1986, p. 73) states that the empirical evidence for the existence of a social norm of reciprocity is overwhelming and an extensive bibliography is offered to support this view. The depth of Becker’s discussion on reciprocity goes beyond the scope of this paper, but his work does help to lay a solid foundation for the existence and importance of the concept of reciprocity in committed caring relationships. Mutuality/reciprocity can exist regardless of whether the contribution from each member is seen to be ‘equal’. A dyadic relationship can be one in which one party gives more than the other, or the care giver gives care for a reason different from that expected by the care
receiver, but as Coeling et al (2003) propose, the interaction follows an agreed set of negotiated ‘rules’ (Coeling 2003).

The dyad may not always have a pleasant relationship, or may comment on their problems hinting at unresolved issues of power and control in the relationship. Healthcare professionals who maintain an awareness of the four constructs of reciprocity as described by Carruth (1994) when interacting with spousal dyads, may explore and support the ‘rewards’ that each person perceives they receive from the other. This can be affirming and empowering for both members of the dyad. If the relationship is perceived to be unequal, professionals may explore the motivation for staying in the relationship. For some, it may be gratitude for past care or gifts (payback); a desire to make up for past deficits, a sense of duty or moral obligation based on spousal vows, or perhaps, the convenience of maintaining the ‘status quo’ and the perceived difficulties that might be incumbent in making a change. Altruism is not seen as an element of reciprocity by Becker (1984). There may be need for further constructive guidance by healthcare professionals in the form of developing negotiating skills or seeking and utilizing further respite or support resources. Smith (1999) rates mutuality between caregiver and care recipient as a variable that affects quality of life and caring relationships (Smith 1999).

**DISRUPTIVE LIFE EVENTS AFFECTING THE WESTERN EXPECTATION OF CONTINUITY OF LIFE**

Illness has been called ‘intrusive’ by many writers and Gail Becker (Becker 1997) explores the notion of viewing life-altering situations as ‘disruptions’ to the Western cultural expectation of linearity in the life course. Western cultural values of ‘life as a journey’, work and ‘doing’ as contrasted to the Eastern value of ‘being’, provide a useful background for explaining responses of carepartners in MS to progressive losses of ability that affect their lives, change spousal roles, and effectively limit the ability of the individual to exert control over his/her destiny. Becker (1997, p7) challenges the concept of ‘life as a journey’, which is the prevailing cultural expectation and suggests it may be necessary for carepartners to reconceptualize their own situation, recognizing that it is not easy to go against cultural norms, expectations and beliefs.
Other Western formulations that follow the ‘linearity’ concept are recognized in Erikson (1963) and his ‘ages and stages of man’, Duvall (1971), in the linear ideas proposed for family development over time, and perhaps Kubler-Ross (1978), who proposed linear stages of Grief and Loss. Each of the above-mentioned theorists have modified their strictly linear ideas as research in real life has suggested the presence of greater flexibility, variability and movement in a disorderly rather than linear fashion among the ‘steps’ or ‘stages’.

Becker (1997), a medical anthropologist, published a book representing many years of work interviewing persons who have experienced disruptions to their lives, including chronic degenerative illness. Becker concluded that Western culture emphasizes linearity in the expected life course, but accepts that real life is more unpredictable than this ideal (Becker 1997 p.5). When disruptions occur, Westerners attempt to restore order or linearity with emphasis on the individual and self related to society. Multiple sclerosis is a disease that primarily affects persons of Northern European ancestry and who may be expected to subscribe to the Western cultural expectation of linearity in their lives as described by Becker. Becker believes that ‘bodily experiences are given voice through narrative’ (Becker 1997 p. 81). She reports that following a disruptive life event, people go through a period of ‘limbo’ (p 119), or stunned inactivity, before they can take steps to restore order in their lives by whatever coping methods they deem best. Biographical disruption may be triggered not only by any major event such as the onset of a chronic disabling illness, but also by any major changes in that condition. The illness and its meaning for the person’s life must be continually rethought (Becker, Radius et al. 1978, p.123).

COPING WITH DISRUPTIVE LIFE EVENTS

Coping

Folkman (1966) has been interested in the area of coping for over twenty years developing typologies and coping scales with Lazarus, whose seminal work is credited with starting the study of coping as early as 1966. Lazarus and Moskowitz (2004) reviewed and critiqued the coping literature to the turn of the century (Lazarus and Moskowitz 2004). The authors examined past work and discussed new developments while recognizing the extensive and often argumentative debate about the merits of
coping research, which is a complex, multidimensional field of study that tries to explain who thrives under stress, and who does not and to explore effective interventions (Lazarus and Moskowitz 2004). In this thesis, the work of Lazarus and Folkman (1984) and their eight ways of coping has been explored with carepartners experiencing multiple sclerosis as their principal stressor. However, other theories and typologies were also explored as the interviews were analyzed.

Caring and coping: coping congruence, couple coping

It has been difficult to clearly separate the literature relating to caring and coping and there is considerable overlap in concepts and disciplines which are researching these topics. Coping theories, typologies and strategies will be explored later in this chapter. However a brief digression will address the concept of ‘coping congruence’ discussed by Pakenham (1998). His study, building on the work of Barbarin (1983) and Revenson (1994), suggests that congruence between the partners coping responses may be used as a predictor of adaptation. Coping congruence has also been explored by Lazarus and Folkman (1984). Pakenham’s study with people with MS aimed to extend the current knowledge of the coping process in care giver/receiver dyads and to add to the limited research on the psychosocial impact of MS on both carepartners and their dyadic relationship. The concept of ‘couple coping’ emerges at this time.

Dyadic coping is described as the interplay between the stress signals of one partner and the coping reaction of the other (Revenson 1994).(See Glossary). Revenson describes this process as follows: “couple’s coping can be conceptualized in terms of restructuring the relationship and the response to the illness to maximize congruence between the coping styles used by husband and wife”.(Revenson 2004, p.126; Revenson et al 2005).

Bodenmann (2001) explored the concept of coping congruence in relation to dyadic coping, but results were inconclusive. It appears that there is as yet no clear determination whether congruence in coping styles in spousal dyads aiming to reduce the stress of coping with chronic illness is conducive to adaptation in all cases. It seems that this is still an individual and personal matter related to individual differences and possibly to cultural expectations (Bodenmann in Smelser and Baltes 2001). This suggests there is scope for further research on the benefits of coping congruence in dyadic couples.
Bodenmann (2005) notes a change in the literature in the past decade from an individual-oriented perspective when viewing illness as a personal issue, to a broader view placing illness in a social context that includes variables such as social support, family resources and marital functioning. This change in focus has led to different conceptualizations of the dyadic coping process as one that involves both partners in their efforts to establish and maintain close relationships, to maintain congruence of individual coping efforts within both partners, and interpersonal coping processes involving both partners in order to reduce problem and emotion-focused stress (Barbarin, Hughes et al. 1985; Coyne and Smith 1991; Bodenmann 2001; Bodenmann 2005; Bodenmann 2005). Various strategies were identified by these authors exploring the concept of relationship-focused coping described as ‘active engagement’ in which both partners are involved in constructive problem-solving and helping to explore the feelings of the other; ‘protective buffering’ which included hiding concerns, denying worries and avoiding disagreements. These authors assume that relationship-focused coping preserves and enhances social relationships (reducing dysfunction in relationships) and emphasises the importance of empathic coping which includes affective awareness of the partner’s problems and communicating this understanding to the partner in an appropriate manner (Bodenmann 2001).

In his discussions of a dyadic focus on carepartners with MS, Pakenham (1998) concluded that if psychological intervention is advisable, it should include both care giver and care recipient, although he found no studies to support this recommendation in the literature (Pakenham 1998). This same author suggested that coping-skills training be offered to couples to foster adjustment to MS. He notes that this training needs to be ongoing in view of the ever-changing and episodic nature of MS, where one strategy may not suffice in all instances nor at all times (Pakenham 1998). An earlier study by Kramer (1993) suggested the teaching of adaptive relationship-focused coping strategies. It has been noted earlier that the spousal relationship changes with the increasing level of dependency of the person with MS, and the concomitant increase in the burden of care experienced by the partner, including loss of employment and valued leisure activities in many cases. This is a very real issue for dyads that needs to be addressed by healthcare professionals as suggested by Kramer (1993) and Pakenham (1998).
Lyons et al (2002) note the fact that family caregiving has relied only on the perspective of the caregiver without considering systematically the views and opinions of care recipients. They discovered in their study of sixty three caregiving dyads that there is little disagreement about care recipients, but considerable variation in agreement between carer and care recipient on their appraisal of caregiving difficulties. Relationship strain was perceived by the carer but not by the recipient in many cases (Lyons et al 2002).

Badr (2004) developed a scale to simultaneously measure emotion-focused, problem-focused, and relationship-focused coping, using several existing scales as a basis. Results of this interesting study showed couples who were more congruent in their use of active engagement, and more complementary in their use of protective buffering and avoidance coping, reported greater marital adjustment. Although husbands and wives may employ different coping strategies, the results highlight the importance of examining the ways in which spouses cope together in the face of a shared stressor. Badr (2004) remarks that couples may need help in learning strategies that are acceptable to them to support and enhance their relationship when coping with the stressors of chronic illness.

Coping has been described by Lazarus and Folkman (1984) as “the cognitive and behavioural efforts used to manage the internal and external demands of situations that are appraised as stressful” (Lazarus and Folkman 1984) (See Glossary). These same authors later (1998) published an historical analysis of work done by researchers over the past fifty years in developing coping theory, analysing historical and perennial issues related to coping. Many psychologists have contributed to our current knowledge of stress, how individuals appraise stress and what measures they take to cope with it, expanding on earlier work that identifies stress management as either problem-focused or emotion-focused. Lazarus and Folkman (1984) developed and revised a Coping Inventory based on extensive interviews, and identifying eight ways of coping. (Lazarus and Folkman 1984). These instruments have been used in many research studies and although very useful, they have not been found to apply to all situations. Persons seldom use one strategy exclusively, and it is difficult to perceive which ones are seen to be most effective by persons undergoing episodic stress in chronic progressive illness.

Early coping theorists, as discussed by Carver, Scheier et al (1989), recognize two basic types of coping: problem-focused (strategies aimed at altering the source of stress) and
emotion-focused (strategies aimed at reducing the emotional distress brought about by the stressful situation). Later theorists have categorized seemingly unique behaviours within these two basic types, but this has not always been easy. Studies examining coping congruence in marital dyads related to adjustment have produced inconclusive results as they attempted to identify gender differences in coping styles. There is agreement that many different variables entered into the choices people made regarding a coping style to address a given stressful situation (Lazarus and Folkman 1984; Carver, Scheier et al. 1989; Hewson 1997; Badr 2004).

It was at first hypothesized that problem-focused coping and couple coping congruence equaled good adjustment, but it was later argued that adjustment was better if the male used problem-focused coping strategies and the female used emotion focused coping (Barbarin, Hughes et al. 1985). In these earlier studies, the causes of the stressful event were different and there may be many other reasons for the inconsistent findings making it difficult to generalize any findings to other situations. Carver et al. (1989), for example used a sample of undergraduate university students facing a stressful situation to develop their coping scales (Carver, Scheier et al. 1989). This population (university students) may have appraised the threat of their stressor very differently from persons experiencing a life-altering or life-threatening illness situation. It thus appears that the concept of congruence in coping, although interesting, is not yet clearly supported by empirical research studies (Bodenmann 2005). Congruence in the couple’s perception of reciprocity in their relationship, may be worthy of further study and interpretation in terms of marital satisfaction. As we saw earlier, Pakenham (1998) argued that psychological interventions for couples with MS should include both Carepartners. He recommends that conjoint therapy may be more effective than individual focused therapy when psychological intervention is indicated (Pakenham 1998, p.276).

Instruments to identify coping styles and strategies have been developed over the years and efforts have been made to evaluate the effectiveness of these in the assessment of coping and adapting to stressors. One of the more recent coping assessment instruments was developed by Pakenham (2002), specifically designed to measure coping in multiple sclerosis. This instrument, the Coping with MS Caregiving Inventory (CMSCI), was compared to the (WOC), the Ways of Coping Inventory of Lazarus and Folkman (1980; 1984).
Hewson (1997) developed a model called the Episodic Stress Responses Model (ESSR), while working with families experiencing the losses of abilities involved in rearing a hearing-impaired child. Her work suggests that major stressors can be seen as large, identifiable events that can exceed the stress threshold for an individual, or can be an accumulation of ‘hassles’ which can have the same effect on the individual coping with losses of ability. This model was later applied to families experiencing the losses of ability that occur in MS (Hewson and Germanos 2003). These researchers argue that the use of the Kubler-Ross Loss and Grief model should be replaced with the ESSR model which does not pathologize grieving that is extended beyond the Kubler-Ross Model’s acceptable time parameters. Viewing losses of ability from a pathological point of view, according to Hewson (1997), is counterproductive for positive outcomes and adjustment. Hewson (1997) maintains that persons have a stress threshold within which they are capable of coping quite well from their own resources. It is only when this threshold is exceeded, that the normal coping mechanisms do not work (Hewson 1997). Appraisal of stressors depends on many variables and is unique to the individual (Shaw 1999). It is suggested that carers and care recipients coping with multiple sclerosis experience grief not only at the initial diagnosis but episodically during the trajectory of the disease as losses of ability and freedom are noted and pleasurable activities are curtailed by the illness. Coping strategies change according to the unique situation of the individuals involved and their appraisal of the stressors at any particular time.

The Hewson-Germanos study, reported at the 2003 Sydney MS Conference, found five identifiable coping strategies used by persons with MS including:

1. looking for causes (seeking information),
2. hoping for a cure,
3. managing life,
4. adjusting to changes as they occur, and
5. dealing with it, living life and ‘just doing it’

This typology is perhaps more useful than the older Lazarus and Folkman (1984) Eight Ways of Coping (WOC) when dealing with multiple sclerosis. Conclusions from their study suggest that the ESSR Model is a better model to apply in situations of progressive
losses of ability such as MS rather than the older Kubler Ross Model (Hewson and Germanos 2003).

Factors influencing coping include the context of the stressful situation and may be health related, work related or family related; may depend on who is involved, how the event is appraised, on gender and on age. A study by Lazarus (Lazarus 1991), revealed that work related stress favours problem-focused coping strategies while health related stress favours emotion-focused strategies. However, later analysis by Lazarus suggests it is unlikely that any one method of coping is used exclusively by any one person when facing a new stressor (Lazarus 1998).

The focus of this present research study has been on the lived experience of carepartners, where one member of the spousal dyad had been diagnosed with multiple sclerosis. Chapter Six: Multi-tiered Analysis of Interview Transcriptions, reports on the perceptions, both positive and negative, related by interviewees of their experience as carepartners in MS, at a particular point in time.

The concept of making meaning through caring was also present in the literature, together with unspecified reported ‘gains’ in the care giving experience. Interestingly, the neutral view in describing the care giving experience called ‘appraisal’ emerged as the period of time when the person or dyad goes through a ‘moment of truth’ as they face an uncertain future with multiple sclerosis and ask themselves “Will we make it through this choppy water?” (Bogle, Percy et al. 1999), and then set out to make some sort of plan to cope with this reality. Bogle et al (1999) suggest that this process of appraisal and decision making depends considerably on the premorbid personality of those involved (Bogle, Percy et al 1999).

The term ‘hassles’ is also mentioned by several authors and their cumulative stressful effect is described by Hewson 1997, and Hunt 2003. (Hewson 1997; Hewson and Germanos 2003; Hunt 2003). Pozzilli et al (2000) agree that there is a reciprocal effect on the spousal dyad when one partner is experiencing physical or emotional difficulties. Thus healthcare professionals need to be alert to this situation and explore flexible and acceptable interventions to improve the situation for the benefit of both.
A few recent studies have explored the lived experience of husbands and wives living with MS (Cheung and Hocking 2004; Courts, Newton et al. 2005) capturing the experiences of loss and gain experienced by the dyads. Others have explored coping and psychosocial adjustment among PwMS (McCabe, McKern et al. 2004), as they examined the observed coping strategies used by three hundred and eighty one persons in their study sample. Their findings suggest problem-focused coping strategies assist PwMS to adjust to their illness more effectively and there is a need for healthcare professionals to develop educational programs to teach these strategies to their clients. (McCabe, McKern et al. 2004).

As noted by Folkman (2004) in her study, and discussed earlier in the “Limitations” section (Chapter One), the present study depends on self-reports and is subject to distortion and bias based on memory problems and retrospective falsification (Folkman and Moskowitz 2004). Frank (2005) reminds researchers that every story changes each time it is told. Cognitive and behavioural changes in MS such as memory loss present additional potential problems when analysing the stories told by PwMS. (Frank, Melbourne Workshop, University of Melbourne, 2005). Assessment of coping will always have to depend on self-report measures, or use of observational and inferential techniques. However, using heuristic inquiry and allowing the voice of the observer/researcher to be heard, may in some cases support the self-reported statements made by participants, or may provide conflicting views to challenge deeper analysis and clarification (Moustakas 1995).

SUMMARY OF CHAPTER TWO
Chapter Two has reviewed current literature relating to Caring, Carers and their needs, moving the focus of the study to the dyadic spousal caring relationship and the concept of “carepartners” that includes the care recipient and the dyadic relationship. Concepts of reciprocity and mutuality are explored in the context of a changing relationship exposed to the challenges of chronic illness for the carepartnership. Some issues of chronicity, including depression and chronic sorrow are briefly addressed. Finally, the literature on coping theory is briefly explored as it relates to the ways of coping used by individuals and couples when facing a disruptive life event such as MS. In Chapter Three:
Methodology and Methods, the rationale for selection of the methods for this study is discussed, together with the literature support for these methods.
Chapter Three: Methodology and Methods

INTRODUCTION

This descriptive, phenomenological and hermeneutic research study uses both quantitative (descriptive and inferential statistics) and qualitative (interviews, observation and narrative analysis) methods to seek breadth and depth of information on the lived experience of care partners where one member of the dyad has been diagnosed with multiple sclerosis. The study seeks to understand how the person with multiple sclerosis and the identified care partner perceive MS to impact on their lives and relationships. Perceived reciprocity is explored as a possible mediating factor in life satisfaction of persons with MS and their care partners.

The proposed study was presented to the University of Melbourne Human Ethics Committee, to ensure that the Methodology met the criteria demanded by the University. A few clarifications were requested by this Committee and they required an assurance in the interests of confidentiality, that all documents would be sent out to each participant separately and not as a couple. It was also recommended that persons be interviewed separately for the same reason. When these modifications to the design were agreed to, permission was received to go ahead with the collection of data (See Appendix D).

This chapter includes: a review of the research questions itemized in Chapter One; description of the two phases of the study; rationale for selection of mixed methods in the study; the population and study sample; a description of the survey and the rationale for selection of the items included; description of the measurement scales; piloting of the survey; recruitment strategies, and the plan for data entry and statistical analysis. Also included are the criteria for selection of the sub-sample for interview; format and plan for interview, and plan for analysis of transcribed interviews. A further section discusses triangulation of quantitative and qualitative data that have emerged from the two phases
of the research. A summary of the methodology and methods chapter and an introduction to the Data Analysis Chapters conclude this chapter.

**TWO PHASES OF THE RESEARCH**

**Phase One:** consisted of a demographic questionnaire, four scales measuring depression, reciprocity, life satisfaction and functional wellness and four open-ended questions together with the statistical analysis of these data.

This ‘self-report’ survey packet was mailed to persons expressing an interest in participating in the study. A variety of recruitment strategies were used to reach the population of persons with multiple sclerosis residing in Australia. Each survey packet consisted of a demographic questionnaire and four measurement scales containing statements to which the participant was asked to agree or disagree, using a Likert scale for degrees of agreement or disagreement. These are described below. Also included were explanatory letters and consent forms, together with a postage-paid return envelope (see Appendix A.5). Information obtained from the returned surveys was entered into an SPSS (Statistical Package for the Social Sciences) computer program and a preliminary descriptive statistical analysis of results was completed (see Chapter Four-A). Analysis of the original data set provided little data on ‘carepartners’ and their relationship. Thus, the data set was split and a new file was labeled “pairs only”, to identify dyads of carer/person with MS, believing that the phenomenon of interest (the impact of MS on committed caring relationships) might be found in this subset. Further inferential statistical analysis was completed on this dyadic file. (see Data Analysis Chapter Five). Analysis of the four open-ended questions followed a quasi-statistical style as described by Polit and Hungler (1997, p.378). Themes (topics) included by participants in their responses were listed fully, and then grouped into similar categories. Results were tabulated according to frequencies as described in Chapter Four-B. The four open-ended questions were a part of the fourth scale (the Functional Wellness Inventory). Analysis of the data contained in Phase One of the study was used to inform selection of a pool of ‘carepartners’ for interview in Phase Two, described below.
Phase Two: Qualitative methods used in this phase included interviews and observations conducted in the homes of the carepartners. As the researcher taped and transcribed all the interviews these transcriptions were subjected to an extensive multi-tiered analysis to identify the main concerns, coping strategies, and essence statements used by interviewees to describe the impact of MS on their lives and relationships. A hermeneutic analysis of observations and insights identified by the researcher forms a part of this Phase. (See Figure 6.1, Chapter Six).

Marshall and Rossman (1995) agree that there is a wide array of methods subsumed under the heading of ‘qualitative research’. They describe the process of designing qualitative research as one of immersion in the everyday life of the participants in the chosen research setting and seeking to understand more deeply the participants’ perspectives on their world. This type of inquiry is viewed as an interactive process between the researcher and participants. It is both descriptive and analytic and relies on people’s words and observable behaviour as the primary source of data (Marshall and Rossman 1995). In this study, the participants are experiencing life with MS. Of interest are the choices made of words and metaphors used to describe their reality. Careful listening may unveil statements that illuminate their key concerns and needs as well as their unique interpretation of their current life situation.

Preliminary analysis of the whole data set (n=203) obtained in Phase One provided a useful demographic description of the population sample, and further descriptive and inferential statistical analysis of the ‘pairs only’ sub-set helped to inform the selection of an interviewee pool of care recipient/carer dyads (n=85) from which the sub-sample was selected for interview in Phase Two, as mentioned above. Time and cost constraints on the study limited the available pool to Victorian residents (n=23 ‘carepartners’) from which twelve spousal pairs were selected for face to face interview. Since 89% of the identified pairs were heterosexual spousal dyads, it was from this group that the sub-sample was recruited (see Data Analysis Chapter Five).
Phenomenology, hermeneutics and heuristic inquiry (See Glossary)

This qualitative phase of the study is described as phenomenological and hermeneutic, and employs the principles of heuristic inquiry described by Moustakas (1995). (see Glossary). Moustakas defines this type of inquiry as:

A type of inquiry that seeks to discover or find the nature and meaning of experiences; the researcher is present as a person throughout the process, and through internal search and self-dialogue, the researcher understands the phenomenon with greater depth (Moustakas, 1995, p.24).

According to Patton (1990),

Phenomenology is a theoretical perspective that attempts to understand social phenomena from the actors’ own perspective. The important reality is what people perceive it to be” (Patton 1990) p.57).

Self-perception represented an overarching perspective for this researcher throughout this thesis. The interviewee was asked to “tell your story” of life with MS as each perceived it. The question to be asked is: “What is the essence of the phenomenon as experienced by these persons?” (Polit. and Hungler 1997, p. 203).

Hermeneutics is a theoretical approach that can inform qualitative inquiry and assists with placing other theoretical orientations into perspective. According to Patton (1990), hermeneutic philosophy asks:

What are the conditions under which a human act took place that makes it possible to interpret its meanings? Palmer (1969) explains: ‘hermeneutics originated with German philosophers’, and is described as ‘the study of interpretive understanding of meaning in narratives’ (Patton, 1990, p.84).

Origins of the hermeneutical technique hark back to the practice of interpreting legends and stories in early Greece. Palmer explains that to make any sense of or to interpret any text, it is important to know what the author (the teller, or interviewee) wanted to
communicate (Palmer, 1969, in Patton, 1990, p.84). To place any qualitative study in hermeneutic context it is necessary to know the researcher as well as the researched. Both voices are heard in the narrative analysis. (see “Prologue: Positioning of the Researcher”, and Chapter Six, which contains direct quotes from interviewees).

**RATIONALE FOR SELECTION OF MIXED METHODS AND TRIANGULATION**

According to Polit and Hungler (1997), the purpose of the methods section is to communicate to readers what the researcher planned to do to answer the research questions or to solve the research problem. This section describes selection of methods, together with the rationale for their selection. Polit and Hungler (1997) describe quantitative design as having linear progression whereas qualitative design is circular and iterative. The researcher is continually examining and interpreting qualitative data and making decisions as to how to proceed based on observations and interview transcriptions as these are revisited in progressive depth (Polit and Hungler 1997).

According to Darlington and Scott (2002), the use of quantitative and qualitative methods in the same research study is justified when the researcher believes that one method alone would not serve to answer the research questions. This was the case in this research as the issues to be examined were both complex and multifaceted. Darlington and Scott (2002) rather colourfully describe quantitative methodology as being on ‘high, hard ground’, where questions posed can readily be transposed into hypotheses that may be tested statistically. On the other hand, qualitative research is described by these authors as referring to the ‘swampy lowland’ that depicts much of human experience and behaviour. These phenomena are best explored using qualitative methods such as observation and interview (Darlington and Scott 2002). Of course, when mixed methods are used, there is the risk of obtaining conflicting findings. It may be noted, for instance, that findings in the different methods ‘may not speak to each other’ (Darlington and Scott 2002, p.138). However, each method is selected to examine a different aspect of a given phenomenon and to shed light on a different research question. Mixed methods research is used extensively in current research designs and is now recognized as a type of research in its own right as discussed in the recent text by Creswell and Plano-Clark (Creswell and Plano Clark 2007).
Overview of Mixed Methods Research (MMR)

As greater understanding of MMR develops, the definition may evolve, but according to Creswell and Plano-Clark (2007):

Mixed Methods Research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of quantitative and qualitative approaches in many phases of the research process. As a method, it focuses on collecting, analyzing and mixing both qualitative and quantitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone (Creswell and Plano-Clark 2007, p.5).

Advantages of using MMR over a single world view or epistemology (quantitative or qualitative methods alone) include:

Mixed Methods Research

1. Provides strengths that offset the weaknesses of both quantitative and qualitative research,
2. Allows more comprehensive evidence for studying the research problem than either of above methods alone. Researcher has permission to use all of the tools available for data collection.
3. Helps answer questions that cannot be answered by one method alone,
4. Encouragers researchers to collaborate across the sometimes adversarial relationship between quantitative and qualitative researchers,
5. Encourages the use of multiple worldviews or paradigms rather than the typical assumption of certain paradigms for quantitative research and others for qualitative research. It encourages the researcher to think about a paradigm that might encompass all of quantitative and qualitative research, such as pragmatism, as
suggested by Tashakkori and Teddlie (2003), or using multiple paradigms in research,

6. It is 'practical' in the sense that the researcher is free to use all methods possible to address a research problem. Researchers use both 'numbers' and 'words', and solve problems using both inductive and deductive thinking, employing skills in observing people as well as in recording behavior. It seems natural for researchers to employ mixed methods research as a preferred mode of understanding the world. (Creswell and Plano-Clark, 2007, p.10)

This mixed methods sequential exploratory design consists of two distinct phases: the quantitative followed by qualitative (Creswell, Plano-Clark et al 2003). In this design the researcher first collects and analyzes the data describing the study sample demographically as well as statistically analyzing the numeric data from selected measurement scales included in the survey packet (the quantitative phase). These data help to inform selection of an interview pool of persons believed to possess the phenomenon of interest ('Carepartners' in caring relationships and dealing with MS). The second or qualitative phase consisting of interviews and observations by the researcher follows next in the sequence. These data are analyzed. Where results/findings from each phase were unclear or inconclusive, Triangulation of methods was used to illuminate the findings (as in the case of the Reciprocity Scale and its results) as illustrated in Figure 1.3, p.30. Thus each phase helped support or refute the findings of the other or raised further questions for research providing broader and deeper understanding of the phenomenon of interest. In this study three of the four mixed methods research designs as presented in Table 4.2, p.85, of Creswell and Plano-Clark (2007) are represented.

However, statistical results from the first phase added useful information and substance to the qualitative findings and are in keeping with the pragmatic approach to the use of a variety of research methods advocated by Tashakkori and Teddlie (2003), Creswell (2003) and Creswell and Plano-Clark (2007).

**Rationale for use of Mixed Methods Research design.**
This researcher believed that no single method could provide the depth of understanding that was desired when examining caring relationships under the impact of MS.”
Triangulation (see Glossary)

In this research study, the researcher has chosen to use triangulation of findings obtained in each method to increase trustworthiness, and to highlight any areas where further research seemed indicated. According to Patton (1990), triangulation, or the use of multiple methods in the study of a single phenomenon strengthens the study design. Data analysis in this study used both an iterative and sequential approach, with the researcher being mindful of data obtained by both methods. Patton (1990) further suggests that triangulation is a powerful solution to the problem of relying too much on any single data source or method. Earlier work by Lincoln and Guba (1988) argued for methodological purity, saying that mixed methodologies were undesirable and made it difficult for a researcher to mix inductive and deductive strategies at the same time. These views have been widely contested by researchers, and Guba and Lincoln have since revised their view (Guba and Lincoln 2005). The use of mixed methodologies in research has become the norm rather than the exception (Lincoln and Guba 1985; Patton 1990; Darlington and Scott 2002; Creswell and Plano Clark 2007).

Since this thesis focuses on the lived experience of dyads coping with the daily challenges of multiple sclerosis and its impact on the caring relationship, observation and interview complemented and enhanced the surveys and measurement scales. However, surveys and scales were also considered necessary to identify the characteristics of the population with MS, residing in Australia, and their identified carers, from which a smaller sub-sample was drawn for face-to-face interview (see Figure 1.1. Map of Australia.). As previously noted, the descriptive statistical analysis of the survey and measurement data helped to inform selection of the interview pool.

THE POPULATION AND THE STUDY SAMPLE

The population from which the study sample was drawn consisted of persons diagnosed with MS and their identified support person or carer residing in Australia during the time of recruitment of participants. Precise numbers of this population have been difficult to obtain, and estimates varied from 15,000 to over 20,000 persons. Victoria was estimated to have 3700 to 4000 persons with MS, but it is believed that these numbers under-represent the true picture (Multiple Sclerosis Society of Victoria, 2003). Current longitudinal studies (Simmons, 2004) are providing more realistic figures (see Figure 3.1
“Australian Multiple Sclerosis Latitude Prevalence Gradient”). Several reasons have been put forward for the lack of hard data on incidence and prevalence of MS worldwide, including the reluctance of doctors to label a person as having MS until more than one identifiable episode suspicious of MS has occurred; the varying availability of modern diagnostic technology, and the fact that MS is not a reportable disease (MS Victoria Conference 2004).

Participation was by self-selection. There was no attempt to use random selection, and findings are not generalizable (See limitations, Chapter One). Characteristics of this population have been described more fully in Chapter One under the heading: ‘Incidence and Prevalence of Multiple Sclerosis in Australia’.

Figure 3.1. Australian Multiple Sclerosis Latitude Prevalence Gradient (map is reproduced here with permission from the Executive Officer of the MSRA, 2006)
DEVELOPMENT OF THE SURVEY INSTRUMENTS

The demographic survey and measurement scales were designed to obtain information from both the care recipient and the carer. It was therefore important to make the documents clear, concise, consistent in presentation, legible, of a reasonable length, and relevant to both the carer and the person with MS (PwMS). The surveys were colour-coded, but identical in other respects, with only one small section indicating that questions specifically referred to the PwMS only. A space on the outside of each survey folder was provided for alphanumeric coding purposes. Several scales that measured the phenomena of interest were reviewed and rejected, and those retained were scales that met the desired criteria. Scales were rejected if they were too lengthy, relevant to only one person in the dyad, or included repetitive statements present in other scales. When a choice was available, self-selection scales were used. The final survey packet consisted of:

1. A demographic questionnaire designed by the researcher,
2. Four scales;
   - The Center for Epidemiological Studies-Depression (CES-D);
   - Caregiver Reciprocity-II (CRS-II),
   - Life Satisfaction Index-Z (LSI-Z), and
   - The Functional Wellness Inventory (FWI),
3. A letter describing the study and giving directions, as well as
4. A consent form for participation in the study,
5. A consent to interview, and
6. A postage paid envelope for return of completed forms and survey documents to the researcher. (See Appendix A.1, A.2, A.3, A.4, and A.5).

The questionnaire and scales are described in detail below with the rationale for the choices offered. Reliability and validity of the scales each demonstrated a satisfactory alpha coefficient of reliability greater than 0.80. All scales have been fully discussed under a descriptive paragraph for each scale and analyzed in Chapter Four-A.

THE DEMOGRAPHIC QUESTIONNAIRE

Many demographic questionnaires have been designed to obtain a baseline profile of participants in research study samples. Several existing questionnaires were examined for
guidance, but none met the specific criteria for this study and therefore a unique
demographic questionnaire was designed by the researcher and included selected
variables that were later used in the analysis of data. The rationale for inclusion of certain
variables is discussed in this section.

Initially, the study was intended to include only the State of Victoria, Australia, but after
publication of the call for participants on the MS Australia website, (see Appendix E.1) it
became evident that persons from other States were also interested in the study and these
participants were accepted. Persons offering to participate but residing in countries other
than Australia, (over twenty initially, and rising to forty) were excluded. They were
thanked for their interest by email but advised that due to constraints of design, distance
and cost, they could not be included at this time. It is evident from overseas responses that
there is scope for an international study on the impact of MS on caring relationships.

Items are listed below as they occur on the survey form (see Appendix A.5). The rationale
for each item is given.

1. **Name** was not requested or included, for privacy reasons, but details identifying each
participant were recorded in ‘The Code Book’ that is kept in a locked cabinet.
Contact details included name, address, gender, whether PwMS or Carer, email
address (if any), telephone number and State of residence. Other items recorded in
the book included: the date that the survey was posted, date returned, and whether or
not a ‘Consent to Interview’ was signed. Personal identifiers were needed in the event
of non-response, to enable a reminder contact to be made and to make arrangements
for interview if participants were selected in Phase Two of the study. This
information will be destroyed at the conclusion of the study according to University
of Melbourne protocol. The Code is alphanumeric and consists of 8 numbers/letters
that include:
- Identification number -ID, 000,(001-300),
- Recruitment method (0S=snowball, SC= short circuit, 0W = web, etc.), Gender,
  (X= female; Y=male),
- Whether a person with MS or a carer (a=person with MS; b=carer) and
• State of residence (V=Victoria, Q=Queensland, W=Western Australia, T=Tasmania, A=ACT, S=South Australia, N=New South Wales, D=Northern Territory).

2. **Gender:** Male/female. The literature varies in its reporting of the prevalence of MS in males and females, however, the commonly reported ratio is 2 females to 1 male (Noseworthy, Lucchinetti et al. 2000). Later reports by the MS Society (2005) indicate that the ratio of females to males is increasing, and now approaches 3:1 (Burks 2004 Melbourne MS Conference). Recent reports suggest that more older women are now being diagnosed than has been previously noted and there is an 8% increase in the overall incidence of MS in Australia with a higher ratio of females to males than previously noted (MSRA 2006).

3. **Age bracket.** A seven-step age range was provided, grouping ages in tens, except for those over sixty who were identified as ‘60 and over’. MS is a disease affecting young adults mainly in their most productive working years. Diagnosis is commonly made between the ages of twenty and fifty, but Wollin (1999), suggests a more realistic age range may be fifteen to fifty-five (Wollin 1999). Although MS has been diagnosed in children, this is not common and it is relatively uncommon for diagnosis to be made after age fifty-five. However, it was expected that many participants would be in the over sixty age range, since MS can have been diagnosed many years before their participation in this study. More persons under the age of sixty might be expected to use the internet. Many of those who elected not to participate were in the younger age groups but believed they should not be included since they were still employed and this interesting opinion is addressed later. Although diagnostic methods are more refined at the time of writing, it has been common in the past for several years to elapse before confirmation of diagnosis.

4. **Country of birth.** Studies indicate that prevalence of MS is higher in temperate climates of the world, or in persons who are ethnically related to these populations (Murray 2005). MS is very rarely seen in Black or Asian populations unless there is a Caucasian parent or ancestor (Geisser 2003), but these statistics appear to be changing. (See Epidemiology section, Chapter One).

5. **How long have you lived in your present State?** There is some literature to support the finding that personal susceptibility to MS may be affected by having lived the
first fifteen years of life in a temperate climate. (Hammond and English 2000; Noseworthy, Lucchinetti et al. 2000).

6. **Which town or suburb?** Of interest to note if there appeared to be any evidence of clusters of PwMS, although this was difficult to determine due to the relatively small size of the sample. This variable was also included to assist in the selection of interviewees from urban, regional or rural localities. However, it was not used in data analysis as no further useful data emerged from this question.

7. **Home ownership?** This is an accepted indirect indicator of socioeconomic status of participants. Results were compared to the norms for the general Australian population (see Data Analysis Chapter Four–A- ABS, Census 2001/Australia/Victoria).

8. **Education.** This may be a significant variable in the self-selection of volunteers for the study, since those with higher levels of education may be more likely to have computer skills, access to a computer and may be interested in participating in research.

9. **Marital status.** Five options were given for selection. Some studies have suggested that separation or divorce is fairly common among people with MS (MSNA Conference, New Zealand 2007). However, these assumptions have been questioned by research which suggests that the divorce rate among persons diagnosed with MS does not appear to be different from divorce rates for the general population (McCabe, McDonald et al. 1996).

10. **Living arrangements.** Four options were offered, from living alone, living with a partner, living with other family members, or with persons who were non-family. This variable may affect life satisfaction and scores on the Functional Wellness Inventory (FWI), which measures perceived satisfaction of ten basic human needs (Zuluaga 2000)

11. **Dependent children.** Presence or absence of children in the home may affect other variables.

12. **Age and gender of dependent children.** (See previous comment)

13. **Principal income provider?** Yes or No. This variable was of interest in the analysis of the impact of MS on employment. However, the small size of the interview sub-sample did not allow valid conclusions to be drawn from the data analysis.
14. **Current income from all sources.** No numeric value was requested, but three options were given: ‘satisfactory’, ‘barely enough’, ‘not enough to meet my/my family’s needs’? Although no specific income range was requested or needed, this wording was consistent with this researcher’s belief that the person’s perception of satisfaction of basic needs is paramount (Patton 1990; Zuluaga 2000). Perceived poverty or financial stress has been stated to be a key variable affecting life and marital satisfaction and functional wellness (DeJudicibus and McCabe 2002).

15. **Employment.** Several options were offered, although it was recognized that many possibilities were not covered by the options. A “self employed” option was added prior to analysis of data, due to inclusion of this statement by several participants. For analysis, this variable was reduced to three: (1) some work, (2) disabled, unable to work, and (3) other.

16. **Type of work.** Five options were offered. Again, options existed that were not listed, such as ‘self-employed’, resulting in a potentially incomplete picture. The category ‘self employed’ was added prior to analysis of data, for the same reason as in Employment, above.

17. **Require assistance from persons outside family?** Yes/No. This variable was seen as one of the key indicators of perceived disability and was used as part of a composite variable created later (see Perceived Disability Index, Chapter Four).

18. **If yes, which community services are used?** These questions were included to give some indication of the level of assistance needed by the participant, and to identify which community agencies were most commonly used to meet these needs.

19. **Mobility?** Four options were offered. Selection of option 4: “I cannot go anywhere without considerable assistance”, was selected as a second variable in the development of the PDI (see Chapter Four-A). Since mobility is frequently a serious problem for PwMS, this variable was an important inclusion in the questionnaire (Murray 2005). (see common symptoms of MS, Chapter One).

20. **How often were you home alone?** Three options were offered. This variable was included to offer some insight into the social interaction or perceived social isolation of the participant, in conjunction with the next three questions.

21. **Out last week?** See previous comment.
22. **Where did you go?** Seven options were offered, and responses were considered to be indicators of the level of social isolation or family and community involvement (see graph Destination, Chapter Four, Figure 4.1)

23. **Activities or hobbies?** Space was provided for individuals to list interests, activities and hobbies to suggest social activity and interaction and to identify any possible environmental connections with MS. Note: No useful data was provided for analysis as few participants answered this question.

24. **Self-assessment of overall health?** Five options were offered. It has been noted in the literature that perception of health does not always relate to actual presence of disease or disability, but to how the person “feels” about their health, and this perception can have a marked impact on their attitude or life view (Allen 1910; Travis 1977). If the person selected “fair” or “poor” as their perceived level of health, this was selected as an indicator in the development of the PDI scale. (see development of PDI Scale, Chapter Four)

25. **Person with MS?** Yes/No. Two other options allow the carer (support person) to describe their role more precisely.

26. **For person with MS only – how many years since diagnosis?** Recent advances in diagnostic studies allow MS to be diagnosed fairly soon after the onset of symptoms. However, it is not uncommon for older persons with MS to have been aware of symptoms for many years before a definitive diagnosis of multiple sclerosis had been given. This variable is not considered to be an indicator for the level of disability, since MS symptoms can be very vague and diverse, since the disease follows such a wide variety of trajectories and since there is no apparent measurable correlation between disability and time since diagnosis. There is some evidence, however, that in general, the longer the time elapsed since diagnosis, the greater the possibility for increased losses of ability, both physical and cognitive (MS conference, Sydney, 2002).

27. **Other concurrent diagnoses?** Recent research has attempted to link MS with other diseases such as arthritis, diabetes and other autoimmune diseases. This question was included to explore the experience of the study sample with concurrent diseases, or
serious conditions that may have resulted from MS. The person was asked to list other diseases for which they were currently being treated.  

28. Type of MS? Persons were asked to write in the type of MS that they have been told they have at time of diagnosis. An additional selection of ‘I don’t know’ was included.  

SELECTION AND DESCRIPTION OF SCALES

This research study focused on life experiences from the point of view of the participants, therefore self-perception and self-report scales were chosen. These are believed to more closely reflect the actual experience of the person (Patton 1990; Anderson and Goolishian 1992; Courts, Buchanan et al. 2004). However, Folkman and Moskowitz (2004) remind researchers that self reports are also subject to faulty memories and retrospective falsification, which advises caution in interpretation (Folkman and Moskowitz 2004). Scales were avoided if they were too lengthy, too technical, or were not believed to measure common experiences for both the person with MS and the identified carer. The scales needed to include all the desired information without overburdening the participant.

The four scales selected are discussed in detail below. They included:

1. The Center for Epidemiological Studies – Depression (CES-D) scale (Radloff 1977),
2. The Caregiver Reciprocity Scale II, (CRS-II) (Carruth 1996),
3. The Life Satisfaction Index-Z (LSI-Z) (Wood 1969), and the

Center for Epidemiological Studies – Depression (CES-D) Scale

It has been widely agreed in the literature that depression is present in a high percentage of persons with chronic illness, including MS and in carers of these persons. It was considered important to use a screening tool to measure this phenomenon in the study sample (Bay 2002; Clinic 2003). There are a number of depression scales and many of these were reviewed for possible use in this thesis. The CES-D, designed by Radloff

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3 Very few were noted, and some wrote in comments such as: “I only have multiple sclerosis – isn’t that enough?” (pilot participant Q ay). Treatment was noted, however, for complications related to MS, such as bowel and bladder problems, depression, fatigue and muscle spasticity.

4 Terms for the different manifestations or ‘types’ of MS are still unclear and are continually being revised, thus this question provided no useful information, and the majority chose ‘I don’t know’.
(1977), is a widely and currently used scale that measures depression and mood by making statements relating to ‘Feelings during past week’. The CES-D was developed to measure depression in the general population (USA), and it has proved to have a high level of reliability and validity in studies over the years, and in several countries (McDowell and Newell 1996).

This twenty item set of statements measures current (past week) indications of depressed mood, especially the affective component. Items for use in this scale were selected from previously used and validated depression scales, including the Beck Depression Index (BDI), the Zung Self Rating Depression Scale, Raskin’s Depression Scale and the Minnesota Multiphasic Personality Inventory (MMPI), as well as items from the literature. The CES-D correlates well with the above-mentioned scales. The scale was selected because it has been widely used, has excellent reliability and validity, good discrimination between members of the general population and the psychiatric population, and it is easy to administer and score. Range of scores lie between zero and sixty with higher scores indicating greater levels of depression. Mean scores for the general population range between 7.9 and 9.25, while mean scores for a psychiatric sample was 24.42. A cut off point of 15-16 has been suggested, but this may be taken higher to avoid false positives. The instrument is not a diagnostic tool, but must be considered a screening instrument only. High scores suggest further investigation of depression may be warranted.

The CES-D has good internal consistency, with an average alpha coefficient of reliability of .85 for the general population and .90 for the psychiatric population. The scale has fair stability as measured by test-retest scores ranging from .51 to .67 (when re tested two to eight weeks later) and dropping to .32 to .52 when re tested from three to twelve months later. This is not surprising since the scale measures perception of mood during the past week and this is liable to change over time in the general population.

The CES-D has excellent concurrent validity, and correlates significantly with other depression and mood scales as mentioned above. It discriminates well between members of the general population who say they ‘need help’ and those who do not. McDowell and Newell (1996) agree with Radloff (1977) about the cutoff point for this scale, and concur that it should be used as a screening tool only. These authors also suggest that if over five
items are missed on the scale, a score should not be calculated. McDowell and Newell (1996) reviewed several studies in which this scale was used and concluded:

The CES-D is one of the best-known survey instruments for identifying symptoms of depression. It has been extensively used in large studies and norms are available. It is applicable over age and sociodemographic groups and has been used in cross-cultural research studies. Its limitations are that it cannot discriminate between primary and secondary depression induced by other conditions, and whose treatment and course may be different. It may not discriminate depression from general anxiety. Although the CES-D compares favorably with other self-report scales, concerns remain about its specificity (McDowell and Newell 1996).

The unpredictable nature of MS may contribute to depression and or anxiety. Thus, scores on this scale were viewed with caution.

**Caregiver Reciprocity Scale II (CRS-II)**

Carruth of Hammond, Louisiana (USA) developed the original Caregiver Reciprocity Scale (CRS) as part of her doctoral studies (1994). The scale was designed to test the concept of reciprocity among adult children, care givers of their elderly or dependent parents (Carruth 1994). Carruth describes caregiver reciprocity as the collective expressions of exchanges and balance between the care recipient and the care giver, as well as among family members (Carruth 1997). The CRS-II was modified in 1997 to use as a measure of reciprocity among elderly spousal caregivers. Reciprocity refers to the bi-directional exchange of valued resources between and among individuals. The desire to reciprocate, according to Becker (1986) is acquired and contributes to equilibrium within relationships.

Carruth suggests that the decision to take on a care giving role for an adult, dependent parent establishes a new relationship. This relationship change is true for the dyad as well as for other family members (Carruth 1997, p.93). The same could be said for other situations in which the relationship has changed subtly over time, or drastically due to a
sudden decline in the care recipient’s abilities, from caring partner to care giver or care recipient.

Definitions and perspectives on reciprocity were derived by Carruth (1994) from an extensive review of the literature on reciprocity and by analyzing contents of interviews conducted prior to the development and refinement of the scales. The CRSII measures the quality of interpersonal exchanges between care giver and care recipient as well as between care giver and family members. The scale consists of nineteen statements derived from interviews with care givers in similar situations to those in the study group. Four constructs were identified in the development of this tool as salient components of caring, and statements were ascribed to each as follows:

- warmth and regard, (seven statements);
- intrinsic rewards of giving, (five statements);
- love and affection, (four statements); and
- balance within family care giving, (three statements).

These constructs formed four subscales within the CRS and the CRSII. The original twenty two item scale was reduced to nineteen items following psychometric testing of the instrument and its component items. Although the CRSII was used in a study of elderly spousal caregivers, it has also been applied in other studies, including minority groups in the US (Carruth 1997).

Carruth (January, 2004, personal communication) stated that four scores were recorded for participants in each of her studies, but since there was excellent correlation between and among constructs, a single score would be able to replace multiple scores for each participant without prejudice to reliability and validity. Carruth also stated that she had administered the scale to caregivers (carers) only, and not to both members of the dyad.

Thus, my study represents the first time the CRS II has been administered to both care receiver and care giver. The author of the instrument expressed considerable interest in this new application. However, it may be necessary to review the scoring when care recipient and care giver are both tested, and to suggest the meaning to be ascribed to widely divergent or congruent scores. Congruence and divergence were noted in scores
obtained by each carepartner and further interpretations were sought through concurrent analysis of the interview data that are relevant to the constructs of reciprocity as delineated by Carruth (1994; 1997). 5

A five point Likert scale was used to determine agreement/disagreement with the statements, ranging from 1, strongly agree, 2 agree, 3 undecided, 4, disagree, and 5 strongly disagree. There were no right or wrong answers, and participants were asked to select their degree of agreement/disagreement with the statements. Six items were reverse scored, and the total score was obtained by summation of all responses. No attempt was made in this study to divide the score into its component subscales. Low scores were considered indicators of high perceived reciprocity in the relationship.

Carruth (1997) suggested that:

increasing caregivers’ awareness of the reciprocal nature of the relationship and the level of gratification derived from the caregiving role may be an effective approach in helping carers to achieve and maintain family satisfaction (Carruth 1997 p.99).

She further suggested that:

focused interventions increasing the ability of caregivers to identify gratifications in the light of demanding physical care need to be designed to encourage the caregivers to recognize their internal rewards system (Carruth, 1997 p.99).

Reliability & Validity. Extensive psychometric testing of both instruments (the CRS and the CRS II) was conducted, including use of two panels of experts, and pilot studies to eliminate unrelated items. Inter-item reliability, item-subscale, item total, test-retest and alpha coefficient correlations were performed and yielded satisfactory levels of reliability. The extent of construct validity, using exploratory factor analysis and convergent and

5 Carruth’s unique scale was presented at a research conference (1995) attended by this researcher, who discussed with the author, the possible use of the reciprocity scale in a PhD proposal being designed at the time. This proposed study related to ‘care partners’ (of any age) in which one member of the dyad had a chronic disease. Carruth agreed that the concept of a “care partnership” was a good one and that the CRS II could be a useful scale, giving her permission for its use.
discriminant validity (LISREL - structural equation modeling) was determined (Carruth 1994, 1996, 1997). It was postulated that reciprocity may be a mediating factor in perceived family satisfaction. In the application to carepartners in MS, scores on the reciprocity scale were compared to life satisfaction scores and scores obtained on other scales used in the survey. (see data analysis of scores on scales Chapter Four-A and Chapter Five).

Early respondents in this study appeared to misunderstand the fact that the scale applied to both care-giver and care recipient. It was evident that care recipients could not readily see themselves as ‘carers’ of the well partner. This problem was partially resolved by adding the following amendment to the scale reading:

Please Note: Both the carer and the person with MS are requested to respond to all statements. ‘My partner’ and ‘The person I care for’ are to be regarded as interchangeable.

No further problems have appeared since this amendment, but it is still unclear if all participants fully understood the concept.

Life Satisfaction Scale (LSI-Z)

The LSI-Z is a short, simple and easy to administer thirteen item scale developed from the original Life Satisfaction Index of Neugarten, Havinghurst and Tobin in 1961. It has been widely used to measure general feelings of well being in elderly populations in the U.S. and Australia. Other studies, as reported by McDowell and Newell (1996) have used the scale to measure life satisfaction in persons with chronic illness, with satisfactory results, and an acceptable alpha coefficient of reliability. The original scale has undergone several revisions and refinements over the years, culminating in the LSI-Z credited to Wood, Wylie and Schaefor (1969). Many scales were reviewed for possible use in this study. The terms Life Satisfaction and Quality of Life are now considered synonymous in the literature, with greater emphasis on the latter in more recent times. Descriptions of both scale terms imply that ‘morale’ is the key concept being measured. However, Neugarten et al (1961) identified five attitudes associated with life satisfaction:

1. zest for life as opposed to apathy
2. resolution and fortitude vs. resignation
3. congruence between desired and achieved goals
4. high physical and psychological self-concept
5. happy, optimistic mood tone

Wood, Wylie & Schaefor (1969) revised the scale and reduced the statements from twenty to thirteen, but the five attitudes above remain intact. While Quality of Life scales are valuable and comprehensive instruments, they do not measure self-reported perceptions. It appears to this researcher that parameters indicating ‘quality of life’ are set by others in relation to such variables as income, health, social network, and others. The person completing the scale must then indicate to what extent they meet these externally set criteria in order for someone to measure their ‘quality of life’. The LSI-Z, on the other hand, asks the participant for their own perception of their satisfaction with life related to the above five attitudes. This subtle difference led to the selection of the LSI-Z for this study. Although the scale was originally designed for use with older adults, it is applicable to adults at any point in the life course. Reliability and validity levels are satisfactory. Test-retest reliability for the LSI-Z ranged from .80 to .90 in three samples of person with chronic disease (McDowell and Newell 1996). Although multiple sclerosis has been described as a disease of young people, most commonly affecting those between the ages of 20-40, or 15-55 according to (Wollin 1999), this disease continues throughout the life span in varying degrees of severity. In this study, approximately 50% of participants were over fifty years of age. Thus it was arguable that this scale was relevant to the study sample, and its self-report nature is consistent with this researcher’s view that a person’s own perception of their reality is paramount when considering life satisfaction.

McDowell and Newell (1996) conclude their extensive discussion of the scale by stating:
The Life Satisfaction Index-Z has been extensively used and has several strengths, including reliability, strong correlations with other scales and availability of reference standards. Despite these strengths, there have been a number of critical reviews of the LSI-Z which question what precisely the scale measures, including failure to reflect conceptual distinction between such concepts as quality of life, anomie, happiness and morale. The single score obtained on the scale obscures the multidimensional nature of the scale. The wording of some items has been criticized.

The meaning of certain words and phrases by persons with different cultural backgrounds is recognized, and may cause different interpretations than those intended by the creator of the scale. These differences may occur even within seemingly homogeneous populations using the same basic language such as English, or may be due to regional differences within a common geographic area.

McDowell and Newell (1996) further state:

> Despite the conceptual uncertainties of the LSI-Z and despite its age, we do not recommend discarding it in favor of other life satisfaction scales, most of which have been less thoroughly evaluated. Its psychometric properties rival those of the best among comparable indices: the task is to identify clearly, what, in conceptual terms, the scale measures (McDowell and Newell, 1996. p.202).

The five attitudes associated with ‘morale’ ascribed to the measurement scale and contributing to life satisfaction appear well-represented in the statements contained in the LSI-Z.

**The Functional Wellness Inventory (FWI)**

The Functional Wellness Inventory (FWI), designed by Carter (Carter 1990), consists of twenty-nine statements and four open-ended questions designed to explore the client’s perception of any deficits in their ten basic needs as delineated in the Zuluaga-Raysmith (Z-R) Model (Zuluaga 2000). This Model is described in some detail in Chapter One, and
illustrated in Figure 1.2. The Model is used as a conceptual framework for this study of the impact of MS on ‘carepartners’ living with the condition, and is based on multidisciplinary theoretical foundations.

Several existing health assessment instruments were reviewed in the attempt to find one that measured perceived satisfaction with the ten basic needs. The FWI was selected to achieve this goal. This instrument is based on the original work of Carter (1990), who developed and tested the Functional Wellness Index as part of her doctoral studies in Texas, USA. It demonstrated excellent levels of reliability and validity. Carter reported that with a sample of 101, the alpha coefficient of reliability for the Functional Wellness Index was 0.86. (Carter 1995).

The statements in the original Carter document were carefully checked against the ten needs of the Z-R Model by this researcher and a few minor changes in wording were made. The original statement: ‘I think of death and suicide’, was separated by this researcher to become two separate statements, since thoughts of death can be considered age/condition-appropriate, or reasonable in situations of severe or chronic illness, while thoughts of suicide should always be investigated further by healthcare professionals.

In addition, four open-ended questions were added by Zuluaga (1994) to the instrument to further focus on the client’s most pressing concerns, strengths and values. Responses to these open-ended questions have been found to be very helpful in planning further interventions with home health clients in the community. It is this revised instrument that has been used in the published study mentioned below, and in this current research study with persons with MS and their identified carers.

At the suggestion of the University of Melbourne Human Ethics Committee (2001), and in the interests of maintaining confidentiality, surveys were mailed out to individual participants separately with the request that each complete the forms themselves and post them back to the researcher. However, it is possible that another person may have helped some participants. This needs to be considered in analyzing the trustworthiness of the results. Several statements in the FWI offer support for statements used in other scales in this study.
The Functional Wellness Inventory was used as a health assessment tool for clients and carers in Home Health Nursing and in two baccalaureate nursing education programs over a period of three years in the U.S. Both novice and expert nurses found that use of the instrument facilitated the rapid identification of the most pressing needs of clients. Most users reported they had saved at least one professional visit by using the instrument for client assessment. A research study implementing the Model with a sample of home health clients and their caregivers was completed on 1996 and the results were published (Zuluaga, 2000). In this published study, the FWI was found to have an alpha coefficient of reliability of .84. Responses are scored using a five point Likert Scale: 1=Always; 2=Usually; 3=Sometimes; 4= Rarely and 5=Never. Of the twenty-nine items in the scale, ten items were reverse scored. Possible scores range from 29 to 145 with low scores suggesting high-level functional wellness, or perceived satisfaction with basic needs. Statements relate to the ten basic needs as listed in the following table. It will be noted that some statements relate to more than one need and this is consistent with the inter-relatedness of needs. Individual needs may be identified by item analysis. (Note: Chapter Five discusses the breakdown of this scale into two subscales for greater clarity in the inferential statistical analysis).

In summary, The Z-R Model (see Chapter One, Figure 1.2) proposes that every person has ten basic needs and to the extent that these needs are perceived to be met to a satisfactory level by the entity, the entity will be able to function autonomously in the community from their own resources and without need of community services. The entity (see Glossary) exists on a wellness-illness continuum, and may choose by their lifestyle choices to move freely along this continuum towards high level wellness or towards preventable illness and premature death (Travis 1977). Travis (1977) and Kubler Ross (1978) agree that there is always a potential for a higher level of wellness, even in the face of disease, disability or impending death. In this study the Model is applied to persons with MS and their identified main carer or support person. Each person is considered independently, and scores of care recipient/carer dyads are compared in the statistical analysis, with the dyadic significance of the scores discussed in the narrative transcriptions analyzed in Phase Two. (See Data Analysis)
Table 3.1. Ten Needs of the Z-R Model Related to Items in the FWI.

<table>
<thead>
<tr>
<th>Ten Basic Needs of Z-R Model</th>
<th>Number of items relating to each need</th>
<th>Statements relating to each need</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical Health (PH)</td>
<td>8</td>
<td>2,3,4,7,10,11,15,23</td>
</tr>
<tr>
<td>2. Mental, Emotional, Social and Spiritual Health (MESSH)</td>
<td>14</td>
<td>1,3,5,6,8,9,13,15,16,17,18,19,28,29</td>
</tr>
<tr>
<td>3. Income</td>
<td>3</td>
<td>12,13,14</td>
</tr>
<tr>
<td>4. Accommodation</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>5. Communication</td>
<td>2</td>
<td>23,24</td>
</tr>
<tr>
<td>6. Safety/Security</td>
<td>1</td>
<td>21</td>
</tr>
<tr>
<td>7. Mobility</td>
<td>2</td>
<td>7,22</td>
</tr>
<tr>
<td>8. Knowledge</td>
<td>1</td>
<td>26</td>
</tr>
<tr>
<td>9. Need/Oppportunity for Development</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>10. Need / Opportunity to make a contribution / purpose in life</td>
<td>2</td>
<td>27,28</td>
</tr>
</tbody>
</table>

As can be seen in the above table, some items overlap with two or more basic needs. Justification for the large number of statements relating to MESSH, (Mental, Emotional, Social and Spiritual Health), relates to the variety of dimensions of importance to human beings that fall under this psychosocial category.

The Functional Wellness Inventory was separated into two subscales, the FWI(ph) and the FWI(messh), for descriptive and inferential statistical analysis of ‘pairs only (See Chapter Five). One major limitation of this measurement scale is the low number of statements allocated to many of the basic needs.

**Researcher note:** Interpretation of the open-ended questions was based on thematic analysis of content, and frequency of themes. Additionally, replies indicated in a clear manner, values perceived by the entity to enhance their wellbeing and life satisfaction. In some cases these may appear unrealistic, but often offer a basis for dialogue with the health professional. There are possible cultural implications as some persons appear to be reluctant or unable to discover their own strengths, and again there is an opportunity to dialogue with the health professional to help identify and reinforce visible strengths. (See thematic analysis, Chapter Four-B)
PILOTING

Survey Instruments and documents. In early 2001, after the University of Melbourne Human Ethics Committee granted permission to proceed with the research study, (Appendix D) and prior to sending any surveys to participants, draft documents were pilot-tested with a group of fifteen female post-graduate colleagues who expressed their willingness to review the papers and make comments to improve clarity as needed. Members of the group were asked to carefully review these documents as if they were participants and to make any relevant suggestions. In addition to the draft survey booklet, a brief questionnaire was prepared for each peer participant to complete after reviewing and completing the survey documents.

The peer group was arbitrarily divided into two groups to simulate the study sample dyads. One group was asked to imagine that they had been diagnosed with MS and the other was asked to think of themselves as caring partners of a person with MS (PwMS.). Survey booklets were colour-coded: Gold for PwMS and Blue for Carers. The pilot group, however, comprised females only, and this presented a problem in the simulation. Females outnumber males in the MS population worldwide, so there are a large number of male carers whose simulated views could not be tested in this pilot exercise. Nevertheless, several useful suggestions emerged, resulting in minor changes to the documents.

Piloting the draft documents with a group of peers and faculty proved to be helpful and participant feedback resulted in some refinements in question and statement wording. One proposed scale was excluded (The Caregiver Burden Scale) since all persons in the pilot group agreed it related primarily to one member of the dyad and not to the other and violated the criteria set by the researcher stating that all scales had to refer to both members of the dyad. The survey (questionnaire and scales) was intended for use equally by the person with MS and the main carer, who were being asked to see their relationship as one of each caring for the other. This concept was not easy for many early participants to grasp as previously noted. The concept of the reciprocal nature of the relationship of care giver/care recipient was further explored at interview with twelve spousal dyads in Phase Two of the study. Following the piloting of the documents and making the desired
changes, 400 survey booklets were printed and posted to participants as requests were
received over the next ten months (n=264 posted).

MULTIPLE STRATEGIES USED IN RECRUITMENT OF PARTICIPANTS
Initially, there were expressions of interest to participate in the research study from
various countries in the Northern Hemisphere as well as from every State in Australia.
Responses followed a dissemination of information about the research study on MS
Australia website, at http://www.msaustralia.org.au. The web, of course, reaches every
corner of the globe (see web notice in Appendix.E). Approximately forty potential
participants responded from the US and Canada, all parts of the UK, Yugoslavia,
Switzerland and Spain as well as a large number from Australia. It was necessary to
amend the initial notice on the internet, limiting the study to Australian residents. Thus,
the study sample was drawn from the Australian population of people with MS and their
identified carers (see Chapter One, Figure 1.1).

Recruitment Strategies
1. Recruitment advertisement on the internet. Requests to participate in the study
continued to come in by email from overseas in the ensuing months after placement
of the notice on the above website (May 2002). An email was sent to every individual
thanking them for their interest and explaining that the study was limited to Australia
due to constraints of the study design, distance and cost issues. (see Appendix E.1)
2. Recruitment flyer. A copy of this flyer was sent to all Victorian MS Centres. A flyer
was included in all packets sent out by MSSV (Multiple Sclerosis Society of
Victoria) to newly diagnosed patients over the ten month recruitment period. Copies
of this flyer were also distributed to Victorian residential MS Centres, respite centers
at Williamstown and Watsonia, the Footscray MS Centre, as well as to Barwon
Health in Geelong. (see Appendix E.2)
3. A recruitment letter was sent to all Australian State MS Societies. A flyer was
included with these letters, together with the request that the Society inform their
members of the research study to ensure that all persons with MS in Australia would
have the opportunity to participate if they so desired. Several State MS Societies,
including Queensland, New South Wales, the ACT and later Victoria, assisted and many participants were obtained in this manner. (see Appendix E.4)

4. **An advertisement was placed in newsletters and periodicals** that are circulated to PwMS in several States, including *Short Circuit* (circulation 4000 at the time), *MS News*, and *MS Life*. (see Appendix E.3)

5. **Chat room.** Several e-mail recruitment messages were posted on the MS website/discussion page sponsored by MSSV. As a result, several persons offered to take part in the study. This chat room is used by persons with MS and their families as an informal communication venue, for sharing information and for mutual support during stressful times in the disease trajectory.

6. **Snowball sampling.** Individual referrals were also responsible for a few participants. A limited number came in by referral from professionals who became aware of the study and others were obtained from persons working closely with MS groups and individuals.

7. **An amendment statement was placed at the end of the survey booklet** to enhance its use as a recruitment device: ‘Volunteer participants from all parts of Australia are still needed for this research study. Please share the contact details with other persons with MS and their main carers who may be willing to help. Thank you’. This note was placed on all surveys posted, but there was no indication that this had been an effective recruitment device.

**Process of Recruitment**

At the time active recruitment of participants closed (March 17, 2003), 263 expressions of interest from persons living in Australia had been received and surveys were posted to all of these between April 16, 2002 and March 1, 2003. The return rate after the close of recruitment remained at 203 or 77%. Since the focus of the research was on the dyadic relationship, pairs were sought for the study. If the applicant was a person with MS, they were asked the following question by the researcher:

‘This is a study of the impact of MS on caring relationships: Is there a person you would identify as your main support person or carer, and would this person also be interested in participating in this PhD research study? If so, please give me a name and address and I will post a survey to him/her also.'
Of the 203 surveys that were included in the preliminary data analysis (see Data Analysis, Chapter Four-A), there were 115 PwMS and 88 Carers. The unequal numbers were due to the fact that not all PwMS identified a willing carer or support person, and some carers did not choose to participate, or had recently relinquished their role after the death or institutional placement of their partner. However, no one was refused participation for lack of a partner. The study included 33 males and 82 females with MS. These numbers are consistent with the predominantly female incidence of the disease. There is no argument that the disease affects more females than males worldwide (MS Victoria Conference, 2004).

The participant numbers for this research study were not necessarily representative of the incidence and prevalence of MS in each Australian State, and related more closely to the recruitment efforts in each State. Tasmania’s State MS Society declined to disseminate information about my study saying, when asked, that their PwMS were over-researched. This State, although known to have the highest incidence and prevalence of MS in Australia, was regrettably under-represented in this study.

Several types of caring relationships were identified among the dyads (see Chapter Five). The most common relationship was a heterosexual spousal one. There was one Lesbian relationship, several parent/adult child with MS, two siblings, and a few parents with MS/adult-child carers. (See data analysis, Chapters Four-A and B and Chapter Five).

**ANALYSIS OF SURVEY DATA AND OPEN-ENDED QUESTIONS**

The (SPSS) Statistical Program for the Social Sciences was used to provide descriptive statistics, including frequencies and percentages, and to analyze scores obtained by participants on the measurement scales. This analysis included mean scores, standard deviations and standard error of the mean (see Data Analysis, Chapter Four-A). A review of this descriptive analysis of the original data set suggested that the file needed to be split to separate ‘Pairs Only’ for further descriptive and inferential statistical analysis, since the focus of the study was on the impact of MS on the relationship of the dyad - care giver and care recipient. Chapter Four-B includes a thematic analysis and frequencies of the four open ended questions included at the end of the Functional Wellness Inventory. Chapter Five identifies the types of caring relationships and reports the inferential.
statistical analysis of these using correlations, ANOVA’s (analyses of variance), multiple regressions, and paired t-test analysis of the data for care giver and care recipient. As previously stated, findings from Chapters Four-A, Four-B and Chapter Five, helped to inform selection of an interview pool, from which twelve spousal dyads were selected and interviewed in Phase Two.

**SELECTION OF INTERVIEW POOL FOR PHASE TWO - RATIONALE FOR SELECTION**

Splitting the original data set to identify dyads, (that is: a person with multiple sclerosis and an identified carer or support person) revealed several types of caring relationships, including heterosexual spousal pairs, one female, same sex pair, several adult child with MS and parent carer, sibling pairs, and two who identified a ‘good friend’ as carer. Nearly 90% of the sample consisted of heterosexual spousal dyads (see Data Analysis Chapter Five). Although most Australian States (except the Northern Territory) were represented in the study sample, Victoria provided 43% of respondents. Thus, for reasons of expediency, design, cost and time, the sub-sample for interview was drawn from spousal dyads residing in Victoria, who met the criteria for selection.

**PILOT INTERVIEWS AND REFINEMENT OF INTERVIEW GUIDE AND FORMAT**

Prior to selection of the interview pool, the researcher contacted two early respondents who had indicated their willingness to be interviewed and arranged pilot interviews with these in two States other than Victoria. The purpose was to use the interviews to refine the interview guide, to determine the best format for interviews, and to identify any potential problems in the interview process that might be corrected prior to conducting the interviews with the twelve dyads to be selected later. One set of pilot interviews was conducted in Queensland and another in Tasmania (see Appendix C.1 and C.2).

Both these interview sets were useful in the refinement of a loose interview guide that was designed for use only as a prompt if the interviewee failed to address the phenomena of interest as they ‘told their story’ of living with MS. The intent was to allow the
interviewee to tell their experience from their own perspective with as little direction as possible (see Appendix B)

Taylor and Bogdan (1984) assert:

In contrast to the positivist, who seeks facts or causes of social phenomena, the phenomenologist is committed to understanding social phenomena from the actor’s perspective. The important reality is what people perceive it to be (Taylor and Bogdan 1984, in Patton, 1990, p.57).

**Interview format**

The format for interviews included offering interviewees the option to meet in their own homes or in an alternative venue of their choice where suitable private and uninterrupted space could be provided; at a time and date agreeable to all. All elected to be interviewed in their own homes. After inviting a participant to ‘tell me your own unique story of life with multiple sclerosis’, prompts were offered by the researcher only when needed to cover areas of concern that seemed to be unclear. Time was offered towards the end of each interview for the person to ask questions of the researcher or to speak of related concerns. Interviews were limited to a maximum of one hour each, in recognition of the fatigue factor experienced by many persons with MS. Both PwMS and carer were interviewed separately in all but one case, and on the same visit. All interviewees were asked permission by the researcher to make follow up phone calls to clarify any areas of doubt at the time of interview transcription or analysis. This permission was granted in all cases and two follow up calls were made.

**MULTI-TIERED ANALYSIS OF INTERVIEW TRANSCRIPTIONS**

All interviews were tape recorded and transcribed by the researcher. This method, although time consuming, allowed the researcher to hear and comment, making ‘memos’ on such items as lengthy pauses, inappropriate laughter or unexpected responses, and to review these during the process of data analysis and data reduction. Transcriptions were subjected to three or more tiers of analysis over a period of time (see Schema Chapter Six, Figure 6.1) Metaphors and repeated phrases used by participants were examined,
emerging themes were noted, perceived strengths discovered through adversity were identified, and coping strategies were compared with the Ways of Coping delineated by (Lazarus and Folkman 1984), as well as with other potentially useful typologies (Hewson 1997; Jalowiec, Murphy et al. 1984). Other tiers consisted in using the original words, metaphors and phrases of the participants to capture the ‘essence’ of the experience of living with MS as a PwMS or a Carer, and placing the transcriptions in the contextual framework of the ten basic needs to confirm their pressing concerns.

TRIANGULATION OF RESULTS (PHASE ONE) AND FINDINGS (PHASE TWO)

As previously described by Patton (1990), use of multiple methods (triangulation) is a powerful solution to the problem of relying too much on any single data source or method. Although findings and results from the methods used may not appear to agree in some cases, as suggested by Darlington and Scott (1996), this difference can open avenues for new research. Congruence, on the other hand offers support to the research findings. Brietmayer, Ayers et al (1993) support the use of triangulation as an evaluation of completeness and purpose of the research.

Early respondents to my research study discussed their many dilemmas in dealing with MS in chat rooms, and when one would ask ‘Why don’t you tell them (speaking of the MS Society) what you need?’, the response was ‘We tell them but they don’t listen’. Surely these are the voices of people who feel disenfranchised and marginalized. Thus triangulation is believed to strengthen the trustworthiness of the study and its findings (See Chapter Seven).
SUMMARY

The Methodology chapter has provided an introduction describing the study; reviewed the research questions; discussed the two phases of the study with a rationale for the use of mixed methods; described the population and study sample and provided a detailed description of the survey packet and its contents. After describing the piloting of the survey and interview documents, this chapter discusses recruitment strategies; the process of recording and posting responses as they came in and then goes on to discuss the plan for descriptive statistical analysis of survey data. The splitting of the complete data set into two files, with the new file named ‘pairs only’ that was later subjected to further descriptive and inferential statistical analysis is outlined. Data derived from statistical analysis of both data sets and thematic analysis of open-ended questions were later used to inform selection of an interview pool from which twelve spousal dyads residing in Victoria were chosen for interviews in Phase Two of the study. This chapter describes selection of interviewees, discusses the interview guide, the format and setting of interviews, and mentions the two interstate pilot interview sets in the early stages of the study. Plans for a multi-tiered analysis of the interview transcriptions are included as well as strategies for data reduction and condensing transcriptions to their essence or meaning. Finally, triangulation of results obtained in Phase One and findings in Phase Two, is discussed as a method of adding rigor and trustworthiness to the study and enabling the research questions to be answered more fully from a variety of perspectives.

Chapters Four-A and B, and Chapter Five describe the statistical analysis of the data sets, and Chapter Six discusses the multi-tiered qualitative analysis of interview transcriptions.
Chapter Four-A: Data Analysis

Descriptive statistical analysis of SPSS output for total study sample (n=203)

STUDY PARTICIPANTS
As discussed in Chapter Three, there was a seventy-seven percent return rate from the call for participants sent out throughout Australia, resulting in 203 surveys returned with usable data by the close of recruitment in March 2003. Data from these surveys were entered in the SPSS (Statistical Program for the Social Sciences) program. These entries were carefully checked for accuracy by a third person, and preliminary descriptive statistics were obtained to clean the data and identify any existing errors. Several new variables, including scores obtained by participants on the four measurement scales, were included to facilitate later analysis.

Table 4.1. Responses to recruitment call for participants.

<table>
<thead>
<tr>
<th>Surveys</th>
<th>Initial recruitment=n</th>
<th>Late recruitment=n</th>
<th>Totals=n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed</td>
<td>200</td>
<td>(4-1)=3</td>
<td>203</td>
<td>77.6</td>
</tr>
<tr>
<td>Refused</td>
<td>5</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>57</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>262</td>
<td>24</td>
<td>262</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Late responses (Between March 1-21, 2003)
A total of four surveys were received before the deadline of March 21, 2003 in response to twenty-four reminder letters. Three of these were carer surveys, and one was a PwMS. Eight respondents indicated they no longer wished to participate. In one instance where
both parents (carers) filled out separate surveys, only one was selected for inclusion in the study, thus reducing the total number for analysis to 203. The twofold rationale for exclusion of the second carer follows: It appeared from the survey response that the mother of the adult person with MS performed more of the caring functions than the father, although of course, he provided important emotional support as well. Since all other persons in the study nominated one carer or support person, this second carer was dropped to maintain consistency. There was only a 50% response rate to reminder letters, and only three more valid participants were able to be added to the study. It could be concluded from these results that reminder letters did not often contribute greatly to augmenting the data set.

RELATIONSHIPS

Table 4.2. Relationship Status of Participants.

<table>
<thead>
<tr>
<th></th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>115</td>
<td>56.7</td>
</tr>
<tr>
<td>Carer</td>
<td>88</td>
<td>43.4</td>
</tr>
<tr>
<td>Total</td>
<td>203</td>
<td>100.0</td>
</tr>
</tbody>
</table>

UNEVEN NUMBERS

Total participant data from the 203 surveys included PwMS \( n=115 \), carers \( n= 88 \). Numbers were uneven because some persons with MS did not have a carer, or the carer was not willing to participate, and conversely, there were persons who were carers, and the care recipient was either recently deceased, in care, or was unable to participate.

Since the focus of interest in this study was on the impact of MS on the caring relationship, recruitment was targeted at both persons (dyads), but no one was refused participation for lack of a partner as noted earlier. Initially eighty-seven potential pairs comprising a PwMS and a Carer were identified for further statistical analysis. Two pairs contained excessive missing data and were excluded, reducing the number to eighty-five dyads with usable data. Persons without partners were included only in the demographic
description, with appropriate comments as indicated if the partner did not wish to participate for some identified reason. The data file was then ‘split’ to include ‘pairs only’, and further inferential statistical analysis was performed on these eighty-five pairs (see Chapter Five). Twelve pairs were selected for interview in the second phase of the study (see Chapter Six).

GENDER
The sample included eighty-two females with multiple sclerosis, and thirty-three males with MS. The female/male ratio for this sample was consistent with worldwide and Australian epidemiological data on gender distribution for multiple sclerosis. All sources agreed that females outnumber males although the actual ratio differs with different sources and ranges from 2:1 to 3:1 (see discussion of multiple sclerosis in Chapter One).

AGE
Table 4.3. Age Characteristics of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age group</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>21 – 30 years</td>
<td>7</td>
<td>6.1</td>
</tr>
<tr>
<td></td>
<td>31 – 40 years</td>
<td>22</td>
<td>19.1</td>
</tr>
<tr>
<td></td>
<td>41 – 50 years</td>
<td>21</td>
<td>18.3</td>
</tr>
<tr>
<td></td>
<td>51 – 60 years</td>
<td>43</td>
<td>37.4</td>
</tr>
<tr>
<td></td>
<td>61 or over</td>
<td>22</td>
<td>19.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>115</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>21 – 40 years</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td></td>
<td>31 – 40 years</td>
<td>14</td>
<td>15.9</td>
</tr>
<tr>
<td></td>
<td>41 – 50 years</td>
<td>17</td>
<td>19.3</td>
</tr>
<tr>
<td></td>
<td>51 – 60 years</td>
<td>23</td>
<td>26.1</td>
</tr>
<tr>
<td></td>
<td>61 or over</td>
<td>29</td>
<td>33.0</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>88</td>
<td>100.0</td>
</tr>
</tbody>
</table>
In this sample, 57% of the PwMS were over fifty years of age, while 44% were between the ages of 21-50. It is unlikely that the sample distribution reflected the true population distribution of persons with MS. However, this percentage of older persons in the study sample justifies the use of some of the measurement scales designed for older persons, namely, the CES-D and the LSI-Z. There are few participants in the ‘newly diagnosed’ age range, which is reported in the literature to be in the younger adult years between 15-55 (Wollin 1999). There are instances of childhood MS and there have also been confirmed diagnoses of persons in their 60’s. One possible reason for the low number of ‘newly diagnosed’ could be that many of these people were still functioning reasonably well in employment and family life and therefore did not consider participation in a study such as this to be relevant to their present life situation. If this proved to be a reasonable argument, they would also perhaps find little spare time to complete a survey and agree to a time-consuming interview. The literature reports that there is an element of denial in the early years following diagnosis of MS, and therefore, this group of people would not consider such a study to be of relevance to them (Perham 1995).

Persons in the older age range appeared to exhibit a fairly low level of disability according to the ‘perceived disability index’ (PDI) (see Glossary and discussion later in this chapter). The PDI is a composite measure of disability designed by the researcher for this study and derived from participant responses to six statements included in two of the original measurement scales.

It must be noted here that reliable and accurate epidemiological data of incidence and prevalence of multiple sclerosis in Australia were not available at the inception of this research study, and the data that was available varied with the source. Ongoing research studies are presently under way to fill this gap in current knowledge, and to provide an accurate data base to facilitate research studies and effective resource allocation (Simmons 2004). (See Figure 3.1)

**PLACE OF BIRTH**

Of the persons with MS (PwMS), 81% were born in Australia or New Zealand, as were 77% of Carers. Ten percent of PwMS were born in the United Kingdom (UK) and 14% of Carers were born in the UK. No effort was made to determine if those born in Australia
had ethnic connections to Northern European countries, although several in the small interview sub-sample volunteered this information (see Chapter One).

STATE OF RESIDENCE

Table 4.4. State of Residence of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>State of residence</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>ACT</td>
<td>8</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td>NSW</td>
<td>16</td>
<td>13.9</td>
</tr>
<tr>
<td></td>
<td>Qld</td>
<td>27</td>
<td>23.5</td>
</tr>
<tr>
<td></td>
<td>SA</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>Tas</td>
<td>6</td>
<td>5.2</td>
</tr>
<tr>
<td></td>
<td>Vic</td>
<td>50</td>
<td>43.5</td>
</tr>
<tr>
<td></td>
<td>WA</td>
<td>7</td>
<td>6.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>115</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>ACT</td>
<td>6</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>NSW</td>
<td>12</td>
<td>13.6</td>
</tr>
<tr>
<td></td>
<td>Qld</td>
<td>22</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>SA</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>Tas</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td></td>
<td>Vic</td>
<td>36</td>
<td>40.9</td>
</tr>
<tr>
<td></td>
<td>WA</td>
<td>6</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>88</td>
<td>100.0</td>
</tr>
</tbody>
</table>

All States in Australia were represented in the study sample except for the Northern Territory. Percentages for each State have been influenced by recruitment methods implemented by the researcher, and are not necessarily representative.

Requests were made of each State MS Society in Australia to inform their membership of the details of the proposed research study. Responses to these requests varied from State
to State. The researcher had little control over these variables, and the limitations this placed on the study.

After becoming informed of the presumed effect of a latitude gradient on the incidence and prevalence of MS, several persons reported that they had moved from the cooler, more southern States to warmer climates in the North of Australia in the belief that this might favourably impact the trajectory of MS for them. Thus, the State of residence at the time of the study did not always reflect the participant’s State of birth.

Although participation was by self-selection, all computer-literate persons in Australia had access to recruitment notices on the web for a period of 10 months. Approximately forty-four percent of the sample resided in Victoria. State MS Societies that disseminated information about the study included Queensland, the ACT, and later, Victoria. NSW apologized for not sending out information at the time requested, due to pressure from other priorities at the time; South Australia, Western Australia and the Northern Territory failed to respond and the Tasmanian MS Society declined on the grounds that “Our MS population has been ‘over-researched’ in our opinion” (personal communication, Tasmanian MS Society, 2002). They were reluctant to trouble PwMS residing in Tasmania with further questionnaires at the time. Thus Tasmania, which is known to have the highest per capita incidence and prevalence of MS in Australia, is under-represented in this study. (Simmons 2004). The only participants from this State were obtained from snowball referrals and a few internet contacts.
### HOME OWNERSHIP

Table 4.5. Home Ownership of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Ownership status</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Owner</td>
<td>70</td>
<td>60.9</td>
</tr>
<tr>
<td></td>
<td>Buyer</td>
<td>21</td>
<td>18.3</td>
</tr>
<tr>
<td></td>
<td>Renter</td>
<td>19</td>
<td>16.5</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>5</td>
<td>4.3</td>
</tr>
<tr>
<td></td>
<td>Total has MS</td>
<td>115</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Owner</td>
<td>62</td>
<td>70.5</td>
</tr>
<tr>
<td></td>
<td>Buyer</td>
<td>13</td>
<td>14.8</td>
</tr>
<tr>
<td></td>
<td>Renter</td>
<td>10</td>
<td>11.4</td>
</tr>
<tr>
<td></td>
<td>Board</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>Total has Carer</td>
<td>88</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Approximately 80% of PwMS owned their own homes or were buying a home. About 16% rented accommodation. These percentages, although slightly higher, are fairly representative of the home ownership data for the general population in Australia (Australian Bureau of Statistics 2001 census Australia/Victoria).
Table 4.6. Education of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Highest Level of Education</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Primary</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>41</td>
<td>35.7</td>
</tr>
<tr>
<td></td>
<td>Trade</td>
<td>21</td>
<td>18.3</td>
</tr>
<tr>
<td></td>
<td>Tertiary</td>
<td>32</td>
<td>27.8</td>
</tr>
<tr>
<td></td>
<td>Postgraduate</td>
<td>19</td>
<td>16.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>115</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Primary</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>29</td>
<td>33.0</td>
</tr>
<tr>
<td></td>
<td>Trade</td>
<td>14</td>
<td>15.9</td>
</tr>
<tr>
<td></td>
<td>Tertiary</td>
<td>28</td>
<td>31.8</td>
</tr>
<tr>
<td></td>
<td>Postgraduate</td>
<td>14</td>
<td>15.9</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>88</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**Education**

Approximately 28% of PwMS in the study had tertiary education and 17% held postgraduate degrees. Among carers education levels were slightly lower, with 42% in these categories. The study sample included a variety of professionals, including accountants, occupational therapists, a forensic physician, nurses, teachers, social workers, university lecturers and psychologists. These persons could be more likely to have access to a computer and skill in its use. They might also be interested in helping with such a research study in the belief that participating may help advance knowledge about the disease. Another possibility is that they may have chosen to participate in the study as a way of coping by ‘intellectualizing’. However, these are conjectures only. A comparison of selected study variables with the Australian Bureau of Statistic data for 2001, is provided later in this chapter.
MARITAL STATUS

Table 4.7. Marital Status of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Marital Status</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Married</td>
<td>80</td>
<td>69.6</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>8</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>10</td>
<td>8.7</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>15</td>
<td>13.0</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>115</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Married</td>
<td>76</td>
<td>86.4</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>4</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>4</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>88</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Marital status

Of the PwMS, 70% were married or in a permanent relationship, 14% were divorced or separated and 15% were widowed or single. Essentially, 30% reported that they were single. Carers reported that 86% were in a permanent relationship and 14% were single. Discrepancies in the numbers perhaps reflected the participant’s perception of the nature of their relationship. Data analysis recorded marital status of participants at the time of the study only and did not relate to previous marriages that may or may not have broken down as a presumed result of MS. Several of the interviewees were in second marriages and only one specifically blamed MS for the breakdown of his first marriage.
LIVING ARRANGEMENTS
Of the PwMS, 68% lived with a partner, 18% lived alone; and 14% lived with other family members or non-family, while 85% of carers reported living with a partner and 8% lived alone.

DEPENDENT CHILDREN
In this total study sample, 26% had dependent children at home, while the majority (74%) did not have dependent children. The number of grown children who did not share accommodation was not recorded on the survey. The only way the researcher knew if there were grown children was if the participant offered this information in the context of their responses to open-ended questions or later at interview. Responses often related to the distance adult children lived away from their parents or in terms of the social support and assistance they provided. Dependent children at home may be related to participant’s perception of income satisfaction. However, despite the obvious financial and energy cost of dependent children, responses to open-ended questions suggest that young children provided a valuable source of happiness and joy to participants (see Chapter Four-B).

MAIN INCOME EARNER
PwMS reported that 37% were main income earners while 60% of carers were main income earners; 3% did not respond and represent missing data.
INCOME SATISFACTION

Table 4.8. Satisfaction With Total Income.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Income Satisfaction</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Satisfactory</td>
<td>70</td>
<td>61.9</td>
</tr>
<tr>
<td></td>
<td>Barely Satisfactory</td>
<td>30</td>
<td>26.5</td>
</tr>
<tr>
<td></td>
<td>Not Enough</td>
<td>13</td>
<td>11.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>113</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Satisfactory</td>
<td>56</td>
<td>65.1</td>
</tr>
<tr>
<td></td>
<td>Barely Satisfactory</td>
<td>23</td>
<td>26.7</td>
</tr>
<tr>
<td></td>
<td>Not Enough</td>
<td>7</td>
<td>8.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Missing data: Two persons (1.7%) with MS and two carers (2.3%) did not respond.

Income satisfaction

Participants were not asked to indicate a dollar figure for their income, as explained in Chapter Three, but rather to indicate their perception of their level of satisfaction with their total income from all sources to meet their own and their family needs. Previous research reports that MS has a negative impact on family income (DeJudicibus and McCabe 2002), and it has been found that people are often reluctant to disclose their actual income, believing perhaps that there is a hidden agenda for the question. No participant refused to answer the question as it was phrased in this study. Sixty two percent (62%) of PwMS perceived that their income was satisfactory for their needs, and 65% of carers also perceived their income was satisfactory.

Since over 50% of respondents were over fifty years of age, it could be assumed that they may be receiving supplementary incomes from early retirement and that these, together with available community services may be perceived to satisfactorily meet their needs. However, this cannot be confirmed from the data. Twenty-seven percent in both groups believed their income from all sources was barely satisfactory to meet needs and 12 % of PwMS believed their income was not enough. In many of these cases there were growing children in the home or the family was receiving support from family support services.
Eight percent of Carers also perceived their income was not satisfactory. There were some inconsistencies in the responses, however, when these were compared with income-related statements in other parts of the survey.

**EMPLOYMENT**

Thirty eight (38 %) percent of PwMS in this study were retired, which is perhaps not surprising since a large percentage of the sample were over the age of fifty (see table 4.3 above). Only 3 % stated they were disabled and unable to work. This variable was used later in the development of a new composite measurement variable designed to identify perceived level of disability. (See ‘Development of the PDI scale’ later in this chapter).

**TYPE OF WORK**

The type of work options given included ‘home duties, clerical, unskilled labour, skilled tradesperson and professional’. It became apparent early in the descriptive statistical analysis that the selection did not adequately cover every situation for participants, several of whom wrote in ‘self employed’. This category was added to the list for statistical analysis.

**NEED FOR ASSISTANCE**

Table 4.9. Requires Regular Assistance.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Requires Regular Assistance</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Yes</td>
<td>40</td>
<td>35.1</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>74</td>
<td>64.9</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>114</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Yes</td>
<td>14</td>
<td>16.1</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>73</td>
<td>83.9</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>87</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Note* One person (0.9%) with MS and one carer (1.1%) had missing data.
Require regular assistance from others
Responses to this question revealed that 35% of PwMS required assistance, and 65% did not need outside help, suggesting a fairly low level of disability in the study sample. Only 16% of carers said they needed help and 83% of carers denied needing assistance. This was also a variable included in the composite PDI scale described below.

USE OF COMMUNITY SERVICES
Slightly less than half of the PwMS (45%) utilized community services, and 17% of carers also stated that they used community services. Fifty three percent (53%) of PwMS did not use community services and 81% of carers denied using community services. Again, these figures perhaps reflect the level of disability of the PwMS in the study sample, which seemed to be in the mid-range, excluding both the newly diagnosed (described in this study as three years or less since diagnosis), who might be self-sufficient at this time and the very disabled who would require a full range of assistance at home or in an institution.

TYPE OF COMMUNITY SERVICES
Services used
There were a variety of services used, with differences noted reflecting different State-based provision of services. Since many respondents used initials only to designate the agency used, and each State offered different sources of assistance, this variable proved difficult to analyze. Services most commonly mentioned were home help, home nursing care, and physiotherapy.
### MOBILITY

Table 4.10. Mobility Status of Participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Mobility</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Drive Own Car</td>
<td>68</td>
<td>59.1</td>
</tr>
<tr>
<td></td>
<td>Someone Drives Me</td>
<td>27</td>
<td>23.5</td>
</tr>
<tr>
<td></td>
<td>Public Transport</td>
<td>7</td>
<td>6.1</td>
</tr>
<tr>
<td></td>
<td>Cannot Go Without Lots of Help</td>
<td>13</td>
<td>11.3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>115</td>
<td>100.0</td>
</tr>
</tbody>
</table>

| Carer        | Drive Own Car            | 86                     | 100.0|
|              | Someone Drives Me        | 0                      |     |
|              | Public Transport         | 0                      |     |
|              | Cannot Go Without Lots of Help | 0                   |     |
|              | Total                    | 86                     |     |

*Note. Two carers (2.3%) had missing data.*

### Mobility

Persons were asked whether they were able to drive themselves to where they wanted to go, or if others needed to drive them, if they used public transport, or if they required a great deal of help to leave their homes. This question was considered to be a key indicator of the level of disability for a PwMS. Sixty percent (60%) of PwMS in the study sample were able to drive themselves; 24% needed to be driven by family or friends; 6% used public transport and thirteen persons (11%) were so disabled that they required a great deal of assistance to leave their homes. Of the carers, 98% drove themselves, and 2% did not respond to the question, possibly believing that the question was irrelevant to them. (This variable was considered to be another key indicator of perceived disability (see PDI below). Some potential problems with interpretation existed. For instance, if the respondent selected ‘use public transport’, it could mean that they were mobile enough to manage using buses or trams or trains, or that they required the use of specialized taxis or vans to transport them in their wheelchairs. This question could have been worded more clearly.
HOME ALONE- FREQUENCY

How often were you home alone?
This variable provided little useful information and was omitted from the descriptive analysis.

NUMBER OF OUTINGS PER WEEK? (SEE FIGURE 4.1)

How many times did you leave your house last week?
With PwMS, these numbers varied from 0 to 40 trips. Twenty percent (20%) averaged daily trips out of the house per week (7 trips); 59% left the house less frequently (0-6 times) and the remaining 20% left more often (8-40). There were only 3 persons who went out over 21 times (or 3%). The one response of ‘40’ may have been an attempt to be amusing or an error in reading the question. Among carers, responses ranged between 2-28, with 12% reporting 6 trips out and 27% reporting 7 trips per week. These two categories accounted for 39% of carers in the sample. Twenty percent reported fewer than 6 trips out and 39% reported more than 7 with 15% claiming 10 trips. Mean number of trips for PwMS was 6.3 and for carers was 8.6.
WHERE DID YOU GO? (DESTINATION)

Persons with MS (a) and Carers (b) were offered several options to account for their trips out of the house, including shopping (PwMS = 31%; Carers = 35%), to the doctor, dentist, therapist, other health professional (PwMS = 21%, Carers = 13%), church or social event (PwMS = 14%, Carers = 13%), visiting family or friends, (PwMS = 24%, Carers = 26%), day activity center, (PwMS = 3%, Carers = 2%), concert/sporting event, (7%, and 9% respectively), When “other” was selected, it was sometimes interpreted as ‘work’. A total of 15 participants did not complete this question accounting for missing data.

As can be seen in Figure 4.1 above, the most common activity for both groups was a trip to the shops, while visiting family and friends was next in frequency. Visits to medical professionals were slightly more frequent for PwMS than for carers as might be expected. There was little difference in other categories.
SELF-PERCEPTION OF HEALTH

Table 4.11. Participants’ Self-Perception of Health.

<table>
<thead>
<tr>
<th>Perception of Health</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
</tr>
<tr>
<td>Person with MS</td>
<td>5 4</td>
<td>26 23</td>
<td>42 37</td>
<td>37 32</td>
<td>5 4</td>
</tr>
<tr>
<td>Carer</td>
<td>23 26</td>
<td>35 40</td>
<td>19 22</td>
<td>8 9</td>
<td>1 1</td>
</tr>
</tbody>
</table>

Self-perception of health

‘Self-perception’ is a concept that is valued throughout this study. The perception that individuals had of their own health was of interest. It is noted here that self-perception is subjective and often differs from health assessments made by health professionals. Self-perception may be better or worse than could be inferred from the presence or absence of serious medical conditions. A perception of poor health may be related to other variables. A self-perception of good or excellent health may be related to a higher level of life satisfaction, or to an optimistic and positive attitude. There may also be a relationship between a negative self-perception of health and depression. These possible correlations will be explored later in this chapter. This variable has been selected as a key indicator of disability when participant selects ‘fair’ or ‘poor’ as their perception of health. (See Development of PDI below)

Only 4% of PwMS rated their health as excellent, 23% as very good, 37% as good and 32% as fair, with only 4% rating their health as poor. Notably, 26% of carers reported excellent health, 40% stated that their health was very good, with 22% reporting good health; 9% reporting fair health and 1% claiming poor health. Two percent of carers did not respond and therefore there are missing values for these participants. Options for this variable appeared to discriminate well at the extremes between PwMS and Carers in their self-perception of health. At interview, it was noted that several carers had health conditions or past injuries which may have accounted for their self-perception of health as ‘fair’ or ‘poor’. This perception may also be due to carer burden or burnout. In many
cases, PwMS did not perceive themselves as being severely disabled and that their health was overall very good, good or even excellent.

**FOUR SCALES USED IN THE SURVEY: DESCRIPTION AND ANALYSIS OF SCORES; DEVELOPMENT OF THE PERCEIVED DISABILITY INDEX (PDI)**

Four scales were included in the survey: Depression; Reciprocity; Life Satisfaction and Functional Wellness

Table 4.12. Comparison of Mean Scores, Standard Deviations, and Standard Errors of the Mean on Four Scales for Persons with MS (PwMS) and Carers (n=203).

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number</th>
<th>M (PwMS)</th>
<th>SD (PwMS)</th>
<th>SEM (PwMS)</th>
<th>M (Carers)</th>
<th>SD (Carers)</th>
<th>SEM (Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>115</td>
<td>16.89</td>
<td>9.73</td>
<td>10.52</td>
<td>8.64</td>
<td>0.98</td>
<td>0.92</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>109</td>
<td>32.79</td>
<td>34.26</td>
<td>12.40</td>
<td>9.72</td>
<td>1.19</td>
<td>1.04</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>115</td>
<td>15.56</td>
<td>18.39</td>
<td>6.80</td>
<td>5.39</td>
<td>6.34</td>
<td>0.58</td>
</tr>
<tr>
<td>Functional Wellness</td>
<td>115</td>
<td>63.22</td>
<td>54.55</td>
<td>11.22</td>
<td>11.33</td>
<td>1.05</td>
<td>1.21</td>
</tr>
</tbody>
</table>

Scores attained on the four scales were recorded for each participant as variables on the SPSS program. Means, standard deviations and standard error of the means are presented in Table 4.12 above.

As might be expected in the presence of a chronic, progressive illness, persons with MS recorded higher depression scores than carers (PwMS 16.89, Carers 9.73). It was noted that the depression mean score for PwMS was above the suggested cutoff point for this scale (15/16). The literature reports high levels of depression in studies of persons with chronic illness (Shapiro 2002).

Scores on the Reciprocity scale were congruent in most cases with mean scores of 32.79 and 34.26 respectively (reflecting only a 1.47 point difference). This may be difficult to interpret and on first view appears to suggest that each member of the dyad viewed
reciprocity in the caring relationship similarly. It might also mean that one member of the
dyad (usually the carer) completed the forms for both participants, with or without the
permission of the other. It may well be that any perceived differences in replies might not
be reflective of the actual feelings of the other in these instances. Some persons with MS
found it difficult to see themselves as co-carers, and a number verbalized this view at
interview. There were also several telephone calls from persons who had received the
survey asking for clarification of this concept. Surveys sent out later and containing the
amendment to the CRS-II did not pose this problem. However, it is still not clear if all
participants comprehended the concept of being a ‘co-carer’ or ‘carepartner’. The scope
of this study did not enable analysis of the meaning of widely differing scores in
carepartners.

Carers reported slightly higher life satisfaction (Carers 18.39; PwMS 15.56), as might be
expected, and lower scores on the Functional Wellness Inventory (FWI), indicating a
higher level of functional wellness or satisfaction with the ten basic needs. The Functional
Wellness Inventory proved difficult to interpret, however, and the scale was later
subjected to item analysis and broken down into two separate scales as reported in
Chapter Five. The new FWI became two scales: the FWI(ph) and the FWI(messh), and
provided clearer results on statistical analysis.

**DEVELOPMENT OF THE PERCEIVED DISABILITY INDEX (PDI).**

Initial perusal of the SPSS output for descriptive analysis of the sample suggested that
another variable, derived from the information contained in the surveys, and giving some
indication of perceived disability, would be very useful in the inferential statistical
analysis of a ‘split file’ representing ‘pairs only’. Thus a new variable was created and
named the Perceived Disability Index (PDI). This variable was applied only to the person
with MS, and is composed of six existing variables contained in the survey, as follows:

1. (p.2, #14 on survey ‘Employment’) selects #7 “I am disabled and unable to work”
2. (p.2, # 16 on survey ‘Do you require regular assistance from persons who are not
   family members?’) selects “Yes”.
3. (p.3 #19 on survey ‘Mobility’) Selects #4 “I am unable to go anywhere without
   considerable assistance”
4. (p.3 #24 on survey ‘How do you perceive your health?’) Selects “Fair” or “Poor”
5. (p.9 #7 on survey ‘My activities are limited by my disease or disability’) selects “Always” or “Usually”.
6. (p.10 #24 on survey’ My hearing, vision and speech are satisfactory for my communication needs’) Selects “rarely” or “Never”.

**Scoring on PDI**
A person with MS may score from 0 =no perceived disability to 6 = severe disability perceived. This variable was applied to the 23 PwMS in the potential interview pool of spousal pairs residing in Victoria from which was selected the 12 pairs for interview.
Table 4.13. Six perceived disability indicators for PwMS in interview pool (n=23 Victorian spousal dyads.

<table>
<thead>
<tr>
<th>Employment</th>
<th>Assistance</th>
<th>Mobility</th>
<th>Health</th>
<th>Activities limited</th>
<th>Vision/ Hearing/ Speech</th>
<th>TOTAL PDI INDEX</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
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<td>1</td>
<td>1</td>
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<td>1</td>
<td>3</td>
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<td>16</td>
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<tr>
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<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>23</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>23</td>
<td>23</td>
<td>23</td>
<td>23</td>
<td>23</td>
</tr>
</tbody>
</table>

Range 0-6 X=1; 0= no perceived disability; 5= severe disability perceived

Sixteen PwMS in the sub-sample perceived little or no disability as measured by the PDI (scores of 0-1). Three perceived high disability (PDI scores 4-5).
It may be concluded that the sub-sample does not represent the severely disabled. The most common limitation cited is the limitation of activities (n=12). Surprisingly, mobility was only perceived to be limited by two persons, who also scored high in other items in the PDI scale.

As mentioned above, this index was only applied to the person with MS in the dyad and was included in statistical analyses conducted on the ‘split file of pairs only’, reported in Chapter Five.

DISCUSSION OF THE DESCRIPTIVE STATISTICAL ANALYSIS OF THE TOTAL STUDY SAMPLE (N=203)

The initial preliminary statistical analysis responds to the research question: ‘What are the characteristics of persons electing to participate in the study with a working title of: “Impact of Multiple Sclerosis on committed caring relationships”? Although the recruitment information clearly stated that the study sought persons with multiple sclerosis for the study, together with an identified carer or support person, it was evident that many who filled out the forms and returned them did not have an identified carer or support person, and it would be impossible to discover the impact of MS, if any, on spousal relationships, family members or support persons. There were also a few carers who responded without having a care recipient with MS, but the same problem arose in these cases.

A need for further statistical analysis became evident. Since the focus of the study was on dyadic care partners, these were identified. Eighty-seven dyads emerged, but two contained missing data and were dropped, leaving eighty-five pairs with usable data. These were then placed in a separate file named ‘split file of pairs only’ for further inferential analysis. Chapter Five presents the analysis of the ‘pairs only’ file.

Demographic characteristics of the total study sample (n=203) reflected the known worldwide female predominance of persons affected by MS, with a ratio of 2.5 females for each male with MS. However the geographic gradient for incidence and prevalence of MS was not supported in this study, presumably due to recruitment factors. Average age of respondents was about 50% over fifty years of age. All States in Australia were
represented in the study sample except the Northern Territory, with Victoria providing over 43% of participants. Tasmania was under-represented due to reasons already cited. A high percentage of home ownership was noted (88%), and this is slightly higher than the National or Victorian average (ABS statistics for Australia and Victoria 2001). The study sample had higher levels of education than the general population, but lower employment rates than would be expected relative to their level of education, suggesting that MS had a negative effect on employment or had forced early withdrawal from paid employment. Only 37% of PwMS were in full time employment.

Approximately 70% of the study sample were married or in a permanent relationship and 30% were single (widowed, divorced, separated, or never married). Twenty six percent had dependent children at home. Sixty two percent of PwMS perceived that their income was satisfactory for their needs. Thirty five percent required regular assistance with their daily needs, less than half used community services and 11% required considerable assistance to go out of their homes. Twenty percent reported a daily outing from home and the most common destination was to the shops with family visits in second place. Persons with MS visited the doctor nearly twice as frequently as carers. There was little difference in other categories (see Figure 4.1 above ). Self perception of health was of interest, with 64% of PwMS reporting their health as Excellent, Very good or good and only 36% reporting their health as fair or poor. Scores on the four scales used to measure depression, reciprocity, life satisfaction and functional wellness provided mixed results.

**Depression:** Mean scores for PwMS on this screening instrument were slightly higher than the recommended cutoff score of 15/16 (16.89), with significantly lower mean scores for carers (9.73). This is consistent with the ongoing presence of a chronic progressive and unpredictable condition like MS.

**Reciprocity:** Scores for PwMS and carers were remarkably congruent, but there were problems in attempting to interpret these as explained previously; namely, there were no established criteria for administering and scoring the scale to both the care giver and the care recipient, and no indication of meaning of congruent or widely differing scores. Triangulation may offer further insights for analysis of reciprocity in the relationships of pairs when exploring the comments made by interviewees that reflect the presence of the
constructs of reciprocity identified by Carruth (1994) and comparing these with the scores obtained by participants in Phase One on the CRS-II.

**Life Satisfaction Index:** Carers’ scores on this scale suggested slightly higher level of perceived life satisfaction than PwMS as might be expected.

**Functional Wellness:** Results of this scale were inconclusive with PwMS showing slightly higher scores than carers and thus reflecting lower perception of basic need satisfaction and functional wellness. The scale was later subjected to item analysis and compared to the ten basic needs of the Z-R Model. It was divided into two scales as reported earlier.

Summary of the preliminary statistical analysis of the total data set indicated a need for splitting the data file to identify care giver/care recipient pairs for further inferential and descriptive statistical analysis since it was believed that this ‘pairs only’ data set would contain the phenomena of interest. These had been identified as the impact of MS on committed caring relationships, and reciprocity as a possible mediating factor in life satisfaction, and would allow a clearer exploration of the factors impacting the relationship of carepartners.

**COMPARISON OF SELECTED VARIABLES IN THE STUDY SAMPLE WITH AUSTRALIAN AND VICTORIAN POPULATIONS:**

**2001 CENSUS DATA**

“How do the characteristics of the study sample compare with the general population of Australia, and the State of Victoria, from which the sample and sub-sample were drawn?”

It was only possible to partially answer this question due to the differences in the terminology and measurement methods used by the Australian Bureau of Statistics and in this study (ABS 2001/Census). The summary table below compares variables of home ownership, education and marital status for the population of Australia, Victoria and the study sample.
Table 4.14. ABS Census Data for 2001 for Australia, Victoria and study sample: Partial comparison of selected variables; marital status, home ownership; education and employment.

<table>
<thead>
<tr>
<th>2001 Census Data</th>
<th>Population numbers</th>
<th>Marital status = married (%)</th>
<th>Home ownership = own/buying (%)</th>
<th>Education (%)</th>
<th>Employed Fulltime/part time (%)</th>
<th>N=PwMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>18,972,350</td>
<td>50.7</td>
<td>66.2</td>
<td>34.7/66.3</td>
<td>65.1/31.9</td>
<td>15,000/18,000</td>
</tr>
<tr>
<td>Victoria</td>
<td>4,644,950</td>
<td>51.6</td>
<td>70.7</td>
<td>34.8/65.2</td>
<td>64.6/32.4</td>
<td>4,000/5,000</td>
</tr>
<tr>
<td>Study sample</td>
<td>203</td>
<td>77.0</td>
<td>77.0</td>
<td>46</td>
<td>37</td>
<td>115</td>
</tr>
</tbody>
</table>

Discussion of key points in above table:

- **Population**: The study sample of n=203 represents nearly 1% of the Australian population, and the Victorian interview sub-sample n=46 represented nearly 1% of the Victorian population.

- **Marital status**: Since the focus of this study was on pairs consisting of a PwMS and an identified carer, it is not surprising that numbers of married persons in the study sample exceed both the State and National averages. This is consistent with the carer literature which reports that most informal caring in chronic illness is provided by spouses (Aronson, Goldenberg et al. 1996; Wollin 1997)

- **Home Ownership**: The study sample contains a slightly higher percentage of home owner/buyers than the Australian and Victorian populations.

- **Education**: Categories from the Census Data for 2001 were reduced to two: those with graduate or postgraduate qualifications and those with no stated qualifications. The first figure in this category in the above table represents a combination of those used in the census including; postgraduate diplomas or degrees, bachelors degrees and advanced diplomas or certificates; the second number represents those with no stated qualifications. The study sample has a slightly higher representation of the higher educated group.
• **Employment:** The first figure represents full time employment and the second is part time. For the purpose of statistical analysis in this study, employment categories were reduced to three: some work; disabled or unable to work and other. The figure on the table represents ‘some work’ (full or part time). It was problematic to compare many variables with the 2001 Census data due to differences in terminology and extensive categories of employment. Thirty seven percent of PwMS in the study reported they were main income earners and 60% of carers also claimed this status. This category is difficult to compare with Census data. However, as might be expected, persons with MS have a lower percentage of members who are employed than either their carers or the general population, despite their higher level of education and suggesting that their losses of ability due to the disease have a negative impact on employment.

• **Estimated number of persons with multiple sclerosis in the population:** The Census data provides no information in this regard and the figures in the table represent ‘guesstimates’ (Multiple Sclerosis Society of Victoria, 2004), based on the literature. Longitudinal studies are currently in progress in Australia to provide a more reliable numeric data base (Simmons 2004). See MSRA (2005) map of latitude gradient in the incidence of MS in Australia, based on data from the abovementioned Longitudinal Study (Figure 3.1)

• **Income:** Income was not compared since questionnaires used in this study did not ask for a tangible monetary figure. Participants were asked for their level of satisfaction with their income in relation to meeting their needs. Thus, no comparison is possible with the general or State populations. However, a total of 62% of PwMS and 65% of Carers were satisfied with their income (see table 4.8, above).

• **Marital status and divorce rate:** There has been some disagreement in the literature about the rate of divorces experienced by people diagnosed with multiple sclerosis. Anecdotal data obtained in chat rooms contain comments by some males with MS deploiring the limited success and duration of their relationships, and although some say MS could be implicated, they admit that their selection of partners may be the cause of this lack of desired commitment in their relationships (MS Victoria internet chatroom, 2003). However, research by McCabe and McDonald fails to support the belief that the divorce rate for PwMS is higher than the general population (McCabe,
McDonald et al. 1996; McCabe, McKern et al. 2004). Census data does not support any relationship between divorce and disability.

It is generally agreed that facilities for long term placement of persons with multiple sclerosis are limited, and often disabled persons are placed in nursing homes where their needs may or may not be adequately met. However, there is no available Census data relating to numbers of young people in nursing homes broken down by diagnosis, and it is impossible to guess how many persons with MS may be in this number nationwide. Persons with MS may also be placed in nursing homes for respite periods when their main carers require a break from daily care at home. Again, this number is unclear and cannot be reported.

The four open-ended questions did not lend themselves well to statistical analysis, but were subjected to thematic analysis and frequencies and are reported in Chapter Four-B. These responses offered some insights into the participants’ salient interests, strengths, values, needs and compelling concerns. These insights were included in a brief summary of information compiled for each of the interviewees and the contents of these were pursued later during interview by the researcher. Some of these comments are discussed in Chapter Six: Qualitative Data Analysis.

DISCUSSION AND SUMMARY
Respondents in this study were drawn from the population of persons with MS and their identified carers residing in Australia during the ten months of recruitment (See Figure 1.1). Descriptive statistical analysis of the total study sample, which included 115 persons with multiple sclerosis and 88 carers, contained a higher number of females than males with a ratio of 2.5:1 which was consistent with the worldwide incidence and prevalence of MS in females. The presence of 85 pairs was revealed in which one member of the dyad had been diagnosed with multiple sclerosis. Data contained in this ‘pairs only’ file were later subjected to further descriptive and inferential statistical analysis. Over 50% of the total sample was over fifty years of age, with few in the ‘newly diagnosed’ group, and few in the severely disabled group.
Although MS is described as a disease affecting young adults, the presence of such a high percentage of adults over fifty years of age in the study sample assumes that participants had been diagnosed many years prior to the survey. All participants were English-speaking and over 80% were born in Australia. Every State in Australia was represented in the study sample, except the Northern Territory, however the numbers in the study for each State do not reflect the expected geographic gradient for incidence and prevalence that has been recognized globally. Recruitment strategies and variable dissemination of information of the call for participants throughout the country may have influenced this discrepancy in expected numbers.

Home ownership was slightly higher than the national average and education levels were notably higher than the national average. Seventy percent of the sample were married or in permanent relationships. Given the higher level of education of the study sample, only 37% were employed either full or part time, which is lower than the general Australian population, although 60% of carers reported some employment which approaches the national average. Again, it may be inferred that multiple sclerosis may have forced many out of the work force earlier than would be considered normal in the working career of an adult person.

Thirty five percent of the study sample required regular assistance with their activities of daily living and 45% reported the use of community services. These figures suggest a mid-range of disability as mentioned above. Limitations in mobility were evident with nearly a quarter needing someone else to drive them when they went out and 11% requiring considerable assistance to leave their homes. Twenty percent averaged a daily trip out of the house with the most common destinations being a trip to the shops or to visit family or friends. Sixty percent of PwMS perceived their health as good or very good, with 62% of carers reporting this level of health as well.

Scores on measurement scales revealed a mean depression score of 16.89 for PwMS, indicative of a level of depression above that of the general population on this screening instrument. The cutoff point suggested by the creators of the scale is 15/16. Carers mean scores were 9.73 which are just below the level of concern. Reciprocity scores between PwMS and Carers showed considerable congruence but provided little useful information relating to the concept of reciprocity which is considered central to caring relationships.
Further research is needed to refine the CRSII and its scoring when applying it to both members of a caring dyad as was done for the first time in this study. Life satisfaction was correlated with depression. Higher levels of depression were correlated with lower life satisfaction scores as might be expected. The functional wellness inventory also needs further research to refine it and make it more precise in the measurement of the perceived satisfaction with basic human needs. Development of a Perceived Disability Index derived from selected items contained in two of the scales used in the study, proved to be useful in the further statistical analyses performed in Chapter Five. The next chapter provides a thematic analysis of the four open-ended questions contained in the Functional Wellness Inventory.
Chapter Four-B: Data Analysis

Thematic Analysis and Coding of Four Open-Ended Questions - Total Study Sample (n = 203)

CODING, THEMES AND FREQUENCIES OF OPEN-ENDED QUESTIONS

The Functional Wellness Inventory (FWI) was the fourth scale used in the survey for participants in this research study. The scale measured functional wellness and the satisfaction of the participant with the ten basic needs of the Z-R Model (Chapter One, Figure 1.2). It concluded with four open-ended questions that respondents were asked to briefly complete. These unfinished statements have been useful in past research studies using the instrument to identify the most pressing concerns and unmet needs of respondents (Zuluaga 2000). Responses also relate to values and strengths that people perceive they have and that may contribute to life satisfaction and coping with stressors in their lives. Some responses to the questions assist with interpretation of some statements in the Functional Wellness Inventory relating to the ten basic needs of the Z-R Model: Physical Health; Mental, Emotional, Social, and Spiritual Health (MESSH); Income, Accommodation; Mobility; Safety/Security; Knowledge; Communication; Opportunity for Development and Opportunity to make a contribution.

Analysis of the open-ended questions followed a quasi-statistical style as described by Polit and Hungler (1997). Themes for each open-ended question were listed fully, then grouped into similar categories and frequencies, as tabulated on the following charts under four headings representing the four questions, with separate charts to capture the responses of PwMS and Carers. A general discussion follows the charts for each question.
Brief survey summaries were developed for each participant including highlights of their survey contents; responses to each of the four questions for each participant, and scores obtained on measurement scales. These summaries provided a useful method of data reduction and were used later during interviews, allowing the researcher to review areas of individual concern. Later analysis of the themes included collapsing of similar themes as suggested by Strauss and Corbin (Strauss and Corbin 1998 p.59). When several concepts were expressed by an individual, all concepts were recognized, thus accounting for large numbers.

Question 1 was analysed using the ten basic needs of the Z-R Model as a framework (Zuluaga 2000)

Of the 22 themes and ideas identified in responses to Question 1: “I could be healthier and happier if…”, the most common statement expressed by PwMS, was: “I did not have MS” (n=27). In view of the fact that 50% of the respondents had been diagnosed with MS, this was not surprising (The remaining respondents were carers). Related responses included “a cure was found for MS” (n=3) and a desire for freedom from some of the symptoms of MS such as fatigue, pain, vision problems, decrease in mobility and perceived lack of productivity. The desire for more energy (less fatigue) accounted for n=19. “Better mobility” was desired by n=15; “Desire to exercise more” (n=13); “lose weight” (n=5); “healthier lifestyle” (n=4), and “better care of self-body” (n=3). Thus 89 responses related to a perceived deficit in Physical Health/Mobility. This is consistent with the principal problems encountered by persons with MS. Tables are arranged in order of frequency of themes.

Question 2 :”If I could afford it, I would…” related mainly to ‘Income’, so the analysis is based on themes considered valuable in terms of what money could buy.

Income is closely related to employment and has a significant effect on other aspects of life if perceived to be inadequate. Issues of fatigue also entered into this area of concern for persons wishing to work less or retire from work as the progression of their disease made full time work unrealistic or difficult. The putative cognitive losses that often accompany MS may also enter into the employment concern. PwMS often wished that necessity did not keep the partner in the workforce beyond the time desired for retirement.
Question 3: “My greatest strengths are….” was problematic for analysis, due to the reluctance of many participants to recognize strengths in themselves.

It appeared that many persons had a difficult time identifying personal strengths which allowed them to cope with the challenges of life and the changing needs of MS. This may be a cultural artifact, since it is not considered socially acceptable for people to ‘brag’ or ‘skite’ about their abilities in some cultures, which favour a more self-effacing approach to personal talents and strengths.

Responses were grouped into strengths internal to the person, perceived interpersonal skills as a part of their personality, behaviour patterns, and external: valued support systems, belief systems, persons or pets. The chart is arranged according to frequencies of named strengths. Responses of PwMS and carers were compared and interesting differences/similarities were noted.

Responses to Question 4: “My happiest time was /is….” were examined in terms of past, present and future, with possible implications discussed. Only a few perceived their happiest time was yet to come. Themes and frequencies for each question follow.
Chart 4B.1. PwMS responses to Question 1.

<table>
<thead>
<tr>
<th>Question: PwMS (n=108), I could be a lot healthier and happier if…</th>
<th>Frequency of theme</th>
<th>Perceived Need(s) Deficits recognized</th>
</tr>
</thead>
<tbody>
<tr>
<td>I did not have multiple sclerosis</td>
<td>27</td>
<td>PH</td>
</tr>
<tr>
<td>I had better mobility</td>
<td>15</td>
<td>Mobility/PH</td>
</tr>
<tr>
<td>I had less financial worries; financial situation was better; partner could work less</td>
<td>15</td>
<td>Income/MESSH</td>
</tr>
<tr>
<td>I exercised more</td>
<td>13</td>
<td>PH</td>
</tr>
<tr>
<td>I had more energy; less fatigue</td>
<td>11</td>
<td>PH</td>
</tr>
<tr>
<td>Freedom from other MS symptoms; sleeplessness, fatigue, pain, perceived lack of productivity</td>
<td>8</td>
<td>PH</td>
</tr>
<tr>
<td>I were not so lonely; social isolation; had more social activities; had a friend to share my thoughts; still had my partner (now deceased)</td>
<td>7</td>
<td>MESSH</td>
</tr>
<tr>
<td>I had a confidante; someone to share; better relationships</td>
<td>7</td>
<td>MESSH</td>
</tr>
<tr>
<td>Had a better job; more congenial job; job closer to home; worked fewer hours so I could spend more time with family; could work part-time; worked less; could retire</td>
<td>7</td>
<td>PH/Income/MESSH</td>
</tr>
<tr>
<td>I could lose weight</td>
<td>5</td>
<td>PH</td>
</tr>
<tr>
<td>I could move to better accommodation; better climate</td>
<td>5</td>
<td>PH/Housing</td>
</tr>
<tr>
<td>I could afford to eat healthy; have better lifestyle; afford regular massage, counseling, etc</td>
<td>5</td>
<td>PH/Income</td>
</tr>
<tr>
<td>I could care for myself better</td>
<td>3</td>
<td>PH</td>
</tr>
<tr>
<td>A cure was found for MS</td>
<td>3</td>
<td>PH</td>
</tr>
<tr>
<td>I was .years younger; I could still play volleyball, etc.</td>
<td>3</td>
<td>PH/MESSH</td>
</tr>
<tr>
<td>I had better access to transport; more available community transportation facilities</td>
<td>2</td>
<td>Mobility</td>
</tr>
<tr>
<td>No response offered</td>
<td>2</td>
<td>?</td>
</tr>
</tbody>
</table>

**Discussion:** Persons with MS overwhelmingly perceived their greatest needs deficits for better health and happiness were related to physical health, including freedom from the debilitating effects of MS, that included mobility impairment, fatigue and energy deficits precluding an active productive working life and limiting family activities. These deficits were closely followed by financial concerns, loneliness, social isolation and a desire for more suitable housing (accommodation) for their changing needs. Thus, physical health, mobility, income, and MESSH were the most notable needs deficits for people with MS.
Chart 4B.2. Carers responses to Question 1.

<table>
<thead>
<tr>
<th>Question 1: Carers (n=85). I could be a lot healthier and happier if…</th>
<th>Frequency of theme</th>
<th>Perceived Need(s) Deficits recognized</th>
</tr>
</thead>
<tbody>
<tr>
<td>My partner were in 100% good health; did not have MS; MS was not in our lives</td>
<td>13</td>
<td>MESSH</td>
</tr>
<tr>
<td>I worked less; had a less stressful job; had more time for family; had more uncommitted time</td>
<td>12</td>
<td>MESSH/Income</td>
</tr>
<tr>
<td>I Lost weight; did not eat foods I shouldn’t</td>
<td>9</td>
<td>PH</td>
</tr>
<tr>
<td>I did more exercise</td>
<td>9</td>
<td>PH</td>
</tr>
<tr>
<td>I could afford to buy the proper food; could pay my bills</td>
<td>9</td>
<td>Income/PH</td>
</tr>
<tr>
<td>A cure could be found for MS; my partner were healthier and happier</td>
<td>8</td>
<td>PH/MESSH</td>
</tr>
<tr>
<td>I am happy and content</td>
<td>6</td>
<td>No deficits recognized</td>
</tr>
<tr>
<td>No response offered</td>
<td>6</td>
<td>?</td>
</tr>
<tr>
<td>I were younger</td>
<td>5</td>
<td>PH/MESSH</td>
</tr>
<tr>
<td>I were free of my own illnesses (PTSD, need of hip replacement, asthma)</td>
<td>5</td>
<td>PH</td>
</tr>
<tr>
<td>I did not smoke and drank less; took better care of my body; my health; stopped smoking;</td>
<td>5</td>
<td>PH</td>
</tr>
<tr>
<td>I didn’t take life too seriously; worry too much; don’t prioritize</td>
<td>4</td>
<td>MESSH</td>
</tr>
<tr>
<td>A comfortable retirement could be assured; I could retire</td>
<td>4</td>
<td>Income/MESSH</td>
</tr>
<tr>
<td>A good support network was available for us; I were not so lonely; I didn’t feel isolated and left out</td>
<td>3</td>
<td>MESSH</td>
</tr>
<tr>
<td>I understood the impact of MS on my relationship with my wife</td>
<td>1</td>
<td>MESSH</td>
</tr>
</tbody>
</table>

Responses considered irrelevant to the question were not considered. n=5.

**Discussion:** Carers believed they could be healthier and happier if MS had not entered their lives; expressing a strong desire for their affected partners to be free of the disease and its limitations. Their most pressing concerns related to MESSH more than physical health, since their desires were predominantly for their partner with MS. However a number revealed serious physical conditions of their own in addition to increasingly demanding carer duties that contributed to their having to relinquish their jobs, thus placing financial stress on the family and limiting their own work and recreational activities. Many deplored the lack of a satisfactory and ongoing support system to assist them with their carer duties and allow some time to themselves. Reliable, affordable and
available respite from their caring duties would have been welcomed. It is interesting to note that Wollin (1999) and others report an underutilization of existing respite and community services by carers, which is attributed to a lack of knowledge of these services. Wollin (1999) suggests that it is the role of healthcare professionals to inform carers of the availability of these services, despite some of their admitted inadequacies. Interestingly, six carers said they had no needs and were quite happy and six offered no response to the question, which cannot be explained.

However, there appears to be a strong case for development and planning of ongoing assessment, education and support programs for persons with MS, their carers and families.
Chart 4B.3. PwMS responses to Question 2.

<table>
<thead>
<tr>
<th>Question 2. PwMS (n= 108). If I could afford it, I would …</th>
<th>Frequency of theme</th>
<th>Perceived Need(s) Deficits recognized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buy a property, suitable home; car- custom-made for MS; buy a scooter</td>
<td>16</td>
<td>Income/Accommodation/mobility</td>
</tr>
<tr>
<td>Travel – around Australia; overseas</td>
<td>16</td>
<td>Mobility/MESSH</td>
</tr>
<tr>
<td>Help my children buy a house; help children and family; help others</td>
<td>15</td>
<td>MESSH/need to make a contribution</td>
</tr>
<tr>
<td>Other purchases included new clothes; furniture; computer and internet lessons; craft supplies and lessons; renovations; complete university studies; find a cure for MS; renovations; rebuild a church; “buy a new immune system”</td>
<td>10</td>
<td>PH; Opportunity for development; opportunity to make contribution; accommodation et al.</td>
</tr>
<tr>
<td>Buy regular services from masseur, physiotherapist, nutritionist, etc.</td>
<td>9</td>
<td>PH &amp; MESSH</td>
</tr>
<tr>
<td>Would hire help on a regular basis</td>
<td>7</td>
<td>PH &amp; MESSH</td>
</tr>
<tr>
<td>Take a holiday with partner and family; send partner on holiday</td>
<td>7</td>
<td>MESSH</td>
</tr>
<tr>
<td>Give money to MS research; money to charity</td>
<td>6</td>
<td>MESSH/make a contribution</td>
</tr>
<tr>
<td>Would increase family contacts by flying to different locations to see family</td>
<td>6</td>
<td>MESSH</td>
</tr>
<tr>
<td>Buy an airconditioner; move to a different climate-not too hot and not too cold</td>
<td>5</td>
<td>PH</td>
</tr>
<tr>
<td>Open a flower shop; buy a business; seek financial security by playing the stock market</td>
<td>5</td>
<td>MESSH &amp; income</td>
</tr>
<tr>
<td>No response given</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>Pay off the mortgage &amp; pay off our debts</td>
<td>4</td>
<td>MESSH</td>
</tr>
<tr>
<td>Would work less and retire</td>
<td>4</td>
<td>MESSH</td>
</tr>
<tr>
<td>I would not live much differently; I have all I require</td>
<td>4</td>
<td>No perceived needs deficits</td>
</tr>
<tr>
<td>Would move to a purpose built home</td>
<td>4</td>
<td>PH/Housing/Mobility</td>
</tr>
<tr>
<td>I would rather be home (now in nursing home). Suggests money not enough for this</td>
<td>1</td>
<td>MESSH and others</td>
</tr>
<tr>
<td>Adopt a child from overseas</td>
<td>1</td>
<td>MESSH</td>
</tr>
</tbody>
</table>

**Discussion:** Greater Income, more suitable accommodation and mobility were mentioned as the most pressing items that money could buy. Five persons did not respond and four would not live any differently, thus implying satisfaction with their present situation. One female who had recently moved to a nursing home rather reluctantly, implied that money
could not return her to her home, where she preferred to be. Her husband’s health had deteriorated due to the increasing caring needs of his wife and he was no longer allowed to continue his dedicated care at home. If the response “I would move to a purpose built home” were added to the first response (16 +4 =20), accommodation would seem to be the greatest unmet need that better income could help. Mobility needs reflect a desire for greater ability to move around in the home and neighbourhood (scooter, suitable car) as well as a desire to be able to travel more widely (visit family interstate, travel around Australia, travel overseas, take a holiday with family). The need to make a contribution is evident in the expressed wish to contribute to MS research, to give money to charity; to help rebuild a damaged church, or to help family members financially. Funds to facilitate purchase of greater personal care presumably to ease the physical burdens and limitations of MS (massage, physiotherapist, household help, nutritionist) were also a priority. Since fatigue is the single most debilitating symptom of multiple sclerosis that affects all aspects of the persons’ life including ability to work and to participate in family activities, it is not surprising that help was valued and sought (Kroencke, Lynch et al. 2000; Bakshi 2003). A few sought to discover ways to increase their income such as playing the stock market, or buying a business with the goal of paying off the mortgage for the family and paying off other debts. Others sought opportunities to develop personal skills such as craft and computer classes.

<table>
<thead>
<tr>
<th>Question 2. Carers (n=85). If I could afford it, I would …</th>
<th>Frequency of theme</th>
<th>Perceived Need(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel around Australia; overseas</td>
<td>25</td>
<td>Mobility/MESSH</td>
</tr>
<tr>
<td>Buy a house</td>
<td>11</td>
<td>accommodation</td>
</tr>
<tr>
<td>Have a holiday with partner; send partner on holiday</td>
<td>10</td>
<td>Mobility/MESSH</td>
</tr>
<tr>
<td>Retire; buy/build a motor home; work less (part time)</td>
<td>9</td>
<td>MESSH, accommodation</td>
</tr>
<tr>
<td>Provide for my children; help my family financially</td>
<td>7</td>
<td>MESSH/Income</td>
</tr>
<tr>
<td>No response given</td>
<td>6</td>
<td>?</td>
</tr>
<tr>
<td>Pay off long term debts, including the mortgage</td>
<td>6</td>
<td>Income/MESSH</td>
</tr>
<tr>
<td>Give more to research; give to those in need</td>
<td>6</td>
<td>MESSH/make a contribution</td>
</tr>
<tr>
<td>Home improvements</td>
<td>5</td>
<td>Accommodation</td>
</tr>
<tr>
<td>Buy a car</td>
<td>5</td>
<td>Mobility</td>
</tr>
<tr>
<td>Go to the gym regularly; buy proper foods; go out more</td>
<td>4</td>
<td>PH/MESSH</td>
</tr>
<tr>
<td>Hire domestic help</td>
<td>3</td>
<td>PH &amp; MESSH</td>
</tr>
<tr>
<td>Find a cure for MS</td>
<td>3</td>
<td>MESSH</td>
</tr>
<tr>
<td>Make my financial future secure; increase assets</td>
<td>2</td>
<td>MESSH/Income</td>
</tr>
<tr>
<td>Cancel the winter; move to a better climate</td>
<td>2</td>
<td>PH</td>
</tr>
<tr>
<td>I would continue my life; I can afford anything I want</td>
<td>2</td>
<td>No perceived needs</td>
</tr>
<tr>
<td>Change jobs so I can spend more time at home</td>
<td>1</td>
<td>MESSH/Income</td>
</tr>
</tbody>
</table>

Discussion: Carers also sought greater financial security by increasing their assets and paying off long term debts such as mortgages. Overall, their greatest desire seemed to be having the resources to provide relief from their caring duties, allowing more personal time to maintain and improve their health and fitness, to hire domestic help; to purchase a house, home improvements, a car or motor home and to travel – around Australia, overseas; to send partner on a holiday or to go on a holiday with their partner. Carers also expressed a desire to make a contribution by contributing to the less fortunate, to MS research and to family members. Two persons said they could afford anything they wanted and were content with their lives. Although none specifically mentioned
caregiving as a burden, there was an implied desire to ‘get away’ and have time to take care of their own health and interests.

Chart 4B.5. PwMS responses to Question 3 – Perceived strengths.

<table>
<thead>
<tr>
<th>Question 3. PwMS (n=108), I believe my greatest strengths are ...</th>
<th>Frequency of theme</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>My willingness to help others *</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>My positive attitude</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>9</td>
<td>Why?</td>
</tr>
<tr>
<td>My sense of humour</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>My husband/wife/family/marriage</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Endurance; stubbornness; I don’t give up.</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Compassionate</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Determination; drive; focused</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Able to accept change; conditions; criticism</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Faith, trust in God</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Creativity</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Get on well with others</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Patience</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Perseverance; persistence</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>My caring nature *</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Intellectual ability</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Loyal friends</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Communication skills</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Strong; steadfast</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Tolerant</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Cheerfulness</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Honesty</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>My love for others; family</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Strength</td>
<td>Count</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>I don’t ‘whinge’ about MS</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Desire for self-improvement</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Hugs and warmth</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Loyalty</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Ability to cope</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Organizer; planner</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Good listener</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Inner strength</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Generosity of spirit</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Empathy</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Sense of family</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Pets; cat; dog</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Practicality</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>My personality</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Not many strengths</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

**Discussion:** The difficulty that people seem to have in admitting their strengths has already been mentioned. Nine persons failed to respond to the question and two said they had ‘not many strengths’. Thus 11 persons could be included in this category, which is equal to the number identifying ‘my positive attitude’ as their greatest strength. If two other categories are combined: ‘my willingness to help others’ (n=12) and ‘my caring nature’ (n=6), this strength is seen by eighteen persons. Other strengths mentioned by individual respondents included; trustworthy; good work ethic; logical thinking; adaptability; forgiveness; a happy disposition; ‘me’. The meaning of the last statement ‘me’ is difficult to interpret. It would seem that healthcare professionals and support persons could reinforce perceived and observed strengths in the PwMS to enhance their perceived life satisfaction and self esteem (Carruth 1996). Such comments as: “A sense of family”, “loyal friends” and “pets” were perceived as strengths in answer to this question, suggesting that comfort and support was provided by them. Thus 21 derived their ‘strength’ from family, friends, and pets. A strength that is notable by its absence on the list for PwMS and yet has been observed frequently in many PwMS at interview is ‘a
sense of humour’, which is believed to support persons during difficult times and to enhance human friendships, lessening somewhat the daily challenges of the condition, and lifting the spirits. Six Carers mentioned this strength.


<table>
<thead>
<tr>
<th>Question 3. Carers (n=85). I believe my greatest strengths are …</th>
<th>Frequency of theme</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>My love for husband/wife/family</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Ability to care for another person*</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Positive outlook; positive attitude</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Compassion</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Sense of humour</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>My cheerful, optimistic, caring nature</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>A good listener</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Patience</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Tenacity; determination</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Willingness to help others*</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Intelligence</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Loyalty</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Quiet self-confidence</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Hard worker; diligent</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Communication skills</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Family/friends</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Perseverance</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Realistic; practical</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Creativity</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Faith</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>My kind, affectionate nature; sensitivity</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Stable, balanced view of most things</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>
Discussion: Carers recognized their ‘willingness’ and ‘ability’ to care for others as strengths, accounting for 12 responses together. These items were separated in the tabulation because it could be argued that there is a difference between a ‘willingness’ and an ‘ability’. However, they both imply that the caring role is a strength in itself. Interestingly, no carers failed to respond or denied having any perceived strengths, although one said “I am not sure anymore”, suggesting some discouragement at the time of completing the survey. These findings support the perceived difficulty that PwMS as care recipients demonstrated in seeing themselves as co-carers of their partners, and were unable to see their contribution to the relationship until reminded by others that this was the case. When reminded at interview of their contribution to the relationship in terms of love and affection and affirmation of their partner, the care recipient sometimes showed disbelief while others smiled and appeared pleased with this insight. Other individual responses included: honesty; caring person; reliability; organizer; willingness to learn; optimism; not sure any more; life experiences; common sense; love for animals; insight; personality; adaptability; ability to support family; get on well with others; self-awareness; forgiving; taking life as it comes; equanimity; resolve disputes amicably; inner strengths (beliefs). Only three Carers noted their faith or inner beliefs as strengths.
Chart 4B.7. PwMS responses to Question 4 – Happiest times.

<table>
<thead>
<tr>
<th>Question 4. PwMS (n= 108). The happiest time of my life was/is ...</th>
<th>Frequency of theme</th>
<th>Past</th>
<th>Present</th>
<th>Future</th>
<th>Relating to self/other (S/O)</th>
<th>?=unknown meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past activities or events; achievements; capabilities; travels; holidays; younger days</td>
<td>31</td>
<td>X</td>
<td></td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>When I did not have MS</td>
<td>12</td>
<td>X</td>
<td></td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>Marriage; having children; watching them grow</td>
<td>11</td>
<td>X</td>
<td></td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Now! Realizing day by day that I can survive on my own, achieve goals surrounded by loving family and friends</td>
<td>10</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Giving birth to children; pregnancy</td>
<td>9</td>
<td>X</td>
<td></td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>Courtship and early marriage days</td>
<td>8</td>
<td>X</td>
<td></td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Now</td>
<td>7</td>
<td></td>
<td>X</td>
<td></td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>When children were young; babies; time with family</td>
<td>7</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Time with children and family; becoming a family</td>
<td>6</td>
<td></td>
<td>X</td>
<td>X</td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Time with partner; reconciled with partner</td>
<td>5</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Present capabilities</td>
<td>5</td>
<td></td>
<td>X</td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>Working days; running my own business</td>
<td>4</td>
<td></td>
<td>X</td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>So many happy times</td>
<td>4</td>
<td></td>
<td>X</td>
<td>X</td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>Past; before loss of significant other; relationship; health</td>
<td>4</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Happy marriage</td>
<td>3</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Special events; birthdays; parties; graduations</td>
<td>3</td>
<td></td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>The day my partner came into my life</td>
<td>2</td>
<td></td>
<td>X</td>
<td></td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>Ahead of me; the future</td>
<td>2</td>
<td></td>
<td></td>
<td>X</td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>Religious experiences</td>
<td>2</td>
<td></td>
<td>X</td>
<td>X</td>
<td>?</td>
<td></td>
</tr>
</tbody>
</table>

Discussion: Themes in these responses predominantly revolved around the joys of family life, having children and watching them grow. Some specified that ‘early’ marriage days were the happiest, while others recalled the advent of a partner in their lives. Forty responses were in this category. Thus, special ‘other persons’ contributed to their happy
recollections. The second predominant response involved past achievements and accomplishments and special events that were recalled with pleasure. Thirty eight can be counted in this category, which could be interpreted as relating to the self rather than to others. Twelve enjoyed the time of their lives before MS was diagnosed. Two reported a religious experience. Seventeen stated “now’ and were able to list the reasons they were thankful including being surrounded by loving family and friends. Two felt that the best was yet to come, and four stated there were many happy times but did not elaborate, and five quoted their present capabilities as their source of happiness. Other single answers included: arrival of grandchildren; marriage and travel; pets (dog/cat). By far the greatest number of happy occasions recalled related to past events. The present accounted for thirty eight responses, while only two related to the future. Most happy occasions involved others in family or close relationships, a large number also related only to the individual, although this may be hard to interpret with so little information present in the brief responses to open ended questions.

<table>
<thead>
<tr>
<th>Question 4. Carers (n=85). The happiest time of my life was/is …</th>
<th>Frequency of theme</th>
<th>Past</th>
<th>Present</th>
<th>Future</th>
<th>Relating to self/other (S/O)</th>
<th>?=unknown meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married life; newly married</td>
<td>20</td>
<td>X</td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Past times, activities and achievements; better financial times; school days; sporting achievements; university days; younger days; travels</td>
<td>19</td>
<td>X</td>
<td></td>
<td></td>
<td>S</td>
<td></td>
</tr>
<tr>
<td>Now; every day of my life</td>
<td>16</td>
<td>X</td>
<td>X</td>
<td></td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>Birth of children; watching them grow</td>
<td>15</td>
<td>X</td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Time with family; partner</td>
<td>13</td>
<td>X</td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Before diagnosis of MS for my partner</td>
<td>10</td>
<td>X</td>
<td></td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>When children were young</td>
<td>3</td>
<td>X</td>
<td></td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>Most of the time; hard to pick any one time</td>
<td>3</td>
<td>X</td>
<td>X</td>
<td></td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>A special occasion (in the past)</td>
<td>3</td>
<td>X</td>
<td></td>
<td></td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>Working life</td>
<td>3</td>
<td>X</td>
<td></td>
<td></td>
<td>?</td>
<td></td>
</tr>
<tr>
<td>When relationships in the family are good</td>
<td>2</td>
<td>X</td>
<td>X</td>
<td></td>
<td>S &amp; O</td>
<td></td>
</tr>
<tr>
<td>No response given</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Still coming! Retirement and traveling around Australia</td>
<td>1</td>
<td></td>
<td>X</td>
<td></td>
<td>?</td>
<td></td>
</tr>
</tbody>
</table>

**Discussion:** Responses were remarkably congruent in content with PwMS, and while PwMS cited time before MS was diagnosed (n=12), their carers (n=10) also cited the time before their partners were diagnosed as happier times. One carer says “the best is yet to come” when retirement and travel are anticipated, and two gave no response, suggesting some uncertainty. Marriage, (especially early marriage and courtship days), family life, with the caveat ‘when the relationships are good’, and children accounted for fifty three responses, and past achievements and events accounted for twenty five. Nineteen said “now,” “every day of my life” or had difficulty picking any particular time. Other single responses included: activities with partner that were dreamed about; and “no special times- good and bad”.

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SUMMARY AND DISCUSSION OF FINDINGS FROM OPEN-ENDED QUESTIONS

Responses to these four open ended questions provided some valuable insights into the most pressing needs, strengths, and values perceived by the 203 participants in the study. They highlight the accepted findings in the literature of the importance of social support networks, both formal and informal, for persons dealing with a chronic degenerative disease such as multiple sclerosis. (Des Rosier, Catanzaro et al. 1992; Good, Bower et al. 1995; Becker 1998; Burggraf 1998). When responses of PwMS and Carers are compared, there is considerable congruence in their responses as they identify their perceived needs for better health and happiness. The two salient themes were a desire to be free of the disease and its troublesome and debilitating side effects, greater support, both physical and psychological, and an urgent need for respite services for carers. (Pfeiffer 1990; Hayes 1999; Boeije, Duijnstee et al. 2003) Both groups listed past achievements and events as their happier times, and a similar number included positive relationships, marriage and children as their happiest times. Both groups had difficulty in identifying their strengths, which were evident to observers. Partners with MS were coping with significant obstacles that demanded a variety of strengths. Reinforcement of these strengths by healthcare professionals and others would serve to enhance self esteem and a sense of accomplishment in managing difficult life challenges. Although many programs exist, it appears that those who need these support and respite services are either unaware of their existence or find them unacceptable for a variety of reasons as yet unknown. Further research using the Functional Wellness Inventory with its four open ended questions and involving participants from the general population could determine if themes are similar or different from this sample of persons with MS and Carers. However, this is beyond the scope of this study.

INTRODUCTION TO CHAPTER FIVE

Chapter Five reports findings from a descriptive and inferential statistical analysis of the file labeled ‘pairs only’ derived from the total study sample. Eighty five pairs were identified with a variety of types of caring relationships, and consisting largely of heterosexual spousal dyads (89%). The predominance of spouses in caring relationships has been noted in the literature, and the current study supports this finding. Unlike many
other situations in which a female spouse is caring for a male who is aged, frail or disabled, the situation with multiple sclerosis includes more male carers, due to the predominance of MS in females as previously noted.
Chapter Five:
Data Analysis

Descriptive and Inferential Statistical Analysis of pairs (dyads) in the study sample (n=85)

THE “PAIRS ONLY” DATA SET
A ‘dyad’ or pair in this study represents a person diagnosed with multiple sclerosis and the person identified by him/her as a main support person or carer. Eighty-five pairs meeting the criteria and containing usable data were identified in the total data set, reflecting several types of caring relationships, which included:

- Spousal – heterosexual, with one Lesbian pair
- Sibling – brother and sister
- Adult child with MS / parent carer
- Adult child carer / parent with MS
- Person with MS / unrelated carer-friend (gender unspecified)
DESCRIPTIVE ANALYSIS OF SUB-SAMPLE

Types of dyads

Table 5.1. Types of Dyads in the Sub-Sample.

<table>
<thead>
<tr>
<th>Type of Dyad</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spousal</td>
<td>76</td>
<td>89.4</td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Adch/MS/parent</td>
<td>6</td>
<td>7.1</td>
</tr>
<tr>
<td>Child/MSparent</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
</tbody>
</table>

As demonstrated in Table 5.1, the overwhelming majority of dyads were spousal pairs (n=76=89%), with all others combined accounting for 11%. The second largest group comprised adult children with MS / parent-carer.

GENDER

Table 5.2. Gender of PwMS and Carers in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Male</td>
<td>25</td>
<td>29.4</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>60</td>
<td>70.6</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Male</td>
<td>53</td>
<td>62.4</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>37.6</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Males with MS numbered twenty-five or nearly 30% of the sample, while females with MS represented 70%. The larger number of females with MS is consistent with current available information which accepts the predominance of females in the worldwide
population of people with MS, as stated earlier. This female predominance is true for Australia. (Exact ratios differ and range between 2:1 and 3:1 Ratio in this research study fell between these parameters at 2.5:1).

AGE

Table 5.3. Age of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age group</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>21 – 30 years</td>
<td>6</td>
<td>7.1</td>
</tr>
<tr>
<td></td>
<td>31 – 40 years</td>
<td>15</td>
<td>17.6</td>
</tr>
<tr>
<td></td>
<td>41 – 50 years</td>
<td>16</td>
<td>18.8</td>
</tr>
<tr>
<td></td>
<td>51 – 60 years</td>
<td>32</td>
<td>37.6</td>
</tr>
<tr>
<td></td>
<td>61 or over</td>
<td>16</td>
<td>18.8</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>21 – 30 years</td>
<td>4</td>
<td>4.8</td>
</tr>
<tr>
<td></td>
<td>31 – 40 years</td>
<td>14</td>
<td>16.7</td>
</tr>
<tr>
<td></td>
<td>41 – 50 years</td>
<td>16</td>
<td>19.0</td>
</tr>
<tr>
<td></td>
<td>51 – 60 years</td>
<td>21</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>61 or over</td>
<td>29</td>
<td>34.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
</tbody>
</table>

In this subset of pairs, slightly less than 50% (42.3%) were under age 50, with 58% over 50 years of age. This is consistent with the age distribution of the total study sample. As previously noted, there are very few ‘newly diagnosed persons with MS’ in the sample. The possible reasons for this have been alluded to earlier, and include the following: persons with an early diagnosis may not perceive any change in their lifestyle and may not perceive themselves as ‘ill’; they may be fully employed outside the home or at home and may have little or no interest in participating in a research study which they believe might have little relevance to their current situation. There is also a reported element of denial in many persons following a diagnosis of multiple sclerosis and there are persons who choose to keep their diagnosis a private matter and do not disclose it to friends or
employers until it is absolutely necessary to do so (Saunders 2001). There is also the initial belief that they will overcome the disease, that MS will not progress in their case or that a cure will soon be found. The element of denial in early MS may contribute to the under-representation of younger participants in this study.

**COUNTRY OF BIRTH**

Table 5.4. Country of Birth of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Country of birth</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Australia</td>
<td>70</td>
<td>83.3</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>9</td>
<td>10.7</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>5</td>
<td>6.0</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Australia</td>
<td>68</td>
<td>81.0</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>10</td>
<td>11.9</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6</td>
<td>7.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**Place of birth.** Over 80% of the persons in the sub sample were born in Australia, 10% in the United Kingdom, 6% in Holland and other countries accounted for nearly 4%. One person did not respond. This is consistent with the current literature discussing incidence and prevalence of MS in populations whose genetic origins derive from temperate climates and who mainly have a Northern European heritage (see Chapter One – epidemiology and geographic distribution of MS). The study did not recruit any non-English speaking respondents.6

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6 Note: The Multiple Sclerosis Society of Victoria indicated that at least 3% of their clients are non-English speaking, but there have been no reported studies of non-English speaking persons with multiple sclerosis in this State. This lack of ethnic diversity may be due to a shortage of multi-lingual researchers and offers an interesting topic for future research on MS. (MSSV 2002)
### HOME OWNERSHIP

Table 5.5. Home Ownership of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Ownership status</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Owner</td>
<td>57</td>
<td>67.1</td>
</tr>
<tr>
<td></td>
<td>Buyer</td>
<td>17</td>
<td>20.0</td>
</tr>
<tr>
<td></td>
<td>Renter</td>
<td>9</td>
<td>10.6</td>
</tr>
<tr>
<td></td>
<td>Board</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Owner</td>
<td>61</td>
<td>71.8</td>
</tr>
<tr>
<td></td>
<td>Buyer</td>
<td>12</td>
<td>14.1</td>
</tr>
<tr>
<td></td>
<td>Renter</td>
<td>9</td>
<td>10.6</td>
</tr>
<tr>
<td></td>
<td>Board</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Average home ownership (including buyers) of the pairs in the sub-sample was calculated at 87.1%. This is higher home ownership than the General Australian population of 66%, and the Victorian population of 71% (Australian Bureau of Statistics 2001 Census). Ten percent rent a home and the remaining 2% report other housing arrangements. Home ownership in the sub-set is slightly higher than the total study sample (Total sample = 79.2% and sub sample 87.1%).
INCOME SATISFACTION

Table 5.6. Income Satisfaction of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Income Satisfaction</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Satisfactory</td>
<td>53</td>
<td>63.1</td>
</tr>
<tr>
<td></td>
<td>Barely Satisfactory</td>
<td>20</td>
<td>23.8</td>
</tr>
<tr>
<td></td>
<td>Not Enough</td>
<td>11</td>
<td>13.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Satisfactory</td>
<td>55</td>
<td>66.3</td>
</tr>
<tr>
<td></td>
<td>Barely Satisfactory</td>
<td>21</td>
<td>25.3</td>
</tr>
<tr>
<td></td>
<td>Not Enough</td>
<td>7</td>
<td>8.4</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>83</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**Sixty three percent** of PwMS reported satisfaction with their income from all sources while 37% perceived their income to be barely satisfactory or ‘not enough’, suggesting that they experience concerns about their ability to meet daily and future financial commitments. Sixty-six percent of carers were also satisfied with their income.

Comparing these results to the total study sample revealed congruence with only one percentage point difference in the scores of both PwMS and Carers (see Table 4.8 Chapter 4-A).
**EMPLOYMENT**

Table 5.7. Employment Status of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Employment Status</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Full-Time Outside Home</td>
<td>13</td>
<td>15.5</td>
</tr>
<tr>
<td></td>
<td>Full-Time at Home</td>
<td>8</td>
<td>9.5</td>
</tr>
<tr>
<td></td>
<td>Part-Time Outside Home</td>
<td>13</td>
<td>15.5</td>
</tr>
<tr>
<td></td>
<td>Part-Time at Home</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>9</td>
<td>10.7</td>
</tr>
<tr>
<td></td>
<td>Disabled/Unable to Work</td>
<td>31</td>
<td>36.9</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Full-Time Outside Home</td>
<td>28</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>Full-Time at Home</td>
<td>8</td>
<td>9.5</td>
</tr>
<tr>
<td></td>
<td>Part-Time Outside Home</td>
<td>15</td>
<td>17.9</td>
</tr>
<tr>
<td></td>
<td>Part-Time at Home</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>23</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>Disabled/Unable to Work</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>4</td>
<td>4.8</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>84</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Employment

Only 16% of the PwMS in the dyadic sample were fully employed outside the home, and 10% worked full time from home. Nearly 4% were self-employed. It may be inferred that 25% of the PwMS in the sub-sample were the primary income earners. Nineteen percent worked part time, 11% were retired and 37% stated they were disabled and unable to work. Two percent were unemployed and a further 2% did not respond to the question. For purposes of inferential statistical analysis, these categories were reduced to three: some employment, disabled/unable to work; other. If any amount of work is considered in the ‘work category’, it would appear that 46% of people with MS in this study had some form of employment at the time of the study. This may be difficult to compare with the 2001 ABS Census data. However, it appears that, given the same level of education, the study sample has fewer persons with MS in employment than the general population (ABS 2001 Census data).

EDUCATION

Table 5.8. Highest Level of Education Status of Pairs in the Sub-Sample.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Highest Level of Education</th>
<th>Number of Participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with MS</td>
<td>Primary</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>33</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Trade</td>
<td>13</td>
<td>15.3</td>
</tr>
<tr>
<td></td>
<td>Tertiary</td>
<td>25</td>
<td>29.4</td>
</tr>
<tr>
<td></td>
<td>Postgraduate</td>
<td>13</td>
<td>15.3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
<tr>
<td>Carer</td>
<td>Primary</td>
<td>3</td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td>Secondary</td>
<td>29</td>
<td>34.1</td>
</tr>
<tr>
<td></td>
<td>Trade</td>
<td>14</td>
<td>16.5</td>
</tr>
<tr>
<td></td>
<td>Tertiary</td>
<td>26</td>
<td>30.6</td>
</tr>
<tr>
<td></td>
<td>Postgraduate</td>
<td>13</td>
<td>15.3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>85</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Forty percent of the respondents with MS in the sub-sample were educated at primary or secondary level. Fifteen percent had trade or TAFE (see Glossary) education, and nearly 45% claimed tertiary or post-grad education. (See Table 4.6.Chapter 4-A for comparison with total sample).

Note: The sub-sample appears to have a higher level of education than the general population, however, the study sample is too small to make a realistic comparison with the total population of Australia.

Inferential Statistical Analysis of ‘pairs-only’ subset – ANOVAs, Multiple Regressions, Correlations and Paired t-Tests.

Various statistical procedures were performed on the ‘pairs only’ data including Analyses of Variance (ANOVAs), Multiple Regressions, Correlations and Paired t-tests, to discover significant or marginally significant effects of selected independent variables on the scores obtained by participants on the four scales used in the study and considered as dependent variables. Note: The Functional Wellness Inventory in its original form failed to provide the desired level of discrimination and was subjected to item analysis resulting in two separate sub-scales, the FWI (ph) and the FWI (messh), which were then used in the statistical analysis as separate dependent variables (see Glossary). Reference was made initially to this statistical manipulation in Chapter Three.

Statistical significance was accepted at a level of probability (alpha) equal to or less than .05, which is commonly accepted for research studies in the Social Sciences. Results with an alpha between .05 and .1 were considered marginally significant. Results with levels of probability above .1 were not considered to be significant statistically.

- Alpha < or = .05 as statistically significant
- .05 < Alpha < .1 as marginally statistically significant
- Alpha >.1 not significant
DEPRESSION SCORE OF PERSON WITH MS AS THE DEPENDENT VARIABLE

A between-groups, factorial ANOVA was performed, with pair type, employment of person with MS (PwMS), employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index (PDI) of PwMS, as between-subjects independent variables AND depression score of PwMS, as the dependent variable.

Table 5.9. Analysis of Variance for Depression Score of Person with MS.

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>2.099</td>
<td>.152</td>
</tr>
<tr>
<td>Employment of PwMS</td>
<td>2</td>
<td>1.189</td>
<td>.311</td>
</tr>
<tr>
<td>Employment of Carer</td>
<td>2</td>
<td>2.078</td>
<td>.134</td>
</tr>
<tr>
<td>Sex of PwMS</td>
<td>1</td>
<td>5.541</td>
<td>.022</td>
</tr>
<tr>
<td>Age of PwMS</td>
<td>4</td>
<td>.752</td>
<td>.560</td>
</tr>
<tr>
<td>Age of Carer</td>
<td>4</td>
<td>1.146</td>
<td>.343</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>.393</td>
<td>.677</td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>1</td>
<td>.017</td>
<td>.897</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>1</td>
<td>.067</td>
<td>.797</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>3.917</td>
<td>.052</td>
</tr>
<tr>
<td>Within-Group Error</td>
<td>64</td>
<td>(76.945)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Values enclosed in parentheses represent mean square errors.

There is a significant main effect of sex of PwMS, on depression score of PwMS; F(1, 64) = 5.541, p = .022. Higher depression scores were noted for women. A study by (Chwastiak. L, Ehde et al. 2004), using a large community sample of people with MS, and the CES-D scale, noted clinically significant depressive symptoms in nearly 42% of subjects as evidenced by a score >or = to 16, and 29% of subjects demonstrating moderate to severe depression with scores > or = to 21. They suggest clinicians should evaluate depression in patients with recent diagnoses of MS, major changes in functioning or limited social support (Chwastiak et al 2004).

Research has supported the belief for some time that depression is more common in females than males in the general population with a ratio of two females per male affected.
(Kessler 2003). In cases involving chronic, life altering illness, it may be difficult to differentiate depressive symptoms from ‘chronic sorrow’ as described by (Hainsworth 1993). (see Chapter Two).

There is a marginally significant main effect of the Perceived Disability Index (PDI) of PwMS on depression score of person with MS, $F(1, 64) = 3.917, p = .052$. It could be expected that persons who perceived themselves as more disabled, as measured by the PDI, would also score higher on the Depression Scale, although this was only a small main effect.

Effects of all other independent variables on depression score of PwMS were not significant, with all alphas greater than .134.

**MULTIPLE REGRESSION**

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND Depression Score of PwMS as the dependent variable.
Table 5.10. Summary of Simultaneous Multiple Regression Analysis for Variables Predicting Depression Score of Person with MS.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE (B)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 = PwMS</td>
<td>6.100</td>
<td>4.210</td>
<td>1.449</td>
<td>.152</td>
</tr>
<tr>
<td>Ptype2 = Carer</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of PwMS = some work</td>
<td>3.465</td>
<td>3.211</td>
<td>1.079</td>
<td>.285</td>
</tr>
<tr>
<td>Employment of PwMS = disabled/unable to work</td>
<td>5.447</td>
<td>3.602</td>
<td>1.512</td>
<td>.135</td>
</tr>
<tr>
<td>Employment of PwMS = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of Carer = some work</td>
<td>1.115</td>
<td>2.869</td>
<td>.389</td>
<td>.699</td>
</tr>
<tr>
<td>Employment of Carer = disabled/unable to work</td>
<td>14.430</td>
<td>7.080</td>
<td>2.038</td>
<td>.046</td>
</tr>
<tr>
<td>Employment of Carer = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of PwMS = Male</td>
<td>-5.491</td>
<td>2.333</td>
<td>-2.354</td>
<td>.022</td>
</tr>
<tr>
<td>Sex of PwMS = Female</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of PwMS = 21-30 Years</td>
<td>-8.083</td>
<td>7.179</td>
<td>-1.126</td>
<td>.264</td>
</tr>
<tr>
<td>Age of PwMS = 31-40 Years</td>
<td>.264</td>
<td>5.037</td>
<td>.052</td>
<td>.958</td>
</tr>
<tr>
<td>Age of PwMS = 41-50 Years</td>
<td>1.210</td>
<td>4.904</td>
<td>.247</td>
<td>.806</td>
</tr>
<tr>
<td>Age of PwMS = 51-60 Years</td>
<td>-.603</td>
<td>3.815</td>
<td>-.158</td>
<td>.875</td>
</tr>
<tr>
<td>Age of PwMS = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Carer = 21 – 30 Years</td>
<td>11.041</td>
<td>7.105</td>
<td>1.554</td>
<td>.125</td>
</tr>
<tr>
<td>Age of Carer = 31 – 40 Years</td>
<td>3.283</td>
<td>4.860</td>
<td>.676</td>
<td>.502</td>
</tr>
<tr>
<td>Age of Carer = 41 – 50 Years</td>
<td>1.128</td>
<td>4.445</td>
<td>.254</td>
<td>.800</td>
</tr>
<tr>
<td>Age of Carer = 51 – 60 Years</td>
<td>-3.441</td>
<td>4.118</td>
<td>-.836</td>
<td>.406</td>
</tr>
<tr>
<td>Age of Carer = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Satisfactory</td>
<td>-2.785</td>
<td>3.541</td>
<td>-.786</td>
<td>.434</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Barely sat.</td>
<td>-1.033</td>
<td>3.617</td>
<td>-.286</td>
<td>.776</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Not Enough</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>-.147</td>
<td>1.124</td>
<td>-.131</td>
<td>.897</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>-.296</td>
<td>1.143</td>
<td>-.259</td>
<td>.797</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1.986</td>
<td>1.004</td>
<td>1.979</td>
<td>.052</td>
</tr>
</tbody>
</table>
The independent variables accounted for 38.1% of the variation in the depression scores of PwMS. Holding all other variables constant, PwMS, who were disabled/unable to be employed were significantly more depressed than PwMS who were not disabled/unable to be employed by 14.43 depression units on average. (p = .046). Holding all other variables constant, females with MS were significantly more depressed than males with MS by 5.49 depression units on average (p = .022). The Perceived Disability Index (PDI) of PwMS, was a marginally significant predictor of depression scores in a PwMS, (Beta = 1.986, t = 1.979, p = .052). Holding all other variables constant, a one unit increase in the Perceived Disability Index (PDI) of PwMS, is associated with a 1.99 unit increase in depression scores in a PwMS. All other variables in the model were not statistically significant.

**RECIROCITY SCALE SCORE OF PWMS AS THE DEPENDENT VARIABLE**

A between-groups, factorial ANOVA was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index (PDI) of PwMS, as between-subjects independent variables AND reciprocity scale score of person with MS as the dependent variable.
Table 5.11. Analysis of Variance for Reciprocity Scale Score of Person with MS.

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>.259</td>
<td>.612</td>
</tr>
<tr>
<td>Employment of PwMS</td>
<td>2</td>
<td>.226</td>
<td>.798</td>
</tr>
<tr>
<td>Employment of Carer</td>
<td>2</td>
<td>1.616</td>
<td>.207</td>
</tr>
<tr>
<td>Sex of PwMS</td>
<td>1</td>
<td>.002</td>
<td>.967</td>
</tr>
<tr>
<td>Age of PwMS</td>
<td>4</td>
<td>.877</td>
<td>.483</td>
</tr>
<tr>
<td>Age of Carer</td>
<td>4</td>
<td>.480</td>
<td>.750</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>.438</td>
<td>.647</td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>1</td>
<td>.069</td>
<td>.794</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>1</td>
<td>.005</td>
<td>.946</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>2.556</td>
<td>.115</td>
</tr>
<tr>
<td>Within-Group Error</td>
<td>63</td>
<td>(88.868)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Values enclosed in parentheses represent mean square errors.

All effects of the independent variables on the reciprocity scale score of PwMS were not significant at the p.05 level. All alpha levels were greater than .115

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND Reciprocity Scale Score of PwMS, as the dependent variable.
Table 5.12. Summary of Simultaneous Multiple Regression Analysis for Reciprocity Scale Score of Person with MS.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE (B)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 = PwMS</td>
<td>2.819</td>
<td>5.535</td>
<td>.509</td>
<td>.612</td>
</tr>
<tr>
<td>Ptype2 = Carer</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of PwMS = some work</td>
<td>-.453</td>
<td>3.463</td>
<td>-.131</td>
<td>.896</td>
</tr>
<tr>
<td>Employment of PwMS = disabled/unable to work</td>
<td>-2.416</td>
<td>3.875</td>
<td>-.624</td>
<td>.535</td>
</tr>
<tr>
<td>Employment of PwMS = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of Carer = some work</td>
<td>-.347</td>
<td>3.084</td>
<td>-.112</td>
<td>.911</td>
</tr>
<tr>
<td>Employment of Carer = disabled/unable to work</td>
<td>13.160</td>
<td>7.616</td>
<td>1.728</td>
<td>.089</td>
</tr>
<tr>
<td>Employment of Carer = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of PwMS = Male</td>
<td>-.103</td>
<td>2.514</td>
<td>-.041</td>
<td>.967</td>
</tr>
<tr>
<td>Sex of PwMS = Female</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of PwMS = 21–30 Years</td>
<td>.243</td>
<td>8.200</td>
<td>.030</td>
<td>.976</td>
</tr>
<tr>
<td>Age of PwMS = 31–40 Years</td>
<td>7.734</td>
<td>6.036</td>
<td>1.281</td>
<td>.205</td>
</tr>
<tr>
<td>Age of PwMS = 41–50 Years</td>
<td>5.292</td>
<td>5.361</td>
<td>.987</td>
<td>.327</td>
</tr>
<tr>
<td>Age of PwMS = 51–60 Years</td>
<td>4.332</td>
<td>4.156</td>
<td>1.042</td>
<td>.301</td>
</tr>
<tr>
<td>Age of PwMS = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Carer = 21 – 30 Years</td>
<td>6.672</td>
<td>7.977</td>
<td>.836</td>
<td>.406</td>
</tr>
<tr>
<td>Age of Carer = 31 – 40 Years</td>
<td>-2.465</td>
<td>6.468</td>
<td>-.381</td>
<td>.704</td>
</tr>
<tr>
<td>Age of Carer = 41 – 50 Years</td>
<td>.309</td>
<td>5.062</td>
<td>.061</td>
<td>.952</td>
</tr>
<tr>
<td>Age of Carer = 51 – 60 Years</td>
<td>.314</td>
<td>4.553</td>
<td>.069</td>
<td>.945</td>
</tr>
<tr>
<td>Age of Carer = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Satisfactory</td>
<td>-.932</td>
<td>3.978</td>
<td>-.234</td>
<td>.815</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Barely Satisfactory</td>
<td>1.793</td>
<td>3.917</td>
<td>.458</td>
<td>.649</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Not Enough</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>-.334</td>
<td>1.277</td>
<td>-.262</td>
<td>.794</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>-.084</td>
<td>1.230</td>
<td>-.068</td>
<td>.946</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1.744</td>
<td>1.091</td>
<td>1.599</td>
<td>.115</td>
</tr>
</tbody>
</table>
The independent variables accounted for 21.9% of the variation in the reciprocity scale scores of PwMS. Holding all other variables constant, carers who were disabled/unable to be employed were marginally significantly more depressed than carers who were not disabled/unable to be employed by 13.16 reciprocity scale units on average (p = .089). All other variables in the model were not statistically significant. Further interpretation of this scale is discussed using triangulation of methods in Discussion Chapter Eight.

**LIFE SATISFACTION SCORE OF PERSON WITH MS AS THE DEPENDENT VARIABLE**

A between-groups, factorial ANOVA was performed, with pair type 2 (spousal), employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as between-subjects independent variables AND life satisfaction score of person with MS as the dependent variables.

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>.847</td>
<td>.361</td>
</tr>
<tr>
<td>Employment of PwMS</td>
<td>2</td>
<td>.221</td>
<td>.803</td>
</tr>
<tr>
<td>Employment of Carer</td>
<td>2</td>
<td>.458</td>
<td>.635</td>
</tr>
<tr>
<td>Sex of PwMS</td>
<td>1</td>
<td>.061</td>
<td>.805</td>
</tr>
<tr>
<td>Age of PwMS</td>
<td>4</td>
<td>.897</td>
<td>.471</td>
</tr>
<tr>
<td>Age of Carer</td>
<td>4</td>
<td>1.121</td>
<td>.354</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>1.906</td>
<td>.157</td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>1</td>
<td>.872</td>
<td>.354</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>1</td>
<td>.252</td>
<td>.617</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>10.427</td>
<td>.002</td>
</tr>
<tr>
<td>Within-Group Error</td>
<td>64</td>
<td>(37.825)</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* Values enclosed in parentheses represent mean square errors.

There is a significant main effect of perceived disability index (PDI) of PwMS on life satisfaction score of person with MS, $F(1, 64) = 10.427$, $p = .002$
All effects of other independent variables on life satisfaction scale score of person with MS were not significant, at the p.05 level All other alphas were > .157

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND Life Satisfaction Score of PwMS, as the dependent variable.
Table 5.14. Summary of Simultaneous Multiple Regression Analysis for Life Satisfaction Score of Person with MS.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE (B)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 = PwMS</td>
<td>-2.716</td>
<td>2.952</td>
<td>-920</td>
<td>.361</td>
</tr>
<tr>
<td>Ptype2 = Carer</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of PwMS = some work</td>
<td>-1.481</td>
<td>2.252</td>
<td>-658</td>
<td>.513</td>
</tr>
<tr>
<td>Employment of PwMS = disabled/unable to work</td>
<td>-.714</td>
<td>2.525</td>
<td>-283</td>
<td>.778</td>
</tr>
<tr>
<td>Employment of PwMS = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of Carer = some work</td>
<td>1.015</td>
<td>2.012</td>
<td>.505</td>
<td>.616</td>
</tr>
<tr>
<td>Employment of Carer = disabled/unable to work</td>
<td>-3.398</td>
<td>4.964</td>
<td>-685</td>
<td>.496</td>
</tr>
<tr>
<td>Employment of Carer = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of PwMS = Male</td>
<td>.405</td>
<td>1.635</td>
<td>.248</td>
<td>.805</td>
</tr>
<tr>
<td>Sex of PwMS = Female</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of PwMS = 21–30 Years</td>
<td>3.289</td>
<td>5.034</td>
<td>.653</td>
<td>.516</td>
</tr>
<tr>
<td>Age of PwMS = 31–40 Years</td>
<td>.363</td>
<td>3.531</td>
<td>.103</td>
<td>.918</td>
</tr>
<tr>
<td>Age of PwMS = 41–50 Years</td>
<td>-3.306</td>
<td>3.438</td>
<td>-962</td>
<td>.340</td>
</tr>
<tr>
<td>Age of PwMS = 51–60 Years</td>
<td>-1.861</td>
<td>2.675</td>
<td>-696</td>
<td>.489</td>
</tr>
<tr>
<td>Age of PwMS = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Carer = 21–30 Years</td>
<td>-7.536</td>
<td>4.981</td>
<td>-1.513</td>
<td>.135</td>
</tr>
<tr>
<td>Age of Carer = 31–40 Years</td>
<td>-4.514</td>
<td>3.407</td>
<td>-1.325</td>
<td>.190</td>
</tr>
<tr>
<td>Age of Carer = 41–50 Years</td>
<td>-1.628</td>
<td>3.116</td>
<td>-522</td>
<td>.603</td>
</tr>
<tr>
<td>Age of Carer = 51–60 Years</td>
<td>1.286</td>
<td>2.887</td>
<td>.445</td>
<td>.658</td>
</tr>
<tr>
<td>Age of Carer = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Satisfactory</td>
<td>-1.485</td>
<td>2.483</td>
<td>-598</td>
<td>.552</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Barely Satisfactory</td>
<td>-4.353</td>
<td>2.536</td>
<td>-1.716</td>
<td>.091</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Not Enough</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>.736</td>
<td>.788</td>
<td>.934</td>
<td>.354</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>.402</td>
<td>.801</td>
<td>.502</td>
<td>.617</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>-2.272</td>
<td>.704</td>
<td>-3.229</td>
<td>.002</td>
</tr>
</tbody>
</table>
The independent variables accounted for 40.3% of the variation in the life satisfaction scores of PwMS. Holding all other variables constant, PwMS, with a perceived barely satisfactory income had marginally significant less life satisfaction scores than PwMS with a non barely satisfied income by 4.35 life satisfaction units on average (p = .091). The Perceived Disability Index of a PwMS was a significant predictor of life satisfaction scores in a PwMS (Beta = -2.272, t = -3.229, p = .002). Holding all other variables constant, a one unit increase in the Perceived Disability Index of a PwMS is associated with a 2.27 unit decrease in life satisfaction scores in a PwMS. All other variables in the model were not statistically significant.

FUNCTIONAL WELLNESS INVENTORY OF PERSON WITH MS AS THE DEPENDENT VARIABLE

A between-groups, factorial ANOVA was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as between-subjects independent variables AND Functional Wellness Inventory Score of PwMS as the dependent variable.

Table 5.15. Analysis of Variance for Functional Wellness Inventory of Person with MS.

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>.067</td>
<td>.797</td>
</tr>
<tr>
<td>Employment of PwMS</td>
<td>2</td>
<td>1.040</td>
<td>.359</td>
</tr>
<tr>
<td>Employment of Carer</td>
<td>2</td>
<td>2.279</td>
<td>.111</td>
</tr>
<tr>
<td>Sex of PwMS</td>
<td>1</td>
<td>3.445</td>
<td>.068</td>
</tr>
<tr>
<td>Age of PwMS</td>
<td>4</td>
<td>.483</td>
<td>.748</td>
</tr>
<tr>
<td>Age of Carer</td>
<td>4</td>
<td>1.025</td>
<td>.401</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>3.267</td>
<td>.045</td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>1</td>
<td>.015</td>
<td>.902</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>1</td>
<td>.071</td>
<td>.791</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>16.849</td>
<td>.001</td>
</tr>
<tr>
<td>Within-Group Error</td>
<td>64</td>
<td>(76.247)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Values enclosed in parentheses represent mean square errors.
There is a marginally significant main effect of sex of PwMS on Functional Wellness Inventory Score of PwMS. F(1, 64) = 3.445, p = .068

There is a significant main effect of income satisfaction of PwMS on Functional Wellness Inventory Score of PwMS. F(2, 64) = 3.267, p = .045

There is a significant main effect of perceived disability index (PDI) of PwMS on Functional Wellness Inventory Score of PwMS, F(1, 64) = 16.489, p < .001

All effects of other independent variables on life satisfaction scale score of PwMS were not significant, with alphas exceeding .111

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND Functional Wellness Inventory Score of PwMS as the dependent variable.

Table 5.16 is omitted since the results suggested a need for factor analysis of the scale. The Following this factor analysis, the FWI scale was divided into two sub-scales: the FWI(ph) and the FWI(messh), as reported below, and previously alluded to in Chapter Three (see Glossary).

The independent variables accounted for 50.9% of the variation in the functional wellness inventory scores of PwMS. Holding all other variables constant, carers who were disabled/unable to work had marginally significantly greater functional wellness inventory scores than carers who were not disabled/unable to work by 13.59 functional wellness inventory units on average (p = .058). Holding all other variables constant, females with MS had marginally significantly greater functional wellness inventory scores than males with MS by 4.31 functional wellness inventory units on average (p = .068). The Perceived Disability Index of PwMS was a significant predictor of functional wellness inventory scores in a PwMS (Beta = 4.06, t = 4.06, p < .001). Holding all other variables constant, a one unit increase in the Perceived Disability Index of the PwMS is
associated with a 4.06 unit increase in functional wellness inventory scores in a PwMS. All other variables in the model were not statistically significant.\(^7\)

The Functional Wellness Inventory failed to provide the desired information in its original form and was subjected to item analysis to determine the number of statements corresponding to the ten basic needs of the Z-R Model (see Chapter One). This analysis resulted in a breakdown of the scale to two sub-scales: the FWI (physical health) and the FWI (mental, emotional, social and spiritual health), or FWI(ph) and the FWI(messh). Further statistical analyses were performed on these sub-scales.

**FUNCTIONAL WELLNESS INVENTORY - PHYSICAL HEALTH - FWI(PH) OF PWMS AS THE DEPENDENT VARIABLE**

A between-groups, factorial ANOVA was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as between-subjects independent variables AND FWI(ph) Score of person with MS as the dependent variable.

---

\(^7\) Higher scores on the FWI indicate lower functional wellness.
Table 5.17. Analysis of Variance for Functional Wellness Inventory Physical Health \([FWI\text{ (ph)}]\) of person with MS.

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>1.685</td>
<td>.199</td>
</tr>
<tr>
<td></td>
<td>Employment of PwMS</td>
<td>2</td>
<td>.076</td>
<td>.927</td>
</tr>
<tr>
<td></td>
<td>Employment of Carer</td>
<td>2</td>
<td>2.800</td>
<td>.068</td>
</tr>
<tr>
<td></td>
<td>Sex of PwMS</td>
<td>1</td>
<td>.130</td>
<td>.720</td>
</tr>
<tr>
<td></td>
<td>Age of PwMS</td>
<td>4</td>
<td>.403</td>
<td>.806</td>
</tr>
<tr>
<td></td>
<td>Age of Carer</td>
<td>4</td>
<td>1.015</td>
<td>.406</td>
</tr>
<tr>
<td></td>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>1.587</td>
<td>.212</td>
</tr>
<tr>
<td></td>
<td>Education of PwMS</td>
<td>1</td>
<td>.053</td>
<td>.818</td>
</tr>
<tr>
<td></td>
<td>Education of Carer</td>
<td>1</td>
<td>.229</td>
<td>.634</td>
</tr>
<tr>
<td></td>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>19.326</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>Within-Group Error</td>
<td>64</td>
<td>(11.054)</td>
<td></td>
</tr>
</tbody>
</table>

*Note*: Values enclosed in parentheses represent mean square errors.

There is a marginally significant main effect of employment type of carer on FWI(ph) Score of person with MS, \(F(2, 64) = 2.800, p = .068\)

There is a significant main effect of perceived disability index of PwMS on FWI(ph) Score of person with MS, \(F(1, 64) = 19.326, p < .001\)

All effects of other independent variables on FWI(ph) Score of person with MS were not significant, \(ps > .199\)

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND FWI(ph) Score of PwMS as the dependent variable.
Table 5.18. Summary of Simultaneous Multiple Regression Analysis - Functional Wellness Inventory (ph) of Person with MS.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE (B)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 = PwMS</td>
<td>2.071</td>
<td>1.596</td>
<td>1.298</td>
<td>.199</td>
</tr>
<tr>
<td>Employment of PwMS = some work</td>
<td>.396</td>
<td>1.217</td>
<td>.325</td>
<td>.746</td>
</tr>
<tr>
<td>Employment of PwMS = disabled/unable to work</td>
<td>-.002</td>
<td>1.365</td>
<td>-.002</td>
<td>.999</td>
</tr>
<tr>
<td>Employment of PwMS = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of Carer = some work</td>
<td>2.565</td>
<td>1.087</td>
<td>2.359</td>
<td>.021</td>
</tr>
<tr>
<td>Employment of Carer = disabled/unable to work</td>
<td>.855</td>
<td>2.684</td>
<td>.319</td>
<td>.751</td>
</tr>
<tr>
<td>Employment of Carer = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of PwMS = Male</td>
<td>-.319</td>
<td>.884</td>
<td>-.361</td>
<td>.720</td>
</tr>
<tr>
<td>Sex of PwMS = Female</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of PwMS=21 – 30 Years</td>
<td>-3.217</td>
<td>2.721</td>
<td>-1.182</td>
<td>.241</td>
</tr>
<tr>
<td>Age of PwMS=31 – 40 Years</td>
<td>-1.384</td>
<td>1.909</td>
<td>-.725</td>
<td>.471</td>
</tr>
<tr>
<td>Age of PwMS=41 – 50 Years</td>
<td>-1.685</td>
<td>1.859</td>
<td>-.892</td>
<td>.376</td>
</tr>
<tr>
<td>Age of PwMS=51 – 60 Years</td>
<td>-1.254</td>
<td>1.446</td>
<td>-.876</td>
<td>.389</td>
</tr>
<tr>
<td>Age of PwMS=61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Carer = 21 – 30 Years</td>
<td>3.066</td>
<td>2.693</td>
<td>1.139</td>
<td>.259</td>
</tr>
<tr>
<td>Age of Carer = 31 – 40 Years</td>
<td>.225</td>
<td>1.842</td>
<td>.122</td>
<td>.903</td>
</tr>
<tr>
<td>Age of Carer = 41 – 50 Years</td>
<td>.723</td>
<td>1.685</td>
<td>.429</td>
<td>.669</td>
</tr>
<tr>
<td>Age of Carer = 51 – 60 Years</td>
<td>-1.683</td>
<td>1.561</td>
<td>-1.049</td>
<td>.298</td>
</tr>
<tr>
<td>Age of Carer = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Satisfactory</td>
<td>-2.392</td>
<td>1.342</td>
<td>-1.782</td>
<td>.080</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Barely Satisfactory</td>
<td>-1.764</td>
<td>1.371</td>
<td>-1.286</td>
<td>.203</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Not Enough</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>.098</td>
<td>.426</td>
<td>.231</td>
<td>.818</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>-.207</td>
<td>.433</td>
<td>-.479</td>
<td>.634</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1.672</td>
<td>.380</td>
<td>4.396</td>
<td>.001</td>
</tr>
</tbody>
</table>
The independent variables accounted for 50.7% of the variation in the FWI(ph) scores of person with MS. Holding all other variables constant, carers who were disabled/unable to work had significantly greater FWI(ph) scores than carers who were not disabled/unable to work by 2.57 FWI(ph) units on average (p = .021). Holding all other variables constant, PwMS who had a satisfactory income had marginally significantly smaller FWI(ph) scores than PwMS who did not have a satisfactory income by 2.39 FWI(ph) units on average (p = .08). The Perceived Disability Index of PwMS was a significant predictor of FWI(ph) scores in a PwMS, (Beta = 1.67, t = 4.396, p < .001). Holding all other variables constant, a one unit increase in the Perceived Disability Index of the PwMS is associated with a 1.67 unit increase in FWI(ph) scores in a PwMS. All other variables in the model were not statistically significant.8

**FUNCTIONAL WELLNESS INVENTORY (MENTAL, EMOTIONAL, SOCIAL, SPIRITUAL HEALTH)= FWI(MESSH) OF PWMS AS THE DEPENDENT VARIABLE**

A between-groups, factorial ANOVA was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as between-subjects independent variables AND the FWI(messh) as the dependent variable

---

8 Once again, higher scores on this scale represent lower functional wellness.
Table 5.19. Analysis of Variance for Functional Wellness Inventory (Mental, Emotional, Social, Spiritual Health) of person with MS.

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 (spousal)</td>
<td>1</td>
<td>.365</td>
<td>.548</td>
</tr>
<tr>
<td>Employment of PwMS</td>
<td>2</td>
<td>.793</td>
<td>.457</td>
</tr>
<tr>
<td>Employment of Carer</td>
<td>2</td>
<td>2.168</td>
<td>.123</td>
</tr>
<tr>
<td>Sex of PwMS</td>
<td>1</td>
<td>4.268</td>
<td>.043</td>
</tr>
<tr>
<td>Age of PwMS</td>
<td>4</td>
<td>.463</td>
<td>.762</td>
</tr>
<tr>
<td>Age of Carer</td>
<td>4</td>
<td>1.107</td>
<td>.361</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS</td>
<td>2</td>
<td>2.307</td>
<td>.108</td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>1</td>
<td>.097</td>
<td>.756</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>1</td>
<td>.001</td>
<td>.999</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>1</td>
<td>7.954</td>
<td>.006</td>
</tr>
<tr>
<td>Within-Group Error</td>
<td>64</td>
<td>(41.442)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Values enclosed in parentheses represent mean square errors.

There is a significant main effect of sex of the PwMS on the FWI(messh) of the PwMS, F(1, 64) = 4.268, p = .043

There is a significant main effect of perceived disability index of PwMS on the FWI(messh) Score of PwMS, F(1, 64) = 7.954, p = .006

All effects of other independent variables on the FWI(messh) Score of the PwMS were not significant with alphas exceeding .1

A multiple regression was performed, with pair type, employment of PwMS, employment of carer, sex of PwMS, age of PwMS, age of carer, income satisfaction of PwMS, education of PwMS, education of carer, perceived disability index of PwMS, as independent variables AND the FWI(messh) Score of PwMS as the dependent variable.
Table 5.20. Summary of Simultaneous Multiple Regression Analysis for Functional Wellness Inventory (messh) [FWI(messh)] of person with MS.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE (B)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ptype2 = PwMS</td>
<td>1.866</td>
<td>3.090</td>
<td>.604</td>
<td>.548</td>
</tr>
<tr>
<td>Ptype2 = Carer</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of PwMS = some work</td>
<td>2.966</td>
<td>2.357</td>
<td>1.259</td>
<td>.213</td>
</tr>
<tr>
<td>Employment of PwMS = disabled/unable to work</td>
<td>1.910</td>
<td>2.643</td>
<td>.723</td>
<td>.472</td>
</tr>
<tr>
<td>Employment of PwMS = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment of Carer = some work</td>
<td>2.570</td>
<td>2.106</td>
<td>1.221</td>
<td>.227</td>
</tr>
<tr>
<td>Employment of Carer = disabled/unable to work</td>
<td>9.928</td>
<td>5.196</td>
<td>1.911</td>
<td>.061</td>
</tr>
<tr>
<td>Employment of Carer = other</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of PwMS = Male</td>
<td>-3.536</td>
<td>1.712</td>
<td>-2.066</td>
<td>.043</td>
</tr>
<tr>
<td>Sex of PwMS = Female</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of PwMS = 21 – 30 Years</td>
<td>-2.758</td>
<td>5.269</td>
<td>-.523</td>
<td>.602</td>
</tr>
<tr>
<td>Age of PwMS = 31 – 40 Years</td>
<td>.182</td>
<td>3.696</td>
<td>.049</td>
<td>.961</td>
</tr>
<tr>
<td>Age of PwMS = 1 – 50 Years</td>
<td>2.433</td>
<td>3.599</td>
<td>.676</td>
<td>.501</td>
</tr>
<tr>
<td>Age of PwMS = 51 – 60 Years</td>
<td>1.418</td>
<td>2.800</td>
<td>.506</td>
<td>.614</td>
</tr>
<tr>
<td>Age of PwMS = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Carer = 21 – 30 Years</td>
<td>7.926</td>
<td>5.214</td>
<td>1.520</td>
<td>.133</td>
</tr>
<tr>
<td>Age of Carer = 31 – 40 Years</td>
<td>-.042</td>
<td>4.566</td>
<td>-.012</td>
<td>.991</td>
</tr>
<tr>
<td>Age of Carer = 41 – 50 Years</td>
<td>.551</td>
<td>3.262</td>
<td>.169</td>
<td>.867</td>
</tr>
<tr>
<td>Age of Carer = 51 – 60 Years</td>
<td>-2.409</td>
<td>3.022</td>
<td>.797</td>
<td>.428</td>
</tr>
<tr>
<td>Age of Carer = 61 years or over</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Satisfactory</td>
<td>.510</td>
<td>2.599</td>
<td>.196</td>
<td>.845</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Barely</td>
<td>4.300</td>
<td>2.655</td>
<td>1.620</td>
<td>.110</td>
</tr>
<tr>
<td>Income Satisfaction of PwMS = Not Enough</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education of PwMS</td>
<td>-.258</td>
<td>.825</td>
<td>-.312</td>
<td>.756</td>
</tr>
<tr>
<td>Education of Carer</td>
<td>.001</td>
<td>.839</td>
<td>.001</td>
<td>.999</td>
</tr>
<tr>
<td>Perceived Disability Index of PwMS</td>
<td>2.077</td>
<td>.737</td>
<td>2.820</td>
<td>.006</td>
</tr>
</tbody>
</table>
The independent variables accounted for 38.8% of the variation in the FWI(messh) scores of the PwMS. Holding all other variables constant, females with MS had significantly greater FWI(messh) scores than males with MS by 3.54 FWI(messh) units on average (p = .043). The Perceived Disability Index of PwMS was a significant predictor of FWI(messh) scores in a PwMS, (Beta = 2.077, t = 2.82, p = .006). Holding all other variables constant, a one unit increase in the Perceived Disability Index of PwMS is associated with a 2.077 unit increase in FWI(messh) scores in a person with MS. All other variables in the model were not statistically significant.

CORRELATIONS

Pearson’s product moment correlation coefficients were calculated to assess measures of association between FWI(ph) of PwMS or carer and FWI(messh) of PwMS or carer. Correlation coefficients were squared to generate coefficients of determination.

Table 5.21. Pearson’s Correlation Coefficients Between Functional Wellness Subscales for People with MS or Carers.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. FWI(ph) PwMS</td>
<td>-</td>
<td>.130 (n = 84)</td>
<td>.593*** (n = 85)</td>
<td>.160 (n = 84)</td>
</tr>
<tr>
<td>2. FWI(ph) Carer</td>
<td>-</td>
<td>-</td>
<td>.295** (n = 84)</td>
<td>.711*** (n = 84)</td>
</tr>
<tr>
<td>3. FWI(messh) PwMS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.330** (n = 84)</td>
</tr>
<tr>
<td>4. FWI(messh) Carer</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: * p < .05. ** p < .01, *** p < .001 (two-tailed).

There was a significant, positive correlation between FWI(ph) of PwMS and the FWI(messh) of the PwMS, r(85) = .593, p < .001. Thus greater FWI(ph) Scores of PwMS were associated with significantly greater scores for FWI(messh) for PwMS. The FWI(ph) scores of PwMS and FWI(messh) Scores of PwMS share 35.16% variance.

There was a significant, positive correlation between the FWI(ph) of carers and the FWI(messh) of PwMS, r(84) = .295, p = .007. Thus greater FWI(ph) Scores of carers were associated with significantly greater scores for FWI(messh) of PwMS. FWI(ph) Scores of carers and FWI(messh) scores of PwMS share 8.70% variance.
There was a significant, positive correlation between FWI(ph) of carers and (FWI(messh) of carers, \( r(84) = .711, p < .001 \). Thus greater (FWI(ph) scores of carers were associated with significantly greater scores for FWI(messh) of carers. FWI(ph) scores of carers and FWI(messh) scores of carers share 50.55% variance.

There was a significant, positive correlation between FWI(messh) Scores of PwMS and FWI(messh) Scores of carers, \( r(84) = .330, p = .002 \). Thus greater FWI(messh) Scores of people with MS were associated with significantly greater scores for FWI(messh) of carers. FWI(messh) Scores of people with MS and FWI(messh) Scores of carers share 10.89% variance.

**PAIRED SAMPLES T-TESTS**

Paired samples t-tests were carried out on the following pairs of variables: FWI(ph) of PwMS and FWI(ph) of carers, FWI(messh) Scores of PwMS and FWI(messh) of carers, Depression Scores of PwMS and Depression Scores of carers, Reciprocity Scale Scores of PwMS and Reciprocity Scale Scores of carers, Life Satisfaction Scale Scores of PwMS and Life Satisfaction Scale Scores of carers.

- Alpha \( \leq .05 \) as statistically significant
- \(.05 < \text{Alpha} < .1 \) as marginally statistically significant
- All p values are two-tailed.
Results:

- PwMS had significantly greater FWI(ph) Scores (M = 19.74, SD = 4.15) than carers, (M = 14.61, SD = 3.92), t(83) = 8.824, p < .001.
- PwMS had significantly greater FWI(messh) Scores (M = 30.25, SD = 7.19) than carers, (M = 27.99, SD = 6.72), t(83) = 2.57, p = .012.
- PwMS had significantly greater Depression Scores (M = 15.87, SD = 9.75) than carers, (M = 9.87, SD = 8.74), t(84) = 4.619, p < .001.
- Carers had marginally significantly greater Reciprocity Scale Scores (M = 34.24, SD = 9.80) than PwMS, (M = 32.34, SD = 9.34), t(83) = 1.804, p = .075.
- Carers had significantly greater Life Satisfaction Scale Scores (M = 18.24, SD = 5.41) than PwMS, (M = 16.17, SD = 6.80), t(83) = 2.671, p = .009.18

SUMMARY OF RESULTS FROM THE DESCRIPTIVE AND INFERENTIAL STATISTICAL ANALYSIS OF VARIABLES IN THE “PAIRS ONLY” SUB-SET

Significant findings are presented here in bold and summarized in Boxes 1 and 2, Chapter Seven.

Eighty-five pairs meeting the criteria of a person with MS (PwMS) and an identified Carer or support person were identified in the total study sample of 203 persons.

Five different types of relationships comprised the sub-sample with the predominant type being a heterosexual spousal relationship (n=76=89%). All other types together accounted for 11% (see Table 5.1).

Females outnumbered males with MS (70%: 30%), with approximately half the participants being under and half being over the age of 50 years.

As previously noted, the ‘newly diagnosed’ (less than 3 years since diagnosis) are under-represented in this study.

Home ownership in the total sample and in the sub-sample was higher than the Australian general population. A higher rate of home ownership may be related to the
fact that the average age of the study sample participants was older than the general Australian population.

**Sixty-three percent of the PwMS were satisfied with their income**, while 37% perceived their income to be barely or not satisfactory to meet their needs.

**Education levels were higher than the general Australian population.** Given these higher levels of education, (60% educated at TAFE level or above).

**Only 24% PwMS were in full-time employment** in the community or at home at the time of the study. However, the sample was too small to draw any valid conclusions about this correlation.

**ANALYSES OF VARIANCE – MEASUREMENT SCALES**

Analysis of Variance with Depression as the dependent variable. A statistically significant main effect of gender on depression scores was noted; women had higher depression scores than men and there was only a marginally significant effect of PDI scores on depression. Multiple regression tests, (holding all other variables constant), showed **PwMS who were disabled or unable to work were significantly more depressed than those who were working**; **females with MS were more depressed** and the PDI was marginally significant as a predictor of depression. All other variables were not statistically significant.

**Reciprocity.** The same tests were repeated using reciprocity as the dependent variable. **All effects of the independent variables on reciprocity scores of PwMS were not significant at the p.05 level.** Once again it is noted that no measurement criteria exist for the application of this scale to both care giver and care recipient. **Only congruence or non--congruence can be noted in the dyadic scores, and the researcher must rely on subjective observations at interview and on comments made by participants reflecting expressions of warmth and affection and relating to other constructs of the Carruth (1997) measurement scale (CRS-II).** Thus, multiple methods (triangulation) were used to assist with the interpretation of the important construct of reciprocity in spousal caring relationships.
Life Satisfaction. Again, the same tests were repeated on this dependent variable. Analysis of variance disclosed a significant main effect of the PDI of PwMS on life satisfaction scores of the PwMS. All other independent variables were not significant at the p.05 level. Multiple regressions revealed that the PDI was a significant predictor of LSI-Z scores for PwMS, and while other variables were not significant, income satisfaction was a marginally significant predictor of life satisfaction scores.

Functional Wellness Inventory. Analysis of variance revealed a significant main effect of income on the FWI scores of PwMS. There was also a significant main effect of the PDI on the FWI, and only a marginally significant main effect of gender on FWI. All other variables were not significant. Multiple Regressions produced inconclusive results except for Carers who were disabled or unable to work who had higher FWI scores, indicating lower functional wellness. All other variables were not significant. When this FWI scale was broken down into two separate scales as described above and subjected to the same statistical tests, the results provided similar main effects, highlighting the following: There was a significant main effect of the PDI on FWI(ph); persons with MS who were unable to work had higher scores than those who were able to work; PwMS who perceived satisfactory incomes had lower scores on the FWI(ph) scale, but only marginally; and the PDI was a significant predictor of FWI(ph). Analysis of Variance for FWI(messh) revealed significant main effects of the gender of the PwMS on the FWI(messh) scores, as well as a significant main effect of the PDI score on the scale. Multiple regression found females scored higher on the FWI(messh) scale and the PDI was a significant predictor of FWI(messh) scores in PwMS. All other variables were not significant.

Correlations. Using Pearson’s Product Moment correlation coefficients to measure associations between the FWI(ph) of PwMS or Carer and the FWI(messh) of PwMS or Carer, a significant positive correlation was found between the FWI(ph) of PwMS and the FWI(messh) of PwMS. Similar correlations of scores of PwMS and Carers were noted in both directions, suggesting a close association of physical health and mental, emotional, spiritual and social health of care giver and care recipient.

Paired sample t-tests. Results of these paired t-tests revealed the following: (1) Persons with MS scored significantly higher than Carers on the FWI(ph) and FWI(messh)
(indicating lower overall levels of functional wellness) and depression, and (2) Carers had marginally better scores on the Reciprocity scale and the Life Satisfaction scale than Persons with MS.

INTRODUCTION TO CHAPTER SIX: PHASE TWO OF THE STUDY – A MULTI-TIERED QUALITATIVE ANALYSIS OF 24 INTERVIEW TRANSCRIPTIONS

Chapter Six introduces and reports on the multi-tiered qualitative analysis of interviews conducted after analysis of the survey data from Phase One had been completed. The preliminary descriptive data analysis of the total data set (Chapters Four A and Four B) and subsequent inferential and descriptive statistical analysis of the ‘split file’ (Chapter Five), helped to inform the selection of the interview pool from which the 12 spousal dyads were selected.
Introduction to Phase Two of the study

“The Uninvited Guest”: the experience of 12 Carepartners coping with multiple sclerosis

Chapters 6-9 comprise Phase Two of the study which consists of a multi-tiered, qualitative analysis of interview transcriptions obtained from twelve spousal dyads living in Victoria during this phase of the study. Using a variety of perspectives, the analysis explores emergent themes, pressing needs, coping strategies, metaphors and essence statements that capture insights into the lived experience of twelve ‘carepartners’ with MS at a point in time. Direct quotes from participants are used to illustrate some of the insights obtained at interview. The research has implications for further research, for review of health policy, and for the education and practice of health professionals working with couples and families impacted by MS.

Chapter Six describes a multi-tiered qualitative analysis of the interview transcriptions as illustrated in Figure 6.1.

Chapter Seven summarizes and discusses findings emerging from both phases of the study, responds to the research questions and looks at questions arising from the data.

Chapter Eight offers a discussion of the findings and concepts emerging from data analysis of Phase Two interviews and uses triangulation of methods to enlighten the interpretation of selected concepts. Contributions to new or expanded knowledge are identified, together with new directions for research and practice.

Chapter Nine is entitled Conclusions and Recommendations. It identifies conclusions emerging from the data and discusses recommendations for further research, for policy
changes, for the education and practice of healthcare professionals; PwMS and their families and highlights the pressing needs identified by the study sample as delineated in the thesis. These findings suggest a strong case for reviewing existing health policy and programs to meet the needs of persons with MS, their carers and families.

An Epilogue concludes the paper with the researcher’s comments on the bi-directional impact of researcher and researched in the study, highlights what has been learned and looks at possible new directions for research and practice of healthcare professionals working with Carepartners in MS.
Chapter Six:
Qualitative Analysis of Interview Data

THE INTERVIEW POOL: SELECTION OF SUB-SAMPLE
Statistical Analysis of the survey data obtained in Phase One, as reported and discussed in Chapters Four and Five, helped inform the selection of a sub-sample for interview in Phase Two of this research study. As previously noted, issues of cost and time demanded that interviewees be selected from the State of Victoria, Australia, only. Of the 85 pairs in the nationwide sample, 23 dyads were found in the State of Victoria who met the criteria of couples in committed spousal caring relationships where one member of the dyad had been diagnosed with multiple sclerosis and the other was the identified carer or support person. All had signed consent forms ten to eighteen months prior to interview. Twelve couples were contacted by telephone and all agreed to be interviewed. The interview sub-sample comprised six males with MS and six females with MS and their respective heterosexual partners. Participants resided in suburban, country, regional and rural areas of Victoria.

Selection of spousal couples only for interview, is a limitation of the study and is not intended to minimize the lived experience of those coping with MS who are single or in a type of relationship other than spousal. The focus of interest in this study has been the impact of MS on the committed caring relationship of the person with MS and their identified main support person or carer at the time of the study. Several couples were in second marriages, but only one specifically stated that his first marriage broke down as a result of his personality changes due to MS. Caregiving as a dyadic process is only recently emerging in the literature, but has implications for ongoing assessment, education and support in the management of couples with MS (Pakenham 1998; Bodenmann 2001; Lyons, Zarit et al. 2002; Cheung and Hocking 2004; Bodenmann 2005; Bodenmann 2005; Wilkens-Blank and Finlayson 2007).
SUMMARIES

I prepared brief summaries for each participant from information contained in the survey data including scores obtained on their measurement scales and responses to the open-ended questions as well as any data that seemed unusual and might be pursued later at interview. Summaries were reviewed prior to each interview and formed the basis for possible questions or probes following the open-ended interview if these topics were not spontaneously addressed during the narrative. (See Appendix B).

REFLECTIONS ON METHODOLOGY

Although I designed this study as cross-sectional, it could be considered in some respects to share ground with longitudinal studies, since roughly ten to eighteen months had elapsed between the first (survey) and second (interview) contact and there were some observable changes noted in the participants’ situations that had occurred during the intervening time. All participants agreed at interview to further telephone contact with me if questions arose during the data analysis. Further contact was made with one couple to follow up on suggestions made during their interview.

I tape-recorded and transcribed all interviews myself to allow me to pick up voice tones, pauses, observations and non-verbal cues that might help with the interpretation of the narratives, as suggested by Moustakas (1995), and Seidman (1998). In keeping with the phenomenological and hermeneutic nature of this phase of the study where first person perspectives are understood as capturing the lived experience of both researcher and participant, I will frequently use the first person and I will identify questions that continued to arise during the complex analysis. The research design for this mixed method research study was complex and could be considered as comprising several tiers as well as several levels and layers of meaning. The analysis is both sequential and iterative and includes direct quotes from participants to illustrate emergent themes, and includes my observational and reflective comments recognizing the two-directional impact of participant and researcher (Padgett 2004).
MULTI-TIERED ANALYSIS OF INTERVIEW TRANSCRIPTIONS

Figure 6.1. Schema for multi-tiered qualitative analysis.

- **Data reduction Step 1**
  - All themes identified
  - PwMS Themes
  - Carers' Themes
  - Analysis for common themes
  - Dyadic Themes and Concerns

- **Second Tier Analysis**
  - Identification of all coping strategies
  - PwMS Strategies
  - Carers' Strategies
  - Analysis for common strategies
  - Couple coping as team
  - Individual strategies

- **Third Tier Analysis**
  - Data reduction: Essence Statements
    - MS - Friend or Foe? "Metaphors & Statements" encapsulating
    - "What it is like for me living with MS at this point in time"
  - Compare quantitative results & answer R. questions

- **Fourth Tier Analysis**
  - Transcriptions in the context of the conceptual framework - The Z-R Model
OVERVIEW OF SCHEMA

I devised a multi-tiered schema (Figure 6.1 above) for analysis of the transcriptions, and designed to capture several facets of the dyadic experience of living with the uncertainties of multiple sclerosis as a PwMS or as a Carer. The first tier addressed the main topics or themes mentioned in the open-ended interviews. All topics were listed, then separated into columns under PwMS and Carer and these topics were grouped whenever possible and reduced to the most common groupings (see Table 6.1). Two topics emerged that were of special interest and had not been extensively addressed in the literature: (1) expectations of health professionals (met and unmet) and (2) a notable difference in the perception of the importance of cognitive changes by PwMS and by Carer. These two phenomena were explored further. Three themes on the list were addressed more fully in later tiers of analysis. These included ‘coping strategies’, ‘perception of MS’ impact on their lives’ and ‘pressing needs and concerns’.

The second tier attempted to identify coping strategies employed by the couples, using some of the existing typologies for guidance. ‘Couple-coping’ emerged as a phenomenon of interest and required a further review of the literature (now included in Chapter Two). As I reviewed the transcriptions, I asked many questions. Was this couple working together as a team or partnership as they faced life’s challenges with MS or did they each appear to be following their own independent agenda as they sought solutions? Could they be called ‘carepartners’? How did they perceive their relationship? What valued elements did each person mention about the other and how did these impact the spousal relationship? It would be unrealistic for this one-off interview to be expected to capture accurately all the challenges or nuances in their relationship that couples experienced when coping with a chronic, unpredictable, progressive, neurological illness such as multiple sclerosis; an illness that was disrupting their life plans in every dimension.

The third tier opened with the question: “Do you consider MS a Friend or Foe?” (Korosi 2003). Interviewees were at first surprised that I should ask such a question, and the immediate response for most was “Foe, of course”! Emotional outbursts, sighs and groans were not uncommon. I was seeking metaphors or essence statements that illuminated their perception of the impact of MS on their lives and relationships. The stories related by participants contained unspoken feelings or feelings that were revealed
in the choice of words used; in metaphors chosen to describe their situation; in the sighs, silences or emotional outbursts as they recounted their experiences. Patton (1990) suggests “a great deal of meaning can be conveyed in a single phrase or with a powerful metaphor (Patton 1990).

Finally, a fourth tier or meta-analysis of the interview transcriptions helped to identify the most pressing needs and concerns of the carepartners in the context of the ten basic needs of the “Z-R Model for Assessment of the ten basic human needs across the lifespan (Zuluaga 2000)”. (See Chapter One, Figure 1.1). This Model has been used as a conceptual framework for the study, and is in keeping with the iterative nature of the study.

The single interview must be considered a snapshot of the perceived situation at a particular point in time, at interview, recognizing the dynamic and ever-changing nature of human life experiences.

In an attempt to address some of these questions and dilemmas, I followed the multi-tiered schema for transcription analysis and included illustrative comments from participants. My comments and reflections as researcher and observer have been included in the interests of clearer understanding, while recognizing that these comments are subjective and reflect my impressions only.

INTRODUCTION TO DYADIC PAIRS

(a) Coding of interviewees in multi-tiered analysis of transcriptions

Interview transcriptions were coded alphanumerically and reviewed sequentially for analysis from different perspectives as illustrated in Figure 6.1.

Coding identified the following:

- ID number for dyadic pair (1-12)
- a = PwMS
- b = Carer
- x = female
- y = male
Thus, 2ax indicates a female person with MS from dyad #2; 11ay is a male with MS from dyad #11; 1by is the male carer in dyad #1 (see Glossary).

This coding is used at the end of all quotations used throughout the thesis.

MEETING THE 12 ‘CAREPARTNERS’

Couple #1 (1ax and 1by)
This couple was referred by snowball sampling (referral from a mutual friend). The diagnosis of MS was suspected when she was in her early 30’s following a dramatic episode of severe weakness when she could not get out of the bathtub. Her husband was overseas on business but her friends provided help and support. Not too much was known about MS 35 years ago and what she read, she described as “death by tomorrow, sort of thing (1ax)”. She visualized herself as becoming very disabled eventually. She and her husband gave some serious consideration to their life goals and what they wanted to do before retirement, demonstrating an example of what Lazarus and Folkman (1984) refer to as ‘Positive and Planful Problem -Solving’ as their coping style of choice (Lazarus and Folkman 1984). They followed their plan, enjoying extensive overseas travel and an active social life as the disease appeared to remain dormant for the next 20 years, after which it started to progress noticeably. At the time of interview, (approximately 35 years later) her mobility and balance had declined to the point where she had recently moved from requiring a walker to needing an electric wheelchair where she spent the day. The couple had purchased a van that her husband drove and that she could drive into with her wheelchair, limiting their need for specialized taxis and allowing them greater independence and the ability to do things together, eating out or visiting friends who had wheelchair- accessible housing.

They had recently sold their home and had made plans to move to a retirement community within a few months. Purposeful planning was still evident as a lifetime coping strategy. When asked at interview if she was happy with the decision they made 35 years ago, she replied affirmatively. Each member of the dyad spontaneously and independently expressed admiration and affection for the other and were observed to have a strong level of reciprocity in the relationship. Scores on the CRSII reciprocity scale were equal (congruent). They minimized problems related to MS, such as bowel, bladder
and sexual problems, but fatigue was recognized as the most debilitating factor limiting their daily lives and social activities.

Notable changes between the time of survey and the time of interview (12 months) included decreasing mobility requiring use of an electric wheelchair instead of a walker and a planned move from their current home to a retirement community that allowed them to specify building changes to accommodate the wheelchair: no steps, wide doors, wheel-in shower and a convenient single level, open floor plan. Garden maintenance was also available at this facility. They had spent several years researching the retirement accommodation market and were happy with their choice. Their plan was fulfilled on time and to their satisfaction. In the case of the carer, he had abandoned his loved pastime activity of gardening (mentioned in the survey) to devote more time to his ever more demanding role as a carer, which he said he enjoyed and preferred to do himself rather than have “strangers do her personal care (1by)” saying he considered outside help an “intrusion”. However help with housework was acceptable at this time.

The couple appeared to have adequate income and managed it well to allow them the freedom to follow their chosen life plan. There were no observable negative effects of MS on their caring relationship. Both had negative impressions of the information and services offered by the MS Society and offered recommendations for improvement. They sought alternative resources when needed. Each displayed a keen sense of humour and a strong desire at interview to maintain their independence. They demonstrated excellent skills at developing and capitalizing on their extensive friendship group (social capital). They regularly invited friends over for dinner and were pleased that many times the friends would provide the dinner as they all enjoyed a pleasant evening together. He admired her resilience in the face of the problems she faced with MS. Both were community leaders and were involved in The University of the Third Age (U3A), a bridge group, a book club, and they occasionally attend the local MS support group. They believed that professionals should know about available resources and that someone like a ‘case manager’ would be of value to people with MS and their families to turn to in time of need.
Couple # 2 (2ax and 2by)

This couple was recruited by snowball sampling. I was shopping for a handrail at a hardware store and the man who served me became interested in my need for this item. As we spoke, he told me his wife had MS, and I invited them to participate in my research study. He agreed immediately. I asked him to talk to his wife and if she also agreed, I would post them the survey papers. He responded the next day, and I sent the documents.

At the time of interview this person had been diagnosed with MS for over 20 years. The carepartners had two teenage sons attending a nearby private school, and finances were not considered adequate at this time. He was employed part time, but appeared to have periodic contracts he managed from home to supplement his income.

He was his wife’s sole carer and preferred to assist her with her personal care (as did 1by above). Extended family lived nearby and offered some support with cooking for the family.

She was wearing a cast on her arm on the day of interview, which she explained was the result of a fall in her kitchen the previous week. She was expressing increasing frustration with her level of dependence following the break, but repeated the phrase “but we are happy” several times. Interestingly, her husband gave a different version of her fall, suggesting conflict between them or some discomfort with the interview process. It is not uncommon in my experience, for interviewees to require several visits before they feel comfortable in disclosing delicate family matters to the interviewer or professional helper. He described his wife as jealous, with which she agreed, and he gave an anecdote to illustrate this assertion. He expressed a need for a family holiday and a regular ‘break’ for himself. His statement “we are in this together and I’ll be there for you when you need help (2by)”, reflects his view that he had a steadfast commitment to the relationship. There were no affirming comments on his part about his wife, although she said he was ‘wonderful’ and “he’s stood by me 100% (2ax)’.

He frequently mentioned that he saw her as ‘stubborn’ and ‘jealous’ and that he perceived her as being unwilling to accept help even when doing so would help them both. She agreed that she was ‘stubborn’ and ‘independent’ and she did not like to ask others for help. She failed to fill out the reciprocity scale prior to interview but completed it in my presence. She explained that she had difficulty seeing herself as a ‘carer’ of her husband,
but was pleased that she might be contributing something positive to his life. Scores on this scale were exactly the same, suggesting they viewed their caring relationship similarly, but my observations failed to support this belief.

The theme of failed expectations from healthcare professions arose once again, and she reported statements by the doctors she saw as well as conflicting advice on the wisdom of having children which she interpreted as lacking in sensitivity. These experiences are discussed later under ‘themes’. Having just suffered a serious setback in the form of a broken wrist the week before the interview, it is possible that this one-off interview may not have been representative of this couple’s lived experience with MS. Her carepartner seemed interested in making contact with the MS Society and exploring any options for holidays for the family. Both were reluctant to accept outside help, but had recently agreed to get help with personal care and housework while she had the cast on her arm.

Changes since survey was completed: Her mobility had declined somewhat, increasing the burden on her carer/husband. However, the recent broken arm was an unexpected incidental event apparently unrelated to the progress of MS between contacts. There were issues of driver safety that were noted but not discussed.

**Couple #3 (3ay and 3bx)**

This 51 year old male was recruited through an informative flyer included in the packet sent by the MS Society to newly diagnosed persons. He was diagnosed with MS only two years before the interview, but the diagnosis alarmed him considerably as his elderly mother had MS and was in a wheelchair. He immediately had visions of a ‘worst case scenario’ for himself. This fear of future in a wheelchair was reported by Janssens (2003) and was observed in several persons in this study. This PwMS had visited his mother during her frequent hospitalizations and was aware of the seriously disabling potential of MS, and although he said he “became depressed after diagnosis it did not last long. (3ay)”. After some reflection, he decided:

“MS has changed the ‘playing field’. I need to lower my expectations. My mind has sort of accepted the MS at times. I don’t understand the changes that are happening in my body, but I just have to adjust to it (3ay)”.

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Like several other males in the study sub-sample, he reported being exceptionally fit prior to the diagnosis, participating in football and other sports. Females also stated they had always been well prior to MS. He said he was thankful that the disease did not strike when he was younger as he had been able to accomplish most of his lifetime goals, except for travel, but this is a desire his wife did not share. This was a second marriage for both and they had grandchildren who often spent the school holidays with them. He viewed MS as an antagonist who was often “winning the battle (3ay)”.

He expressed strong affection for his wife, denying that he needed a ‘carer’ but accepting that he needed moral support and affection. They both reported a long standing friendship and being ‘very close’, to the point they could ‘almost read each other’s minds’. At the time of interview, both partners seemed to have accepted MS in their lives. He was recently made redundant at his place of employment, and his case was being investigated by a legal firm referred by the MS Society to ensure he received the best redundancy package possible. Their CRS-II (reciprocity) scores differ by 9 points (moderately congruent), but each expressed a strong value placed on their longstanding friendship. She included the concept of ‘payback’ as one of her reasons for caring, mentioning the care he gave her after a serious horse riding accident early in their marriage, which had a lengthy rehabilitation period. They were able to see each other as ‘carepartners’ with each caring for the other. Words used to describe his symptoms included: “weird”, and “strange”, and these terms recur in different interviews, suggesting that the sometimes vague symptoms of MS are hard to describe. There were no apparent changes in their home situation since completing the survey.

Couple #4 (4 ax and 4 by)

The couple was recruited through an advertisement placed in “Short Circuit”, the magazine for PwMS. This couple was in their early thirties and had 2 small sons. They were facing the challenge of MS, diagnosed 2 years ago, as a united team although the husband admitted he needed more information about MS in order to better understand its impact on his wife. He was overcoming the initial belief that his wife could help herself more and was possibly not doing all she could. He prided himself on being a good provider for his family and having a job that allowed them a good living and was very secure. His wife described him as a ‘workaholic’. He admitted that his job had probably
been more important to him than his wife and family, but he was re-evaluating his priorities. They both stressed that they had been friends for a long time, with a long-standing friendship that preceded the marriage, and both agreed they could speak openly about most things without arguing. However, she noted that she was uncertain about how her husband really ‘felt’ about things as he seldom showed emotion. The diagnosis of MS was reached after much angst and misunderstanding with reports of inadequate medical support or information and repeated trivializing of her symptoms that were admittedly vague and difficult to describe. She feared she was “going mad (4ax)”, and this was perceived as worse than any physical diagnosis (Couple #6 expressed this same view). Additionally, she suffered from ‘panic attacks’ that were now under control with support from a psychologist. She described episodes of weakness and inability to coordinate her hands enough to sign her credit card when shopping. She praised the help received from the MS Society and the nurse who was sent out to teach her to inject the interferon drugs.

He deplored the frequent need to change agreed social plans with family and friends which had been anticipated with pleasure, when his wife’s illness flared up or she was overcome with fatigue. Purposeful planning was evident as a coping style in response to her appraisal of MS and a ‘worst care scenario’ of life in a wheelchair or total disability in a nursing home. They were in the process of building a purpose-built home close to their boys’ school and near public transport, although she was still able to drive and to carry out most of her activities as a wife and mother. He agreed to these changes, which included a one-level structure without steps, with wide doors and wheelchair access to the shower, to name a few, but he viewed these adaptations primarily as a good financial investment primarily.

Both were very independent and were reluctant to accept outside help in any form. This reluctance even included occasional babysitting as they were adamant that all parenting was their responsibility. Grandparents who lived nearby had expressed a desire to have the boys from time to time but this was not considered acceptable by the couple. They took the young boys (4 and 6 years old) everywhere they went.

There was a 17 point difference in their reciprocity scores indicating no congruence, and although on observation, there appeared to be a firm commitment to the spousal
relationship, I had concerns for the future of the relationship as the disease progresses. Their communication was open and without conflict.

Some changes were noted between survey and interview. This family had changed residence to a rental home from which they were directing the building of their purpose-built home nearby. Since he worked long hours, he left the day to day management and decision-making related to the building to his wife and she seemed to be coping with this well. No other changes were evident, except that the ‘panic attacks’ were now under control and she was pleased about this improvement.

**Couple #5 (5ax and 5by)**

This couple was recruited through Short Circuit. They had been in a long term relationship since she was 17 years of age, at which time she had a startling incident where she was unable to get out of bed and had to be carried downstairs by her partner. He described her as “no lightweight (5by)” (suggesting that she had been overweight for some years). She remained downstairs for several days and then the episode resolved with no further problems for the next 7 years. Further symptoms developed at that time leading to a diagnosis of MS. They both expressed appreciation for the help they had received over the years from the MS Society as special needs developed. She had many mobility aids but said she only needed them when she was under a lot of stress, which “causes the MS to get worse (5ax)”.

They seem to have accepted MS as “just one of those things that comes along in life”- the good with the bad. Both carepartners were obese by their own admission and on my observation. They were both receiving disability pensions and stated they found it hard to make ends meet, describing their financial situation as “robbing Peter to pay Paul (5by)” and saying: “we are unable to buy the proper food rather than just the cheapest (5ax)”.

They had concerns that were unrelated to MS that occupied most of their energy. Two concerns were their inability to have a child (2 miscarriages) and the considerable fear for their safety due to threats of physical harm coming from her family. They had to take several legal steps, including name changes, to cope with these threats and were moving to a new location at the time of interview. The marriage has had its “ups and downs (5ax)” and was described as being “on and off the rocks (5by)” over the years, but both
claimed they were the best of friends and managed to sort out their differences. Each expressed positive and affirming comments about the other.

Purposeful planning had been applied to their life goals as they prepared to undertake a business course prior to opening a television repair shop. They recognized this learning need since a previous business venture failed due to their perceived lack of knowledge. Otherwise, there were elements of ‘Distancing’, as a coping strategy as identified by Lazarus and Folkman (Lazarus and Folkman 1984). They ‘just get on with their lives’, as described by Hewson and Germanos (Hewson 2003) minimizing the impact of MS on their relationship and their lives. He asserted that she had memory problems which she denied and this often led to arguments. Important papers were misplaced and conversations forgotten. As an example, during the interview, she was observed to glance at the bulletin board in the kitchen and call out excitedly to her husband in the next room, saying: “There it is, Luv (5ax)”, pointing to an important missing document that she had misplaced.

It was difficult to appraise the effect that her cognitive changes may have on their functioning as a couple. There was a 5 point difference in their reciprocity score, indicating only moderate congruence, but on observation, and despite their many reported arguments, they seemed to have an affectionate and loving relationship, perceiving themselves as partners. Both had a high depression score on the screening tool at survey time, but say “things are better (5ax and 5by)” now that they have addressed some of the problems with their extended family.

Changes between contacts included a legal name change and an address change that made it more difficult to locate the couple for interview.

This couple was unique in their overwhelming appreciation for the support and services provided to them by the MS Society of Victoria, while deploiring the lack of ongoing support from the neurologist after diagnosis, saying: “I was a bit upset that he never suggested he would ‘keep an eye on it (MS) (5ax)’.”
**Couple #6 (6ay and 6bx)**

This couple learned of the study through a call for participants on the internet. The 53 year old male PwMS was diagnosed with MS 10-15 years ago. It has followed a very slow but progressive course and he now requires a walker or wheelchair for outings that require much walking. This was a second marriage for both, with one son, aged 23, living with them. The PwMS is no longer able to work as an accountant due to cognitive changes affecting memory, decision making and problem solving skills. They mentioned financial concerns. The couple had decided to move to more suitable accommodation early in the diagnosis, anticipating later mobility problems. This decision had been made ten years prior to the interview but they had not yet found a place that suited them. His wife was employed part time and she enjoyed this position very much. However, she admitted that she would probably have to leave employment as her caring duties became more demanding. She expressed great fondness for her husband but admitted she often resented the increasing burden of the caring role and felt “taken for granted (6bx)” at times. She mentioned ‘payback’ as a reason for her devoted care, citing her husband’s help when she was seriously ill with asthma. They both noted that they valued the sexual part of their relationship, but that MS had now adversely affected this. Towards the end of the interview when I asked if he had any questions, he responded: “Yes, I thought this was a study on relationships (6ay)”, suggesting that nothing had been said about sexual issues in MS. I explained that in an open-ended interview, the direction of the conversation was left to the interviewee, and I invited him to express his concerns. He reported a loss of libido as well as erectile dysfunction and was concerned about the impact this had on his wife. He accepted information and a referral to specialist help in this matter.

He expressed relief when finally given a diagnosis of MS, as he found it easier to cope with a “named condition (6ay)”, rather than with the vague and worrisome symptoms he thought were “in my head (6ay)”. His wife, however, said:
“When he told me, he was so calm..., but I ran upstairs and burst into tears. My greatest worry was for our only son (aged 12 at the time)...I was worried about the impact on him... After that, I was O.K., except that I leaped ahead...I mean...I had him in a wheelchair next weekend and tried to do too much for him, which was not appreciated... plus...I had a stupid, irrational fear of wheelchairs. My daughter (from her first marriage), God love her, took me to the MS Society where I was shown a room full of wheelchairs, and the person convinced me they were just a means to an end. I was O.K. after that (6bx).”

He praised the educational programs offered by the MS Society and was an active volunteer there as well as volunteering to read for a vision service. She reported that they attended information sessions about MS, saying:

“Yes, we did all that and then decided to ‘just get on with it’. We have a wonderful group of friends and enjoy doing things together...although I think the camping may have a ‘shelf life’ and he may not be able to participate much longer as he feels the cold so (6bx).”

Reciprocity was evident on observation, but there was an underlying sense of resentment in the carer, who expressed feelings of guilt for admitting it. There was a 21 point difference in their scores on the Reciprocity scale, suggesting a lack of congruence, but verbalized and observational evidence do not support this notable difference.(see critique of CRSII Scale Chapter Seven). He denied he needs a ‘carer’ but did appreciate the moral support and understanding given him by his wife. They joked about their infirmities, asking each other: “Are you the primary care giver today or am I? (6ay and 6bx)”. No changes were noted between contacts.

**Couple #7 (7ay and 7bx)**

This PwMS said he had heard of the study in several places but probably made contact because of the advertisement in Short Circuit. He worked in law enforcement for many years, was now retired and was in a second marriage. He believed that the changes caused by MS to his personality were responsible for the eventual breakdown of his first marriage when he could no longer ‘keep up’ with his fun-loving wife. She left him 20 years ago and he married her best friend. It appeared to me that this relationship was in
some difficulty at present as they communicated poorly, seemingly unable to resolve long-standing issues between them. Both admitted difficulty in expressing love and affection. Their social life was minimal and restricted to golf for him and infrequent and uncomfortable events with family for her. His outings were limited by bowel and bladder problems. He was a man of few words, spoke with a rather flat affect, and concluded the interview with the following statement: “I love my golf and I don’t talk much (7ay)”. He was afraid he would soon have to give up the golf due to his severe heat intolerance and increasing weakness which seemed to cause him much sadness.

The interview with his wife was difficult as she used the forum to vent her anger about a relative who lived nearby but was perceived to have offered no help at all during her recent incapacitating illness and about the lack of affection and companionship offered her by her husband. Both had difficulty expressing their feelings to each other as previously noted, although the wife seemed to be able to tell me some of her feelings. Both were sensitive to rejection. She was in a very low mood when we spoke but she said she was starting counselling the following week. She was recovering from a case of the ‘flu’ that kept her in bed for seven days. Our original interview had to be postponed by a week. She said she felt helpless and abandoned during her illness. After the interview she wrote me a note thanking me for “listening to me (7bx)”.

This couple was socially isolated and admitted they could no longer drive for any distance and limited themselves to the local area. They felt the MS Society had shown very little interest in them and had not returned telephone calls seeking information. This seemed to be a common problem with families in regional areas, who reported that public transport into the city was scarce or non-existent, especially for the elderly or disabled. He intimated that if a diabetes nurse could visit him regularly, why was there no one to show an interest in the many problems he attributed to MS? Their home was comfortable and well maintained (by the wife). There was a 20 point difference in their reciprocity scales, suggesting no congruence and my observation and their verbalization supported this finding.

Couple #8 (8ay and 8bx)
This couple heard of the study through a flyer in a newsletter. They found great strength in the concept of ‘partnership’ in every aspect of their lives, expressing strong
commitment to each other and noting improvement in communication between them over the years. His MS had progressed very slowly over the past 24 years and he was still able to work in the family business at a sedentary job where he could take breaks as needed when fatigue overcame him. He also managed the financial end of the business.

He walked with a noticeable limp, and his wife reported that she did most of the driving as his driving skills were no longer good. They both reported that ‘the doctors were not too helpful’, giving an obscure diagnosis that the couple later had to look up themselves to come to the conclusion that it was multiple sclerosis. This discovery on their part was later confirmed by a neurologist. No information or support was given as they slipped into a deep depression. After deciding to try all sorts of alternative therapies and dietary approaches to no avail, they decided to just ‘do our own thing’ and ‘get on with life’. He then became active in the local MS support group where he acted as a mentor for others who were newly diagnosed, recognizing that: “Everyone is different and MS affects each person differently (8ay)”. He valued the support of his partner and said: “This support is so important (8ay)”’. When asked about the effect of MS on their relationship, she said:

“If anything it has improved it. I love him just as much if not more than I did before because we are both more comfortable with each other....mind you, (she added quickly) he’s not the man I married, but then, not many men are as they get older. His MS has been called ‘non-aggressive’...just very slow. He’s never had any of the drugs...just something for the ‘runs’ and something for the bladder. He hasn’t seen a neurologist for 4 years. He is not too disabled. We pull together, not against each other and we talk about everything. He just keeps on working (office work)..if he wakes up and it is a good day, well it is a good day for me as well. But there is always the worry about tomorrow....the uncertainty of it all (8bx)”.

Despite their insistence that they have a true and equal partnership, it may be that she was gradually taking over more of the work as his disability slowly progresses and she may be compensating for his increasing forgetfulness by encouraging him to keep copious reminder notes. Overall, they believe they are coping very well with the MS and address each new development using a problem-focused approach based on their strong sense of ‘partnership’. There is a 6 point difference in their CRS-II scores (moderate congruence), but my observations at interview suggest a strong affectionate and reciprocal relationship.
He described his former role as a mentor for newly diagnosed people with MS as one he enjoyed and found rewarding. He said he felt he was making a contribution and then added that he believed people were encouraged by meeting someone who had the condition for several years and was still working and still functioning reasonably well. There appears to be an underlying sense of chronic sorrow (Hainsworth 1993, 1994, 1996) and dread of future developments as the condition progressed. Their sense of uncertainty about the future was compounded by their delicate financial situation which depended on the success of their current business venture.

The only change between contacts seemed to be her report that his driving skills were poorer and that he seemed to be tiring more easily. Both proudly reported the arrival of their first grandson in another State.

**Couple #9 (9ay and 9bx)**

This 40 year old male, recruited through a call for participants in a newsletter, was born in Tasmania and believed his first symptoms suggestive of MS came at about 19 years of age. He related a period of severe stress prior to its onset brought about by the sudden death of his father. The first signs of MS appeared shortly after, followed by double vision and several bouts of weakness, but he minimized the impact of MS in his life, attributing his problems with fatigue, poor memory, staggering gait and cognitive and emotional problems to a stroke and a ruptured aneurysm that occurred in succession only a few years ago. He said he “found out a bit about MS (9ay)” and he knew the bad things that could happen to people but decided to basically ignore this information. This could be interpreted as an example of “Escape/ Avoidance”, one of the coping strategies described by Lazarus and Folkman, (1984). He justified his admittedly heavy use of marijuana by saying he believed that smoking marijuana prevented MS from progressing and it made him feel better. He said: “As far as MS is concerned, I’m top of the world (9ay)”. He and his wife had one child, a girl aged 9 at the time of interview. He said they were concerned at first about passing on MS but were reassured by doctors that there was a very small chance of this, so they decided to have a child.

He chose to work night shift because there was less traffic going to and from work and because there were fewer people to interrupt his work in the factory. He worked on a large printing press. He admitted to drinking and smoking in addition to the marijuana and
reported that he has frequently been involved in fights at the ‘pub’. He seemed to be aware of the many risks he was taking in his lifestyle and said: “Why do I do it? Because I can. I take life as it comes (9ay)”.  

There was a widely different perception of his ‘short fuse’ as described by his wife. Their relationship appeared to be that of a child-parent with his wife than one of a husband and wife. The wife acted like a patient and indulgent parent with a difficult child making every effort to keep the peace in the face of what she perceived as his unreasonable behaviour, yet expressing some resentment at the need for the ‘parental’ role. Reciprocity scores differed by 8 points suggesting moderate congruence, but there appeared to be little reciprocity in this relationship as observed at interview. He tended to joke about aspects of the behaviour that upset his partner. There were too many confounding variables in this dyad to be able to analyse the impact of MS on their relationship. It was possible that the differences in the relationship can be tolerated and that his ‘risk taking behaviour’ is balanced by her “non-risk taking behaviour”. However, I got the impression that it would not take much for her to abandon the relationship, but that is of course, a subjective assessment.

**Couple #10 (10ax and 10 by)**

This couple learned of the study through the MC2 internet chat room sponsored by the MS Society. The 65 year old female was diagnosed with MS 13 years ago at her husband’s retirement and has suffered progressive losses of ability since then. She spoke with a flat affect and somewhat slurred speech. She used a walker all the time and a wheelchair when going out. She tried to portray a positive attitude and repeats the phrase “we are some of the lucky ones (10ax)”. However there was an underlying sense of sadness, and much sighing as she related the losses she had suffered, even as she said she was thankful that the disease did not emerge while she was raising her 4 children and that she had been able to live a full and active life, enjoying water skiing, travelling and other activities with family and friends. She also said she was glad that she was able to do many of the outdoor chores while she was well, such as mowing the lawn and gardening while her husband worked full time.

She now stated it was only fair for him to take over these tasks and the housework as well since she was no longer able. The concept of ‘payback’ returned (as noted in couples # 3,
and #6). However, this concept was not always perceived equally by carers who felt ‘taken for granted’ for all their efforts (Couples #6,#11 and #12). This feeling is not seen as conducive to a reciprocal spousal relationship or to marital satisfaction. Despite the heavy and increasing burden on care for this retired teacher, he seemed to be committed to carrying out the carer role. He had willingly given up a part time job he took up after retirement to be with his wife whose balance was increasingly poor and who was having many falls in his absence. Reciprocity scores were congruent with only one point difference. Each expressed positive comments about the other and when he was asked about his perception of the impact of MS on their relationship, the husband said:

   “Everyone gets frustrated with their marriage at times, but no, I don’t think MS has had a negative effect on our relationship. It is still a loving relationship (10by)”.

There were perhaps many unspoken feelings he may have had about the way his retirement was turning out. He was an independent person who preferred to do the personal care for his wife and was reluctant to accept help from persons outside the family (as with couples # 1 and #2). Both were actively negotiating with the Council to build a safe walking track to the nearby town and derived much satisfaction from this community activity to improve the safety of pedestrians and persons with wheelchairs or pushers along a busy street.

Couple #11 (11ay and 11bx)
This couple was unsure of the source of their information about the study, but believed it was a notice in a newsletter or on the internet. Unlike the other dyads, over half of this interview took place with both participants present at the same time. I judged this to be the best course, since he was tiring noticeably as we spoke and his wife happened to arrive after 20 minutes. However, I was able to grasp a severe “Catch 22” situation in his narrative that was reinforced by his wife. His current situation included severely disabling fatigue due to his MS. His job was in a city that required a 2 hour drive each way; was uncongenial, with a boss who did not make any allowances for his personal needs. He was concerned that he would not be able to find a comparable job that paid as well and allowed him to meet his family’s financial commitments if he were to leave. He was also fearful of being made redundant. His description of his level of exhaustion was poignant.
Both angrily described an unsatisfactory delivery of diagnosis, rudeness and total lack of support from health care providers. They were allowed to research the meaning of MS by themselves on the internet. He reported being in tears as he saw the long list of possibilities in his future and the large number of his symptoms that matched those described. He reported an instance of arriving at a nearby city on his way home from work one day and being totally disoriented, not knowing where he was and feeling very ill. He was able to reach his wife by telephone, and she came to get him, and drove him home. It was evident that the present work and travel situation presented considerable safety risks due to his exhaustion when driving. This couple was immobilized by the enormity of their challenges, and were unable as a team to formulate any plan to start to resolve them due largely to his disabling fatigue. They could perhaps be described as being in a state of ‘limbo’ as noted by Becker (Becker 1997) in her book discussing people’s responses to disruptive life events. They requested ideas and assistance from me which I offered them. However, when I contacted them several days later they had not acted on any of these suggestions. No reason was offered for this.

Changes between contacts. He was no longer able to go boating or fishing and his fatigue level had reached an impossible level for him.

**Couple #12 (12ax and 12by)**

This couple could not clearly recall the source of their information about the study. This chairbound, 50 year old female with MS diagnosed over 10 years ago, told a story of delays in reaching a diagnosis, and sadly related all her losses of ability, her fear of passing the disease on to her three daughters, and the failure of medical practitioners over the years to meet her expectations. She noted the lack of empathy and support before, at and after diagnosis with an oft-repeated tale of being trivialized as a neurotic woman prior to diagnosis. Reciprocity scores differed by only 3 points suggesting congruence. She appreciated the devotion and care given by her husband. Her husband, in his early 60’s left employment and became his wife’s full time carer. He expressed love and affection for his wife and a firm commitment to the marriage, while admitting that he appreciated every minute he was able to find for himself. Although reciprocity was observed in the relationship, the situation was reaching a stage where more help or respite might be
needed to avoid carer burnout, despite his expressed strong values for commitment to his role.

Changes noted between contacts included lessened mobility. She was formerly able to get by with a walker and now was awaiting funding for an electric wheelchair. Her husband had left employment in order to be her full time carer.

**FIRST TIER ANALYSIS OF INTERVIEW TRANSCRIPTIONS:**

**EMERGENT THEMES (SEE FIGURE 6.1 )**

I reviewed all transcriptions looking for emerging themes which are described as similar concepts or statements made during interview by more than one participant and these were listed broadly as a group. Then I divided this large group into two sections: PwMS and Carers. The many themes were further grouped into similar topics and reduced to no more than ten themes that appeared to represent the most pressing concerns of the group and were considered the most significant for further analysis and discussion. These have been identified in Table 6.1. Although care has been taken during this first step in data reduction not to lose important data, the reality is that any attempt at data reduction must lose some data (Miles 1994; Frank 2004). Themes were listed side by side as I sought themes that appeared to be common to each partner and themes that, although similar, seemed to be viewed from a different perspective by care givers and care recipients. Not all themes have been addressed in detail in this study, and many have been mentioned only in passing since they have been covered extensively in the literature. This is not to limit their importance, but to allow me to spend more time on the two that were selected for further discussion, because they appear to raise important issues that have not been fully covered in the literature at the time of writing, and which seem to have implications for policy change and for education and practice of professionals working with couples and families with MS. Several themes that emerged are analysed in greater depth in separate tiers (coping strategies-Tier 2, perception of impact of MS and Tier 3, metaphors and essence statements).

As might be expected, most themes emerging from the narratives of PwMS were related to the disease itself and to their feelings, questions, fears, and concerns as well as real and potential losses of ability since MS entered their lives. Themes also related to the impact
of the disease on their spousal and family relationships, on their sense of partnership and mutual appreciation as well as on their ability to work, to interact actively with their family, and to financial problems associated with very early retirement from the work force.

Main themes emerging from interview transcriptions

1. Troublesome physical symptoms relating to the presence of MS
2. Cognitive and behavioural changes in PwMS-different perspectives
3. Economic and psychosocial impact of MS on partner, family, ability to work and to access retirement funds
5. Expectations of Health Professionals: met and unmet. Why can’t they tell me/ why won’t they tell me what is wrong?
6. Views of MS-Friend or Foe? (See third tier analysis)
7. Living with MS: varied ways of coping (see second tier analysis)
8. Pressing needs, concerns and access to available resources (see analysis in context of conceptual framework)
9. Suggestions for improvement in communication and support

1. Troublesome physical symptoms related to MS

PwMS frequently noted the adverse effects of extreme fatigue on their activities and relationships. This was dramatically reported by all participants with MS as their most debilitating symptom, as illustrated by the following example.

“So tired, so tired, always so tired...too tired to talk, too tired to play...too tired to make love...too tired to make decisions...can’t play ball with my son...it takes all weekend to recover from the week's long days of driving to work ...then start again” (11ay).
And

“I see MS as an antagonist who is ‘winning the battle’. I tell it (MS): You are not going to win; I am going to keep on going...until the fatigue kicks in...then I just lapse into sleep” (3ay).

**Bowel and bladder problems** were specifically mentioned by at least three participants as limiting their social activities.

One male said:

“Gotta be careful when we go out or there are ‘accidents’. Couldn’t go to a funeral last week because there was no toilet nearby” (7ay).

And another:

“I’ve always had trouble with my bladder-since I was 12. I tell people: ‘I was born in Australia but my bladder was made in China” (11ay).

And a third male said:

“Bladder and bowels are a bit of a problem in the last 12 months...Need to be close to the toilet when I need to go...no problems with sex...never was much of a priority anyway” (9ay).

**Loss of libido and sexual problems** were reported by four couples aged between 30 and 55, and one older couple (over 65) said:

“Of course our sex life has gone down the tube. It doesn’t bother us now but it was a pest when we were younger” (1ax).

2. **Cognitive and behavioural changes: different perceptions of the importance of these**

As I examined all the emerging themes, I noted that several were shared in common by both Carers and PwMS. However, the perspective of each was notably different in the impact of perceived cognitive and behavioural changes on their lives and relationships.
While PwMS frequently mentioned **memory loss and growing inability to concentrate and make decisions**, these changes and others, including ‘moodiness’, were related to me as minor annoyances and brushed aside lightly as not being overly important in their lives. Their partners however, viewed these changes as seriously affecting their lives, their relationships and their future.

It had been a useful decision to interview the couple separately in order to capture these notably different perceptions of cognitive changes. The University of Melbourne Ethics Committee had suggested that individuals be interviewed separately in the interests of maintaining confidentiality and this proved to be a valuable modification of my original design. These subtle differences in perspective might not have been picked up in a joint interview, where one interviewee usually takes a more dominant role in responding to questions. The following example illustrates this different perspective:

“After a short run, my left foot just kept clipping the pavement. I thought there was gum stuck to my shoe, but there wasn’t. It just kept getting worse and worse…..had trouble concentrating too…and working out problems. I was always very precise, almost anal, but now...(laughing) I just can’t remember things” (3ay).

His wife said, after virtually repeating verbatim the story of the onset of the first physical symptoms….

“When he was diagnosed it was pretty terrifying…I was more than a bit concerned…he felt a bit weird, felt really strange and yes, I became really concerned when he became disoriented. Then he was made redundant at work” (3bx).

Some Carers perceived the cognitive and emotional changes as having a marked effect on the relationship, with the partner having extreme mood swings, (sometimes described as ‘a short fuse’), over-reacting about very minor daily family occurrences, being unable to join in family discussions, being very vague and requiring the spouse to take on increasing decision-making roles in the running of the family’s affairs.
“Little things bothered him a lot. He has a short fuse. We almost split up.
Our daughter too, has learned the boundaries with him. She’ll say ‘Daddy is a bit ballistic today’ and I’ll say: ‘Yes dear, you know what to do about it’ and she’ll go away and leave him alone. She loves him dearly and he does too, but she knows how to manage him...and she is only nine years old.” (9bx).

He described a situation jokingly where he was refused entry into a ’pub’ as he was thought to be drunk already due to his staggering gait. He said he grew angry, was eventually allowed in but was later challenged again by the bouncer and asked to leave. His wife described it as a “knock-down, drag-out fight with the bouncer” (9bx).

3. The economic and psychosocial impact of MS, together with the physical and cognitive changes were often observed by the partner to have the potential to affect the PwMS’ ability to keep their present job or to have been responsible for recent dismissals or redundancies.

There was a general concern about the ability of participants to access superannuation funds at a relatively young age when they were forced to leave employment due to the physical and cognitive changes brought about by MS. They were unaware of any alternative sources of income available to them, and a disability pension alone was deemed inadequate to meet the commitments of young families.

These differences in perception of the importance of MS-related behavioural and cognitive changes need to be noted by healthcare professionals who may offer practical interventions and strategies to carepartners to lessen the impact of MS on the relationship (see Figure 8.1, Chapter Eight, Impact of MS on committed caring relationships).

4. The Caring relationship: concepts of reciprocity, mutual appreciation, friendship, open communication, a sense of partnership, enjoying each other’s company

The concept of ‘friendship’ or being ‘best friends’, noted by some couples, suggested the marital relationship was mutually satisfying despite its ups and downs. The following couples emphasized the concept of ‘friendship’ in their relationship as a valued construct.
Couple #5 independently admitted their marriage had been “on and off the rocks”, but their mutual and long-standing friendship kept them together. They still hoped to have a child despite being on disability pensions and facing an uncertain future with MS.

Couple #3 have been quoted as being able to ‘read each other’s minds’, and liking each other’s company.

Couple #4 each remarked on the importance of their long lasting friendship that preceded their marriage and continues unchanged, despite the misunderstandings related to fatigue and their widely divergent scores on the reciprocity scale. They scored 25 and 42 respectively; a 17 points difference when the mean difference was 2 points in the subsample. This lack of congruence could be interpreted as a low level of perceived reciprocity in the relationship, however, despite their differences, constructs of reciprocity were evident on observation.

Couple #6 remarked on their active social life and the enjoyment they shared in travel and other activities together and with groups of mutual friends.

Couple #8 emphasized the ‘partnership’ element in their relationship and derived value from shared activities and good communication, mutual support, love, trust and friendship over the years. Perceived ‘friendship’ and ‘liking each other’ in a spousal relationship may be regarded as a positive factor in marital satisfaction and could be included in the constructs of reciprocity.

“We are partners in everything. I get so much support from my partner....that is so important...we do talk openly now” (8ay).

He intimated that their communication had become more open in recent years, especially on sexual topics. They came from different cultural backgrounds but had managed to reach a level of communication that suited them both at the time of interview. There are numerous positive and affirming comments made by each about the other during the interview, as well as the comment that they “feel comfortable with each other” (8bx).
“We are one of the lucky ones. We pull together, not against each other, and we talk about everything, whether it is sexual, financial or whatever. Impact of MS on our relationship? If anything it has improved it. I love him just as much if not more than I did before because we are both comfortable with each other. Mind you...he’s not the man I married, but then not many men are as they get older. The part of our relationship that has stayed the same is our enduring love and trust. I have become more independent and more confident. I feel good that he still loves and trusts me and relies on me.” (8bx).

The concept of a ‘partnership’ in their relationship was highly valued by both members of the above dyad who repeated the term both in their survey responses and during their independent interviews. Each felt they were contributing to the team despite the increasing load on the wife as her husband’s illness continued its slow but progressive impact on his abilities. At the time of interview they faced an uncertain and vulnerable financial future as they had just opened a fairly large specialty shop and could only afford one part time worker to help out.

4.(b) Honesty (truthfulness) and sincerity in dialogue? Trust/distrust in the relationship? Absence of observable reciprocity constructs and its impact on perceived marital satisfaction?

It is often difficult as an interviewer to determine the extent of veracity in the dialogue when people try to put themselves in the best possible light as they relate sensitive family matters and it is entirely possible that the ‘truth’ may be ‘slightly bent’. This concept is recognized but has not been examined further in this study, which is based on single interview data and observation of a small sample.

The following woman speaks with questionable sincerity about her situation, listing all her problems and losses and finishing her sentences with “but we are happy” (2ax). She admits to being a jealous person and this appears to be a problem for her husband who would enjoy a “night out with the boys” (2by) occasionally. He said she was fearful that he might be out with another woman. She told me a different story than her husband about the way she fell and broke her arm, avoiding the true story which she believed her husband and health providers might not have appreciated. As I was leaving, he told me
the different story that she fell at the ‘pokies’;⁹ saying: “Now there are three people who know the truth: you, my wife and me”. He later expressed resentment of her “squandering my hard earned money” (2by)’. He cited his marriage promises as important to him, and his own extensive health history as contributing to his high level of patience and understanding.

“I am happy with life because I am blessed. I have two beautiful boys and I have a husband that’s very supportive and has stuck with me 100%. A lot of women with MS….their husbands have left them because they can’t cope with it. I try not to push him too much because he is always there to help me anyway”. (2ax)

Her husband added:

“When she was diagnosed with MS we were engaged and she asked me if I wanted to opt out of the marriage, I asked why? We are in this together and I’ll be there to help you if you need any help. She had been in a relationship before and she is very jealous – especially of blondes. Her previous partner left with a blonde. She is so jealous she does not want me to go out with the blokes now and then. I need a break. But we are a partnership, absolutely.” (2 by)

The following quotes illustrate the constructs of reciprocity described by Carruth (1996), including mutual regard, affection and esteem for partner, affirmation of valued personal qualities, and offer some reasons carers have given for continuing with their dedicated caring role when this had become very difficult. Some reasons given included ‘payback’ for past care by partner with MS, and others referred to a strong commitment to their marital vows: ‘for better for worse, in sickness and in health’. Others intimated they had a ‘duty’ to care for their partner. No participant actually used the term ‘reciprocity’, but two couples stressed the importance of ‘partnership’ and ‘working together’ in their relationship.

It needs to be noted that mutual affirmation was not noted in all dyads, at least two of whom were in extremely difficult situations at the time of interview when MS only

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⁹ Note: ‘pokies’ is a term used for poker and slot machines used for gambling in Australia.
allowed them to focus on their own overwhelming needs and concerns. Carers were expressing the need for regular respite and relief from their increasingly onerous role, together with feelings of guilt for openly stating these needs (6bx and 10by). One dyad acknowledged that their relationship had its ups and downs, but that overall they loved each other and considered each other the best of friends. The male carer in this dyad assured me that there never was any question of him leaving her. At least one dyad found it difficult to express affection and this theme was not easy to explore during a single interview, where considerable tension was observed together with a notable lack of expressed affection by either partner. This appeared to be a longstanding situation with this couple. The carer in the dyad expressed a yearning for warmth and affection while at the same time fearing rejection if she told her partner of this need. She said:

“I love and adore my little dog and take care of my husband as best I can. I do miss the cuddles, though” (7bx).

Others, however, expressed affirming comments of their partner’s valued qualities.

“I’ve been very lucky. My husband is very supportive. He is also a very accepting person:-very patient and very practical too…I don’t know if it’s from working with animals, or what. He’s brilliant! I get so angry when I can’t do what I want to do. He lets me finish with my tantrum and then he gets me a Scotch…Just what the doctor ordered!. I don’t think MS has had a negative impact on our relationship at all. We enjoy bridge and the U3A. Everyone should have a reason to get up in the morning” (1 ax).

Her partner said

“My story has been at her expense, I suppose, although fortunately she has been affected only in latter years. She seemed to make her way through a lot of difficulties that came up and still handled life and is accepting of life as it is. I guess I always knew MS was a ’life sentence’ if you will. The sentence is not bad for me..it is bad for her…and it is bad for me because I care about her. It is the continuation of the partnership..I don’t see any difference in it.. Effects on our relationship, you ask ? Ah well, sometimes it (MS) is annoying. I’m always cross with it to a degree in the way she’s got to suffer the situation..the main thing is to see some
independent ways to get her to fulfil life to the best of her ability which she
does. She likes playing cards and going out and meeting people and so
forth .(Wife) is the best ‘friend gatherer’ you know. She makes friends
easily. She is right on the ball as far as that is concerned”(1 by).

4.(c) ‘Carer’ or ‘support person’? Perception of role: Communication
and negotiation of changing roles. Payback emerges again
It became apparent that not all participants viewed their relationship with the caring
partner equally. When I suggested that the spouse was a ‘carer’, two respondents assured
me quickly that they did not need a carer, and viewed their partner as a ‘support person’,
whose support, affection and understanding were highly valued, but they were not
considered a ‘carer’. I reviewed earlier transcripts seeking descriptions used by
participants that indicated aspects of their relationship which were valued and which
could give me a better picture of their conceptualization of the ‘carepartnership’. Some of
these descriptions are mentioned in the preceding paragraphs. Two participants stated
directly: “my husband is my carer” (#10 and #12), but others used such terms as:

“we are partners in everything (#8 )”;

“we are best friends” (#3,#4,#5);

“we enjoy each others company and like doing heaps of things together”
(#3); “ we can almost read each other’s minds – when it is a good day for
him, well it is also a good day for me too” (8bx);

“he took care of me when I had a serious accident – now it is my turn”
(3bx, 6bx).

This notion of ‘payback’ emerged several times as previously noted, but with different
feelings, sometimes revealing an admission of being taken for granted by carers who were
feeling overburdened. Was this different to ‘reciprocity’, or does reciprocity include an
element of ‘payback’? Was there a point where the relationship no longer met the criteria
for a reciprocal one as described by Carruth (1997)? What were the implications if this
were so?
The following PwMS made a point of asserting he did not need a carer but viewed his spouse as a valued ‘support person’. This was a second marriage for each member of the following dyad. He was diagnosed with MS shortly after the second marriage. They reported some initial problems with communication in their relationship. Her desire to anticipate his needs and to do too much for her husband was not appreciated. However, they reported better communication and a good relationship at the time of interview. They were then able to resolve any conflicts in a short period of time. She expressed feeling some resentment at the lack of appreciation for an increased workload as his abilities diminish, but also mentioned the concept of ‘payback’ referring to previous care she received from her husband during a period of illness. Themes of communication and negotiation of roles emerged:

“I don’t need a carer, no, but moral support and understanding, ah yes. I worked until 55 and my wife works part time, and I have applied for a disability pension. It is not much, but I am sure she feels the financial pressure. No, I don’t have a problem about not being the breadwinner. Are we partners? Do you mean do we care about each other? Oh YES. I wouldn’t say I couldn’t live without her but once the first two or three years after diagnosis had passed...and that wasn’t an easy time. I mean, I know I can’t do some things but she does not know that and you have to communicate some things and sometimes you communicate them in a bad way...so after the first couple of years out of the way, she couldn’t be more supportive. Look, I have to give her a lot of credit there..Neither of us likes criticism. But...we get over it a lot faster nowadays- in minutes rather than weeks.

I am not sure MS has brought us closer together..We were pretty close to begin with. Sexually, it hasn’t helped..over the past couple of years...where sex was a fairly regular thing..it is not now, but Viagra helps.” (6ay)
Her view, when interviewed separately:

“The impact of MS on our relationship? I try to anticipate him too much – to conserve his energy and he does not always appreciate it and he tells me I am robbing him of the few things he can do. So that is a conflict we have had to deal with. We have a great social life together. We have to be careful where we go because not all places are user-friendly. Our lovemaking has definitely diminished, but we were on holidays last week and it was twice...it was wonderful! That has always been important to us.

And look, I would never say this to him, but I have my moments when I resent the workload that is on me. I am responsible for the garden and the housework and working...one gets so tired. I feel so shallow making these complaints. We are very close and you know, we are closer now... and I found out something I did not know about myself – ‘I am an OK person’...it was good.

I absolutely have made some personal growth. Things don’t bother me, and plus...I’ve had my share of ill health and he’s had to hold the fort many times...now it is my turn” (6bx).

Another male who denied needing a ‘carer’…..

“I am very fortunate to have (wife). She and I are very close. I don’t really need a carer, but moral support, YES!. We can almost read each other’s minds; if I am tired and cross she just says “you go and rest and take it easy”. If anything, MS has enhanced our relationship”. (3 ay).

His wife indicated that one reason she accepts the caring role is as ‘payback’ for care given to her in past injury and illness occasions. They also claim to be best friends. The concept of ‘payback’ appeared in several interviews besides the two mentioned above.
“He took care of me when I had my accident (riding) and when I got asthma, now it’s my turn. We care for each other—we like each other—we have been friends a long time. We both seem to tune in on each other—we always seem to know when there is something wrong with the other. We talk on the phone at least three times a day when I work—we’ve always done that. We love each other and do heaps of things together—so that’s it.” (3 bx)

The following woman with MS developed the illness later in life, when her husband retired. She expressed the belief that she did a lot for him while he worked and now it was his turn. It appeared that she was taking all his efforts as expectations in the circumstances but it may be that he did not fully share this view now that he was a full time carer and she was becoming increasingly dependent upon him for her daily needs. He did say he felt “taken for granted” (10 by) much of the time.

“I get tired, yeah, but I’m very lucky—I have a good husband who understands and lets me go down to have a sleep. He is my carer. He does most things. When he was working I used to do things like cutting the grass and things like that. I am really pleased that I’ve done that because now he does that for me. Things like vacuuming—he does it—and when I fell—he’s the one who took care of me. I did things for him when he was working and he kinda just took over—it was a gradual thing—the MS, I mean—I could walk at first.” (10 ax)

He cited the good times they had enjoyed in their earlier life and noted that they were now working together on getting a safe walking track built by the local Council. He hinted at frustration, but did not elaborate, except to mention his impatience when she washed dishes and broke too many wine glasses, making it necessary for him to take on dishwashing as well. He had just given up a job he took up in retirement and had enjoyed. He was concerned about her safety during his brief absences.
“Yes, the MS has stopped her doing lots of things she used to enjoy doing, like water skiing and travelling and bowls. Well, she enjoys watching me bowl now, knowing the game and all...she gets a lot of pleasure out of that and also enjoys the company of the bowling team...yeah, and travelling. we both love to travel, and we’ve had some good trips together, even after she got the MS and she coped pretty well. Now we are working on getting a walking track built so she can get to the township safely on her scooter. Has MS impacted our relationship? Everyone gets frustrated in their marriage at times, but no..I don’t think the relationship has changed that much. It is still a loving relationship.” (10 by).

5.(a) Expectations of healthcare professionals and (b) agencies- Met and unmet. Where is the help when I need it?

While a few praised the healthcare professionals and the services offered them by agencies in meeting their needs as they arose, the majority of interviewees in this sub-sample indicated that the healthcare professionals, particularly the doctor or neurologist delivering the diagnosis, failed to meet their expectations. Many were described as “blunt”, “rude”, “lacking in people skills” and failing to include the caring family member in their conversations, while using deliberately exclusive body language. No support was offered at the time of diagnosis, and no information that could maintain or support them through changes over time. Several mentioned that the MS Society had not even been mentioned as a source of information and support at the time of diagnosis, and no one mentioned referral to a social worker or nurse for ongoing support. When social workers were mentioned it was in the context of failing to keep the confidentiality of the disclosing partner, causing family discord.

“When he was in rehab..I talked to the social worker and I got so mad...anything I would tell her...she would go and tell him and he would be more agitated with me....I became very ‘anti-social worker’ and withdrew so I would not talk to anyone....I felt so alone...”(9bx).

After diagnosis, patients were not offered follow-up consultations and any further contact was left up to the patient when they developed further symptoms, or chose to seek a second opinion. Many chose to seek a second opinion and changed doctors, often
reporting that “this one was better” ( #2,#11). A few comments are quoted below to illustrate this lack of support, empathy and compassion.

“Finally, 2 years ago, my doc sent me to the neuro and they did all the tests,
Yeah, an MRI as well.“Yes”, he said, looking at the reports and not at me...
‘There are abnormalities..You’ve got multiple sclerosis’. I asked him to tell me about it and he said ‘I want you to go away and research it on the web then come back in ten days with a list of questions’

Pretty blunt, he was...like a baseball bat.
When I came back he said: ‘there are a few medications we can use.. Which one do you want?’  How would I know?
It was like giving me a Chinese menu to read and to choose...
He’s the doctor; doesn’t he know which is best for me?

When I researched it and read all that could happen, it was like looking at a checklist I made up on myself......
I went tick, tick, tick, yup, I’ve got that...and that..and that as well
I had tears streaming down my face as I read.
Shock gave way to gloom.
What would become of me if I could not work?
And what of my wife and kids?
I had two by then – a boy and a girl (now 10)

I changed neuros and this one is better..but....
There’s more to it than MS...there is all the rest...
what of income and super and ????
No one to help...how do I take the first step?
So hard to change.”(11ay)

And his partner said:

“I get angry with the neurologists as well. Their attitude and behaviour is awful.... so arrogant and rude.” (11bx).
She went on to describe in detail the body language of the neurologist as he deliberately
excluded her from his conversation, turning his back to her and failing to recognize her
concern and anguish as a caring partner.

It was interesting to note that only two participants were entirely happy with their
experiences with healthcare professionals and agencies when needs arose in connection
with MS, but even these two were unhappy with the lack of ongoing support or follow up
offered by doctors after diagnosis and beyond. It may be possible that people volunteered
to participate in this study in part, at least, because they had not had good communication
with doctors. They may have been keen to tell their story because they had not heretofore
been ‘listened to’ or ‘heard’. No one in the sub-sample expressed satisfaction with their
first doctor or neurologist (that is: the one who delivered the diagnosis), but thought their
experience with a second one was better. Perhaps this phenomenon may be due to the fact
that some time had elapsed between visits, allowing them to come to terms with the
diagnosis. One couple was entirely satisfied with the services over the years of the
Victorian MS Society.

The following person was very negative about most aspects of her illness and her life and
displayed a deep anger and resentment about the perceived failure of the healthcare
professionals to meet her expectations. She spoke disparagingly about the doctor,
optician, physiotherapists and rehab services for failing to understand multiple sclerosis
and its manifestations in her case. When she consulted him prior to diagnosis, the doctor
was reported to have said “you are just uptight” and again, “you are becoming a neurotic
menopausal woman” (12ax). During a hospitalization, the physiotherapists were reported
to have taken away a medication she viewed as essential to her wellbeing and pushed her
beyond her ability to do the exercises. She became so frustrated during this hospitalization
that she threatened to jump out of the window. When she was eventually allowed to go
home on the weekend pass, she replenished her stock of the medication and brought it
back to the hospital hidden on her person. This covert action was not beneficial to any one
and clouded the possible effects of the treatment plan. The need for clear and open
communication including the patient in the plan of care and securing her cooperation was
not evident in this case.
She also complained about the Government regulations which fail to provide sufficient funding for needed equipment (electric wheelchair) in a timely fashion. She praised the local Council services, transportation facilities, home help, and her carer-husband (12 ax)

5.(b) The interviewees and the Victorian MS Society

Specific comments about the MS Society and its services are cited below. This male with MS lived in a regional area and spontaneously brought up his dissatisfaction with the services of the MS Society.

“I get the MS Society magazines and all, but it seems they are only interested in patients who are on injectable drugs...don't return my calls...it makes me angry...they don't want to talk to me...that’s all right, I don’t like to talk about my problems anyway...I can’t drive and neither can my wife except locally, so we can’t get to their programs in the city. The diabetes nurse stops by regularly, though ...” (7ay)

Was he perhaps implying that if the diabetes nurse could come and visit him regularly for his diabetic condition, someone could be interested and available from time to time to address his MS-related problems?

And another regional couple said:

“When we moved here the neurologist put me on one of the interferon drugs. The MS Society sent someone down to teach me how to inject myself...There is no way I can inject myself...can’t even take out a splinter...no self-mutilation...The person was hopeless...in the end (husband) gave me the injections,...after practicing stabbing an orange for several weeks...didn’t do much for my confidence (laughing),...but we soon gave them (the interferon drugs) away...didn’t seem to do any good, anyway…” (1ax).
And her partner said:

“You ask about needed services? Yes! Knowledge and information…if that is a ‘service’…some of the services of the MS Society have been woefully inadequate. I don’t understand why they do some of the things they don’t do…sort of…Now they have transferred their branch from a regional city to a metropolitan area which covers an extensive geographic area. It is a very inadequate situation. Of course information is available on the internet, but there is nothing more suitable than talking to somebody. I imagine others share my view.

The contacts we have had with the MS Society since we have been here have been bad. When (wife) was on interferon, the person they sent down to instruct her about the shots was hopeless…Only our opinion, of course.

Because of the standard that was set, we did not make further contact with the society or attend their functions…Probably it would have been better to send a female nurse to work with women.

I believe the MS Society has too big an area and they can’t give proper services to the people with MS. If I call with a problem today, they can’t take care of it for two months, sometimes. Another problem I have is with the people who organize MS Conferences in ‘getting it together’. We were interested in going last year and when I rang to get more information they were hopeless…I might just as well have been talking to myself. Consequently, we did not go.” (1 by)

This couple expressed an interest in obtaining a tape recording of one of the panel presentations made at a recent MS Conference on fatigue management, but when I requested it at the MS Society, I was told this was not available – only the medical presentations had been recorded. This highly intelligent, articulate and self-directed couple actively sought information and help from sources other than the MS Society when they needed it.

They and others praised the support of the Independent Living Centre in helping them obtain resources to meet their needs as their disabilities became more notable. They had little patience when their expectations failed to be met. They were particularly annoyed
when public venues, such as theatres, restaurants and art galleries did not provide access for disabled persons, cancelling their memberships or writing letters to effect change.

However, another female with MS expressed a more favourable view of the assistance provided by the MS nurse who was sent to instruct her in injecting her medication:

“The nurse came from the MS Society to show me all about it...I was a blithering mess...couldn’t make up my mind whether I wanted to go on the medication or not...he sorted me out...he was lovely.” (4ax)

Only one couple, as mentioned before, who lived in a suburban area, expressed complete satisfaction with the MS Society in meeting their needs:

“I made contact with the MS Society and went to information days with them. They’ve been fantastic. They’ve been really good with me and helped me through a lot.” (5 ax)

And her partner said:

“Every time we sort of needed something, help was always available. When we were in the concrete block place and the heat was bad, the MS Society paid for half the cost of an air conditioner unit...when she needed OT, it was there...we needed a safety link monitor in place when I was away working...yes, the MS Society were there to help us.” (5 by)

Two male respondents said the neurologist never mentioned the MS Society as a good resource when diagnosed. Both discovered this for themselves, attending classes and becoming active volunteers and offering peer support to others with MS.

“The neurologist who diagnosed me never mentioned the MS Society, and they do have good services and programs for PwMS. I now go over there regularly and volunteer” (6 ay)
And another

“I think the doctor who tells them they’ve got MS should also tell them ‘I know someone who’s got it and you may want to talk to him/her’. With me, the doctors weren’t too helpful...you could tell they did not know anything about MS. Initially when I knew I had it, I felt very dejected...all you was reading about was ‘disabled’ and ‘wheelchair’..of course you can’t tell anyone with any certainty ‘this is how you’ll be in the future...everyone is different’, but I reckon it helps to talk to someone who has it. The good part is that I can help other people now. I do a lot of social work.... get involved with other people and help out with the local MS support group.” (8 ay)

This PwMS highlights the need for a trusted contact person, and ongoing support for newly diagnosed persons. He also pointed out his own need to make a contribution, and the satisfaction he derived from this helping role.

5.(c) Reports of health professionals trivializing their symptoms or failing to believe their description of vague symptoms were common

One theme that was worthy of note was the difficulty of obtaining a diagnosis for their often vague early symptoms; the long time-lapse between first symptoms and diagnosis and several misdiagnoses, one of which (#6) reportedly resulted in unnecessary back surgery;

“I was diagnosed with MS at age 46 after 5 or 6 years of trying to find out what was happening to me...I have to say I was probably more relieved about knowing I had an answer to what was wrong with me...all I wanted was a name...then having a name you can deal with it.” (6ay)

His wife reported:

“Our buildup to getting a diagnosis – I have since learned from talking to others it was fairly typical. He just didn’t know what was wrong with him and he was getting very frustrated. We both knew there was something wrong, but...well, anyway, after about 2 years of tests and an operation on his back that was totally unnecessary, he was diagnosed with MS.” (6bx)
At least two respondents expressed anger and frustration in the belief that doctors knew all along what was wrong with them but were ‘holding out’ on giving them a diagnosis. They believed that doctors owed them clear answers. Three expressed a sense of relief when a diagnosis was finally given, stating that having a diagnosis could be dealt with better than uncertainty.

“I was 22 years of age when I started with numbness in my hand and in my tongue....I just thought it was the celery that I ate that was poisoned. I went to the doctor and he was able to pinpoint exactly...He wrote a referral for me to see a neurologist without me having any idea of why I was seeing him....I just thought...and he more or less knew, and...obviously they are trained for that...they know what they are looking at...ummm...I also had a blockage of vision in one eye...that would have lasted a few weeks...so you know...they were telltale signs that he was able to....”(2ax)

She implied that the doctors knew she had MS long before a diagnosis was given. This is consistent with the reported reluctance of doctors to label a person with MS when suspicious symptoms first appear (Frank 2004). One doctor I spoke to explained that the perceived reluctance is due to the fear of giving a mistaken diagnosis that might have disastrous emotional effects on the patient, even leading to serious self-harm. They therefore wait for confirmation from several tests that have ruled out other options before delivering a diagnosis of MS to their patients (personal communication 2005).

“I actually had a bad experience going to this neurologist.....he was very abrupt...he was rude...I went with my mother to the neurologist and I asked him 'o.k., what is the situation? What’s going on with me, doctor?' ...and he said: ‘what you have is called multiple sclerosis. You are married now. You will never be able to have any children because if you ever have children you will be in a wheelchair’...and so on and so on......Back in those days we did not know much about multiple sclerosis...I had no idea of course...I was in shock.

‘What do you mean, doctor...I can’t do anything? I’m going to be in a wheelchair? What have I got? Have I got cancer? Am I dying? What’s going on with me?’ He said: ‘No, you’ll just be a vegetable, more or less’. What was I supposed to think?
I’m 22 and I think, ahhh...so that was a pretty horrible experience.” (2ax)

Another participant said:

“I went to about three different doctors and they all did the neurological examinations...and they all said: ‘we can’t find anything but it is probably because you are all worked up and...this was about 3 years ago” (4 ax).

After renewed symptoms and severe panic attacks, saying: “I’m just not coping” she told her husband to take her to hospital. “So I went to X hospital and that was a horrible experience too” (4ax). She described her experience as being ‘trivialized’ by medical personnel, except for one nurse who took her seriously. Many persons feared their symptoms were being ascribed to psychiatric conditions and they were ‘going mad’. This seemed more sinister and less acceptable than any physical diagnosis to them.

“I was in hospital one week and in rehab for two more. They finally said they thought it might be MS , but I did not think so because I had been told ‘you haven’t got anything horrible like MS, so don’t worry’. When they told me it might be MS they told me nothing else about it. I did not know if it was something you died from or something you could manage....I did not get the information in an appropriate way.” (4 ax), (These comments highlight the need for timely and relevant information delivered in an empathic manner)

Many others referred to the bluntness of the doctor delivering the diagnosis together with a total lack of support from the medical and healthcare professionals once the diagnosis was delivered. Although needs for respite services were mentioned by several interviewees,(#2 and #12) it has been noted by providers that there is an underutilization of these services (Wollin 1999).

5.(d) Themes related to the role of physiotherapists in the treatment of MS: actual and potential

Some comments by participants have already been mentioned in varying contexts relating to physiotherapists. When hospitalized in rehabilitation units, they found physiotherapists harsh and lacking in understanding of the problems associated with MS which they believed were not benefiting their progress.
One female with MS believed that regular physiotherapy was beneficial for her even though the sessions caused her extreme exhaustion and forced her to rest for several hours afterwards. She had to fund these treatments herself, however.

Another deplored the limitations placed by Government policy on the funding of the number of home visits allowed by physiotherapists and occupational therapists.

Analysis of responses to open ended questions reported in Chapter 4-A suggest that many persons would attend regular physiotherapy sessions if they could afford it.

(6) Perceptions of MS- Friend or Foe? (Korosi 2003)

The responses to my question: “Do you consider MS a Friend or Foe?”(Korosi 2003) elicited surprise at first from some interviewees as well as some very interesting responses suggesting that persons had found strengths through their experience with MS. Initially eight respondents emphatically said: “FOE !”, and then, after reflecting on the question, some changed it to “Both”, suggesting ambivalence and going on to illustrate their experience of personal growth, emerging coping skills or dramatic losses to explain their selection. Some of these responses are quoted more extensively under the Third Tier analysis of transcriptions.

(7) Living with MS: Varied ways of coping

Coping emerged as a theme during interviews, but these strategies will be described in greater depth in the section entitled ‘Tier Two analysis: Coping’, later in this chapter. Both problem-focused and emotion focused strategies were noted, sometimes in the same dyad, and it could be presumed at different times. However, with a single interview it was not possible to verify this assumption. Some recent research studies examine these coping strategies in terms of dyadic couples and discuss whether it is better for couples to use the same or different styles of coping in terms of marital satisfaction. However, results were inconclusive and were not explored further in this study. However, there are studies, such as those by Lazarus and Folkman (1984) which categorize coping strategies into 8 distinct groups, and others (Smyth and Yarandi 1996) and Hewson (2003), which reduce coping strategies to only three. Rigid application of these coping categories to any particular situation or illness condition suggests that this may be a fruitless exercise with few observable benefits. Additionally, the definitions and descriptions of each coping strategy
are often confusing and apply only to certain situations. The coping literature has been reviewed and critiqued in Chapter Two. In this study, participants used a variety of coping strategies for their own reasons as will be discussed in the Tier Two analysis.

(8) Pressing needs and access to available resources. Who is there to turn to when I need help? Increasing losses of ability and overwhelming demand on the carer’s effort and time commitment: Issues of changing needs, access to resources and respite

This theme is addressed more fully in the Fourth tier of analysis, a Meta-analysis of the transcriptions in the context of the ten basic human needs delineated in the Conceptual Framework,

Due to the unpredictable and yet usually progressive trajectory of MS, perceived care needs change over time with the increasing dependence of the recipient and perhaps also the tiring, illness or aging of the carer. The literature reports increasing levels of caregiver burden over time, as the partner with MS develops more mobility problems, and cognitive and behavioural changes. Caregivers devote more and more of their time to caring for the PwMS as well as taking over roles and functions that were formerly the domain of the partner with MS (Stull 1994; Hughes, Giobbe-Hurder et al. 1999; Wollin 1999; Kasuya, P et al. 2000; Buhse 2008).

The principal concern expressed by long-time carers in this study is the lack of time for themselves and the need for reliable and regular respite. This need is often not recognized adequately in the healthcare system, and it is not unusual to hear that the carer receives only two hours of respite time per fortnight. Many have been quoted as feeling some resentment at their overwhelming workload, and yet at the same time expressing feelings of guilt for admitting these feelings. What keeps carers going? Previous quotes from interviewees suggest that many have a strong sense of duty to care for the partner, and others have stated that this sense of duty stems from a strong commitment to their marriage vows ‘in sickness and in health’. There is a notable absence of religious or altruistic reasons given in the study for continuing in the caring role. The concept of ‘payback’, or return for past favours or care, was given by some as a reason for continuing in a difficult caring role but this reason appeared to have both a positive and a
negative perception, depending on who was claiming ‘payback’, the care giver or the care recipient. In some cases it seemed as if there was a feeling that the favour had been repaid many times over.

Several comments quoted in this thesis, point to a changing situation where the PwMS is requiring much more care and the carer has had to relinquish work and leisure pursuits in order to meet these changing needs. Although these pleasurable (and sometimes financially rewarding) activities have been willingly given up, there is an underlying sense of the carer being overwhelmed by it all, and badly needing some regular time to get away from the caring situation. There seemed to be an accompanying sense of guilt in the carers that they were perhaps being selfish and were failing to live up to their strong beliefs in their marriage vows interpreted to mean standing by their spouse in sickness and in health and for better or worse. Three of the male carers in the sub-sample hastened to assure me that ‘leaving is not an option.’ (#2, #5, # 12).

One female with MS, now chairbound and requiring assistance to transfer, was unable to walk unassisted. Her husband had left his employment to be her full time carer and cited his marriage vows as the primary reason he continued as a devoted carer, while acknowledging that he appreciated every moment of time he was able to have for himself. This woman expressed some concern for her husband after telling a long story of her own losses and concerns.

“MS has stressed him to pieces. He worries me at times, doesn’t sit down during the day…he’s my full time carer. And another thing that’s got to him is the loss of income…that’s just unbelievable…all those years that we struggled to pay for this house…which we did before MS hit. We both had super…and now all that is gone. He quit his job at the timber yard because he was afraid I’d fall when he was gone and I was home alone. He is wonderful, but he is tiring too.” (12ax)
He said:

“I’m one of the old school, and I believed that when I got married, I got married for life...that’s what I believe... for better or worse...so I stick by my love. We do have someone who comes around here once a fortnight to give me a break for 2 hours. I go out and take out my frustrations on a little white ball (golf). I am virtually a full time carer. At the time she was diagnosed I was still working and she was managing to cope on her own...still mobile, but as time progressed the scene got worse and I had to give up work to care for her full time. I look forward to my golf weeks that come up once a year...that keeps me going. Ah yes, absolutely, I love my free time...I need it for my sanity.”

(When asked about reciprocity and whether he felt his wife was making a contribution to their relationship, he promptly responded enthusiastically) “Yes! Love. It is a huge thing..it is very important..it is a magnificent word that ...used genuinely...we share love...we certainly do. I can pick when she’s going to have a good day, a bad day or a medium day. The mood swings are a big thing with her and the fatigue..a most disabling thing...you have probably heard this before?”

(12 by)

(9) Suggestions made by PwMS and their carers for improvement in communication, education and ongoing support services from healthcare professionals and agencies

Several participants in this study made suggestions for healthcare professionals that could better meet their needs, and these have been included in earlier quotes. However, their suggestions were often expressed in a critical manner, or in anger.

One carer brought up the following viewpoint that may be worthy of note. He said he perceived that education efforts for people with MS seem to be focused almost exclusively on the individual with MS. The respondent believed that the carer/spouse/partner/family also needed to know about the condition and where the available resources could be found. He suggested the Nerve Centre (NC), Victoria (and all MS Centres) have orientation days for partners and families and involve them as much as possible in all aspects of their work, beyond fund raising. The attitude, he believed, should be one of: ‘we know you are going through MS as well. These are a few things
you need to know that may help you’. He said he often felt ‘left out’, frustrated by his lack of understanding of the disease and its impact on his wife, especially issues of fatigue, and yet he sometimes was reluctant to seek information from the professionals for fear of imposing on scarce time needed by the patients. He also cited his busy work schedule for his lack of time to read about MS. He believed he would be more likely to read an informative letter addressed to him personally, rather than one addressed to his partner. The NC could say: ‘bring your whole family...we are having a tour around’...then kids could say: ‘this is the place that’s trying to find a cure for mum’s illness.’ (4by). He further said that his initial lack of understanding of the disabling nature of fatigue in MS led to several serious misunderstandings with his wife, who he believed was just ‘slacking’ (4by).

SECOND TIER DATA ANALYSIS:
Exploring Coping Strategies: Understanding the different approaches people used to deal with a life-altering condition such as MS

Coping has been defined as:

“The cognitive and behavioural efforts used to manage the internal and external demands of situations that are appraised as stressful (Lazarus and Folkman 1984)” (see Glossary)

This working definition has been used in this analysis of coping efforts used by the study sample. Early work of coping theorists viewed coping as ‘problem-focused; or ‘emotion-focused’, with the first type considered ‘healthier’ than the second which was often labelled ‘pathological’. This narrow view of coping was replaced by other descriptions of ways in which people coped with disruptive or stressful situations in their lives. Lazarus and Folkman (1984) developed an “Eight Ways of Coping” typology that was widely accepted and used in research for many years. However, there were critics who argued that it did not fit every situation or every culture, and recommended that the measurement scale be refined. (See discussion below, and (Smyth and Yarandi 1996; Hewson 2003).

In this research study, I examined strategies used by both PwMS and Carers, recognizing the limitations of a one hour open-ended interview. What did they say and what did I
observe? It was difficult to identify all strategies used but it was evident that couples often used more than a single strategy as they related their stories with MS over a period of years. I have used the existing typologies as a guideline and selected a few illustrated with quotations that refer to that categorization for further discussion.

An interesting question arose during interview analysis. Was this couple working together as a team, or was each carepartner seeking different solutions to their situation independently of the other? Was this important in terms of perceived successful dyadic coping and what were the implications for healthcare professionals working with families with MS?

The coping strategies identified in the literature were useful in understanding the approaches some people used when dealing with a life-altering disease such as MS and a limited number of spousal dyads selected an identifiable single major coping strategy and carried it through when addressing changes as they occurred throughout the disease trajectory. Coping strategies, such as Confrontation (anger), were used by nearly all couples from time to time. Denial was also common in the early stages of the diagnosis. However, it was more common to see several strategies being effectively used by the interview sub-sample at the time of interview.

In other words, each couple sought ways of coping that worked for them. Coping strategies varied with their life view, with the perceived/appraised threat of the disease to their future life plans, and with their perceived position on an uncertain disease trajectory. Some of these strategies are later discussed, using illustrative quotes from participants.

I sought commonalities and differences in the approaches used by each member of the dyad to their stressors and perceived future challenges. This comparison raised a new topic of interest, namely, ‘couple coping’. ‘Couple coping’ is a concept appearing with greater frequency in recent literature of the early Twenty First Century and could have significance in terms of spousal satisfaction, reciprocity in the relationship, the approach by healthcare professionals working with the couple and family, and to changing family goals. Changes occurring in the roles of each carepartner may have been brought about by cognitive and physical changes in the person with MS, and this could affect their coping strategies. (Pakenham 1998; Bodenmann 2001; Bodenmann 2005; Bodenmann
The concept of ‘couple coping’ might also prove useful to include in the planning of an ongoing assessment, education and support program for individuals and families affected by MS (see Conclusions and Recommendations, Chapter Nine).

An attempt was made to group couples exhibiting similar approaches to dealing with life with MS. However, this approach had limitations. One couple (#11) appeared to be in an impossible and rather unique “Catch 22” situation at the time of interview that effectively immobilized them. They seemed unable to find any satisfactory coping strategy to break the impasse and move on from it. They expressed their frustrations with great passion, but were unable at the time of interview to agree on a plan of action to improve the situation. They were unable to identify a trusted source of help in their dilemma, remembering only their unsatisfactory contacts with healthcare professionals in their recent past experience. In the absence of an agreed plan, each was thinking along a different track, with the caring spouse doing most of the thinking due to his overwhelming, prolonged and immobilizing fatigue. He could only focus on his impossible situation: a job he actively disliked in an unconvgenial atmosphere, requiring long hours of travel, and the constant fear that he might lose the position imminently. He said there was little likelihood of replacing it with a job that paid enough for him to keep up with the family commitments. Added to these concerns was his fear of losing his home if he could not pay the mortgage and his inability to access superannuation funds due to his age. He also disliked the weather at his seaside home and would have liked to relocate to a warmer climate. His partner was frustrated by his inability to participate in discussions relating to their future and was thinking of starting a business that could support the family, and yet feeling very much alone as she looked at options. “Couple-coping” did not seem a possibility for this couple at the time of interview. They could be described as being in a state of ‘limbo’ as described by Becker (Becker 1997) in her book on Disruptive Life Events which interrupt the Western expectation of continuity in life. They were effectively immobilized by the enormity of their problems. No other couples in the interview sub-sample presented such a difficult and complex picture.

My interaction with this couple brought about in me an intense sense of empathy, frustration and an awareness of the conflict between my role as researcher and clinician. I felt deeply for the couple in their impossible dilemma, and yet felt bound by the duty of confidentiality. After approaching them by telephone and e-mail several times following
the interview to no avail, I wrote in my diary the following comment “A time-bomb waiting to explode”.

**Review of some typologies of coping identified in the sub-sample**

Several typologies of coping were initially used as a guide to analyse coping and adjustment strategies used by participants in this study. The Eight ways of Coping (WOC) identified by Lazarus and Folkman (1984) include the following strategies:

1. Confronting;
2. Distancing;
3. Self-controlling;
4. Seeking Social Support;
5. Accepting Responsibility;
6. Escape/Avoidance;
7. Planful-Problem-Solving and

Smyth et al (1996) analysed the Ways of Coping scale with their research study using a group of African American Women and a factor analysis which reduced these eight ways to three main factors:

1. Active Coping,
2. Avoidance and
3. Minimizing the situation.

Their study highlights the fact that although very useful, the Eight Ways of Coping do not apply to all populations, situations or cultural groups and suggests that further refinement of the scale is needed (Smyth and Yarandi 1996).
Another type of grouping was used by Hewson and Germanos (2003), who identified the following coping themes derived from their study of persons with multiple sclerosis:

1. Looking for a Cause;
2. Hoping for a Cure;
3. Hoping for a Future;
4. Managing Life;
5. Adjusting to Change;

These concepts could be matched to many of the previously identified themes that have emerged from the current study. However, ‘looking for a cause’ by a person with MS would be limited to ‘wondering what factor(s) contributed to their having the disease’ and could hardly be seen as a coping strategy. ‘Hoping for a cure’ and ‘hoping for a future’, could fall in the category of ‘wishful thinking’ and demand little action on the part of the PwMS or the Carer. ‘Wishful thinking’ is an emotion-focused coping strategy that has been found to have questionable value (McCabe and McKern 2002). The last three themes “managing life”, “adjusting to change” and an attitude of ”dealing with it-living and doing”, are more action-based strategies and these attitudes were displayed by many of the couples I interviewed.

As I examined the interview transcriptions again through the lens of coping and adjustment, various coping ways could be identified in individual narratives and although individuals often used similar coping styles, others were quite different and included samples of both problem-focused and emotion-focused coping. It was impossible to say that any one person or dyad used an exclusive coping strategy at all times. All expressed anger and frustration (Confrontation) at some aspects of the disease and its effects on their lives, although one admitted that “one probably blames it (MS) for more than it deserves (8ay)”.

As I looked at ‘couple coping’, further questions arose. I noted the ways of coping of individuals, but also observed how they were coping as a couple. This question sent me back to the literature as mentioned earlier to see what had been written recently on this facet of coping. (Pakenham 1998; Bodenmann 2001; Cheung and Hocking 2004;
Bodenmann 2005; Bodenmann 2005). Were their coping styles congruent or different and did it matter in terms of marital and life satisfaction and adjustment to life with MS?

Only a few of the Lazarus and Folkman (1984) ways of coping stood out clearly in the narratives and the only one that seemed common to all was the initial response of anger and frustration, or ‘Confrontation’, as described by these authors. Many expressions of anger and frustration with MS and its effects on their lives have already been included when quoting themes and several couples have acknowledged an adversarial relationship with MS. This style continued for some but was soon set aside by others in favour of more positive approaches (Positive Reappraisal), or approaches that better met their individual needs. Some of the Ways of Coping that could be identified in the study sub-sample are mentioned below.

**Positive and purposeful planning**

At least two dyads displayed examples of “Positive and purposeful planning” in their overall approach to the uncertain future with MS. Given the facts they were able to obtain about the disease (Seeking social support/information), they chose to make major plans reflecting changes in their lifetime goals to accommodate what they perceived to be the ‘worst case scenario’, including: progressive losses of ability, life in a wheelchair, fear of abandonment by caring spouse, or placement in a nursing home.

By using ‘Positive and purposeful Planning’ as a coping strategy, it appeared to couples that they could exercise some control over their destinies. Couple #1 spent several days, weeks and months considering their future together. They were in their early 30’s at the time of diagnosis, but started to give serious consideration to retirement goals. They reminded themselves that many people plan pleasant activities for retirement but are not able to achieve these goals due to age, unexpected illness, infirmity or the death of one partner. The obstacle need not be MS. Having made this decision and implemented it, the woman with MS had no serious progression for 20 years. When interviewed 35 years after the initial diagnosis, she was confined to an electric wheelchair and planning their move to a retirement community. The couple still enjoyed an active and satisfying social life, and were pleased that they had made the decision to live life fully, and travel extensively with their 2 daughters while they were young and able. Each one continued to speak highly of the other in affirming and appreciative terms, and were observed to have a
high level of warmth and reciprocity in their relationship (Seeking Social Support). Their scores on the CRS-II were highly congruent (24 and 25 respectively), suggesting they viewed life and their relationship similarly. Triangulation of CRS-II scores and observations at interview, together with their positive and affirming comments about each other, confirmed the presence of high level reciprocity in this couple’s relationship. Seeking congruence of reciprocity in the relationship by matching the scores on the CRSII measurement scale and observations at interview (triangulation of methods) could only be confirmed in one third of the couples interviewed.

The second couple using Positive and Purposeful planning as an identifiable coping strategy were in their early 30’s, had researched the possibilities of MS in their future, and anticipated a ‘worst case scenario’ of life in a wheelchair or a nursing home. This couple was in their third year after diagnosis at the time of interview. They had set about making plans for a home that could accommodate any major changes in mobility, was closer to the school their boys were attending, and was close to the facilities in the country town they loved and where they had a strong friendship and family support group (Seeking Social Support/Information).

Each had made some compromises on earlier life plans even though this had not been easy to do. MS was truly seen as a disruption in their life’s plans, and the adjustment to its constant presence was appraised as difficult. There was an adversarial attitude towards MS, which was described as “A third person in our marriage” (4ax).

They were interviewed only three years after diagnosis and were therefore unable to evaluate the desirability or effectiveness of their coping choices in their particular circumstances. There were several concerns at interview related to the need for ongoing support and education. They had many challenges due to MS, including the parenting needs of their two young boys, their somewhat unrealistic expectations of themselves as parents and their own levels of maturity as a couple. Their views of parenting did not allow them to share the care of their children with grandparents or occasional baby sitters.

A third couple used this strategy, Positive and Purposeful Planning, in a limited aspect of their life. Both were on disability pensions and desired to enter employment or business. They had enrolled in a business course to assist them to open a small business in
the future, thus hoping to avoid the failures of past attempts that they believed were due to their lack of business knowledge. They were approaching their many problems as a team, despite their marriage which they described as being ‘on and off the rocks’. Their most pressing concerns were perceived to be unrelated to MS but related to their inability to have a family, and to serious problems they were having with extended family members affecting their sense of safety and security. In a limited manner, they were attempting to improve their future by undertaking (“pursuing”, in their words) business education. The PwMS also found some ‘benefit-finding’ in MS, saying “It (MS) has helped me to grow up,” (5ax) This remark could be seen as an example of **Positive Reappraisal**.

**Escape/Avoidance/Denial**

This coping strategy could be identified in one person with MS who indulged in serious risk-taking behaviour while admitting that his actions were ‘not the best’ and giving as his reason:

“Why do I do it? Because I can?” and adding: “I almost died twice, so I may as well enjoy life. As far as the MS goes, I’m ‘top of the world.” (9ay)

The PwMS in the above illustration had two serious medical events in recent years that could be considered confounding variables when attempting to identify his coping strategies for MS. His statement also contains elements of **Denial** relating to his perception of MS. Either or both of these events could have had a notable effect on his judgment, and behaviour changes in addition to the MS. There was notable tension in the spousal relationship, and the observed behaviour of the wife was that of an indulgent, but sometimes impatient parent dealing with a child she loved but could not control, and who often led her to frustration and resentment as her own individual and spousal needs were unmet. Risk-taking behaviour is listed by Lazarus and Folkman (1984) as part of **Confronting Coping**, so it is hard to place this dyad in a clear category.

**Seeking information and social support**

These strategies were noted in most dyads. Initially, after diagnosis, people with MS sought all the information available from many sources and appeared to reach a ‘saturation point’. Some seemed overwhelmed as they noted the depressing nature of their readings, and decided to do what they could in life while they still could. One person said:
“I read a lot about it and went to information sessions, but then I basically decided to ignore all that and just put it on the back burner.” (9ay)

Having sought information, he chose avoidance. Another said:

“I went to the library and borrowed everything they had on MS. There wasn’t much knowledge about it in those days, but what there was sounded like ‘death by tomorrow’ sort of thing. I did not even give them to my husband to read but took the books straight back and decided to make plans to enjoy our life as if we were already in retirement. It was a good decision as it turned out and now I am not as angry at MS as I might have been if I had let it take over.” (1ax)

Official sources of support and information about MS were found to be inadequate by this couple and they sought alternate resources themselves when they needed them.

One male sought all the information he could and admitted going down into a deep depression. He got tired of his wife asking him solicitously how he was feeling and they both decided they would:

“Just do our own thing and get on with life.” (8ay and 8bx)

One partner complained that all information was focused on his wife and he felt virtually ignored and left out. As a consequence, he felt he did not fully understand the potential for his wife’s fatigue to seriously affect her life and their social plans. This was the cause of much misunderstanding in their communications and created some tension in their relationship. He realized this and made it his goal to obtain the information he needed, but he felt this period of unhappiness could have been avoided if he had been included in the information packets and letters in the first place. This was perhaps an excuse or an effort to rationalize his knowledge deficit, but he later elaborated his recommendations for the improved information and support of family members of persons with MS when the interview was over (see Chapter Seven, Theme #10).

Keeping his/her feelings to him/herself (Self-Controlling)

One couple communicated poorly and it was evident during the interview that there were many unresolved issues in their relationship. He said the people at the MS Society did not
return his calls, but he had not left a message on their answering service and made no further attempt to ring again, so the expectation of a response was unrealistic. His wife yearned for expressions of affection but said she was afraid to speak to him of her need, fearing rejection. Both preferred to keep their feelings to themselves saying:

“I don’t like to talk about my problems. I don’t talk much” (7ay)

And

“I just adore my little dog and shower affection on her and take care of my husband as best I can. I do miss the cuddles.... I can’t show him any affection– he might reject me. He would have to change.” (7bx)

It is interesting to note that the above couple who had virtually closed themselves off from all social contacts, including family and former friends, were willing to agree to an interview when approached by telephone. Perhaps this could be seen as a call for help, knowing that their situation was not really to their liking. The appointment had to be re-scheduled due to the wife’s (‘flu’) illness that kept her in bed for several days and which she discussed in great detail during her interview, focusing on the perceived abandonment and neglect for their needs during her illness that was demonstrated by a relative who lived nearby, but “never even asked if we needed bread and milk”. After the interviews, the wife wrote me a very nice note expressing her appreciation for my visit and for ‘listening’ to her. I was concerned about her very low mood, but she assured me she had an appointment to see a counsellor later in the week. Her husband was indeed a man of few words showing little emotion except when speaking of his beloved golf that he feared he would soon have to abandon due to his increasing weakness and heat intolerance. However, he was also willing to be interviewed and verbally expressed appreciation for my time.

“Just getting on with it”
A common coping strategy I noted after couples had gone through difficult times and after trying several different coping strategies as they came to terms with MS was just to ‘get on with it’, ‘take life a day at a time’, ‘accept changes as they happen’, and ‘play the cards we are dealt’. Coping strategies changed as the disease progressed and it was not possible during a single interview to identify clear categories at that point in time. Some
were looking forward to potential further losses in ability and others were looking back at decisions they had made at an earlier point in time and focusing on the good times they had shared. Most did this without expressions of regret for past decisions. There were some aspects of **Positive Reappraisal** in couples who identified personal growth and ‘benefit finding’ through adversity, recognizing strengths they did not know they had before facing the challenges of MS.

**Minimizing the importance or impact of MS on their lives: use of humour**

The use of humour was evident in several persons with MS and their partners as they related the effects of the disease on their daily lives. Some of these instances have been quoted in the thesis.

“My vision is still bad. When I light my cigarette, I have to be careful that I light it and not my nose.” (11ay)

And

“Who is the primary caregiver today – you or me? (6bx)”

**Overall view of coping strategies**

In conclusion, it was not possible to place each couple under a single Way of Coping, as several methods were identified in each at the time of interview. Anger, confrontation and frustration were evident in the narratives of each at some time in the disease trajectory and they exhibited this strategy as further changes occurred in their situation. Others had moved to strategies they felt helped them face life with MS when they realized it would be with them for a long time. Seeking Information was common to all but at different levels and several felt that too much information had been given and they coped by “putting it all on the back burner”, while others complained that information had not been forthcoming in an appropriate manner or in a timely fashion, or had not been given with adequate support. The value of social support from friends and family was mentioned by most couples.

‘Planful-problem solving’ appeared to offer a sense of some control over their destinies to those selecting it, while those who accepted that life was not fair and took each day at a
time showed some serenity in acceptance that life contained both the good and the bad. They reflected on the good and accepted the reverses in their lives. Adjustment to MS was not seen as an ‘outcome’ or ‘end point’ in this study, but as an ongoing attempt by couples to cope with the episodic and uncertain nature of multiple sclerosis as it affected life and health. The need for reliable, ongoing support was again noted to be a pressing need, and the potential for learning new skills to cope with new relationship challenges was evident. Many tended to minimize their limitations and approached their situation with courage and humour. Several suggested that regular and acceptable respite from their caring duties would help them cope better with their role of carer, but none mentioned this as an actual coping strategy.

THIRD TIER DATA ANALYSIS: ESSENCE STATEMENTS AND METAPHORS ENCAPSULATING FOR PARTICIPANTS THE MEANING OF LIVING WITH MS AT A POINT IN TIME.

MS-Friend or Foe? Perception of the impact of MS on each of the Carepartners and their relationship

Responses to this question emerged as an interesting theme worthy of further analysis and is expanded in this third tier. As noted before, my question elicited surprise when I asked it and usually was followed by an emphatic “Foe”! Other distinctly antagonistic/adversarial remarks were also noted where people listed all their losses and one referred to MS as a ‘third person in our marriage’…and described it as:

“Waiting quietly in the background until it could jump in and ‘mess up my plans and my life’. I always know it is there. I see it as a third person in our marriage.” (4ax)

One respondent expressed ambivalence and after reflection, changed the initial response to:

“Both, I suppose…I’d rather it hadn’t come, but having come, it has its plusses.” (4ax).
Having said that, she did not elaborate but mentioned some personal strengths she has developed in coping with formerly disabling panic attacks that were making it even harder to cope with the ongoing changes of MS.

Others reported ‘benefit finding’:

“About two years ago I started having serious problems...like balance, numbness, headache, forgetfulness, which have been difficult to deal with because I did not know if they were related to the MS or not ...but I’ve had lots of positives too. I see how bad it can get in some people...I try not to dwell on my disease. I sort of take what comes. I am very patient with the disease but I do get frustrated with it sometimes when it interrupts my life too much. It has shown me how, really, in one way I can hurdle the hardest things you can’t imagine you could go through for a person my age. MS has helped me grow up (5 ax)".

One rather unique response referred to MS in the following way:

“Friend or Foe? Neither. I see MS as an ‘Uninvited Guest’ that we have happily accommodated. We’d rather it hadn’t come....but not an enemy, no. Because if you take that attitude it puts you in an attitude of confrontation and that does not work either. A positive view is best. I absolutely have had some personal growth...things don’t bother me...look, when you get into your 50’s you do put things into perspective a bit more.” (6 bx)

This carer reported personal growth and the discovery that she was “an OK person”. Others were emphatic and passionate in referring to MS as a Foe.

“Definitely a Foe ! (Spoken with strong emphasis and accompanied by a deep sigh) Everything I have ever enjoyed has been taken off me.”(12 ax)

And

“I think it is a foe. (Spoken quietly and sadly.) It depends on how you accept it. No, I do think it is a foe actually...as I was saying before, I don’t drive anymore, I can’t water ski, can’t travel, can’t sew or knit, and I go down a lot (depressed mood). It is very hard to be ...all right (10ax)".
The tone and content of the above two stories illustrated Hainsworth’s (1994) concept of ‘chronic sorrow’ (see Glossary).

Yet another perspective is reflected in these words:

“If I view MS as an intruder that has invaded my body, and if I choose to fight it, I am fighting my own body, and that is not the best.” (7 ay)

And

(Said strongly and defiantly)“Yes I have MS, but it does not define who I am.” (6ay),

**Essence statements**

Each transcription was reviewed and the 20+ pages of verbatim notes for each were reduced, using the participant’s own words, expressions and metaphors and limiting repetitions when possible to extract the “essence” of each interview and to hear an answer to my question “What is it like for you living with MS (as one diagnosed with the disease, or as Carer) at this point in your life?”

“A snapshot of my life with MS at a point in time”

A brief ‘essence statement’ was extracted from the transcriptions for each person in the dyad and in some cases it was possible to find an essence statement that applied to both. These essence statements incorporated their words as well as my observations and feelings where relevant.

Most interviewees described MS as ‘it’, (an entity outside of themselves) and described an adversarial or antagonistic relationship with ’it’ (the intruder), except for the above-
mentioned ambivalent or conciliatory quotes and the few who identified benefits from their experiences with MS.

PwMS and Carers alike expressed feelings of anger with MS and one Carer admitted that, although she knew the partner with MS ‘couldn’t help it’ (fatigue and exhaustion making it impossible for him to participate in family activities and decision making), she sometimes got angry with him (the partner) as well as the disease, expressing remorse for her impatience afterwards. A female with MS also regretted the fact she often ‘took it out’ on her husband when her fatigue and frustration overcame her.

**Note:** All couples except one were interviewed independently on the same day and it was possible to observe their interaction before and after the interview.

**Reflections on the essence statements**

The essence statements noted below provide some valuable insight into the unique experiences of couples living with MS, the Uninvited Guest, in their lives. Their feelings seem to reflect anger at the intrusion, ambivalence as they face an inevitable change in their lives, struggle with the reality of the limitations that MS places on their activities as they lament the many losses of ability that they report. There was a desire in some to fight the intruder, then developing a more conciliatory view as they accepted that changes may be necessary in their life plans and goals. There was an element of fear of an unknown future with spectres of ‘worse case scenarios’ that cloud their enjoyment of life. Creative accommodation of their life circumstances to the needs of MS was evident in some carers as they enjoyed the brief moments of respite from their constant caring duties. When asked to select a label for MS – Friend or Foe?, many were forced to look deeper into their experience and seek anything positive they might have failed to consider before the question was asked. Many reported personal growth and the discovery of abilities they did not realize they possessed when faced with the challenges of MS.

When seeking an ‘essence statement’ for each couple, it was interesting to note that there were only a few of the couples for whom one statement would suffice. In most cases, a different essence statement was found to apply to the PwMS and another to the carer. Many were struggling to work as a ‘couple’ as they dealt with the impact of MS on their relationships and changing roles. However, at the time of interview, they had elected to
participate in the research study as a couple and therefore it must be assumed that they perceived themselves in that light.

Essence statement for Couple #1: “What shall we do in retirement? Let’s do it now”

“We think it is MS? Well, what do we want to do with our lives before I end up in a wheelchair?” (1ax) This thought early in the diagnosis led the couple to examine their lifetime goals and they elected a course of Purposeful Planning, as described earlier. On reflection 36 years later, this coping strategy was determined to be a good one and she said: “I guess I am not as mad at MS as I might have been if we had not had such a marvellous and interesting life.” (1ax). Despite her notable decline in mobility, the couple retained their positive attitude towards life and maintained an active social life. They displayed a high level of mutual regard and reciprocity in their relationship, both measured and observed.

Essence statements for Couple #2: “I thought I would get over it (MS), but it got me in the end, didn’t it?.....But we are happy.” (2ax). And “I’ll be there for you” (2by)

Her statement seemed to reflect a belief that she would somehow overcome the disease after it was first diagnosed, but over the years (20) her confidence in this belief had been shaken and she was somewhat discouraged by the steady progression of the MS and the recent fall that resulted in a broken arm. I was unable to interpret the significance or sincerity of her oft-repeated comment “but we are happy”, which followed lengthy statements about her many losses due to MS and issues that were only hinted at during the interview but not openly discussed. There was a suggestion of some conflict in the relationship which seemed to lack an element of trust and open communication. I was reminded of the phrase in Shakespeare’s Hamlet “Methinks, the lady doth protest too much”, suggesting perhaps that she was not really happy.

His statement: “We are in this together and I’ll be there for you when you need help”. (2by) reflects his steadfast commitment to the relationship, although he expressed a need for regular respite time for himself and a holiday for the family.

Essence statements for Couple #3-“MS has changed the playing field” (3ay) and “We’ll deal with it” (3bx)
“It was just getting worse and worse, MS has changed the playing field and I need to lower my expectations.” (3ay). His statement seems to imply that although he does not understand the changes taking place in his body, he needs to adjust to them, including the imminent loss of his present employment, where he had been passed over for a promotion and had been declared redundant instead. His case was in the hands of a financial counsellor who was negotiating the best possible redundancy package for him. His elderly mother has lived with MS for many years and is now in a wheelchair, although she lives alone and copes reasonably well. He is aware of the many possible effects of MS. Both carepartners expressed a strong sense of affection and friendship, and reported that they enjoyed being in each other’s company. She said she is happy to be his carer since he took care of her when she had a serious accident with a long recuperation period (payback), and expressed no resentment in the role. She added: “I take it a day at a time. We’ll deal with it” (3bx).

Essence statements for Couple #4: “It was a weird feeling- like both sides of my body are separate” (4ax) and “The house must look good from the outside - resale value, you know (laughing)” (5by).

Her statement seemed to explain symptoms that this woman found difficult to express in clear terms, and which caused her to endure misunderstanding by her husband and trivialization by the healthcare professionals. She often feared she was ‘going mad’ as with several other interviewees. Her unruly body was not responding in an expected manner and she suffered frequent panic attacks as her symptoms limited her ability to function as she wanted on a day to day basis as a wife and mother. Her fatigue was disabling yet poorly understood by her husband, who said he often believed she was ‘slacking’ when she could not join him in morning exercises or other social activities. She described him as a ‘workaholic’, often preferring his job and its long hours to his family. Although they never argued, she said she never knew how he really felt about things. He prided himself as being a good provider, but realized that he needed to re-evaluate his priorities to spend more time with his family. They both stressed they had been friends for a long time. He said: “You get angry with it (MS)…the unpredictability of it…seems to be gone and then…’here I am again to mess up your plans’, it says…” (4by). He agreed to the building of a house that would accommodate a wheelchair for his wife that was anticipated in the near future as her mobility became more compromised, but insisted
it needed to “look good from the outside” adding: “resale value you know.”(4by).

Perhaps her statement relating to the split nature of her body during a ‘bout’ of MS could be interpreted to suggest some underlying difficulty in the marital relationship as well.

**Essence of the interview with Couple #5:** “MS has helped me to grow up”(5ax)

**I love her and will do whatever it takes.” (5by).**

Both admitted their relationship has had its ups and downs saying: “it has been on and off the rocks”, but despite this admission they said they were ‘best of friends’ and could usually work out their problems. Their relationship started when she was 17 years of age when she had her first rather dramatic episode of weakness and was unable to get out of bed. Her partner carried her downstairs where she remained for several days before the episode resolved with no further problems for the next 7 years when further symptoms developed that were then diagnosed as MS. He described her as ‘no lightweight’, referring to her longstanding problem with obesity. They had problems unrelated to MS that caused them great distress but which they did not care to discuss at interview. She said “MS has helped me to grow up” (5ax), and he said: “I accept life as it develops. When we move, we will have a better life.” Then he added: “There never was any thought that I would leave her. I love her and will do whatever it takes.” (5by). Both expressed appreciation for the help received over the years from the Victorian MS Society.

**Essence of the interviews with Couple #6:** “Neither Friend or Foe:, I consider MS an Uninvited Guest whom we have happily accommodated.”(6bx).

This couple was in a second marriage for each with MS having been diagnosed shortly after his current marriage. They experienced some initial problems with communication, but now stated they can resolve any differences very quickly. He has a slowly progressing type of MS and requires a wheelchair on outdoor trips, but manages mobility indoors without aids. The couple had an active social life with a camping group that is valued but may have to be limited due to his intolerance to cold weather. They also noted independently that their sexual intimacy was important to them, and they were concerned that MS was affecting this adversely. This concern led him to ask at the end of the interview: “I thought this was a study on relationships ?” (6ay), suggesting that
nothing had been said about this important matter. They accepted a referral to specialist

care in this regard. She responded to the question: “Do you consider MS a friend or foe?”

with a unique response, quoted above as their essence statement “Neither, I consider MS
an Uninvited Guest whom we have happily accommodated.”(6bx). Despite this
conciliatory attitude, this carer was feeling the additional burden of care as her husband’s
health declined and she needed to add garden and heavy household duties to her load as
well as having a part time job outside the home. She expressed some resentment for the
additional work, while sharing feelings of guilt for complaining.

Essence statements for the interviews with couple #7: “I don’t talk much”(7ay) and “I
miss the cuddles” (7bx)

This couple was in a second marriage for each and seemed to be experiencing long-
standing difficulties in their relationship where each found it difficult to give and receive
love. He stated that his first marriage had broken down because he believed MS had
affected him physically and emotionally and he was no longer able to keep up with his
‘fun-loving wife’. He was a man of few words and concluded his short interview with the
words: “I love my golf and I don’t talk much.”(7ay) After sharing many of her
concerns with me including her husband’s lack of affection, she concluded with the
words: “I love and adore my little dog and care for my husband as best I can.” (7bx).
Their reciprocity scores indicated no congruence and my observation confirmed this
finding. They seemed unable to bridge the communication barrier at the time of interview.

Essence of interviews with Couple #8: “We pull together, not against each other”(8bx
and 8 ay).

This couple proclaimed from our first encounter that “We are partners in everything.”(8bx
and 8 ay). They had a strong reciprocal relationship and had developed communication
skills over the years that allowed them to function as ‘partners’. It appeared that his slow
but steady loss of physical and cognitive functions were presenting a problem, but at the
time of interview they were able to compensate for these as the carer took on more
responsibilities for driving and encouraging the use of numerous ‘reminder notes’ for her
husband’s failing memory. Both were anxious about their financial situation which
depended upon the success of their new business venture. Her comment “We pull
together, not against each other” summarized their relationship. He expressed his feeling of satisfaction in acting as a mentor for newly diagnosed PwMS, and could be said to be meeting his ‘need to make a contribution’, referred to in the conceptual framework.

Essence of interviews with Couple #9: Tiptoeing around- trying to keep the peace – I often resent it – little things set him off.” (9bx) and “Why do I do it? Because I can.”(9ay)

This couple did not appear to have a reciprocal relationship at the time of interview. There were several confounding variables in their situation that made it difficult to determine the extent of the impact of MS on his behaviour, which included many risk-taking activities as well as mood swings which upset family members and which he did not seem aware of. He concluded his rather light-hearted tale of using recreational drugs, alcohol, pub brawls and smoking by asking: “Why do I do it? Because I can.” (9ay). He did not perceive MS to be a problem saying: “As far as the MS is concerned, I’m top of the world.” (9ay). His wife gave a different account of his ‘short fuse’, describing unreasonable over reacting to small family events, and accounts of his ‘pub brawls’. It appeared that her spousal needs were poorly met and the relationship was rather than of a ‘parent-child’.

She said there had been several occasions when she had considered leaving him and concluded her interview with the statement: “Tiptoeing around- trying to keep the peace – I often resent it – little things set him off.” (9bx).

Essence of interviews with Couple # 10: “Everyone gets frustrated with their marriage sometimes”(10by) and “It is very hard to be ‘all right’ (10ax)

This couple was coping fairly well with her slow but continual losses of ability. Her husband was her sole carer; a role he stated he preferred to having strangers in the house, but his comment at the end of the interview hints at some increasing impatience with his increasing carer burden. He said: “Everyone gets frustrated with their marriage sometimes. I don’t think MS has had a negative effect on our relationship – it is still a loving relationship.”(10by). When asked if MS was a Friend or Foe, she responded sadly: “A Foe, I think – I don’t drive any more; I can’t water ski; can’t travel. can’t sew or knit and I ‘go down’ (low mood) a lot. It is very hard to be ‘all right’.”(10ax)
Essence of the interview with Couple #11- “So hard to change” (11ay) and Well, sometimes you have to push the partner”(11bx)

This couple could be described as being in a state of crisis as they seemed overwhelmed by their many seemingly insoluble problems, in a ‘Catch 22’ situation; immobilized and unable to take a first step to improve their situation. After the interview, I felt uncomfortable, as mentioned earlier, and wrote the following comment in my journal “A timebomb waiting to explode!”. The problems experienced by the PwMS have been identified earlier, and included severe fatigue, a lengthy drive to and from work at an un congenial workplace which showed no understanding of his special needs, fear of losing this job which he perceived could not be easily replaced with an income that would allow him to meet his family commitments, inability to make decisions due to his fatigue, and inability to interact with his children at play for the same reason. He described his situation as : “So tired, so tired, always so tired- too tired to talk, too tired to play, too tired to make love, too tired to make decisions…..so hard to change.”(11ay). His wife was desperately trying to look at alternatives for the family, but felt the lack of any participation in decision-making due to his continual exhaustion. When asked if she considered themselves a partnership, she responded wryly: “Well, sometimes you have to push the partner” (11bx), implying that he was not contributing much to the partnership at that time. This couple seemed unable to cope as a couple and she was considering starting a family business to replace his current employment. All my suggestions were rejected at the time of interview and on later follow up phone calls and emails after the interview, they had not moved on from their impasse and were not prepared to discuss it further with me. I had to respect their wishes.

Essence of interviews with Couple #12 : “For better or worse”(12by) and “A Foe, of course! Everything I have ever enjoyed has been taken off me by MS.”(12ax).

This PwMS was increasingly mobility-impaired and could no longer walk without assistance. Her husband was her sole carer. They were awaiting funding for an electric wheelchair which they believed would improve their situation, but it was several months since they had applied. She was very much aware of all her losses of ability which she described at length. When asked how she perceived MS, she responded emphatically: “A Foe, of course! Everything I have ever enjoyed has been taken off me by MS.”(12ax).
Her husband took care of her needs while also managing to do some hobby work on his car in the garage at their home and keeping a beautiful garden. He provided his wife with ‘talking books’ and used the time she was listening to do his own activities. However, the strain of the caring role could be noted despite his assertion: “I am one of the old school and I believed that when I got married, I got married for life — That’s what I believe — for better or worse, so I stick by my love. However, I do appreciate every minute I can call my own. Someone comes to give me respite for 2 hours every fortnight and I go and take out my frustrations on a little golf ball.” (12by).

FOURTH TIER ANALYSIS OF INTERVIEW DATA IN THE CONTEXT OF THE CONCEPTUAL FRAMEWORK

The Zuluaga-Raysmith (Z-R) Model has been used as a framework in this study when assessing “carepartners coping with MS” as the ‘entity’ (See Glossary and Chapter One). Main themes, concerns, strengths and coping strategies emerged from the survey and interview data as discussed earlier in this Chapter.

Physical Health (PH)

Perceived physical health problems by carepartners coping with MS were foremost among the list of themes emerging from the data. The PwMS were concerned about their sometimes vague symptoms prior to and after diagnosis, often fearing that they were “going mad”. After diagnosis, fears focused on the potentially unpredictable disease trajectory, with ominous visions expressed of the ‘worst case scenario’ (Life in a wheelchair, abandonment by partner or placement in a nursing home). Many expressed concerns about the possible hereditary implications for their offspring. Physical symptoms causing the most concern were fatigue which affected every facet of their lives and seriously affected productivity. Other common physical problems were reported affecting mobility (staggering gait, poor balance, frequent falls), loss of libido, changed sexual, bowel and bladder function, and concerns about their ability to continue in employment if their health failed. Concerns were expressed by some carepartners about the potential hereditary component of MS for their children. Carers’ concerns related to the physical health of their partner and their own ability to continue to care for them as their dependency level increased. These needs and concerns evoked strong emotional feelings
and are closely related to the next need “mental, emotional, social and spiritual health (MESSH). This is consistent with the inter-relationship of all the needs in the Z-R Model.

Chapter Four-B addresses the thematic analysis of the 4 open-ended questions. The first question “I could be healthier and happier if…” predominantly related to MS and its many unwanted side effects for the PwMS, with carers expressing a desire for the disease to be cured so that the partner could be free of its problems. Some PwMS reported receiving treatment for the MS, but most spoke of treatment for bowel, bladder and spasticity problems as well as the use of mood altering drugs One couple valued the use of Viagra to enhance sexual intimacy. Many persons were facing a slow but continued loss of mobility and strength, but little effort was seen to be made by healthcare professionals to assist them to maintain optimum function with the assistance of physiotherapists and occupational therapists. Interviewees asked if their losses of strength and mobility were inevitable or could be postponed with timely intervention. Several who could afford it were willing to pay for physiotherapist services and massage therapy which they claimed made them feel better.

Mental, Emotional, Spiritual and Social Health (MESSH)

In addition to the fears expressed above, carapartners differed in their perception of cognitive changes as discussed earlier in the thesis. These differences in perception often led to tension and conflict in the relationship. However, these changes were almost universally recognized by participants, with expressions such as: ‘he never was moody before MS’, ‘he/she has a short fuse’, ‘this is not the person I married’, ‘I have to make so many of the decisions now’, ‘I used to be very precise, but I can’t remember things now’, ‘I’ve been made redundant’, ‘I applied for a promotion but I was turned down’.

Social and emotional support from partner, family and friends were topics discussed at interview, and were highly valued. Although some denied needing a ‘carer’ they were quick to point out that they certainly needed ‘moral support’ and affection from the partner. When the care partnership was problematic, both expressed emotional distress, an inability to communicate their emotional needs clearly as well as an inability to express love and affection for the partner. Several carepartners noted a valued social life and activities with friends who had been important throughout their adult lives. Fear of losing this was a concern as the PwMS showed more heat/cold intolerance and was physically
able to participate in fewer group activities. Fatigue was noted as a prime reason for cancelling social engagements. Spiritual life was not spontaneously discussed by study participants in this study, although one couple stated they valued the social support from church membership, and expressed a desire to improve their spiritual life. One notable exception was seen in the experience of one pilot interview couple (See Appendix C 1 and C 2).

Depression emerged strongly in the screening tool as a very common problem among both PwMS and carers, although carers were less depressed than care recipients, and females were more depressed overall than males.

PwMS and Carers valued the care and support of partners, family and social networks, and expressed this as a need when it was absent or in short supply. Social isolation was more evident in regional or rural participants, and was attributed by them to depression, family alienation or neglect, and limitation of their social life due to an inability to drive that was age-related or disease-related. Many would welcome an outreach program providing regular contact in person or by telephone of interested professionals or family. The pervasive presence of sadness and low mood, and admission by several participants that they needed or were currently receiving counselling or treatment for depression needs to be a concern for healthcare professionals working with families with MS.

Knowledge, Information, and questions by participants about the possible origins of MS

‘Knowledge’, was mentioned as a needed resource. A need for accurate information given in a timely fashion according to their needs and requests and relating both to the disease and to available community services, was frequently repeated. Timely information about education forums available to assist them as their needs changed was also noted. Too much information was not always appreciated and led to feelings of being overwhelmed, while not enough information was also considered very frustrating and seemed to imply that the healthcare professional might be ‘holding out’ on the patient, who ‘had a right to know’. They inferred that there was a loss of trust and confidence in health professionals seen to use this approach. The need for a trusted and knowledgeable person to turn to as queries arose and who could respond to the concerns of the carepartnership as well as the individuals involved, emerged as a top priority from the
data and supported the recommendation for establishing an ongoing, comprehensive assessment, education, and support program for all PwMS throughout the disease trajectory (see Chapters Eight and Nine).

Several questions related to ecological implications or environmental factors as possible triggers for MS, and some asked about the potentially harmful effects of childhood exposure to farm chemicals. Other questions related to previous viral infections or to the possible role of severe stress as triggers of MS symptoms. The genetic and hereditary implications for their children was an issue of concern to many of the persons interviewed, as reported in section above. Research has addressed many of these questions but there are no conclusive results as yet. Conflicting advice by healthcare professionals regarding the advisability or ability to have children has been noted. Use of marijuana by people with MS was a topic discussed at interview as well as use of several other non-traditional and complementary treatments currently in use in the community.10

**Communication with health professionals, partners and family**

Needed resources were identified by participants in the two phases of the study and included information and support by healthcare professionals from the time of diagnosis and continuing on a regular or episodic basis according to their assessed and perceived needs. There was a general sense of being given a life-altering diagnosis in a blunt manner, lacking in empathy and ignoring the presence of and important part that partners and family played in the person’s life. Participants expressed this need for support in terms of being left alone without resources to travel a perilous lifelong journey. Essentially they felt they were left ‘up a creek without a paddle’, or asked, with Bogle: “Will I make it through these choppy waters? (Bogle, Percy et al. 1999)” Carers noted a strong need for regular Respite. Carers willingly undertook their caring duties while admitting how much they valued every minute they could call their own and occasionally expressing feelings of resentment with the demands of caring and a feeling of ‘being taken for granted’. Resources for respite seemed minimal in the study sample, and yet the literature maintains that available respite services are underutilized (Wollin 1999). Both PwMS and carers valued support from their social network of family and friends while

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10 The literature and recent conference discussions (Melbourne MS Conference 2004) fail to support use of these drugs and treatments to alleviate the symptoms of MS, although MS Conference presenters denied they would discourage their use if the patient believed they were of help to them (Melbourne MS Conference 2004).
some also valued support from attendance at peer support groups or communicating with others in internet chat rooms.

Several couples noted at interview that communication had ‘improved’, suggesting that clear communication between carepartners in the dyad had been a problem earlier in the relationship or early in the diagnosis of MS. These communication problems were perceived to have a negative effect on the spousal relationship and were often related to a lack of understanding by the partner of the needs and desire for independence of the PwMS. A need was also noted for learning skills in anger management and in negotiation of changing roles as the relationship shifted from caring partners to care giver/care recipient. Some instances of problematic communication had been allowed to grow into chasms that were seen as difficult to resolve or to bridge. At times the barriers to communication were generated by fatigue in the partner with MS but others appeared to be a part of a problematic spousal relationship where neither partner felt comfortable expressing their needs or demonstrating affection.

**Safety/Security**

Safety was a concern expressed by carers relating to their partner with MS. In many cases, the partner was having frequent falls while the carer was at work or away from home for other reasons. This concern made it necessary for the carer to leave employment or restrict their recreational activities outside the home, again highlighting their need for regular respite time while someone else took over the care of their partner. Safety issues related to family or environment were noted by some participants. Driving limitations and restrictions had been imposed on some PwMS in the study, but there did not appear to be any regular assessment of their driving skills.

**Mobility**

This need was perceived by and noted by many participants, who were experiencing progressive losses in muscular strength, balance and mobility, requiring mobility aids, and in some cases reporting great difficulty in leaving their home. Several deplored the delay in being able to access needed equipment and the lack of adequate funding to meet their needs.
Income

It has been noted that only 37% of the PwMS in the study sample were fully employed, but over 60% were satisfied with their income. This suggests that the remaining 40% were experiencing financial difficulties, partly brought about by their loss of work income or perhaps by the inability to access superannuation and other retirement funds at an age considered too young for these benefits. Perceived deficits in individual and family income have been shown to impact life and family satisfaction relating to other needs identified in the Z-R Model such as accommodation and nutrition and the freedom to enjoy a life of their choice (Zuluaga 2000). Recent research studies agree that MS has a considerable negative economic impact on affected families (DeJudicibus and McCabe 2002).

Accommodation/Housing

Changes in mobility status caused housing concerns for many of the study participants. Observable changes were noted between the time of survey and the time of interview, when some participants had either moved or were actively seeking more suitable accommodation. Some were foreseeing this need in the future and were demonstrating purposeful planning strategies by building suitable housing before the actual need had arisen ( #1, #3, #4, #5, #6, #11).

Need for personal development

A few participants expressed a desire to learn computer skills or undertake art or craft classes as they had been forced to leave the workforce early by MS. At the time of interview, a few were enrolled in art and craft classes offered by community agencies ( #9,#10,#12). One couple was undertaking a TAFE business course (#5).

Need to make a contribution

Several participants were actively involved in volunteer work and expressed satisfaction from these activities (#6, #7, #9, #10). Others were trying to find meaning in their situation by participating in research studies that they believed might help others with their condition. One participant expressed satisfaction with his role as mentor for newly diagnosed persons with MS, who could be helped to see that there was ‘life after a diagnosis of MS’. Some noted personal growth and a changed life view as a result of MS,
giving them a new sense of meaning in life (#5). Most interviewees expressed appreciation for the opportunity to ‘tell their own story’, and believed their experiences might help others in similar situations, while giving their experiences a sense of meaning (Frank 2004).

**SUMMARY OF CHAPTER SIX**

Chapter Six has offered a schematic multi-tiered analysis of interview transcriptions, viewing the narratives from several perspectives as indicated in Figure 6.1. Emergent themes were identified and a few salient ones were selected for further discussion. Common themes relating to multiple sclerosis included a strong fear of the unknown trajectory that lay ahead together with its potential to disrupt life plans and goals. Fatigue emerged as the most common and most debilitating symptom. This is a finding that is consistent with literature reports and is also the experience reported by clinicians (Stuifbergen 1997; Krupp 2002; Shapiro 2002; Bakshi 2003; Olsson, Lexell et al. 2005; Lee, Newell et al. 2008). There was an interesting difference in the perception of cognitive changes and their relative importance to employment, relationships and spousal roles such as family decision-making. Partners viewed changes in memory, mood, concentration and problem-solving quite seriously while PwMS took them lightly as mild annoyances. Problems with libido and sexual function as well as bowel and bladder problems were common in both men and women. There was a general feeling of anger with the manner in which the diagnosis was delivered by health professionals and the general lack of support experienced once the diagnosis was given. Information was reported as non-existent, overwhelming, or of questionable accuracy and always lacking in support.

The chapter examines coping strategies used by the persons interviewed, but these proved hard to categorize clearly within any particular typology, and in most cases more than one coping strategy was used by couples. A few strategies met the criteria for ways of coping as described by Lazarus and Folkman (1984), and some reflected the simpler Hewson and Germanos (2003) coping typology. People seemed to be searching for coping ways that were effective for them as their understanding of the disease and its uncertain trajectory became clearer to them. A variety of coping strategies could be identified in some dyads...
at interview, and some demonstrated that they had tried coping strategies that did not work for them and changed to a new way of looking at solutions for changing problems.

The selection of essence statements for interview couples proved challenging to me. Data reduction of any kind always highlights what is left out as well as what is retained. Perhaps some of the essence statements selected veiled the depth of feelings the couples experienced for each other, while others revealed elements of courage, resilience, tolerance and caring that were admirable as they faced daunting challenges in their lives that they never anticipated as they started their committed relationship. MS had changed the playing field for all of them.

**INTRODUCTION TO CHAPTER SEVEN**

Chapter Seven offers a summary of results and findings emerging from Phase One data analysis chapters (Chapter FourA Four B, and Chapter Five) and includes these in two summary boxes (Box 1 and Box 2). Findings emerging from analysis of the interview transcriptions are listed and discussed. The responses to the research questions have been made in the light of qualitative and quantitative findings. It needs to be recognized here that both surveys and interviews can only be considered snapshots of a lived experience caught in a moment of time. Interviewees recognized the dynamic nature of life and were quick to point out that changes had occurred in their lives and in their feelings and adaptations to the illness in the time between survey and interview.
Chapter Seven

SUMMARY OF RESULTS AND FINDINGS EMERGING FROM THE TWO PHASES OF THE STUDY: RESPONSE TO THE RESEARCH QUESTIONS

The research questions as originally framed were re-ordered as the study progressed, data were analyzed and the focus of the study became clearer. Thus a primary question emerged, asking about the lived experience of Carepartners with MS and all other questions became subordinate to the main question. However, questions exploring the mainly quantitative aspects of the population in Phase One provided a needed backdrop to the study and added greater depth and breadth to the findings contributing to trustworthiness and rigor.

The Research Questions

Primary question

1.0. What is the lived experience of couples (a PwMS and a Carer) when one partner has been diagnosed with multiple sclerosis?

Subordinate questions

1.1. What are the main concerns and fears expressed by interviewees?

1.2. What are the main strengths, coping skills and insights reported by interviewees since diagnosis with MS?

1.3. What needed resources are perceived by participants to be available, acceptable, and affordable?

1.4. What implications are there for healthcare professionals emerging from this study?

Results from Phase One of the study (Survey, measurement scales and responses to open ended questions) have been reported in detail in Chapters Four and Five. These results deal with the demographic characteristics of the study population from which the sample
was drawn, and highlight the significance of the measurement scores. Results are summarized in Box 1 and Box 2 below.

**Box 1. Summary of Results Emerging from Phase One of the study**

**Demographic description**

| 1. There were 263 expressions of interest from the Australia Recruitment Catchment Area |
| 2. 203 surveys returned with usable data for descriptive statistical analysis – 77% |
| 3. 85 pairs were identified (a PwMS and a main support person or Carer) |
| 4. 5 types of caring relationship: 89% spousal; 11% other. |
| 5. 43% of total sample provided by Victoria |
| 6. Interview sub-sample derived from Victoria; 6 males with MS and Carer / 6 females with MS and Carer |
| 7. Females with MS outnumbered males 2.5:1 |
| 8. Age: Approximately 50% of the sample were over 50 years of age. |
| 9. Newly diagnosed are under-represented in the interview sub-sample (only 3) |
| 10. Tasmania is under-represented in the total sample |
| 11. Home ownership higher than general Australian or Victorian population (ABS 2001) |
| 12. Income satisfaction: 63% of PwMS satisfied; 37%, barely or not satisfied. |
| 13. Education levels higher that Australian or Victorian General population (60% reported TAFE or higher). However, |
| 14. Only 24% of the sample were employed |
Box 2. Descriptive and inferential statistics

1. **Depression:** There was a statistical main effect of depression scores

2. Females were more depressed than males with MS

3. PwMS who were disabled / unable to work were significantly more depressed than those who were working

4. The Perceived Disability Index (PDI) was marginally significant as a predictor of depression

5. **Reciprocity:** All effects of independent variables on reciprocity scores of PwMS were not significant at the p.05 level

6. Triangulation, using mixed methods could confirm scores in only 1/3 of cases

7. **Life Satisfaction:** There was a significant main effect of the PDI of PwMS on LSI scores reflecting the implication that work had a positive effect on LSI

8. All other measures were not significant at the p.05 level

9. The PDI was a significant predictor of LSI scores for PwMS

10. Income satisfaction was a marginally significant predictor of LSI scores

11. **Functional Wellness:** There was a significant main effect of income satisfaction and the PDI on the FWI scores of PwMS

12. The PDI was a significant predictor of FWI(ph) and FWI(messh) scores.

13. There was a significant main effect of sex and the PDI of PwMS on FWI(messh) scores.

14. **Correlations:** between the FWI(ph) of PwMS or Carer and the FWI(messh) of PwMS and Carer; there was as strong positive correlation. Similar correlations of PwMS and Carers were found in both directions suggesting close association between the (ph) and (messh) of PwMS and Carers.

15. **Paired t-test results:** PwMS scored higher than Carers on the FWI(ph) and FWI(messh), indicating lower overall levels of functional wellness and depression

16. Carers had marginally better scores on the Reciprocity Scale and LSI than PwMS
FINDINGS EMERGING FROM PHASE TWO (INTERVIEWS AND OBSERVATIONS)

Finding 1. Levels of disability of participants: reported, perceived and observed. Ability to work was viewed as proof that they were ‘not really ill’

As previously mentioned, the severely disabled were not represented in the study except for one dyad in which the carer-husband had recently relinquished a full time caring role for his severely disabled wife, finding it necessary to place her in a nursing home when his own health broke down and he was no longer able to deliver the needed level of care. Both accepted the decision but not happily.

On observation, two PwMS in the interview sub-sample were exhibiting rapidly increasing care needs and it could be posited that they were reaching a higher level of disability than was present at the time of recruitment. They had completed the survey over a year before. Since the phenomenon of interest focused on the lived experience of ‘carepartners’ with MS and the impact of MS on their relationship, interviews were limited to dyads residing together.

None of the participants could recall their Expanded Disability Status Scale (EDSS) score and when asked, ticked the box stating ‘I don’t know’. Thirty seven percent reported they were disabled or unable to work. Since the focus of the study was on self-perception of their situation and in an effort to obtain a clearer understanding of their own perception of disability, I developed a Perceived Disability Index (PDI) derived from 6 responses they had made in two of the measurement scales as described in Chapter Five. Scores on this Index ranged from 0-6, with 0-1 indicating little or no disability; 2-4 moderate disability and 5-6 suggesting a high level or perceived disability. Few interviewees scores in the high disability group and the mean score for the sub-sample was 1 (one), meaning little or no perceived disability. However, 33% of affected participants required assistance with the activities of daily living and 11% could not leave their homes without considerable assistance. The PDI scale provided significant results as reported in Chapter Five. Anderson (1992) supports the value of self perception when assessing a client’s situation, and avers that the ‘client is the expert’ (Anderson and Goolishian 1992).
Persons who elected to participate in the study during the ten months of recruitment reported mild to moderate symptoms and disability levels. The newly diagnosed (less than three years since diagnosis) were under-represented in the study for reasons already discussed. Most newly diagnosed persons were still actively employed in the work force with few limitations and they viewed this in many cases as a reason to decline participation in the study. The ability to work was stated as ‘proof’ that they were not really ill, even if they were receiving treatment for MS at the time. One male, in his forties, diagnosed two years prior to the time of our conversation, said: “I have been diagnosed with MS (2 distinct episodes, separated by time and confirmed by MRI) and I have been put on ‘Betaferon’, but my life goes on as before. I ride my bike to work each day and carry a full workload – sometimes I feel like a fraud – I would not have participated in your study” (personal communication 2003). Other survey participants agreed to participate with the caveat “You probably don’t want me in your study as I am still working and life is pretty much going on as usual” (Vic ax). It appeared that the newly diagnosed and those still in employment believed that there was little purpose or mutual gain to be derived by participating in such a study.

Some participants who were in full employment at the time of recruitment, however, expressed serious doubts as to whether they could continue in their current employment much longer; others had been made redundant or had been unsuccessful in obtaining a desired promotion; while some were actively negotiating disability packages with their employers. Some had opted for early retirement, recognizing that their cognitive skills no longer allowed them to fulfill the expectations of their former position. Carers in this latter group sometimes attempted to include part time work or regular leisure time activities in their weekly schedules but found it difficult to continue due to the increasing care needs of their partners.

**Finding 2. Perceived satisfaction with income**

Although no numerical estimate was requested for income in this study, 62% of PwMS were satisfied with their income and 64% of Carers also reported satisfaction with their income from all sources to meet their needs and the needs of their families. Thus less than 40% of the study sample reported financial concerns, such as inability to purchase the ‘right’ food, not just the ‘cheapest’, and sometimes finding themselves in a position of
‘robbing Peter to pay Paul’. Studies in the literature report that MS has a significant economic impact on PwMS and their families (DeJudicibus and McCabe 2002). However, this impact was not clearly supported in the current study sample.

Finding 3. The concept of reciprocity and expressions used by participants that illustrate the constructs of reciprocity as described by Carruth (1997)

The term ‘reciprocity’ was not mentioned by any participants, but the concept of an enduring friendship that had lasted over many years and contained many happy and meaningful events shared with each other and jointly with mutual friends was clearly expressed in the memories they shared. Comments reflected warm and affirming expressions of appreciation for the support of the caring partner as well as the care recipient. The term ‘payback’ emerged in several narratives and bore further examination. Couples spoke frequently at interview of the value they placed on the qualities possessed by their partner and gave examples such as “we are partners in everything”, “we have a long and enduring friendship that preceded our marriage”, “he is understanding and forgiving’, “I don’t need a ‘carer’, but moral support and understanding, yes!”, and other comments already quoted in the paper. Enjoyment of activities together and with mutual friends was valued, and each claimed they could tell what mood the partner was experiencing and how it affected him/her and their relationship. Carers admired the resilience and patience of the affected partner and the ability to make the best of things and keep their sense of humour. It became evident that reciprocity, as perceived by the carepartners was a central concept to their relationship and marital satisfaction.

Conversely, it was evident during interviews, that in some cases where these constructs of reciprocity appeared to be absent or in short supply, as evidenced by their lack of verbalization or affirming behaviours, couples were observed to experience sadness, low mood, and a yearning for some of the qualities mentioned above. Only two couples specifically mentioned a mutual enjoyment of their sexual relationship as being very much valued by both. However, this is a matter that participants may not have been comfortable discussing at a first interview with a strange person.
Finding 4. “Payback”: an interesting but paradoxical concept. Payback in terms of ‘social capital’

Elements of ‘payback’ were present in the narratives of several dyads. The meaning of the word seemed to be different when used by care givers and by care recipients. Carers mentioned ‘payback’ as a reason for their continued caring in a sometimes onerous and demanding role, saying that they had received loving care from the affected person during periods of illness or injury in the past and ‘now it is my turn’. The PwMS said “I helped him/her out in the past so I don’t feel badly taking help now”. “Payback” as a concept opened an interesting topic for further exploration as there appeared to be very different perceptions of its value when viewed by care givers and care recipients separately. It appeared that care givers sometimes felt ‘taken for granted’ by care recipients or ‘resented’ the additional work that they needed to undertake as their partner became more dependent. These care givers also admitted they felt guilty for expressing such feelings.

Can the observations and comments made by participants indicating valued contributions to the relationship they see in their partner be considered ‘social capital”? How is this ‘capital’ used by the couple? In view of the differing perceptions of ‘payback’ and in terms of ‘social capital’, could it be posited that previous favors and services are perceived to be more than repaid? Were carers suggesting that the reciprocal balance in the relationship was shaky and the care recipient’s credit balance had been overdrawn? The present burden of care was becoming too great for some carers and they expressed a need for regular respite. Three males added that they accepted the caring role as part of their marriage vows ‘for better or worse, in sickness and in health’. The issue of ‘payback’ was therefore considered irrelevant by them.

Finding 5. Limitations of the CRS and measures taken to minimize these including the use of Triangulation of methods (measurement, observation and interview)

Measuring caregiver reciprocity, using the Carruth (1997) scale, was problematic as previously noted, especially since the scale had never been applied to both members of a caring partnership. The creator of the scale (Carruth 1997) was very interested in my unique application of the scale and agreed that it made sense to administer the scale to both carepartners in a relationship, and agreed also that there may be problems in its
scoring and interpretation using the existing guidelines (personal communication 2003). It may be of interest to find widely divergent scores in carepartners using this scale and compare these with the interview content but this is beyond the scope of this research which uses a small sample. I had hoped to find enough support for the idea of reconceptualizing the caring relationship in terms of reciprocity, but there was not sufficient data to substantiate this notion at the time of writing and based on the results of such a small interview sample (n-24 persons = 12 Carepartners).

Issues of bias may have entered the interpretation and analysis of responses to scales if PwMS were unable to fill out the forms due to cognitive or physical limitations brought about by MS. It has already been mentioned that PwMS could not imagine themselves to be co-carers of the well spouse and therefore many had difficulty in completing the CRSII. It seemed inconceivable to them that they could be providing anything positive or tangible to the reciprocal relationship with their partner. However, when this possibility was suggested at interview, PwMS seemed pleased by the thought and said it made them feel better about it all. It is evident that healthcare professionals need to be aware of this perception by care recipients and do all they can to support and validate contributions made by them.

It is evident that work is needed to refine the CRSII scale for use in future studies with ‘carepartners’. This potentially useful measurement scale is still lacking in clarity when applied to both members of a carepartnership in chronic illness. The interpretation of scores in its current form is unclear. In the absence of an appropriate scoring guide that was applicable to both carepartners and to assist with interpretation, I used triangulation of methods for analysis (see Figure 1.3, Chapter 1) 11 “Congruence”, suggested that each member of the caring partnership viewed life from a similar perspective relating to the statements in the scale, resulting in scores which differed by less than 5 points. Congruence (after triangulation of scores, observations and verbalizations by both carepartners) in this study, was confirmed in only one third of the sub-sample.

11 First the scores of each carepartner dyad were compared and an arbitrary three level division was established for congruence between partner’s scores. ‘Congruence’ was suggested by equal scores or scores differing by less than 5 points, ‘moderate congruence’ by scores differing by more than 5 but less than ten points, and ‘non-congruence’ by scores differing by more than ten points. For each couple, the interview transcriptions were reviewed and notations were made of pertinent comments made by each of the other, and behaviours observed at interview reflecting the constructs of reciprocity or its absence. Observations and remarks made by participants helped to confirm or refute quantitative results.
Findings 6 and 7. Two interesting findings that demanded further exploration

Many of the findings reported thus far have been mentioned in earlier research studies but at least two topics emerged from the multi-tiered narrative analyses that bore further examination.

Finding 6. Failed expectations of health professionals prior to, at diagnosis and throughout the disease trajectory

Examples of these have been reported earlier with direct quotes from participants and these have implications for further research and for the continuing education of many health disciplines with the potential to affect health policy and improve outcomes in the practice of health professionals. The second finding of interest (#7 below) at this time related to the different perceptions of cognitive changes by carepartners.

Finding 7. Cognitive and behavioural changes in MS: Differing perceptions by carepartners of the presence and/or importance of these

PwMS reported behavioural and cognitive changes such as having ‘a short fuse’, ‘loss of memory’ or ‘ability to concentrate or to problem-solve’ as minor annoyances in their lives and often dismissed their remarks with an attempt at humour. Partners, who were interviewed on the same day but independently of the PwMS, viewed these same changes more seriously, and believed they had a marked negative effect on their relationship, family functioning and ability of the partner to continue in employment. For many years it was believed that cognition was spared by MS (Murray 2005), but more recent research reports that cognitive changes affect over 50% of those diagnosed with MS (Burks 2004). As discussed in Chapter Eight and Nine, these differences in perception of cognitive changes need to be noted by health professionals who must be willing and able to offer support services as needed to address potential financial problems and coping strategies. Again, focusing on the couple or dyad may help forestall breakdown of the caring relationship.

In this study, it could be posited that the change from caring partner to care giver or care recipient, has had an effect on the relationship. In most cases this is seen as a negative effect, some deny any effect, but in others, care partners record some positive effects and
an enhancement of the relationship as they adapt to the changed circumstances (Moos and Shaefer 1986; Tedeschi 1995; Tedeschi 1998; Mohr, Dick et al. 1999).

Finding 8. Metaphors used to describe the lived experience and impact of MS on each care partner and the relationship

A number of participants expressed their thoughts using compelling metaphors and phrases that bear exploration. Patton (1990), states: “A great deal of meaning can be conveyed in a single phrase or with a powerful metaphor (Patton 1990, p.400)”. One Carer previously quoted, said:

“I view MS as an “Uninvited Guest” who we have happily accommodated” (6bx).

There are ambivalent feelings underlying this statement, indicating the presence of a ‘guest’ whose presence was unexpected, not really welcome and whose demands required continual adjustment of social plans and family activities. This couple elected not to have an adversarial relationship with the ‘uninvited guest’, believing that this would be unlikely to encourage ‘it’ to leave and that such a relationship would not be in their best interests overall. A patient and courteous approach was deemed best when dealing with this ‘uninvited guest’, who had unknown plans and ever-changing needs, but now was an integral part of their lives and future. They summarized their approach by saying: “a positive attitude is best” (#6).

A more common approach to MS by dyads was an adversarial or antagonistic one. MS was seen as a mischievous child waiting for the moment when it could be most disruptive to personal and family plans, forcing unwanted cancellations of life plans and events. MS was referred to as: “A ‘third person in our marriage’. I always know it is there just waiting to upset our plans.” (4ax). A third approach seemed to be to take things a day at a time and deal with changes as they occurred.

Analysis of survey data helped inform selection of interviewees in Phase Two, as previously noted, and led to the reordering of the research questions where Question #1: “What is it like for me as a PwMS or a Carer to live with MS at this point in time?”
emerged as the main question, and all other questions were subsumed under it and were responded to from results and findings in both phases of the study.

Finding 9. Frequent mention by participants of physiotherapy as a valued intervention that was not always available, accessible or affordable within the current healthcare system. Reported lack of empathy by some hospital based physiotherapists

A review of the survey documents used in Phase One, that included the four open ended questions, revealed many comments relating to physiotherapy, as a therapy that made PwMS feel better, although they found it sometimes increased the troublesome element of fatigue. Many said they would pay for these services out of pocket if they could afford it. Some deplored the very limited availability of home visits by physiotherapists, when they were finding these helpful in improving their mobility or general wellbeing. Interview transcriptions also contained references to physiotherapy and the sometimes inadequate communication by therapists with clients about the plan of care, leading to conflict. It may be beneficial for the discipline to consider these client comments in the light of best practice, to review their current practice protocols and, if required, to lobby for increased funding for these services with MS clients, as suggested in the last chapter.

HOW THE FINDINGS AND RESULTS RESPOND TO THE RESEARCH QUESTIONS

Primary question: What is the lived experience of “Carepartners” where one partner has been diagnosed with MS: What is it like for me to live with MS at this point in time (a) as a PwMS, or (b) as a Carer?

“A snapshot in time”. (see third tier analysis of interview transcriptions, Chapter Six). The “essence” of the lived experience for 12 spousal dyads living with MS, residing in the State of Victoria and interviewed in their homes was sought as each was interviewed independently. An open-ended interview format was used asking each to “please tell me your unique story of life with MS”. Occasional prompts were offered and requests for further information were made where this seemed indicated, but essentially each person followed their own direction in telling their unique story. An interview guide
was used sparingly and in most cases people covered similar topics in their narratives, relating to early symptoms, their emotional responses to these and their search for a medical explanation; elaborating on their feelings during these periods, and the changes they had made or were planning to make in their lives as a result of MS. These narratives were tape-recorded and transcribed. All agreed to a follow-up telephone call if I had questions while transcribing the notes.

Answers to this main research question were sought through the multi-tiered analysis of interview transcriptions in Chapter Six. This multi-tiered analysis included a fourth tier placing the transcriptions in the context of the conceptual framework based on perceived needs and is in keeping with the iterative and sequential nature of the study that draws from both the quantitative and qualitative methods used in the two phases of the study. Most pressing needs and concerns related to physical health (PH) and mental, emotional social and spiritual health (MESSH), with fears related to possible future progression of losses of ability, and relationships as well as possible losses of independence including the loss of employment or the ability to work and its financial implications for partner and family.

**What are the main concerns and fears expressed by interviewees in this study?**

These are discussed fully and identified from responses to open ended questions (Chapter Four B.) and from the analysis in the context of the conceptual framework. Some fears relating to an uncertain future with MS raise further research questions and need to be addressed in a comprehensive and ongoing multidisciplinary care program in which access is available to a trusted key contact person at all times (see Chapters Eight and Nine).

**What are the main strengths, coping strategies and insights reported by interviewees since they have been diagnosed with MS?**

It was found that many people encountered some difficulty when asked to identify ‘strengths’ in themselves, so it has not been possible to clearly specify these as findings. However, on observation at interview many specific qualities were observed and named by “carepartners”, such as patience, understanding (especially of mood swings and
behavioural changes), a sense of humour, maintaining an active social life, and having a caring nature (See Chapter Four-B)

A variety of coping strategies were noted, including ‘Purposeful Planning’ as identified by Lazarus and Folkman (1984), ‘Confrontation’ (anger), ‘Denial’ and the strategy mentioned by Hewson and described as ‘just getting on with it’ (Hewson 1999). Couples used several identifiable coping modalities at different times, but it seemed that those selecting purposeful planning expressed a sense of being in control of their situation better than those using other strategies to deal with changing situations. Coping mechanisms varied among couples and have already been discussed in the light of existing typologies. Both problem-focused and emotion-focused methods were found and it was not possible to determine which of these was ‘good’ or ‘bad’. People applied coping strategies that worked for them with varying levels of effectiveness.

Purposeful planning appeared to provide a sense of control over their situation and limited expressions of regret later in life when they were asked to evaluate their decisions made many years before, saying they ‘lived life fully’ and were not as angry at MS as they might now be if they had made a different decision. Several said they were pleased that MS had not developed earlier in their lives and had allowed them to fulfill many of their lifetime dreams and aspirations.

A sense of humour was used by some to lessen the importance or impact of the disease on themselves and others, while some took an attitude of ‘Life is short, I may as well enjoy it now’ and reporting risk-taking behaviours. Taking life a day at a time and facing problems as they come was noted in several couples as a way of managing potentially overwhelming fears.

What needed resources are perceived by participants to be available, acceptable and affordable?

This question has been addressed in the multi-tiered analysis of interview transcriptions in Chapter Six and including the 4th tier analysis which contextualizes these within the Conceptual Framework. These resources can be placed in several categories or groups which are consistent with the proposed ongoing, episodic, multidisciplinary program that is discussed in Chapters Eight and Nine.
A. Information / Education Needs
Participants expressed a need for timely and reliable information as needed and offered in language that they could understand; given in manageable increments and with adequate support from a caring and informed person; reliable information about conferences and classes that could improve their situation; availability of a trusted key contact person to turn to in time of need.

B. Services from health care professionals available as needed
Availability of comprehensive, ongoing and timely medical and other health professional services, such as physiotherapy, counseling, management of complications such as bowel, bladder and sexual problems, spasticity, mood swings, or depression were common requests.

C. Support
Access and availability of a trusted and well-informed key contact person to turn to in times of need- a person who could direct the client to appropriate physical and emotional support as their situation changed; available respite services particularly for the carer; self-help group activities including support of peers with MS; opportunities to participate in other special interest groups when desired; regular contact with key contact person.

D. Availability and access to affordable disabled transportation services
Attendance at sporting and leisure activities was valued including accessibility to theatres, concert halls, community centres and sporting venues.

E. Opportunities (Need) to develop skills and talents
Some participants availed themselves of art and craft and computer classes and one couple was enjoying U3A membership.

F. Opportunities (Need) to make a contribution (volunteer activities)
Several participants derived satisfaction from efforts to improve facilities for the disabled in their communities. The concept of ‘giving back’ for what they had received from their community was noted in the interview narratives. One PwMS enjoyed acting as a mentor for newly diagnosed persons, while another volunteered to read articles and newspapers on a vision impaired program. These activities enhanced their sense of self worth and minimized the helplessness often felt with increasing losses of ability.
These and other services could be addressed by a comprehensive multidisciplinary Care program that is beyond the scope of this research study (See New Directions in the care and management of MS Carepartners and families, Chapter Eight). Although the literature addresses certain aspects of the above-mentioned resource needs, there is little evidence of a comprehensive assessment, education and support program to meet the needs of Carepartners in a chronic illness such as MS.

**Contributions of the quantitative phase of the study: Summary of preliminary results and general discussion of characteristics of the study population. (See Box 1 above)**

The preliminary statistical analysis explored the demographic characteristics of persons wishing to participate in a study of the impact of multiple sclerosis on committed caring relationships. Despite the fact that not all participants had an identified carer or support person, and there were some carers offering to participate in the study who had recently relinquished their caring duties, all were accepted in Phase One of the study for descriptive statistical analysis. However, as previously noted, the complete data set was divided later into “pairs only” for further analysis since the phenomenon of interest focused on the dyad. Nearly 90% of the care giver/care recipient dyads were spousal, and the sub-sample for interview was selected from spousal pairs residing in Victoria, a State which provided 43% of the study sample. Selected variables of interest were compared with the Australian Bureau of Statistics Census data for Australia and for Victoria, 2001. Results of descriptive and inferential data analysis have been summarized in Boxes 1 and 2, above).

**Scales and scores: relationships and correlations between selected demographic variables and scores obtained on scales used to measure (a) depression, (b) reciprocity, (c) life satisfaction and (d) functional wellness**

Scales and scores have been fully reported in tables contained in Chapter Four and Chapter Five, with the corresponding results and findings summarized in Box 2. Correlations between and among scales have also been noted and included in Box 2.

Important highlights relating to some scales are included below.
Depression and MS

Overall, PwMS scored higher on depression scales than carers and females scored higher than males (see relevant tables in Chapter Four and Five). The CES-D is admittedly only a screening instrument, but the mean score for persons with MS was higher than the cut-off point suggested for the scale, indicating that there was a higher level of depression in the sample than would be expected in the general population. Some scores were very high, (both PwMS and Carers), but when the presence of ‘low mood’ was discussed with these members of the sub-sample at interview, many admitted that they had been clinically depressed at the time they filled out the survey over a year before, but were no longer feeling so ‘down’. Several in the sub-sample stated they were receiving treatment prescribed for depression. The high level of depression reported by participants suggests that there is a need for health care professionals and family members working with PwMS to be aware of this phenomenon throughout the disease trajectory. Depression has been recognized as a common problem in chronic illness, including MS and recent literature asserts that one in every two persons diagnosed with MS can be described as ‘depressed’ (King 2002; MSRA Newsletter 2005). Recognition of depression as a common problem in MS, medical management and ongoing psychological support would contribute to the wellbeing of PwMS and their carepartners and families. New research in the field of psychoneuroimmunology (PNI) exploring the bidirectional impact of the brain and body systems, suggests that some complementary and alternative medicine strategies may be effective in the treatment of depression. (Kent 2006 MS Conference, Sydney).

There was a gender effect in depression and women were marginally more depressed than males, as noted above. However, the literature reports higher overall levels of depression in women in the general population, so the effect of MS on this measurement is difficult to appraise accurately in this study (Jack 1991; Kessler 2003; Patten, Beck et al. 2003; Chwastiak.L, Ehde et al. 2004)

Reciprocity

Problems with scoring guide of the CRSII have already been discussed at length when applied to both Carepartners (see Finding # 5).
Life Satisfaction and Functional Wellness

Carers reported higher life satisfaction scores than persons with MS and lower scores on the Functional Wellness Inventory, indicating better functional wellness and satisfaction with the ten basic needs. These correlations would be expected, despite the fact that several carers had fairly severe physical problems as well (e.g; horse accident resulting in mild Post-Traumatic Brain Injury (PTBI); multiple surgical treatments for a congenital orthopaedic problem resulting in chronic pain; severe asthma). As would be expected, persons with higher life satisfaction scores were less depressed.

Functional Wellness Inventory: Problems with interpretation

The Functional Wellness Inventory in its original form provided little useful information and it was necessary to go back to the ten basic needs of the Z-R Model (Zuluaga 2000) to analyze the statements further. This item analysis was done with help from a Statistician and the scale was modified and analyzed as two scales based on the two predominant needs reflected in the statements, as discussed in Chapter Five. Statistical analysis of the modified scale provided more information and results were clearer (Chapter Five). There was strong positive correlation between the two new subscales, suggesting a strong link between ‘physical needs’ and ‘mental, emotional, spiritual and social needs’. (More research work is needed with this scale when utilized to identify specific basic needs as delineated in the Z-R Model. Item analysis, except for PH and MESSH is problematic due to the limited number of statements in the FWI addressing the other eight needs of the Model. Further research is needed to refine this instrument.

What are the correlations between and among the scores on the above scales?

These have been addressed and are summarized in Box 2

Relationship between the Perceived Disability Index (PDI) and other variables of interest? See discussion of the scale, (Chapter Five), data analysis and Box 2

The PDI was developed in the absence of participant’s knowledge of their individual EDDS scores (see Glossary), and provided a useful view of their own perceptions of disability as discussed above. Their view and observations by the researcher often differed
as has been reflected in their paradoxical comments which reflect more disability than is admitted, and better overall reported health than was observed.

**SUMMARY OF CHAPTER SEVEN AND INTRODUCTION TO CHAPTER EIGHT**

Chapter Seven has offered a summary of results and findings emerging from Phases One of this study and included these in two summary boxes. Findings from Phase Two (Interviews and observations) have been listed and discussed. The responses to the research question have been made throughout the chapters and reference is made to these citations. Conclusions emerging from the findings are addressed in the next Chapter. Of particular note is the need for a trusted and knowledgeable key contact person as ‘someone to turn to in time of need. This emerges as a vital and urgent need for each person diagnosed with MS. Development of this role is discussed further in Chapters Eight and Nine. Findings from this research study make a strong case for the development of a comprehensive, ongoing, multidisciplinary model of care for persons with MS their carepartners and their families to include aspects of education/information, periodic assessment and support for these families throughout the disease trajectory, as will be discussed in the next chapters.
Chapter Eight: Discussion

What the study tells us: Towards a Multidisciplinary Care Model for Carepartners in MS

WHAT THE STUDY TELLS US
Chapter Eight discusses what is new in this study and in what ways it contributes to or expands present knowledge of the impact of multiple sclerosis on committed caring relationships. It explores new directions emerging from the results and findings of both phases of the study and asks: “What is the study telling us?” As will be discussed, the study holds implications for health service providers working with people with MS.

In reviewing the findings, nine important new areas of consideration emerged in the experience of carepartners living with MS.

1. The term “Carepartner”, and the concept of a “Carepartnership” in MS, in which each member of a dyad is seen as a ‘co-carer’ of the other and in which each contributes valued resources to the relationship opens up new ways of thinking about the care giver/care recipient relationship

The term “carepartner” is, as far as can be ascertained, unique in its application in this study. It is used in the context of two people who are in a spousal or reciprocal relationship. Each partner perceives he/she provides a valued contribution to the health and well being of the other. Although in most spousal or partner relationships, even when ill health or disability is not present, there are likely to be times when one partner is perceived to give more than the other in physical and emotional terms to the relationship, this situation may be considered acceptable by the partners when there is overall mutual
value perceived in the personal qualities and affecional contributions of the partner, together with an underlying belief that the other would do as much if the situation were reversed.

The notion that caregiver and care recipient can and should be seen as co-carers, where each brings to the relationship a valuable contribution and makes the relationship a reciprocal one, is largely absent from the literature until the work of Pakenham (1998). Pakenham suggested the couple should be seen as a unit (Pakenham 1998). The idea of “Couple coping” as a unit in the face of illness, perhaps arising from Pakenham’s work, is now being addressed more frequently in the contemporary literature (Bodenmann 2001; Bodenmann 2005; Bodenmann 2005). (see item 4 below)

Authentic reciprocity seems to imply that each partner feels a certain amount of power to control the relationship as opposed to having feelings of hopelessness and helplessness in the face of an increasing level of dependency or overwhelming burden of care. In this study, when care recipients espoused the ‘victim’ role, perceiving themselves to be a burden to the carepartner, and believing they had little to contribute to the spousal relationship, they also exhibited low mood and low life satisfaction. When it was suggested they were providing a valuable contribution to their carer in terms of love, friendship, affection, or expressions of appreciation for the services of the carer, these care recipients brightened noticeably, saying they had not perceived themselves as having any role in ‘caring for their partner’. However, as they reflected on the idea, they seemed pleased that they were contributing to their partner’s wellbeing and to the caring relationship. For a care recipient to recognize that they contribute positively and actively to a caring relationship is empowering, enhancing the sense of self-worth and giving meaning to life.

The importance of perceived reciprocity in maintaining marital and life satisfaction emerged from the study. It appears, therefore, that every opportunity needs to be grasped by health professionals to identify the strengths observed in Carepartners as they support and reinforce the two-way aspects of the relationship. Saleeby (1997) suggests an effective way of empowering clients is to work with their strengths (Ferguson 1991; Saleeby 1997; Smith 1999).
It is possible then, that increasing the awareness of the care-recipients’ contribution to the reciprocal nature of the relationship, may help to reduce their feelings of helplessness, dependency and depression while increasing self esteem, sense of worth and purpose in life. Further studies seem warranted in this direction. To view themselves as ‘co-carers’, may empower care recipients. Thus the notion of reconceptualizing care giving and care receiving in terms of a reciprocal relationship to enhance this dyadic relationship may offer valuable insights to health care professionals and care partners in chronic illness.

Couples in this study accepted that the care partnership is not static, that life is dynamic and offers good and bad times, recalling the good times they have shared in the past, recognizing times of frustration and often affirming the valued qualities in their partner. Changes in the life course also impact the relationship and need to be taken into account by health care professionals. Changes brought about by the arrival of children, their education needs, launching as young adults, unexpected illness, retirement and the aging process, are but a few of life’s potentially disruptive events that impact a spousal relationship besides the significant impact of MS over time (Erikson 1963; Duvall 1971; Becker 1997).

**Notions of care partners, ‘partnership’ and ‘reciprocity’ from the literature**

Partnership is defined as a relationship between individuals or groups that is characterized by mutual cooperation and responsibility, as for the achievement of a specific goal. This relationship is usually applied to business or international partnerships. Reciprocity is defined by the same source as a mutual or cooperative exchange of favours or privileges, especially the exchange of rights or privileges of trade between nations (http://merriam-webster.com/dictionary).

‘Care Partners’ are described in the context of healthcare providers or insurance groups and their clients; in terms of a medical or support team in cardiology; mental health, palliative and critical care. However, the meaning of the carepartnership is not the same as used in this research study.

A review of the current literature using the keyword ‘carepartner’ found references to partnership when discussing group or team approaches to a problem including patient or doctor and medical team; associations between health care agencies; community agencies.
and client; other groups involved in addressing a particular problem and other such partnership relationships. No reference was found to the concept of partnership between care giver and care recipient except in terms of ‘reciprocity’ and the seminal work of Carruth (1996), who initially identified constructs existing in the caring relationship between elderly parents and their adult child carer. These concepts were later expanded in a further study that included elderly couples caring for each other Carruth (1997). A critique of this potentially excellent and useful measurement tool as used in this research study has already been made (see Chapter Seven-Finding 9).

The concept of reciprocity as reviewed in the mental health literature is seen largely in terms of co-dependence, which suggests a pathological relationship, rather than something that should be supported and which could enhance health and well being for both. Codependency (see Glossary) has been defined as “a kind of addiction frequently seen in relationships involving alcohol or substance abuse in which one person enables the addictive behaviour of the other” (Irvine 1999; Beattie.1987). No mention is made of a carepartnership between patient and a spouse or family member. This study prefers to reject the pathological interpretation of reciprocity, although there may have been aspects of co-dependency and enmeshment in several of the interview couples, where friendship and enjoying each other’s company were carried to an extreme (for instance: phoning each other several times during the working day of the carer; refusing to share the care and supervision of children with even close relatives). These devoted parents failed to recognize the heavy burden that having the children with them at all times placed on the partner with MS who was suffering extremes of fatigue, and on the caring partner, who was expressing a need for respite to pursue his/her own activities from time to time.

The notion of a ‘carepartnership’ as it applies to a person with MS and his/her identified carer or support person, and as used in this study enables us to think differently about the carer/cared for relationship and thus has implications in the care and management of couples and families affected by MS. Reciprocity in this type of relationship needs to be explored further, and existing instruments need to be refined for use in the clinical field. In this study, use of the reciprocity scale was inconclusive, as previously mentioned. However, couples clearly described behaviours in their partner that were valued by them and which could be included in an operational definition of ‘carepartnership’.
2. The importance of reciprocity and partnership as perceived by Carepartners in maintaining the caring relationship

This thesis attempted to describe what ‘carepartnership’ meant from the point of view of the interviewees and to identify constructs reported by participants that enhanced their sense of marital satisfaction. Frequent mention was made to the concepts of partnership, love and affirmation, ‘moral support’, understanding and forgiveness, expressions of admiration, respect, companionship and friendship with their partner, valued social support from family and friends and social cohesion, as discussed in Chapter Six. Notions of partnership differed from couple to couple as noted in the following examples. One couple emphasized their partnership with a phrase previously quoted: “We are partners in everything- we pull together, not against each other” (#8). Another was more dubious about the current status of the partnership saying: “Are we partners? Well, sometimes you have to push the partner” (#11). Yet another asked: “By ‘partners’ do you mean do we care for each other? Absolutely, YES”(#6). Another couple included the concept of friendship in their reply saying: “We are partners and we are also best friends; we can almost read each other’s minds – we like each other and we enjoy doing heaps of things together.” (#3). A strong social network and support group was much appreciated and valued by participants and missed when it was not available.

Partnership was central to the experience of the spousal couples I interviewed in this research study. Each had a unique view and understanding of the term and described it in different terms as discussed earlier. Spousal couples who exhibited little affection or reciprocity at interview spoke of desired behaviours in the partner that were absent or in short supply and which caused them sadness and emotional pain. They expressed an inability to give and receive love and affection and noted a fear of rejection that stopped them from expressing their needs freely to each other. The relationship was seen to be useful but not happy and an over-riding sense of chronic sorrow and low mood was observed as described by Hainsworth (1993) when discussing couples experiencing chronic illness (Burke, Hainsworth et al. 1992; Hainsworth 1993; Hainsworth 1994; Hainsworth, Eakes et al. 1994; Hainsworth 1996).

Simmons, reporting at the 2004 MS Conference, Melbourne, found that depression was more common with PwMS in progressive situations, and recommended psychological
intervention to help these patients handle anger and depression. He suggests that it is not stress per se that contributes to depression, but how it is perceived by the individual (Simmons 2004). Chwastiak and others suggest that clinicians should evaluate depression in patients with recent diagnoses of MS as well as major changes in functioning and limited social support, as mentioned in Chapter Five (Chwastiak et al 2004)

Screening instruments used in this study revealed high levels of depression when compared with the general Australian population. Although this may be consistent with the presence of an intrusive, chronic and progressive neurological illness, this sense of sorrow needs to be addressed by healthcare professionals working with Carepartners with MS in any ongoing program. There is a potential for use of selected complementary therapies to help Carepartners cope with this low mood and depression. Current research in the field of psychoneuroimmunology is exploring the close relationship between the body systems as they communicate with the brain chemically and electrically bringing about changes in behaviour that enhance wellness. Behaviours are also believed to influence the actions of the nervous, immune and endocrine systems. Meditation, imaging, relaxation and stress management techniques are being subjected to rigorous testing with promising results (Kent 2006). Group or individual opportunities to discuss frequently expressed fears may be therapeutic. Participants in this study spoke of the ‘worst care scenario’, including fears of further potential losses of ability or ‘ending up in a wheelchair or nursing home’ and ‘being an unbearable burden to their carepartner’. These fears were never far from the minds of Carepartners in MS. Some were fearful of abandonment by their partner and required frequent words of reassurance from him/her. Ongoing and episodic respite and support needs for carers must be addressed as needed.

The concept of power has been found to be important to the carepartnership and insights have been gained into the manner in which power has been maintained by the apparently weaker partner, sometimes impacting the relationship in a negative manner (Grimwood 1993; Rahman 1994; Saleeby 1997). Changes in the power structure of the dyad were often perplexing to them as they struggled with changing roles and responsibilities required by the physical and cognitive changes of MS. Use of ongoing and available psychological counselling could move these carepartners to a higher level of wellness and marital satisfaction. There may also be a place for the teaching of effective negotiation skills as suggested by Coeling (2003).
Caring relationships are in a constant state of flux throughout the life course, and these changes are made more difficult with the advent of a chronic, usually progressive, degenerative neurological disease such as MS in one of the members, requiring creative measures to adjust to the physical and cognitive changes in a manner acceptable to both partners and to society.

3. The need for healthcare professionals to focus on the couple as a unit whilst maintaining an awareness of the impact of MS on each caring partner and the caring relationship expands our knowledge relating to the psychosocial management of couples living with MS

![Impact of MS](image)

Figure 8.1. Impact of MS on PwMS, Carer and Caring Relationship

The above diagram, (Figure 8.1) illustrates the continuing impact that MS has on the PwMS, the Carer and their caring relationship. This impact is a dynamic and ever-changing one as the spousal caring relationship changes over time under the physical and cognitive changes brought about by MS. The relationship shifts from a relatively balanced one with sometimes tacitly agreed roles, functions and expectations to one where the affected spouse becomes a Care Recipient and the partner becomes a Care Giver. If the
spousal relationship is to survive, it may require support and sometimes intervention by health professionals who are prepared to assess changing needs with carepartners and to offer timely and acceptable support services, matching emerging needs with timely and appropriate resources. Thus it seems imperative that professionals focus on the carepartners as a unit as suggested by Pakenham (1998). Other authors hint at the needs of couples (Knox 2000; Flick 2002; Burks 2004; D'Ardenne 2004), and this topic is taken up later by Bodenmann (2005).

3.(a) The lived experience of individuals with MS

Many studies were found in the literature reporting the lived experience of multiple sclerosis from the point of view of the affected person (Mohr, Dick et al. 1999), and also from the view of the carer (Watson 2003; McKeown, Porter-Armstrong et al. 2004), but the concept of exploring the MS experience and its impact on the relationship from the view of the ‘carepartners’ (the couple or dyad) was not observed in the current literature. However, D’Ardenne and Morrod (2004) devoted one issue of the Journal of Sexual Relationships, to the needs of couples responding to illness, addressing not only the needs of the couples but also the needs of health professionals who must speak to these needs and who often feel poorly prepared for the challenge.

The comments of most participants in this current research study relating to their experiences with healthcare professionals before, at and after diagnosis would support this sense of inadequacy on the part of healthcare professionals when having to give a life threatening or a life altering diagnosis to a patient. It is a bitter pill indeed which must be delivered, and cannot satisfactorily be ‘sugar-coated’. However, ongoing support is needed and it is necessary for health professionals to use compassion, empathy and skill in devising support measures for their patients throughout the disease trajectory (Frank 1995; Reynolds and Scott 1999; Frank 2004).

3.(b) Focus on couples

A focus on the ‘couple’s needs’ is different from a focus on either individual member of the dyad. This research has contributed a new understanding and recognition of the importance of a changing spousal relationship over time as the one person moves from caring partner to care recipient, and the other from caring partner to care giver (See Figure 8.1 above). The sometimes subtle physical and cognitive changes as a result of MS have
been noted to cause confusion and frustration in carepartners who are sometimes not fully aware of what is happening. Many carers have said they initially believed their partner ‘could do better’, and were being ‘slack’ or ‘lazy’ when in reality, they were overcome by fatigue due to MS. The situation was reported to cause tension in the marital relationship. The changing spousal role needs to be included in the focus of the healthcare professionals assessing the impact of MS on the relationship if they are to be able to help this relationship survive and thrive through changing times. As D’Ardenne and Morrod (2004) note, health professionals do not always feel prepared to meet the many and varied challenges that come to them in their practice, and argue for ongoing and periodic workshops and other educational resources to be provided for professionals encountering relationship problems in their practice (D’Ardenne 2004). Frank (1995; 2004) has also addressed the dilemma of the doctor in dealing with some of these difficult issues. A focus on the couple and its needs, together with timely intervention by skilled professionals can offer support to both carepartners as roles and needs change under the impact of MS, maintaining and promoting optimum life and marital satisfaction (Coeling, 2003; Reynolds and Scott 1999).

3.(c) Implications for policy

Placing the “Carepartnership” at the centre of policy and program development has the potential to bring considerable benefit to couples and families with MS. Seeing the ‘couple’ as the focus of care and services in MS may be a reasonable, cost-effective means of improving the life satisfaction and level of wellness of persons/families affected by MS. More research is needed to consider the impact of such policy changes (see Chapter Nine).

4. The presence and importance of cognitive and behavioural changes as a result of MS

In this study, couples (all but one) were interviewed separately but on the same day. Valuable insights were gained by using this separate interview strategy. Perceptions of behavioural changes, reported as ‘having a short fuse’, or ‘over reacting to small events in the household’ were presented differently by carepartners at interview. In particular it was noted that although the presence of memory and cognitive problems were often recognized by both, their perceptions of the importance of these changes to their lives

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were very different, and these differences have been examined in greater depth in this study. Once again, the importance of ongoing support and timely professional guidance stood out in the matter of memory and cognitive changes, since these have been found to be closely related to the ability to continue in employment for the PwMS. Early referral to financial counselling when current employment appears to be at risk, would facilitate the transition from employment to unemployment minimizing the impact on the financial future of the person or couple.

While health professionals can and do offer excellent helpful strategies to cope with memory changes and difficulties with concentration, the changes in the spousal roles under the impact of MS need to be addressed as well, and timely negotiating skills need to be offered, with support for the partner whose increasing burdens of care and household duties seem at times to be overwhelming. This ongoing support needs to be available before crisis events occur such as an unexpected loss of employment, serious health events or breakdown of the marital relationship.

This changing spousal role needs to be included in the focus of the healthcare professionals assessing the impact of MS on the relationship if they are to be able to support a relationship that is experiencing the impact of MS over time. As previously noted by D’Ardenne and Morrod (2004) and Frank (2004), health professionals do not always feel prepared to meet the many and varied challenges that come to them in their practice. Health professionals were perceived by the study sample to fall short of their expectations as discussed in #6 below.

5. Perceived lack of empathy and support by health professionals throughout the disease trajectory

This issue has been addressed with direct quotations from interviewees and supported with the literature references listed above. It is not a new issue but one that recurs in health practice and requires ongoing action in the field of continuing professional education. Consumer satisfaction is important in all businesses and more so in the healthcare professions. This study reveals an overwhelming level of dissatisfaction on the part of patients receiving a life-altering diagnosis from health professionals and specialists with little or no empathy or offer of ongoing support. It also suggests, perhaps, that organizational and management issues need to be analysed in relation to their impact on
the capacities of healthcare professionals to respond effectively to service users’ needs and demands. (See Chapter Nine).

6. Need for ‘a trusted and knowledgeable person to turn to in times of need’

The need for such a trusted and knowledgeable key contact person emerged strongly from this study as demanding further exploration and consideration by those delivering the diagnosis of MS. Such a person has the potential to make a vital difference in the lives of persons with MS, their partners and families.

This person might be most suitably located within the health team that is active in the ongoing support of PwMS and their families. Many possible descriptors have been reviewed when considering who this person should be. Terms such as ‘case manager’, ‘friendly visitor’, ‘advocate’, ‘peer support person’, ‘nurse’ or ‘social worker’ came to mind, but none precisely seemed to fit this unique role. Should this person be a peer or other lay person, or a professional? Why or why not? This person needed to have the capacity, skill and willingness to build a trusting relationship with the newly diagnosed; to demonstrate empathy in each particular situation and be prepared to make referrals to suitable resource persons or facilities as needed.

The Case Management literature describes this role in many different ways and agrees that it varies with the situation, and the particular setting in which Case Managers are employed. Summers (2007), discusses these differences in his study of four approaches to case management in the same organization. When I used the term “Case Manager” with interviewees when speaking of the possible usefulness and relevance of such a person to assist them in their journey with MS, I was surprised by the spontaneous response of two, who said: “I don’t want anyone ‘managing’ me, thank you “. (personal communication 2003).

Thus although the role was viewed as valuable, study participants wanted to see this as a more collegial and mutual relationship where they still maintained control over decisions regarding their situation. It appears then, that much thought must be given to an appropriate and acceptable title from a multidisciplinary perspective.
Such a role requires training and the development of skills in working with a dyad, conflict resolution, and crisis support as well as familiarity with community resources, their eligibility, access criteria and cost. Development of such a role description and identification of a group of persons willing to take on such a role (voluntary or paid) is beyond the scope of this research study, but is an important issue that should be worked on by a group of multidisciplinary professionals with an interest in MS, in partnership with people with MS. This role needs to be developed and implemented with clear guidelines for maximum effectiveness. Exploring and developing the potential role and function of the proposed ‘person to turn to in time of need’, whether an advocate, buddy, or helpful peer, would seem to be of great value. This person would have to be seen as a trusted and knowledgeable resource person who was non-intrusive in the life of the affected person(s); non-directive and prepared to work with the carepartners as they sought available resources to cope with current needs. Such a person needs to be able to establish a trusting relationship with carepartners and who has the capacity to build on the strengths of the care partnership to cope with ongoing changes. These changing relationship needs may be due to MS or to episodic stressful events occurring in the life course. The key role of such a person is to build on, sustain, and maintain the couple-coping capacity. This assistance could be carried over if and when it became necessary to consider temporary or permanent care for the partner with MS for whatever reason.

The ‘advocate’ (or key contact person), would need expertise in working with the couple, which is different from working with each individual (PwMS or carer); in knowing how to build the capacities synonymous with ‘partnership’ for and with the couple. The person would need to identify the type of partnership it is; who comprises the partnership; the relevant stage of the life cycle/course; the strengths of the couple; the stages of the disease progression and its possible trajectory; values that people perceive make a relationship work; and the tasks of a partnership that may help make it work. Also needed is a thorough knowledge of support resources available from Government, non-Government and voluntary agencies to assist families with chronic illnesses such as MS.

In addition to having excellent relationship skills and the ability to develop a strong sense of trust in the client, this ‘advocate’ would need to be able to work with conflict or frustration within the dyad and be wary of being ‘diverted’ from concerns with the couple to concerns with individuals. It is also necessary to keep in mind that the health of one
partner impacts the health of the other as noted by Pakenham (1998), Pozzilli (2004) and Coeling (2003). The role and function of this person needs to be defined and understood by all participants to avoid ‘burnout’ of the advocate, and any sense of abandonment by the Carepartners.

7. A multidisciplinary care model for Carepartners in MS

‘Careplans’ guiding the treatment of persons with MS have been developed in several countries such as Canada, the UK and Australia following a medical model. These excellent documents have explored and identified different domains in the progression of multiple sclerosis, giving clear suggestions for effective interventions both preventively when possible and after the development of new symptoms. It is possible that these careplans can be viewed and expanded from a multidisciplinary viewpoint, addressing the total needs of individuals and carepartners coping with the ever-changing impact of MS on their lives and relationships. Again, this further work is beyond the scope of this study. Multidisciplinary MS health professionals attending a recent MS Conference (November 2007, New Zealand) recognized the absence of such a strategy and expressed considerable interest in the idea of developing an ongoing, comprehensive, assessment, education and support program for all persons diagnosed with MS. The need for timely information, education and ongoing support by PwMS has been amply documented in quotes from the transcriptions of interviewees throughout this research study.

8. Implications for policy, education and research

Placing Carepartners in MS at the centre of policy considerations for allocation of scarce resources and funding has the potential for better cost-effective utilization of these resources. There are education issues that can be addressed in the education of health professionals to enhance their communication skills and to increase their level of empathy and awareness of the emotional impact of serious diagnoses on carepartners and their families. Periodic and regular workshops for health professionals to teach and reinforce these skills and inform them of new developments in the fields of education and communication skills should be a part of continuing education for all health professionals. Continuing research is needed in every discipline seeking to improve the life satisfaction of persons coping with chronic illnesses. (See Chapter Nine).
9. Analysis of the data highlighted the need to review and refine existing measurement instruments used for reciprocity and functional wellness to obtain clearer information in future studies with Carepartners

Results of the statistical data analysis completed in Phase One supported known data relating to multiple sclerosis in several areas, such as age, gender, ethnic origin and a variety of symptoms with variable progression of the disease. Presence of a geographic gradient in Australia for incidence of MS was not supported in this study. There was a high incidence of depression in the study sample using a valid screening instrument. Females were more depressed than males and PwMS more depressed than carers. Education levels were higher than the general Australian population, but expected levels of employment relative to education were lower than might have been anticipated (ABS 2001).

The Reciprocity Scale (the CRSII) failed to provide any useful information as applied in this study, but the concept of reciprocity remains of value when studying persons in committed caring relationships. This scale has been critiqued at length elsewhere, and the measures taken by this researcher to minimize its problems have been reported (see Finding 10, Chapter Seven). The scale does need to be developed further and the scoring guide revised for use with both Carepartners rather than with carers only as is now the case. Present use with only one carepartner gives an incomplete picture of the mutuality of the relationship.

The Life Satisfaction Index (LSI-Z) provided predictable results with carers having better scores than PwMS, and persons who were able to work having better scores (suggesting greater life satisfaction) than the disabled. Use of a revised Functional Wellness Inventory (FWI) provided interesting findings which showed strong correlation between physical health and mental, emotional social and spiritual health of both care givers and care recipients, thus supporting the literature finding that the health of one carepartner affects the other in chronic illness (Pozzilli, Palmisano et al. 2004). This finding emphasizes the importance of supporting the ‘carepartnership’ as proposed in this thesis.

The four open ended questions at the end of the FWI (Functional Wellness Inventory) provided consistent statements indicating a strong desire to be free from the disease and
its undesired physical and psychosocial effects. As previously noted, Pakenham (1998), suggests that carepartners should be treated as a unit by healthcare professionals since they do have such an impact on each other. Helpful interventions should include and target both parties for maximum effectiveness (Pakenham 1998). There is little in the literature relating to couple counselling except in relation to marriage preparation classes or genetic counselling. However, the findings emerging from this study suggest that specialized counselling for couples in care partnerships may be of benefit in supporting the caring relationship.

**SUMMARY OF CHAPTER EIGHT AND INTRODUCTION TO CHAPTER NINE**

Chapter Eight highlights the findings emerging from this study that contribute to or expand current knowledge about the impact of MS on committed caring relationships. While this discussion has been based on an analysis of a limited data set, areas where further research that may benefit Carepartners and their families coping with MS have been highlighted. Two areas of note include the ‘key contact person’ whose role and function need to be carefully determined by MS health professionals in dialogue with MS Carepartners as illustrated by this research, and the second is the development of a multidisciplinary, comprehensive and ongoing plan of care and management for Carepartners in MS.

This project would require the active involvement of many disciplines who currently provide care and services to PwMS, but whose roles could be expanded in the context of ‘best practice’ for their discipline. This study found that the discipline of physiotherapy, for instance, was valued by participants and yet was limited by funding availability in the healthcare system. Many had to fund the services they required from their own sometimes limited resources. There is a challenge to all healthcare disciplines to examine their care delivery to persons with chronic illnesses, such as MS, in terms of best practice and to pursue policy and funding changes if and when these seem indicated.
Chapter Nine addresses the conclusions emerging from the results of data analyses with implications for education, practice and further research for health professionals working with Carepartners impacted by MS.

An Epilogue considers the bidirectional impact of the researcher on the research.
Chapter Nine: Conclusions and Recommendations

This study has contributed new viewpoints in the approach to PwMS and their carers. Central to this is the notion of a ‘carepartnership, where the couple can be seen as ‘co-carers’ with each providing a perceived valuable contribution to the caring relationship. It has raised awareness of the need for healthcare professionals to focus on the partnership, particularly the ever-changing nature of the caring relationship over time and under the influence of MS. The need to identify any potential problems emerging in this relationship and the need to offer timely supportive interventions that are acceptable to the carepartners, such as counselling and respite to prevent its breakdown, were important findings. (See Chapter Seven and Eight).

The study and its findings provide a strong case for new ways of looking at the care and management of PwMS and their carepartners in two clear directions. First, there is an identified need for ‘a person to turn to in time of need’ (Langley 2003). Although Langley’s survey suggested a nurse as being the most appropriate person to fit this role, other professionals who are able to establish a trusting relationship with clients could be considered as well. This ‘key contact person’ has the potential to make a vital difference in the lives of people coping with MS. The role and function requires careful definition and delineation by MS health professionals in collaboration with PwMS and their Carepartners. This person would become a first point of contact; a trusted, available and knowledgeable source of advice or referral to needed resources as changes occur in their lives with MS.

The second identified and well-supported need emerging from the study is for a review of current care and support programs for PwMS and possible development of a comprehensive, multidisciplinary, ongoing and episodic assessment, education and support program for PwMS, their carepartners and their families. As previously
mentioned, this concept was presented at a Conference for MS healthcare professionals in New Zealand, 2007. These Conference attendees supported the idea and agreed that the present healthcare system, together with Government, non-Government and voluntary agencies in Australia, do offer many excellent resources in terms of assessment, medical care and treatment, informative programs and some support services, but there are many identified gaps in the system that have been highlighted in this research. Implications for revision of the existing healthcare system, further research, education and practice are discussed later in the chapter.

CONCLUSIONS

Results obtained from statistical analysis of Phase One of the study were consistent with other international research with regard to gender, age of onset, variability of symptoms and trajectory, as well as demonstrating predictable correlations between functional wellness, life satisfaction and mood. It could be assumed on analysis, that the study sample would not be too different from other samples if they were drawn from the same population. Comparison with statistics provided by the ABS (2001) about the Australian general population in regard to education, home ownership and employment also provided credible results in relation to the study sample.

The suspected geographic gradient of the incidence and prevalence of MS was not clearly supported in this study, although current findings reported by the MSRA (Multiple Sclerosis Research Association) and shown in the map provided in Chapter Three, which is based on an extensive and ongoing longitudinal study, offers strong evidence for this belief (Figure 3.1). This gradient is currently explained by the possible beneficial effect of exposure to Vitamin D from the sun, which is more readily available with greater proximity to the equator. Vitamin D is thus considered protective against MS, but this is not as yet fully supported by empirical research (Jelinek 2000).

The following six conclusions emerged from the triangulation of results obtained in phases One and Two of the study (see Chapter Seven), grouped into topics as discussed below:
1. **Health and financial concerns:** Ability to work has positive correlations with improved perception of Life Satisfaction, Functional wellness and mood. There are issues relating to the need for income replacement in chronic illness and disability. These concerns are paramount in the case of multiple sclerosis, where individuals are often forced to exit the paid workforce many years before they are eligible to access superannuation or other retirement funds, and there are currently no provisions for superannuation for carers.

2. **The caring relationship:** the importance of perceived reciprocity by Carepartners. There is a need for healthcare professionals to focus on the couple rather than on individuals alone and to be aware of this relationship and its need for support throughout the trajectory of MS. Any breakdown of the caring relationship has serious implications for reduced life satisfaction of the couple, reduced income level for the family and may lead to premature placement of young persons in nursing homes.

3. **Expectations of health care professionals (met and unmet):** There is a perceived failure of health care professionals to meet the expectations of carepartners with MS. Extensive support for this conclusion emerges from the findings and have been reported earlier.

4. **Cognitive and behavioural changes (different perspectives):** When PwMS and Carers were interviewed separately, there was a notable difference in their perception of the importance or effect of these changes on their relationship and future employability.

5. **Need for review and refinement of measurement scales:** The Caregiver Reciprocity Scale, in particular, and its scoring methods, needs to reflect the concept of ‘co-caring’ when exploring dyadic relationships as discussed in the critique of the scale in Chapter Seven. The FWI also requires review.

6. **Urgent needs for timely information and ongoing support during changes in the disease trajectory:** There are urgent needs for new directions in the existing care and management programs for PwMS and their families, together with consideration of a comprehensive multidisciplinary program as discussed below.
RECOMMENDATIONS

Recommendations for Further Research, Implications for Education and Practice for Healthcare Professionals and families with MS; review of healthcare policy issues

1.0. Recommendations for Further Research

1.1. A replication study of this research using a larger, international sample would seem warranted in view of the interest shown by potential participants responding to the invitation to participate from several countries, including the UK, Northern Europe, Switzerland, Yugoslavia, Canada and the United States. It appears there is indeed considerable international interest in the impact of MS on committed caring relationships. Multiple smaller studies using samples from individual countries or States might also be of value in the study of the impact of MS on couples in committed spousal relationships (Carepartners with MS).

1.2. Review and refinement of the measurement scales used in this study. Further research is needed to address some of the limitations of the CRS and FWI scales which have provided inconclusive results in this study as discussed previously.

1.3. Review and refinement of the Z-R Model and its measurement scale is needed in order to better address all ten of the basic needs of the model (see Chapter One). Currently, the majority of the items on the scale relate to only two of the needs, giving an incomplete perceived view of the other eight.

1.4. A research study considering reciprocity as a mediating factor in life and marital satisfaction, together with a deeper exploration of the lay understanding of reciprocity in relationships.

1.5. A review of current research studies within the discipline of Physiotherapy on the relative efficacy of physiotherapeutic interventions in multiple sclerosis. Confusion appears to exist in current practice as to parameters of therapy: how much is good, how much is too much (and could therefore be harmful) and under what conditions maximum benefit can be expected. Results from this empirical research by the discipline of Physiotherapy, in the context of ‘Best Practice’, could then be used to address health
policy issues that currently place many limitations on this service as perceived by PwMS, and reported in this study.

1.6. Further research into ‘couple coping’, and possible measures to support and enhance the important dyadic relationship throughout the trajectory of MS. (See Conclusion 2. above)

2.0. Ongoing Assessment and Education of PwMS and families

2.1. Assessment of changing needs in the light of cognitive and physical changes brought about by MS, including home safety and driving skills.

2.2. Education of PwMS and their families, plus information and support, recognizing that individual learning needs vary. The current practice of sending out a ‘newly diagnosed packet’ containing information is good in principle, but can, in the view of study participants, be daunting to the person receiving it. Personal follow-up needs to be available to be of maximum effectiveness. The terminology used in the publications and enclosed articles is often difficult for the lay person to comprehend and further increases anxiety. Many have found the information packet overwhelming. However, when insufficient information was available, PwMS have reported that they believed health professionals were ‘holding out’ on them, and saying they ‘had a right to know what was going on’ in their own bodies. Without the provision of well-timed, clear information and follow-up to ensure understanding, it was apparent that study participants had sometimes allowed their imaginations to fill in the missing information, and led to the previously quoted dread of ‘a worst case scenario’ by many who were imagining a rapid decline in mobility, abandonment by the caring partner, or early placement in a nursing home.

2.3. Education in negotiation skills emerged as a need for PwMS and their carers in this study. Such educational needs included not only knowledge relating to the disease and its many and varied ramifications, but also such topics as negotiation skills to handle changing roles in spousal relationships as the partnership moves from ‘caring partners’ to ‘care recipient and care giver’ as the losses of ability (physical and cognitive) in the PwMS develop. Thus, a focus on ‘couple coping’ may prove helpful and may involve help from a psychologist from time to time.
2.4. Funding options before retirement. Other frequently encountered problems related to the access to superannuation funds or any available pension during the intervening years when the person has had to cease employment and superannuation can be accessed. A workshop or seminar could be offered, including a contact person for arranging severance packages that work in the best interest of the client and family. This knowledge is best provided when the ongoing assessment program team suspects or anticipates that a person with MS may be unable to continue with present employment for much longer. A timely neuropsychological assessment could assist in identifying the appropriate time for suggested interventions. To leave this for too long may disadvantage the PwMS, whose employer may not have the best interests of the employee at heart.

2.5. Inclusion of family members in education programs. All family members and partners of PwMS regardless of their geographic location need to be included in educational and information programs. Although this is currently being done well in urban and metropolitan areas, many in country areas have difficulty accessing these facilities. As Shapiro (2003) says: “MS is a disease of people (Shapiro 2003)”, and it could be said ‘of families’ and certainly of ‘carepartnerships’. Letters and information sent out from agencies to PwMS, are not addressed to family members as well, perhaps because of concerns about privacy. However, caring family members often feel excluded and frustrated by this as they struggle with the effects of MS on their loved one without understanding the debilitating effects of such common presentations as fatigue, cognitive changes and temperature sensitivity, for instance, on family life and family functioning. This lack of understanding can lead to conflict and misunderstanding in family and carepartner relationships. Outreach programs may benefit families with MS living in non-metropolitan areas.

2.6. Current knowledge and treatment options openly communicated. Information needs to include current knowledge about the disease and treatment options, services available to families with MS, assurance of support when questions arise, as well as news of special programs on topics of interest, and opportunities for volunteer activities.

3.0. Education/continuing education for Health Professionals

3.1. Conferences, continuing education workshops and seminars. All MS health professionals could benefit from attending conferences or continuing education programs
providing news of the latest research on bio-psycho-social aspects of MS, including offerings to enhance communication skills when delivering life altering diagnoses, where sensitivity in communicating empathy, hope and support is vital.

3.2. Focus on the couple. Studies exploring how specialist clinicians might work with Carepartners rather than individuals only in caring relationships are essential. This dyadic focus may require somewhat different skills than may already have been learned, for example, understanding how couples cope as distinct from how individuals cope with chronic illness/disability, couple counselling techniques, dealing with confidentiality, adopting a role which is focused on dyadic needs, establishing mutually agreed upon boundaries, responsibilities, and expectations. The need to focus on couples (couple-coping) in medical and psychological assessment and interventions, and to offer support for the caring relationship is an important finding emerging from this study (see Chapter Seven)

3.3. Difficult situations for doctors. Frank (1995; 2004) addresses many of the concerns that doctors express in being able to cope with seemingly insoluble problems on a day to day basis in their practice of medicine, but does not relieve these professionals of the responsibility to develop a ‘renewal of generosity and empathy’ with their patients in the face of chronic or disabling illness. This dilemma together with the continuing development of effective ‘people skills’, need to be an important subject for discussion in medical education and continuing education.

4.0. Health Policy Issues

4.1. Review of health policy relating to funding and services for persons with chronic illness and disabilities (See 5.2 below).

FUTURE DEVELOPMENTS

It would be of interest and value to meet the participants again after the conclusion of this study or perhaps to follow up this study using focus groups composed of small groups of Carepartners to determine their perceptions of current health policy and to seek suggestions for prioritization of new directions in the care and management of carepartners and families affected by MS..
5.0. New Directions in the care and management of Carepartners with MS

5.1. Proposed new role: A key contact person. Of particular importance given what has been learned from this study is the development of a new role: a key contact person (a person to turn to in time of need) for every person diagnosed with multiple sclerosis. As discussed in Chapter Eight, participants in this study indicated that the following programs might be beneficial in meeting many of the needs they revealed.

Each newly diagnosed person would be offered a ‘buddy’, ‘mentor’, or ‘advocate’, who would become a first point of contact as needs or queries arose. The ‘buddies’ could possibly be those who have a particular understanding or experience of MS, for example, professionals or retired professionals, or people with MS who are adapting well; persons who have experience with MS as a carer or partner, and who have undergone a period of training on the available resources or contacts for PwMS and their families. The role of the ‘buddy’ would be to establish a trusting relationship with individual PwMS or Carepartners. This role could best be defined and developed by a core group of MS professionals in collaboration with PwMS and Carepartners.

When Langley (2003), in her survey of PwMS in a northern State, asked participants “What do you see as the role of the nurse?”, she received the rather global response: “A person to turn to in time of need”. The need for such a person seemed to be overwhelming according to the results of Langley’s survey, although it could be argued that this role need not be limited to nurses. Much needs to be done to identify and develop the proposed role and function of this ‘key contact person’, seeking guidance perhaps from specialists in other chronic health fields such as Cancer, Mental Health, Case Management or Parkinson’s Disease. Detailed exploration of this role is beyond the scope of this study and could best be undertaken by a core group of multidisciplinary MS health professionals, PwMS, Carepartners and their families.

5.2. Policy implications- Funding issues. There are implications for review of health and welfare policy relating to persons with chronic illnesses and disabilities, especially for those who have been forced to exit the workforce at an age too early to access retirement income.
There are currently no provisions for superannuation for full time carers of persons with chronic illnesses or disabilities.

Current funding arrangements for ancillary professional services such as physiotherapy could perhaps be reviewed based on empirical research of the effectiveness of such therapy in multiple sclerosis. Persons in this study perceived physiotherapy interventions to be beneficial, but access was limited by cost, which they would have had to bear themselves.

There is potential for diffusion of any innovations or improvements resulting from such a revised program to other areas of healthcare in chronic illness as proposed by Rogers (2004).
Epilogue

As I reflect on the stories that have been entrusted to me by participants in this research study, I must ask the following important questions: How have I, as the researcher/listener impacted the telling of these stories and how have they affected me as a person? I needed to be alert to the possibility of bias in myself as I listened with some admiration to very articulate, courageous and positive storytellers, and with somewhat less empathy to those who spoke haltingly in depressed and monotonous tones about their situation, embracing a ‘victim’ role. Examination of these considerable dilemmas required time, extensive reading and reflection. I did not want to change the essence of any of the stories, nor in any way to underestimate the enormity of the problems participants faced. The daunting task of presenting a snapshot of the lived experience of 12 spousal dyads dealing with an ever-present intruder or ‘Uninvited Guest’ (MS) in their lives was difficult.

The schema of a tiered analysis helped somewhat, but I was ever-conscious of the important and valuable data lost in the process of data reduction. Each time I read the interview transcriptions I vividly recalled the interview and certain inflections of voice, and nuances of speech that are impossible to capture in the written word. I could not address all themes in detail and needed to highlight those that offered new insights into the lived experience, as well as those that I did not find were covered extensively in the recent literature.

Why did these particular people choose to tell me their story? When I remarked to a person I knew who had MS (but who had elected not to participate in the study) that I was overwhelmed by the response to my call for participants, saying I thought there were many persons interested in the subject of the impact of MS on caring relationships, she responded: “Yes, there are a lot of ‘desperate’ people out there” (personal communication 2002). This comment caused me to reflect again on the responsibility that I had undertaken with this research. What expectations did they have of me and could I come close to meeting them? What did my friend mean with her response to my statement? Was she telling me that people with MS have tried many different avenues seeking help
with their illness to no avail and that possibly they saw research studies as a source of hope? What exactly was I trying to accomplish anyway?

I experienced a certain level of anxiety before every interview, wondering what lay before me. How would they accept me? What impressions did they have of me from survey and telephone contacts? In each case, however, I was received warmly and all participants appeared to welcome the opportunity to tell their story. A few recognized that I was nervous and made attempts to make me feel comfortable. I also noted some discomfort in them at first, and was relieved when this soon eased and they started telling me of their own unique encounter with MS in the context of their relationship. I was received as an honoured guest and offered hospitality on arrival. Only one couple postponed our appointment and this was due to illness. For several, it was difficult to find a time when both Carepartners could be home at the same time, but every effort was made to find a time suitable to us all. In one case we had to meet on a Sunday as this was the only time their work commitments would allow.

Some asked me why I had an interest in MS and why I was undertaking the study. I answered their questions briefly and honestly, but did not disclose my family connection with MS unless asked. This disclosure may or may not have influenced their level of openness. However, their question usually came late in the interview or afterwards and probably did not affect the taped comments.

My very first interview was a pilot interview in the early stages of the study. This interview was extremely moving for me, as it represented a family whose situation duplicated my own, but whose son was farther along the MS trajectory and far more disabled at the time than my own family member. With some sense of shock I asked myself: “Am I looking at my own situation in the near future”? This family had asked to be interviewed and we had been in email contact for several months after they completed their surveys. I was in the process of developing my interview guide. Perhaps I could test it with this family. It happened that I was attending a research conference in a city near them the weekend before our meeting. I stayed over an extra day to travel by train to their suburban station, where the couple met me and welcomed me warmly.
The situation on arrival was far from ideal for an interview as my tape recorder was in the back of their car in my briefcase and they started their story eagerly almost as soon as we met. I had to rely on memory for some of the initial details. We spent the day together and I was allowed to conduct interviews with both parents and with their son who had MS as well as with one of his paid carers, who helped to interpret his speech, which was severely impaired. The family remained in contact for several years, giving me updates on their situation and expressing appreciation for my support and encouragement when we met. Although they have not been included in the interview sub-sample, they helped me to refine the interview guide and they have provided me with motivation to continue the study even when my own health problems have seemed overwhelming and I have been tempted to abandon it (See Appendix C.1 and C.2).

Some of the issues encountered by this family in seeking healthcare and resources for their only son have been duplicated in the study sample, and have reinforced the needs for change in many aspects of health care policy, in the need for continuing education of health professionals and improved access to resources for chronically ill young people in the community. This couple suffered rejection and humiliation as they sought the care needed to keep their son living independently as he ardently desired. They showed remarkable courage and resourcefulness in the face of refusals, rebuffs and even bullying from persons and agencies they approached for help. They said they were treated as ‘criminals’ when they inadvertently ‘broke the rules set down by the healthcare system’ in their quest for help.

Interviews with this family were possibly more revealing than those of the study sample since I was able to spend a full day with them, absorbing more than one could in any brief one hour interview.

Reflecting on this encounter makes me realize all too clearly the inadequacies of the one-off interview and how the picture obtained is only a fraction of the true story. People would respond to the invitation to ‘tell their unique story of life with MS’ in the light of their most pressing problems at the time of asking, which might be very different at a different time. Their most dramatic recent problems or memories would probably surface at interview. From my own experience visiting people in their own homes, I know that people will protect themselves from disclosure of sensitive matters until such time as they
feel ‘safe’ with the interviewer. In the meantime, these issues may be altered, coloured or denied to protect the teller. It is problematic to know whether any person can fully understand the innermost thoughts of another, and misconceptions are likely to arise in the interpretation of any story. Frank (2004), speaking at a Melbourne Conference on ‘story telling’, reminds us that every story changes each time it is told. I asked myself how many times each of my interviewees had told their story, and what they had said to others? What had influenced their story the day they told it to me, and what were they hoping to achieve by telling it? These questions can not be answered and one can only speculate.

I can see a paradoxical dilemma that is uncovered by my study. There are the intricacies of ‘storying’ and ‘restorying’, as argued by Frank (2005) which raise the question of how we can be sure that the stories we are using in our research reflect the ‘truth’ of the participants’ experiences and how valid it can be for researchers and readers to draw conclusions about them since they can change in the next telling? It is beyond the scope of this study to deal with all the nuances of narratives and their veracities.

Another question arises for me as I ask how research that is based on such interviews can be considered empirically correct and ethically appropriate? These questions complicate any efforts to tie up ‘loose ends’ in this study and to identify clearly any contributions to new or expanded knowledge on the subject of the impact of MS on caring spousal relationships and the role that reciprocity plays in marital and life satisfaction. Working with narratives is a complex issue involving many variables. My main aim and purpose has been to explore and communicate ideas that might bridge the chasm that exists between academic writing and the practitioners who are seeking to understand and implement ideas emerging from research when dealing on a day to day basis with the human condition. Specifically, in this section, I would like to speak in plain English to all those professionals working with families who are dealing with the difficulties and complexities of living with MS. I would like to encourage health professionals to consider sharing their experiences and even undertaking research studies based on the rich goldmine of experience in their fields of endeavour. It is my sincere hope that what I have written may inspire others to continue work on the suggestions made to enhance the current level of services and support available to people with MS, their carepartners and families impacted by MS.
How did they see me in the scheme of things? Did they see me perhaps as someone who was making an effort to understand their struggles and eventually to help make some changes that may benefit their situation. Was I just a ‘sympathetic ear’, or a ‘sounding board’ to receive all their complaints and frustrations, or perhaps, hearing their own stories, find some solutions to their dilemmas? Some did ask me why I was conducting the study and what I hoped to accomplish, while adding that they had participated in many research studies and nothing seemed to change.

I was aware of the difficulty that any person has to fully understand the deepest thoughts of another, and can only hope that the glimpse I have caught of their reality may be sufficient to highlight areas of concern where change may be implemented to enhance the reciprocal caring relationship and lessen the negative impact which MS may have upon it.

I learned much from participants in the study. There were lessons to be learned in patience, resilience, tolerance, courage, determination, positive and negative lifestyle choices, optimism and the appreciation by many of what they could do rather than what they no longer were able to do. Many had the ability to find humour in the most challenging situations. Reciprocity came to life for me as a valuable construct in caring relationships as expressed and viewed by the participants with terms such as ‘friendship’, ‘partnership’ ‘enjoying being together and doing things together’, finding qualities in their partner such as being forgiving and understanding when times were difficult. When these mutual signs of appreciation were not present, couples were observed to have low mood and an air of chronic sorrow as described by Hainsworth, in his many cited works.

A need for empathic and ongoing support from family, friends and timely professional assistance when needed was evident throughout the process of data collection and analysis. Further work is needed in improving existing programs to meet the changing needs of Carepartners in MS and their families. Developing the profile for a ‘key contact person’, who can be the person to turn to in time of need for every person diagnosed with MS would add valuable support and timely access to resources for all PwMS.

I was totally surprised and humbled by the warm welcome I received and the sense of appreciation that was expressed by all persons I interviewed. It seemed incredible to them that someone would travel to their homes and spend time hearing their own unique
stories. Several wrote me notes of appreciation after my visit. It seemed obvious that they welcomed the interest expressed in their difficult situations, and presumably they would welcome an occasional visit or supportive telephone call from a caring and interested person. I found many people with MS residing in country or regional areas that were aging or losing mobility and were often unable to attend group sessions offered by MS Metropolitan or Regional Centres. They felt even more isolated and abandoned than their city and suburban counterparts.

Why were all the participants in the sub-sample so negative about their experiences with the health care system? Did their past experiences somehow influence their wish to tell their tale and be heard? I was aware of some underlying conflict in some spousal relationships, evidenced by differing versions of the same event, differing perceptions of some of their symptoms, as well as differing role expectations between the spouses. This particular group of participants did not mention the positive experiences they must have encountered with caring and helpful healthcare professionals and this is regrettable as I know these persons are in the majority. I have met devoted carers who support their clients with competence and good humour, and health care professionals who fill the role of the ‘key contact person’ or ‘person to turn to in time of need’ without regard to the rewards they might receive. I saw my task as an opportunity to report what I heard, saw and read in the survey responses and stories of couples experiencing the many challenges of life with MS that they often viewed as an intruder in their well-planned and ordered life goals.

While we need to continue every effort to discover a cure and a cause for multiple sclerosis, we must not forget the large number of people needing our care and support as they cope with MS. Together we can make a difference.
Appendix A:
Letters, Forms and Survey Questionnaire
A.1. LETTER TO PERSONS WITH MS AND THEIR CARERS

The University of Melbourne
April, 2002

To Persons with MS and their main Carers:

I am a PhD student at the University of Melbourne. I am very interested in how people with MS and their main carers cope with the day-to-day challenges of MS in their lives and relationships. I believe this study is very important and will help health care professionals and agencies working with people affected by MS, to better understand their needs, concerns and coping skills. As a result, we may be able to develop strategies that will improve the level of wellness and quality of life of all people affected by MS.

As the principal researcher, I am looking for volunteers to participate in this project. Participants will be asked to complete a questionnaire and express willingness to be interviewed about their life experiences with MS. The questionnaire should only take 30-40 minutes of your time, and I would ask you to return it to me within two weeks in the self-addressed, post-paid envelope provided. This letter is being widely circulated and may include persons who are registered at the MSSV, or who have seen advertisements for volunteers to participate in this study. Many persons with MS will receive this request.

Following this stage, a smaller group will be selected to participate in a face-to-face interview to explore in greater depth, the participants' views of living with MS and the issues of the give and take between the person with MS and the main carer. Each person will be interviewed separately. The interview will take approximately one hour for each person. The Consent Form included in the packet must be signed. There is also a card that asks you to indicate whether you consent to interview. If you do not wish to be interviewed, no further contact will be made with you by the researcher. Whether you choose to be interviewed or not, please return all questionnaires and consent forms in the envelope provided.

The questionnaire asks some questions about your situation, and is followed by a series of statements that have been made by many people in similar circumstances to yours. You are asked to indicate whether you agree or disagree with these statements. Your name is not needed, nor will names appear either in the results or in any publication that may result from the study unless you specifically allow it. Your signed consent form will be filed separately (in a locked cabinet) from the questionnaires. Confidentiality is assured within the limits of the law. The numbers that appear on your forms are for coding purposes only and for follow-up of persons who do not respond. You may, of course, choose not to participate. If you agree to be interviewed, your name will be disguised and the original data will be destroyed once the information has been analyzed. You may withdraw from the study at any time and you may withdraw any unprocessed information.

I hope you will take the opportunity to answer the questionnaire and return it to me within two weeks of receipt. You will be contributing greatly to our knowledge of the effects of this condition on people with MS and their main carers. If you have any questions about the study, please contact me at (03) 9816-8080, or e-mail hhiz123@amgateway.net. You may also call Dr. Elizabeth Ozanne at (03) 8344-9403 or the Executive Officer of the Human Ethics Committee, University of Melbourne at the number listed on your Plan Language Statement which describes the study in some detail.

Thank you once again, for your time and cooperation,
Sincerely yours,

Beatrice H. Zulagia
P.O.Box 4062, Balwyn East Licensed Post Office
387 Belmore Rd.
Balwyn East, Victoria 3103
Plain Language Statement Describing the Study

Project Title: "Impact of Multiple Sclerosis on Committed Caring Relationships"

My name is Beatrice Zulnaga. I am a postgraduate student in the School of Social Work at the University of Melbourne, completing requirements for the degree of Doctor of Philosophy. My research project is under the supervision of Dr. Elizabeth Oanae and Dr. Phillip Swain.

The purpose of the study is to obtain information from persons with multiple sclerosis (MS) and their main carers about their perceived basic needs and life experiences while coping with the challenges presented by MS. I believe that this study will give a greater depth of understanding of caring relationships to health professionals and agencies who may then be able to offer improved education, support and services to persons with MS, their carers and families.

Persons with MS, who volunteer to participate in the study, and their designated main carer will receive separate letters and questionnaire packets of different colours. Although the content of these is the same, you are asked to complete the questions and answer the statements separately and post the signed consent form and completed questionnaires back to me separately in the post-paid envelopes provided.

Since some of the questions and statements may ask for sensitive information, it will be your choice to share or not to share your responses with your partner. Whatever your decision, your responses will remain confidential.

Please cross out the statement that does not apply

1. I wish all my responses to remain confidential between the researcher and myself
2. I am prepared to share my responses with my partner.

In exploring caring relationships, I need the help of a large number of persons who are facing MS and its challenges and who are willing to complete the questionnaire that I have prepared. I would also ask that you read, sign and return the form indicating whether or not you would be willing to be interviewed later. The questionnaire will take no more than 30-40 minutes of your time and the interview should take approximately 1 hour. For the purpose of this study, I am interested in hearing from persons who are in a committed caring relationship, where one person in the relationship has been diagnosed with MS.

(please turn over)
The study is planned in 2 stages. The first stage involves:

1. reading, signing and returning the consent form indicating your willingness to participate in the study,

2. reading and completing the questionnaire which asks a few questions about yourself and your situation, and indicating whether you agree or disagree with the statements made,

3. returning the documents in the post-paid envelope provided as soon as possible (within 2 weeks). There will be a follow-up phone call in 4 weeks if a response has not been received. If your decision is not to participate in the study, the researcher will make no further contact with you. If you decide not to participate, please return all forms anyway in the envelope provided.

4. A form is enclosed in the packet. Please read it, fill it out, sign and return it if you are willing to be interviewed at a later date. Twelve PwMS and their main carers will be selected from these signed forms. I will ring to arrange a suitable time and place for the interview.

The second stage of the study consists of an interview which may take an hour or so for each person. If you consent to interview, I would like to tape-record our conversation to ensure accuracy. A copy of the transcript will be made available to you for review if you would like it. The tape will then be erased and your name disguised in the transcription. No names will be used either in reporting the results, or in any publication that may result from the study. If you become tired or distressed while responding to questionnaires or at interview, you may stop the activity or terminate the interview. You may choose to withdraw from the study at any time. Should you require it, professional counseling can be arranged. You may keep this Plain Language Statement which describes the study and gives contact numbers if you have any questions or concerns.

I look forward to your active participation in this study. Thank you for your time and interest. If you have any questions or concerns, please feel free to contact me at (03) 9816-8680, or by e-mail at bhz125@unimelb.edu.au. Alternatively, you may contact Dr. Elizabeth Ozanne at (03) 8344-9483 or ring or fax the Executive Officer, Human Ethics Committee, University of Melbourne, at (03) 8344-7377, fax 9347-6379.

Sincerely,

Beatrice H. Zuluaga  
Principal Researcher

Dr. Elizabeth Ozanne  
Co-ordinator Research and Graduate Studies  
School of Social Work, University of Melbourne
A.3. CONSENT FORM FOR PERSONS PARTICIPATING IN RESEARCH PROJECT

Consent form for persons participating in Research Project

PROJECT TITLE: “Impact of Multiple Sclerosis on Committed Caring Relationships”

NAME OF PARTICIPANT: (Please print) ________________________________

NAMES OF INVESTIGATORS: Beatrice H. Zulunga
Dr. Elizabeth Ozanne

1 I consent to participate in the project named above, the particulars of which have been explained to me. A written copy of the information has been given to me to keep (Plain Language Statement).

2 I authorize the researcher to use information I may give in the written questionnaire or interview and I understand that my name will not be used at any time in the results.

3 I acknowledge that:

(a) The possible effects of responding to the questionnaire have been explained to me, namely, that I may become fatigued or suffer some minor emotional discomfort from the questions/statements. I may also become tired if the interview is prolonged.

(b) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice, and I may withdraw any unprocessed data I have supplied. I may also elect to stop and resume the activity of responding to questionnaires or interview if I so desire. I may seek counseling or support from a professional if I request it.

(c) The project is for the purpose of research: to gain greater understanding of the lived experience of persons with MS and their main carers and to explore the give and take in the relationship of care giver and care recipient.

(please turn over)
(d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements.

Please cross out whichever statement does not apply in 4 & 5 below

4. I consent (do not consent) to being selected for interview by the researcher.

5. I consent (do not consent) to the researcher using a tape-recording device to record our conversation for the purpose of increased accuracy. A copy of the transcript will be offered me for review and verification if I request it.

My name will not be used in the transcription, or in any reference to the results in any publication arising from the research.

Signature of participant__________________________ Date:__________

Signature of Witness_____________________________ Date__________

Note: This consent form will be separated from your completed questionnaires and will be filed in a locked cabinet at the University of Melbourne to protect your anonymity.
A.4. CONSENT TO INTERVIEW

CONSENT TO INTERVIEW

Name (please print)_________________________________________

Address _____________________________________________

Telephone number or email address __________________________

1. I have completed the signed consent form and questionnaires sent to me in regard to Beatrice Zalnaga’s research study. I am willing to be interviewed by this researcher at a later date, if selected. I am returning this signed card together with the above forms in the post-paid envelope provided. Please contact me to arrange a suitable time and place for the interview.

2. English is not my native language. I am not comfortable speaking English fluently. Please contact me about arranging for an interpreter to be present if I am selected for interview. (Cross out this paragraph if it does not apply.)

3. Please cross out the statement that does not apply.

(a) I wish all my responses to remain confidential between the researcher and myself.

(b) I am prepared to share my responses with my partner.

Name: please print _______________________________________

(Signature) ___________________________ Date __________
A study of the impact of multiple sclerosis on committed caring relationships

Gold folder - Questionnaire and scales for people with multiple sclerosis

Please complete this questionnaire and return in the post-paid envelope provided to the researcher, who is a PhD student at the University of Melbourne:

Beatrice H. Zuluaga,
Balwyn East Licensed Post Office
387 Belmore Road,
Balwyn East, Victoria, 3103

Please return all forms even if you choose not to participate in this study. Thank you.

Survey I.D. number

____
Demographic questionnaire

Questionnaires are to be completed separately by each person. Please fill in the blanks and place a tick in the appropriate boxes. (√)

1. Are you
   - Male □
   - Female □

2. What age bracket are you in?
   - 10 or under □
   - 11-20 □
   - 21-30 □
   - 31-40 □
   - 41-50 □
   - 51-60 □
   - 61 or over □

3. Where were you born? ____________________ (country).

4. How long have you lived in Victoria? ____________ (years).

5. Which suburb, city or town do you live in? ________________.

6. Where you currently live, are you
   - The owner □
   - The buyer □
   - Renting □
   - Boarding □
   - Other □

7. What is your highest level of education?
   - Primary □
   - Secondary □
   - Trade or TAFE □
   - Tertiary □
   - Post-graduate degree □

8. Are you
   - Married (or in a permanent relationship) □
   - Divorced □
   - Separated □
   - Widowed □
   - Never married (single) □

9. Do you live
   - alone □
   - with partner/spouse □
   - with other family members □
   - with others/not family □

1
10. Do you have a dependent child or children living with you?
   Yes  ☐
   No  ☐

11. If yes, please list the age and gender of each. __________________________

12. Are you the principal income provider for your family?
   Yes  ☐
   No  ☐

13. Do you consider that your current income from all sources is:
   ☐ satisfactory to meet my needs (my family’s needs)
   ☐ barely enough to meet our needs
   ☐ not enough to meet my/our needs.

14. Employment. Are you employed at present?
   ☐ full time outside the home  ☐ full time at home  ☐ No, I am unemployed  ☐
   ☐ part-time, outside the home  ☐ part-time at home  ☐ I am retired  ☐
   ☐ I am disabled/unable to work

15. What type of work do you do? (did you do)?
   ☐ Home duties
   ☐ Clerical
   ☐ Unskilled labor
   ☐ Skilled tradesperson
   ☐ Professional (please specify) ☐

16. Do you require regular assistance from persons who are not family members?
   Yes  ☐
   No  ☐

17. Do you use any community services?
   Yes  ☐
   No  ☐

18. If yes, please list the ones you use. ________________________________________
19. Mobility/Access. Are you able to go where you need or want to go?

- I drive my own car □
- Family members or friends drive me □
- I use public transport – bus/tram/train/taxi □
- I cannot go anywhere without considerable assistance. □

20. How often are you home on your own?

- Seldom, or never □
- Several times a week □
- Most of the day, every day □

21. Last week, how often did you go out of your home? ________ times.

22. Where did you go? (tick all that apply)

- Shopping □
- To the doctor/ dentist/ therapist/ other health care professional □
- To church or a social event □
- Visiting family or friends □
- Day activity center □
- Concert/ sporting event □
- Other □

23. What are your favourite activities or hobbies? __________________________

24. How would you describe your overall health?

- Excellent □
- Very good □
- Good □
- Fair □
- Poor □

25. Are you a

- Person who has been diagnosed with multiple sclerosis □
- Carer/Partner/ spouse/significant other of a person with MS □
- Son/ Daughter/ Parent/ Friend of a person with multiple sclerosis □
If you are a person who has been diagnosed with MS, continue on to questions 26 & 27. If you do not have MS, please skip questions 26 & 27, and follow directions at bottom of page. Thank you.

26. How long have you been diagnosed with MS?
   less than one year □
   one to five years □
   five to ten years □
   10 – 15 years □
   over 15 years □

27. Have you been diagnosed with any other diseases such as diabetes, rheumatoid arthritis, lupus, or other diseases for which you are now being treated?
   Yes □
   No □
If yes, please list them. __________________________________________

Thank you for completing this demographic questionnaire. Now, please continue to the next pages which consist of a series of statements that people in similar situations to yours have made. You are asked to indicate whether you agree or disagree with them.

Please follow directions for each set of statements. Your assistance in helping with this research project is very much appreciated.
Following are a few statements about your feelings during the past week.

Using the scale below, indicate the number which best describes how often you felt or behaved this way DURING THE PAST WEEK.

0 = Rarely, or none of the time (less than 1 day)
1 = Some, or a little of the time (1-2 days)
2 = Occasionally, or a moderate amount of time (3-4 days)
3 = Most of the time (5-7 days)

DURING THE PAST WEEK:

1. I was bothered by things that usually don’t bother me.
2. I did not feel like eating. My appetite was poor.
3. I could not shake off the blues, even with help from my family or friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get “going”.
Caregiver Reciprocity Scale II

Many of the statements below come from interviews with other individuals participating in caring relationships. There are no right or wrong answers. Your responses will remain confidential. Please read the following statements and place a tick in the box that represents how you feel.

<table>
<thead>
<tr>
<th></th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>UNDECIDED</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My partner and I have stuck together through thick and thin.</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>My partner gives me undesirable advice.</td>
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<tr>
<td>3</td>
<td>My partner lets me know he/she loves me.</td>
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<tr>
<td>4</td>
<td>I don’t mind giving money to the person I care for if needed.</td>
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<tr>
<td>5</td>
<td>Family members often come to each others’ rescue.</td>
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<td></td>
<td></td>
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<tr>
<td>6</td>
<td>My partner appreciates me.</td>
<td></td>
<td></td>
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<tr>
<td>7</td>
<td>Sharing back and forth with the person I care for is important to me.</td>
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<tr>
<td>8</td>
<td>The person I care for accepts me.</td>
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<tr>
<td>9</td>
<td>I feel gratified by meeting others' needs</td>
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<tr>
<td>10</td>
<td>The person I care for has a way of making me feel bad.</td>
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<tr>
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<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>UNDECIDED</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.</td>
<td>Members of my family appreciate each other.</td>
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<tr>
<td>12.</td>
<td>I spend time with the person I care for when I don't really want to.</td>
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<tr>
<td>13.</td>
<td>The person I care for respects my privacy.</td>
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<tr>
<td>14.</td>
<td>I often get frustrated with my partner.</td>
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<tr>
<td>15.</td>
<td>The person I care for demands too much of my time.</td>
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<td></td>
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<tr>
<td>16.</td>
<td>I am willing to do all that I can for my partner.</td>
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<tr>
<td>17.</td>
<td>I enjoy being able to arrange a special treat for my partner.</td>
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<tr>
<td>18.</td>
<td>My care partner takes me for granted.</td>
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<td>19.</td>
<td>Responsibilities for my care partner are shared in a fair manner among family members.</td>
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</table>

7.
Life Satisfaction (LSI-Z)

Here are some statements about life in general that people feel differently about. Please read each statement in the list and place a tick in the column indicating that you either agree (A) or disagree (D), with the statement. If you are not sure, place a tick in the third column under Not sure (?).

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>As I grow older, things seem to be better than I thought they would be.</td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
<td>I have had more of the things I wanted in life than most people I know.</td>
<td></td>
<td></td>
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<tr>
<td>3.</td>
<td>This is the dreariest time of my life</td>
<td></td>
<td></td>
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<tr>
<td>4.</td>
<td>I am just as happy as when I was younger</td>
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<tr>
<td>5.</td>
<td>These are the best years of my life</td>
<td></td>
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<tr>
<td>6.</td>
<td>Most of the things I do are boring and monotonous</td>
<td></td>
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<tr>
<td>7.</td>
<td>The things I do are as interesting to me as they ever were</td>
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<tr>
<td>8.</td>
<td>As I look back on my life I am fairly well satisfied</td>
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<tr>
<td>9.</td>
<td>I have made plans for things I'll be doing a month or a year from now</td>
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<tr>
<td>10.</td>
<td>When I look back on my life, I did not get most of the things I wanted</td>
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<tr>
<td>11.</td>
<td>Compared to other people, I get down in the dumps too often</td>
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<tr>
<td>12.</td>
<td>I have had pretty much what I expected out of life</td>
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<tr>
<td>13.</td>
<td>In spite of what people say, the lot of the average person is getting worse, not better</td>
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</tbody>
</table>
Functional Wellness Inventory (FWI) – Perception of Basic Needs

The following statements relate to your satisfaction with your basic human needs. Please read the statement and place a tick in the column which indicates whether you agree or disagree with the statement. There are no right or wrong answers. I am interested in how you feel about the statement.

<table>
<thead>
<tr>
<th>1. I make clear and logical decisions</th>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. I care for myself without assistance.</td>
<td></td>
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<tr>
<td>3. I take good care of my health without anyone suggesting it to me</td>
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<td>4. I eat a well-balanced diet, using a variety of foods.</td>
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<td>5. I have someone with whom I can discuss my innermost thoughts and feelings.</td>
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<td>6. I have people I can depend on when I need help.</td>
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<td>7. My activities are limited by my disease or disability.</td>
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<td>8. I think about death.</td>
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<td>10. My life has little purpose any more.</td>
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<td>11. Each day I engage in physical exercise.</td>
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<td>12. I feel rested and refreshed upon awakening.</td>
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<tr>
<td>13. I am satisfied with my living arrangements.</td>
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<td>14. I am unable to buy the foods I should eat.</td>
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<td>Always</td>
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<td>15. My income is sufficient to cover my expenses</td>
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<td>16. I have sexual concerns</td>
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<td>17. I find it difficult to give and receive love</td>
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<td>18. I feel down, sad or blue a lot of the time</td>
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<td>19. My personal relationships are satisfactory</td>
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<td>20. I worry about everyday problems</td>
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<td>21. At times, my problems seem overwhelming</td>
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<td>22. I feel safe in my home and community</td>
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<td>23. I have access to transport that is adequate for my needs</td>
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<td>24. My hearing, vision and speech are satisfactory for my communication needs.</td>
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<td>25. I have access to a telephone when I need it.</td>
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<td>26. I wish I could learn a new skill or hobby</td>
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<td>27. I have enough knowledge to take care of my health needs</td>
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<td>28. I wish I could help someone else</td>
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<td>29. I control the amount of stress in my life</td>
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Now, please complete the following statements very briefly:

1. I could be a lot healthier and happier if ____________________________
   ____________________________
   ____________________________

2. If I could afford it, I would ____________________________
   ____________________________
   ____________________________

3. I believe my greatest strengths are ____________________________
   ____________________________
   ____________________________

4. The happiest time of my life was/is ____________________________
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   ____________________________
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II.
Thank you for completing this questionnaire. Your help is very valuable and may help me understand your perceived needs and the needs of others who are in similar situations to yours. Your answers remain confidential.

Please return the questionnaire and consent forms as soon as possible. You may keep the Plain Language Statement describing the study.

12.
Appendix B:
Interview Guide
INTERVIEW GUIDE

Interview Guide

1. My presence at the home of the participants assumes I have received a completed survey together with a signed consent form for participation in the study and the interview using a tape recording device. Receipt of the completed survey also assumes I have some baseline demographic data and scores obtained by participants on the various measurement scales used in the study, which I may refer to as appropriate during or after the interview with each individual. Since interviews took place 10-18 months after completion of the surveys, it was necessary to review the basic purpose of the study. Many participants said they had taken part in several studies in the interim, and they appreciated the brief review to remind them of the substance of my study. The general review of areas of interest then allowed me to ask one basic question of each participant, leaving the interview as open-ended as possible, enabling me to explore the unique experience each person perceived of day to day living with the challenge of multiple sclerosis and its impact on spousal and family relationships. Following is the brief outline I read to each dyad together and before starting the individual interviews. A few questions are included that were asked in some cases if their spontaneous story did not address these issues.

2. Good morning/afternoon................Thank you for participating in my research study and for returning the completed survey forms I sent you some time ago. The response has been much larger than I expected and analysis of the survey data has taken longer than anticipated. Would you like me to go over the purpose of the study or re-read the informative letter I sent you? If not, are there any questions you would like to ask me about the study? I believe this study is very important for everyone involved in any way with multiple sclerosis, and I value your experiences, feelings and any insights that you have obtained from the daily challenges presented by MS in your lives over the years. As you may recall from the information I sent to you, the study explores the impact of MS on caring relationships, and hopes to learn about coping strategies that people with MS and their carers have found effective. The interview should not take more than one hour of your time. However, if there are questions that come to me after I transcribe the interview, may I ring you to ask about these? Please remember that you may choose not to reply to any questions I may ask and you may withdraw from the study at any time.

3. “I am very interested to hear each unique story and I would prefer to interview each of you separately. Is there a quiet place where we may chat without interruptions? Are you still happy to have me tape-record our conversation to ensure accuracy? Your comments remain confidential and your name will not be used anywhere in the study”. 

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Possible prompts included:
- Please tell me how you felt when you first heard that you of your partner had multiple sclerosis?
- Did you have any idea of what lay before you?
- When did you become aware of the seriousness of the situation?
- Was there anything you did to change where you looked at life differently?
- Were you in a committed relationship before MS came into your life? Did anything change after the diagnosis? Can you tell me about it?
- You must have had many dreams and plans for the future you shared. How have these been affected?
- What has been the hardest change for you to cope with?
- What aspects of your relationship have remained the same?
- What aspects have made you feel good about your role?
- Could you comment on your sense of purpose in life?
- How do you view MS—Friend or Foe?
- Have you discovered strengths in yourself you did not know you had before the challenge of MS arrived?
- How would you regard your relationship with . . . (partner)? Would you say it could be a "partnership"?
- Can you tell me more about the change from care giver or care recipient?
- When you look at your life today, do you see any basic needs that could be filled to make your life better?
- What do you consider your greatest losses?
- Discuss respite availability for you—costs, etc.
- Where do you go or who do you turn to when you need information or help with MS-related issues for yourself or your family? Has this been satisfactory for you?

4. Closing: At about the 35-45 minute point and to allow any issues to emerge that are important to the participant, I asked "Is there anything else that you would like to talk about? If you have any further comments or questions, please feel free to contact me by telephone or email.

5. Thank you once again for sharing your unique story with me and for taking your valuable time to participate in this research study. BHZ 2003
Appendix C:
Pilot Interviews
First Pilot Interviews 30 July 2002. Queensland—Background and first impressions

I had been in email contact with G. ever since she contacted me offering to participate in the study. She, her husband and her son completed surveys and returned them in a timely fashion, giving their consent to interview. I don’t know who helped the son, and this may be significant on analysis. I realized after meeting him that he was obviously unable to physically do this himself. On Friday, the last day of a research Conference I was attending, and after returning from dinner with my colleagues, there was a message for me at my hotel from G., wanting to confirm arrangements for our meeting on Saturday. I rang her and we agreed to meet at the H. station at 10.20 am. She asked me how they would know who I was, and I said, ‘well, there is snow on the top’. She laughed and said – ‘here too?’ ‘We are an older couple, rather frail. Never mind, we’ll find you.’ She and F., her husband, welcomed me warmly when I arrived at the station. They seemed genuinely glad to see me and said later that they did not know why I would want to talk to them. F. and G. were not what I would describe as “frail”, although F. (70), walked with a limp. G., in her 60’s, appeared to be very fit, although anxious and tired. She told me later that she did water aerobics several times a week, and taught computers to a group of seniors. She impressed me as having a strong and determined personality and would be willing to do anything that she could to help her son, who was severely disabled with MS.

Her husband seemed very supportive, and had a twinkle in his eye and a gentle sense of humor. He suggested G. sit in the back with me so “that we could chat”. This was fine except I had my tape recorder in the briefcase in the boot! ‘Oh, memory, help me out!’ Her story, as closely as I can recall it will follow. I added to the story as recollections flashed back. This was not the ideal way to do an interview, I know, but I did jot down a few field notes as I went along and I depended on these to fill in the many gaps. It was a good learning experience for me– ‘always have your tape recorder at hand when interviewing’.

G. was born in Q. and she had primary school education. She seemed rather conscious of this as the meeting progressed, and although she was a very confident and articulate speaker, she seemed to have a feeling of inferiority about her ability to express herself when dealing with persons in authority in the health and welfare system. She told me of several incidents which indicated she has a strong and determined personality when it came to getting needed benefits for her son. She asked me if I had been to “X” (A long-term care facility for people with advanced MS?) I had never heard of it, of course. I asked her how she felt about it and she simply said “It’s awful”. I asked if there was no other suitable facility near her and she said no – ‘the only other option is a nursing home and that is out of the question’.

F. was born in Victoria and the couple was married in Vic, later moving to Q., where they have lived for many years. They had their own small business and were doing quite well, looking forward to a comfortable retirement on the Gold Coast. Their only son attended an expensive school and moved on to QIT to study Engineering after he completed his secondary schooling. He lived with “his mates” and reportedly had a lifestyle typical of young university students. He also sang in a band and had many
friends. He "drank a lot" (according to his mother) and generally led a lifestyle incompatible with his parents. At the age of 22, he reported some numbness in one leg, followed by loss of vision in one eye. Medical tests were done and a diagnosis of 'transverse myelitis' was given. He was treated with steroids and improved for a time.

However, his condition worsened steadily and after many tests, he was diagnosed with Progressive multiple sclerosis. He was no longer able to live with 'his mates'. At one stage, the parents converted a boat shed into an apartment for him, where he lived for two or three years and they cared for him. Meanwhile, and unknown to his parents, he had applied for a housing commission unit, suitable for a disabled person. His disability followed a steadily progressive course, and P went from walker to wheelchair to electric wheelchair, gradually losing the ability to walk, to control bladder or bowel, and later, to swallow or speak properly. He had minimal use of one hand and could only lift it to wave. Despite his significant speech difficulties, he maintained a keen sense of humour. His parents and one of his carers were able to understand his speech. He was, however, able to spell out words if necessary. At interview I observed he was being fed through a 'gastrostomy tube' inserted directly into his stomach. He had an electric hoist to get him in and out of bed and onto the toilet and he could not be left alone and required 24 hour carers. His parents organized the care arrangements and covered the weekend hours themselves.

I was aware of some tension between mother and son. She told me they received a letter saying he had been assigned a housing commission unit (after several years wait), and P accepted it with alacrity. She said, "I never would have allowed him to move in, but it was out of my hands – he was just too sick". It meant that G. had to arrange and organize all the support services he would need to maintain him in his own unit. She reported that it was a battle every step of the way to "get the hours" of help that he needed. Her stories of humiliation and bureaucratic rigidity would have been enough to deter a less determined person from pursuing her son’s needs for the services he required to maintain his independence. She was told to quit her job and move in with him to take care of him. This was not an option. The couple did retire earlier than they had planned (5 years before our meeting), when F. was diagnosed with lymphoma and underwent surgery, chemo and radiation. He is now in remission, (and describes himself as "one of the lucky ones") but has peripheral neuropathy with loss of feeling in his feet and hands; loss of fine motor coordination in the hands and a marked limp. G. went on to tell me that she had tried and tried to get the service hours of help for her son and had met with numerous people, only to be refused again and again. The stories continued of endless struggles "with the bureaucracy".

Finally, she went to her political representative and within days had obtained the first 10 hours of help. I am not sure how all this works in the health care system, or whether it differs from State to State, but it appeared to me that no family should have to undergo such a struggle to get much needed help for a disabled son. When I asked if they received any nursing care, G. hesitated, for here was the story of yet another battle. Apparently, they had been receiving help from 2 agencies at the same time, with G. saying she did not know this was against the law. The ensuing altercation was very traumatic for both parents, and she said they felt 'like criminals'. Both agencies threatened to pull out, believing they had been used unfairly. Eventually, and after much negotiation, G. was able to convince one agency to continue their services. They were persuaded to come twice a week to do bowel care. Another agency
provided carers doing shifts round the clock, but the parents were responsible for a large share of the cost. In addition, the agency insisted the couple fill the weekend overnight shifts, which they did for a long time without a break. When I asked how much wakefulness the night shift involved, G. said, "Some nights, he snores peacefully all night, but other nights he is wakeful and restless. The tube feeding runs all night and this needs to be monitored." G. reported that for the past two nights he had been trying to cough and that his secretions were very tenacious and thick. There was no suction in the unit – they were not allowed to have it because no one was trained in its use and this was considered dangerous in the wrong hands.

G was worried that P might develop pneumonia since he could not cough up his secretions. She said his temperature had also been slightly elevated, which was another concern for her. She was in the process of trying to decide whether to ring the doctor (weekend) in case antibiotics were indicated. She did ring later and the only person she knew and had confidence in was not on call and she was offered the services of a locum. She refused, saying she had had bad experiences with locums before. While we were in the car after lunch, G. kept worrying about what to do. As she talked about it, it appeared she had developed a plan – to wait one hour and then take the temperature. If further elevation occurred, she would call the doctor to come out. I reinforced this action and told her: "G, it seems you have come up with a good plan of what you will do. Now you have one hour to relax and think of other things." Her husband laughed and said "I will remind her of that," with a gentle laugh.

At the time of interview, P. was living in a Housing Commission unit about ten minutes from his parents' home. They visited daily and organized and monitored his carers, reading any notes they may have written on their shifts. The 2-bedroom unit was clean and had all the facilities needed to cater to his disability, including an electric bed, electric wheelchair, electric hoists, bath chair, disabled shower access, and the usual bathroom, cooking and washing facilities. The spare bedroom was used by the night carers or the parents over the weekend. We used it as an interview room for each of the parents. He was well supplied with electronic equipment, television, sound system, and a wide assortment of CD's and DVD's. His carers took him weekly to the local video shop to rent his choice of videos. His mother and some of the carers said they did not share his taste in videos. He went on fortnightly outings and when the weather was suitable, he was taken to a nearby beach for an outing. His favorite pastimes were listening to music, watching videos and enjoying the company of his favorite carer. He became impatient if she was busy about other duties such as washing or hanging out the clothes and would call her back to keep him company. They seemed to share a lighthearted camaraderie and exchanged quips and jokes. She seemed to bring him a 'sense of fun' and companionship.

When I asked P. how he got along with his parents, he said 'fine'. When I asked about his dad, specifically, he said 'dad's great, he's wonderful!', and when I further asked about his mother, he virtually roared the word: 'OVERBEARING'. I was surprised to hear this, but it confirmed the palpable tension between him and his mother that I had observed on arrival. His relationship with his father was strong and positive, and also with his favorite carer (J), who was present on the day of interview. However, the relationship between the mother and this carer was also strong, but negative. The mother saying to me that she did not think this was really the best carer for her son, and saying 'she is a law unto herself', and 'she does her own thing', suggesting she
did not always ‘do as she was told’. The feeling seemed to be mutual, although the
carer was less verbal about the mother.

My impression was that this young man found himself in a particularly helpless
situation and longed for the independence of a young adult male person. By his own
efforts he had sought independent living and succeeded in obtaining it. However,
without the help of his parents and their considerable efforts to obtain the help he
needed to keep him in this independent living situation, it could not have continued
for long and in the circumstances at the time of interview, he would almost certainly
have been placed in a nursing home catering to older persons. All three members of
this family considered this unacceptable. I believe he considered his mother’s efforts
on his behalf to be ‘smothering’, when he longed for independence, and mourned his
previous fun-loving lifestyle. It is also possible that he was suffering cognitive and
behavioural changes due to his rapidly progressing condition that did not allow him to
view his mother more kindly (I was aware of a potential for multidisciplinary
intervention with this family to improve their quality of life, but these ideas could not
be pursued at the time as a researcher).

Throughout our conversations, it became apparent that the parents had serious
financial concerns, and they believed that if they continued in their present pattern,
their own ability to retire with any degree of comfort would be compromised. G.
stated at one point ‘we did not think we would have p. this long’.

Postscript: The couple sold their home and moved to a smaller unit as a way of
managing their financial commitments and limit the amount of time they needed to
spend on upkeep in their own home. F. continued to be a strong support person for G.
and his son; G. continued her teaching of computers to the Seniors and her aerobics
exercises to keep fit. This remarkable woman won a community service award for her
volunteer efforts and for making it possible for others in similar circumstances to
access community services more easily. P. died four years later, peacefully, at home.
His parents sent me a notice of his passing and said: “We are very sad at his passing,
but would be sadder yet if we had never had him”.

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Relationships observed at interview with family consisting of 38 y.o. male PwMS. His mother, father and the son’s favourite paid carer. Good reciprocal relationships indicated by arrows and solid lines. Tensions represented by dotted lines. Other paid carers appear to be accepted in a neutral manner by all – necessary to provide care around the clock for severely disabled PwMS. Resentments verbalized between mother and favourite carer directly and indirectly.
C.2. SECOND PILOT INTERVIEWS

Summary of two pilot interviews

The second pilot interview was a couple referred by snowball sampling and living in Tasmania. The 65 year old woman asserted she no longer had MS since she had received a complete healing at a prayer meeting ten years prior to my visit. She told me she had been diagnosed with MS shortly after her marriage at age 22, with symptoms worsening during and after the birth of her only child. There had been a firm diagnosis of MS based on clinical evidence and a spinal tap, although no MRI had ever been done since that technology was not available to her at the time (early 60’s)

Her illness progressed rapidly, confining her to a wheelchair which she used full time for the next 25 years. She and her husband had sought specialist medical help in Melbourne, London and Europe, including a visit to Lourdes, France, and several treatments had been tried with no improvement. Her husband was very supportive and they managed to adapt to her limited abilities. She kept the accounts for his grocery business and drove the delivery van with hand controls, while an apprentice handled the boxes. She reported an active social life with very supportive neighbours, who often included her, her daughter and her wheelchair in family outings. She managed to move her baby daughter from room to room in the house using a pusher.

On observation the day I interviewed the couple, this lady showed no evidence of impaired mobility or excessive tiredness despite having two young grand daughters to care for during the school holidays. She was a gracious hostess at afternoon tea following the interviews.

This story is included as an interesting case study that will be reported verbatim, as transcribed from the tape recorded notes. Her husband’s report resembled hers closely. They were interviewed separately and on the same afternoon. Both emphasized the importance of their shared faith and the fact that they never lost hope that she would eventually walk again. As Kubler-Ross (1969) said: “Even the most realistic patients left the possibility open for some cure….it is this glimmer of hope which maintains them”...

Val’s story of her remarkable healing follows as it was told to me in response to my prompt and after speaking of her trajectory with MS to that time ten years before our meeting.

“B. What would you really like to hear is your experience when you got out of your wheelchair”

V (laughing brightly) “Twenty five and a half years I was in a wheelchair…that’s a long time. Well, we were in H. at an ecumenical conference and Fr. J.S., from Queensland was the guest speaker. So we went to it and I didn’t realize until later when I read the cover of the brochure that read: “Jesus Heal Me”. I was content. I was getting along all right…One morning we were at morning tea and this lady came over and said to me: ‘Have you got MS?’ And I said: ‘yes’ and she said: ‘Ah, I wanted to have a little talk to you…’ I had MS once’, and I said ‘really?’. Then I said ‘Well, what happened?’…Here she was – a tall and smart woman…she introduced herself and told me she was from the Reformed Church and she’d gone to this conference… and I said: ‘What did you do? Whatever happened?’ And she just
stood there and said: ‘I was healed by the power of prayer’. Ah, I thought, healed by the power of prayer and I’ve been praying all this time to be healed and nothing has happened to me. That really concerned me. And I thought then: ‘well, maybe I’m not meant to be healed... because I’ve been asking so long, maybe I’m not meant to be healed. Ah well, that’s o.k. I’m getting along all right. I suppose... I’ve got no problems... good family support. I’ve got a good husband and all that’. Then I thought: ‘that woman must have something I don’t have – she must have a much deeper faith or trust than what I have. or something. I thought: ‘I’m not going to ask to walk again. I’ll ask the Lord for a deeper and more trusting faith and just forget about walking... because He’s heard all about it. I’ve asked so much for that... He knows, He’s heard all about it. Anyhow, we went back to the next session and Fr J. spoke about the Holy Spirit... very inspiring talk he gave. And at the end of the talk he said: “We are now going to form prayer groups around the hall and if you are needing prayer, you can go on into one of those groups” He said... and this was the interesting part: He said: “I myself won’t be involved in those because I am not here to pray for people. I am here to counsel people. I’ll be sitting in the back of the room and if you have any problems you can come and chat with me”. So my husband asked me “Are you going to go for prayer?” And I said: “yes I will but we’ll have to wait because there were these queues of people waiting. So we sat and waited and waited and waited, and then next... Fr J. came up to the microphone and he said: “I’m sorry folks, but the ladies have sent word to say that lunch is ready and we have to go down now. When you are finished praying with those who are praying now, we’ll go to lunch. But this is another interesting thing....

K (Husband) got up to take me and there was only one door that we could use with the wheelchair that had a ramp leading downstairs. The people who were mobile could just run down the stairs. He got up to take me and he said: “Ah we can’t go because they are still praying... so we sat down again. We were sort of held there. While we were waiting Fr J. came by walking very briskly and when he got near the door he just stopped suddenly as if a boom gate had stopped him. He just stood there a second and then he turned around slowly and looked all around the hall. Then his eyes dropped and he looked down at me. He saw me sitting in the wheelchair and he came back and he asked me: “Were you waiting?” I said I was but it was too late now because we have to go to lunch. He said: “No there is still time” (and then in an aside she said, laughing, ‘...and he wasn’t going to pray for anyone’...). He said: “And what was it you were going to pray for? What was it you would like me to pray for?” I remembered this woman I spoke of and so I said: “for a much deeper faith and for a full release of the Holy Spirit”; and he just said “Yes”. He seemed to be thinking about it. and then he looked at me and said: “Isn’t there something else you would also like?” Well, I thought, I’ve given him my request, maybe the Lord wants me to ask just once more. one more time... (laughing) and that’s it. I won’t ask any more after that. So I said: “yes to be able to walk”, and he said: “right... and he seemed happier with that. Then he said: “Do you believe that after I have prayed with you, you will stand up and walk?” And I just said “Oh, I hope so”. Then he said: “Yes, you don’t pray and hope for things to happen, you pray trusting and believing and knowing that with the Lord the impossible becomes possible” And he had another sort of chat with me. And he explained... it all seemed so simple. And I thought then... well, nobody on earth has helped me. I’ve been everywhere, tried everything... and the Lord is the only one left... and so I left everything in His Hands. Yes I did. He said “Now we can pray”. He just prayed
this... Yes, it was a very short prayer... but powerful... you could feel it go right through your whole being. When he finished, he stood back. he stood away from me... and then he said “Stand up!” I knew I had the arms of the chair to push myself up on... I had no balance... I couldn’t stand without holding on to something... so... no balance whatsoever. So I stood up, but I still had my legs resting against the chair. He said: “Now walk.” Well, I thought, goodness. I was just going to say “I can’t”, but nothing would come. Then I thought... if I say I can’t and get back into that chair, I’m going to be there forever. I’ll never walk. No, I’m not going to do that... so I thought... oh the balance... I hugged myself to give myself some support, and started to walk... just moving forward (laughing), and the fact that I hadn’t fallen... and I got to him. And he said “Well done”. Praise the Lord. Then he said: “now turn around and run”. Turning around, I had to be so careful... the concentration was intense. And I thought... I don’t need to run... I need to be able to walk really well, so I’ll concentrate on walking first... I started walking back... and my wheelchair was sitting there. K. was sitting on the side. There was a woman at the end of the hall and I thought...I wonder if I could walk that far... concentrating every step of the way. As I walked past the chair, I heard K. say: Where are you going? (laughing again) He wanted me to sit down... he thought I was going to fall and break something... and so I didn’t speak... I couldn’t speak... I couldn’t answer him because of my concentration, and I heard Fr. J. say to him: “Just sit down and let her go”, in such a relaxed fashion. Anyhow, I slowly reached the end of the hall and when I turned around and looked at the back of the hall, there was Fr. J. just standing there like this (she gestured with her hands- holding one elbow, while the hand was placed on the side of his cheek)... so unconcerned... like it was everyday stuff... he had that expectant look on his face and his trust... you could feel it... that’s what he had expected to happen and it happened. So anyhow, I got back to the chair and he said “Praise the Lord, Thanks be to God. Then he said: ‘if you are on any medication, stick with it. He did not ask me any questions... he did not want to know how long I had had it or anything.

So, I decided right then. The Lord has stood me up, put me on my feet. It was then up to me to put a bit of effort into improving... to build on that... and I had to work really hard at it. I continued with the physio and the hydro and kept the stick for a bit of security for a while because when I went out I sort of felt that people were watching and saying... “Oh, you are still walking... and that wasn’t very good.

Another interesting thing that happened when we got home... we’d always carried the wheelchair in the boot of the car. I said to K. “Well you can take that chair out... he asked why, and I said: ‘because I’m never going to use it again’ and he said: oh, aren’t you?, and I said “No”. So he took it out of the boot and stood it in front of the car in the garage. I really wanted him to take it away so I couldn’t see it, because it was a bit of a temptation... when we went out sometimes. I’d wonder how far am I going to have to walk today?

And anyhow, I was going out in my own car with hand controls... I could manage with that. K. was in the house... and instead of putting the car into reverse, I accidentally put it into drive and you could hear the crash. K. came flying out of the house and he said: ‘what have you done?, what have you done? I said: ‘Nothing. I only wrecked the wheelchair The amazing thing about it was the garage wall was plaster... the plaster wasn’t marked... the car wasn’t marked, but the wheelchair was
demolished... so then it had to go out (laughing). Then I just had that one stick... we were going out to a New Year’s Eve party and I said to K... "I’ve got to get rid of that stick, or it is going to become a real crutch so I did". That’s going to be my New Year’s resolution... I’d never kept one up until then... That was it.
Appendix D:
Ethics
HUMAN ETHICS COMMITTEE APPROVAL

21 January, 2001

Dr E Ozanne & Dr P Swain
Department of Social Work

Dear Dr E Ozanne & Dr P Swain

Thank you for providing the additional information about the project.

I am pleased to advise that the Behavioural and Social Sciences Human Ethics Subcommittee approved the following project:

Impact of multiple sclerosis on committed caring relationships
Dr E Ozanne, Dr P Swain & Ms B Zulunga
HREC No. 010977

The Project has been approved for the period: 18/4/02 to 31/12/02. It is your responsibility to ensure that all people associated with this particular project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) Limit of Approval: Approval is limited strictly to the research proposal as submitted in your application.

(b) Variation to Projects: Any subsequent variations or modifications you might wish to make to your project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.

(c) Incidents or adverse affects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptability of the protocol including adverse effects on subjects or unforeseen events that might affect continued ethical acceptability of the project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: Projects are subject to monitoring at any time by the ethics committee.

(e) Annual Report: You must submit an annual report on this project at the end of the year, or, at the conclusion of the project if it continues for less than a year. Requests for annual reports are sent out by the Human Research Ethics Office in November/December of each year. Failure to submit a progress report at the end of the year will mean approval for your project will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any further queries or require additional information, please do not hesitate to contact me on telephone no. 3344 7507 or e-mail: k.murphy@unimelb.edu.au.

Please quote the HREC registration number and the name of the project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely,

Karen Murphy
Executive Officer, Human Research Ethics

c.c. Chair, DHEAG, Social Work
Ms B Zulunga

Melbourne Research and Innovation Office
The University of Melbourne Victoria 3010 Australia
Telephone: +61 3 9344 7114 Fax: +61 3 9347 6739
URL: http://www.unimelb.edu.au/research
Appendix E:
MS Australia Call to Take Part in Research
Taking part in research - Impact of MS on Caring
Relationships Project

To all persons with MS and their main carers: Participants needed!

I would like to thank you all most sincerely for your generous response to my call for participants in the research study exploring the impact of MS on caring relationships. Unfortunately, due to constraints in the agreed design of the project, as well as distance and cost, I am unable to include persons residing outside Australia at this time. My sincere thanks to all those who responded from the UK, the US and Canada! I have responded to each of you individually by email. You have certainly made me and other researchers aware of the need for such research on an international basis. There is so much we need to learn from you to help others in similar situations. I am still looking for more participants (people with MS and their main carers) from all parts of Australia. Please accept my apologies for momentarily forgetting the power and scope of the worldwide web.

Beatrice Zulugna
13 May 2002

Has MS changed your life? Either you are the person who has MS or the person who is a principal carer (spouse, partner, caring friend or family) who is committed to facing the daily challenges of life with this condition.

I am a postgraduate student at the University of Melbourne. I am conducting a research study designed to better understand the impact of this condition on your life and on the lives of others affected by MS. I need many participants who are willing to help with this project. Your input and personal experience will be extremely useful for developing strategies in the care of MS. Your responses will remain confidential.

The study is planned in two stages:

(1) The first part consists of a general questionnaire designed to get a profile of participants which will take about 30 to 40 minutes of your time, together with a postage paid return envelope. Contained in this packet will be a full description of the study, a consent form to be signed, and a form that you will need to fill out and return if you wish to participate in the second part of the study.

(2) The second part involves an interview with the researcher (about one hour). You will be invited to tell your story and share the challenges you have encountered since MS entered your life. You will each be interviewed separately.
As I am sure you already know, MS is a disease that affects many persons in nearly all parts of the world. Many studies are being conducted to help us learn more about this mysterious disease and to understand how individuals cope with MS. Your participation in this study will help health care professionals to better understand coping strategies of those affected by MS. Your participation and assistance will be greatly appreciated.

If you are interested in being a part of this research study or if you need further information, please ring Beatrice Zuluaga at (03) 9816 8680 or email bhz123@au.gateway.net. Dr. Elizabeth Ozanne, of the University of Melbourne School of Social Work supervises this project.

I look forward to hearing from you!

Sincerely,
Beatrice H. Zuluaga
Principal Researcher

Dr. Elizabeth Ozanne
Coordinator, Research and Graduate Studies
University of Melbourne, School of Social Work

More information

Beatrice Zuluaga
Principal Researcher
School of Social Work
University of Melbourne

Telephone: (03) 9816 8680
Email: bhz123@au.gateway.net

Last modified: 18 May 2002
E.2. RECRUITMENT FLYER

To all persons with multiple sclerosis and their main carers/support persons

Participants needed

Has multiple sclerosis changed your life? Either you are the person who has MS or the person who is a principal carer (spouse, partner, caring friend or family) who is committed to facing the daily challenges of life with this condition.

I am a PhD candidate at the University of Melbourne. I am conducting a research study designed to better understand the impact of this condition on your life and on the lives of others affected by MS. I need many participants who are willing to help with this project. Your input and personal experience will be extremely useful for developing strategies in the care of MS. Your responses will remain confidential.

The study is planned in two stages. (1) The first part consists of a general questionnaire designed to get a profile of participants which will take about 30-40 minutes of your time, together with a postage paid return envelope. Contained in this packet will be a full description of the study, a consent form to be signed, and a form that you will need to fill out and return if you wish to participate in the second part of the study. (2) The second part involves an interview with the researcher (about one hour). You will be invited to tell your story and share the challenges you have encountered since multiple sclerosis entered your life. You will each be interviewed separately.

As I am sure you already know, multiple sclerosis is a disease that affects many persons in nearly all parts of the world. Many studies are being conducted to help us learn more about this mysterious disease and to understand how individuals cope with MS. Your participation in this study will help health care professionals to better understand coping strategies of those affected by MS. Your participation and assistance will be greatly appreciated. If you are interested in being a part of this research study or if you need further information, please ring Beatrice Zuluaga at (03) 9816-3868 or email bzuluaga@unimelb.edu.au. Dr. Elizabeth Ozanne, of the University of Melbourne School of Social Work supervises this project.

I look forward to hearing from you!

Sincerely,
Beatrice H. Zuluaga                      Dr. Elizabeth Ozanne
Principal Researcher                     Coordinator, Research & Graduate Studies
There are four phases in this study:
1. Stem-cell collection
2. Chemotherapy
3. Repeat stem-cell collection
4. High Bone chemotherapy and transplant
The first three phases are done as outpatients, however phase four is done as an inpatient, requiring up to a month in hospital.
This procedure is being run at the Royal Melbourne Hospital. However, before being considered, you must meet the eligibility criteria that involve:
1. Diagnosis Progressive Multiple Sclerosis
2. Age of twenty to forty-five years
3. Experiencing progressive disability
Like with everything in this world, there are risks involved – a 1-3% risk of dying with this treatment, mainly due to infection or bleeding. It is also only in the experimental stages and there are no guarantees of success. But it is hoped that it will stop or slow down the progression of multiple sclerosis.
It is a frustrating and stressful time, as the trial will take approximately four months and then one month in hospital before it is completed.
An estimated ten people will go through this trial and afterwards doctors will determine whether further trials of stem-cell transplants will be required.
As I want the progression of MS to stop more than anything else in this world, I am prepared to be the third bunny or guinea pig of ten patients to undergo this procedure. Then hopefully we will be a step closer to beating this dreadful disease.
I hope to do a follow up story in the near future and hopefully can tell you of a success story. If anyone is interested in my progression or would like further information, I can be contacted at neene@bigpond.com.au.
ANTHONY VIRGONIA

A research study exploring the effect of multiple sclerosis on committed caring relationships is being conducted by a post graduate student at the University of Melbourne. The Multiple Sclerosis Society of Victoria supports the study.
Many people with MS are needed to volunteer for this project which is designed in two stages. The first stage consists of a questionnaire that should only take 30–40 minutes of your time to complete and return in the post-paid envelope provided. Participants will be asked if they are willing to be interviewed at a later date. From those agreeing to be interviewed, 12 PwMS and their designated carers will be selected for the second stage which involves an interview with the researcher. PwMS and carers will be interviewed separately. Interviews should only take about an hour each. As you know, multiple sclerosis is a mysterious disease that affects many people in nearly all parts of the globe. Many studies are being conducted to help us learn more about this condition and to understand how individuals cope with the daily challenges of MS in their lives. Your personal experiences and insights will be extremely useful for health care professionals as they continue to explore effective interventions in the care of families affected by MS.
This call for participants will be widely circulated. We are hoping for over 400 respondents. For further information on the project, or if you are willing to participate, you are asked to contact the researcher, Beatrice Zulugua at (03) 9816 8680, or email bhz123@au.gateway.net. Dr. Elizabeth Ozanne, Coordinator for Research and Graduate Studies at the School of Social Work, University of Melbourne, supervises the study.

SHORT CIRCUIT 10
E.4. LETTER TO ALL MS STATE SOCIETIES IN AUSTRALIA

To all Multiple Sclerosis State Societies in Australia

September 2002

Allow me to introduce myself. My name is Beatrice Zuluaga. I am a PhD candidate at the University of Melbourne and I am exploring the impact of MS on committed caring relationships. My research study has been approved by the MS Society of Victoria, and by the Human Ethics Committee of the University of Melbourne. Recruitment information has been widely disseminated since April 2002, by means of flyers, the worldwide web (www.msaustralia.org.au), advertisements in Short Circuit, and snowball sampling. Responses have been coming in from all over Australia. However, in order to ensure that the greatest number of persons with MS and their main carers in all parts of Australia have an opportunity to participate if they wish to do so, I am turning to you to request that you do all you can to inform your membership of the study and to encourage participation in the study. Data collection for the quantitative part of the study (a survey) will continue until the end of 2002. The qualitative part of the study consists of in-depth interviews with at least 12 pairs (a person with MS and their identified main carer) selected from the survey respondents. Persons with MS and their carers are seen as the experts in the experience of living with MS, and I believe they have valuable insights to offer others. Three hundred mailed surveys are the goal at present. Your assistance would be greatly appreciated. I attach a flyer with my contact details for dissemination among your members. Please feel free to contact me if you require further information.

Sincerely,

Beatrice H. Zuluaga

hzulag@memorial.upenn.edu
P.O.Box 4062
Balwyn East, Victoria 3103

Phone (03) 9816-8680
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