

# **Exploration of spousal carers' lived experience of loss**

Submission for the degree of  
Master of Health Science

by

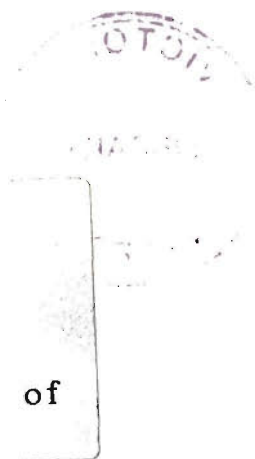
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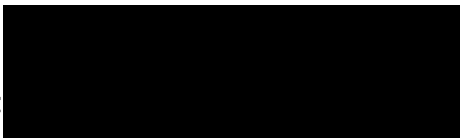
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**DECLARATION**

I declare that the material in this thesis titled “Exploration of spousal carers’ lived experience of loss”, submitted for the degree of Master of Health Science, is the result of my own research except where the work of others is acknowledged. I also declare that this thesis, in whole or part, has not been submitted for an award including a higher degree to any other university or institution.

Signed:



Name: Peta Anne Harten

Date: ....25-05-2001.....

## ACKNOWLEDGEMENTS

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I thank the Multiple Sclerosis Society for allowing me the opportunity to carry out my study and assisting in participant recruitment. In particular I would like to thank all those carers who gave up their time to talk with me so openly and honestly about their lives. I hope my work somehow makes a difference to health care services and nursing support for carers.

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## ABSTRACT

During the last century, much of the literature that discussed loss and grief was developed within an empirical-analytical paradigm. Stage models and theories of grief were proposed to explain and describe a universal process of grieving. Nurses, to a large extent, accept and perpetuate these notions of loss and grief and continue to provide prescriptive care in order to help their patients through each stage of grief. These theories and models fail to recognise individuals' unique circumstances that shape their actions and reactions to loss. Especially, these theories and models are inadequate in informing nurses when caring for people whose loss is not through death.

The aim of this hermeneutic phenomenological study was to explore spousal carers' lived experience of loss. Ten spousal carers of partners with Multiple Sclerosis participated in this study. In-depth, unstructured interviews were conducted and transcribed verbatim. The data were analysed using a modified form of the method outlined by Diekelmann, Allen, and Tanner, (1989). Three relational themes: experiencing the loss, caring as worrying and reinterpreting life meaning, were identified. The constitutive pattern that emerged was weaving through a web of paradoxes. Within this web were three paradoxes: loss/gain, limiting/enabling and vulnerability/strength.

The relational themes and constitutive pattern explicated illuminate these carers' experiences of loss from their perspective thus enabling deeper insight of their experience. The constitutive pattern provides understanding into what these participants (and their families) are living through, their personal strengths, weaknesses, hopes and resources in coping with loss not through death. The findings of the study therefore have implications for nursing practice, education and research, and health service provision.

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# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 BACKGROUND OF THE STUDY**

Spousal carers of partners, who suffer from chronic disease of unpredictable illness trajectory, experience loss or the potential for loss in many ways. The experience of these spousal carers who may live with loss, particularly in relation to employment and income, lifestyle and independence, future goals and relationships, has largely been unexplored. Hence this study was planned, developed and conducted to explore spousal carers' lived experience of loss when caring for their chronically ill partner.

A typical group of carers who engage in a long-term caring role where loss is a continual challenge are spousal carers of people who have multiple sclerosis, (MS). MS is a chronic degenerative disease of the nervous system. The illness trajectory is unpredictable and variable. However, the person's life span is usually not shortened due to the disease (Scheinberg 1983). The person's ability to perform their daily activities of living can deteriorate progressively. Hence, this presents the possibility that the person may have long-term care needs.

Multiple sclerosis is characterised by damage to the nervous system as demyelination occurs. Demyelination is the breakdown of myelin, that is the tissue that surrounds and insulates the nerves to allow for smooth transmission of nerve impulses or messages (Whitaker 1985, Multiple Sclerosis Society of Victoria 1996). This

demyelination totally or partially prevents flow of nerve impulses to and from the brain and hence messages are either distorted or lost. People with MS therefore face the possibility of many losses over time. Loss can be experienced in a multitude of ways involving cognition, mobility, physiological functioning such as bladder and bowel control, and in lifestyle areas such as employment, parenthood, hobbies and overall quality of life (Scheinberg 1985, Multiple Sclerosis Society of Victoria 1996). Because MS is a long-term degenerative chronic illness of unpredictable and variable progression, spousal carers of people with MS were chosen as participants for this study. It was assumed that the losses experienced by the person with MS would present the possibility of loss in some way for their spousal carer and have a profound influence on their carer's life.

Much of the available literature that discusses grief and loss has, in the main, been developed within an empirical-analytical paradigm. According to Allen, Benner and Diekelmann (1986, p.24) within this paradigm there is an "emphasis on theory, the centrality of observation and measurement, the ideal of experimental designs". The focus of research within an empirical-analytical paradigm is rigorous measurement and analysis of objective data gathered by way of observation, specific scales, inventories or questionnaires. According to Allen et al. (1986, p.24) the underlying assumption of the empirical-analytical paradigm is that "the world is structured by law like regularities" and to understand and explain human behaviour such laws can be manipulated as if humans were objects. Theory resulting from such research "is considered to be universal and not bound to the specific context in which it is

formulated". The "ultimate purpose is to provide control through explanation and prediction" (Allen et al. 1986, p.26).

This paradigm not only influenced research but also western thinking and culture and so writers such as Kubler-Ross (1969), Lindeman (1944), McKissock and McKissock (1995), Parkes (1987) and Worden (1991) and others, continued to propose grief theories and stage models of grief to explain and predict responses to loss.

Phenomena such as grief, anticipatory grief and chronic sorrow or chronic grief have been used to describe and label behaviours seen in people experiencing loss. These phenomena will be discussed in the literature review.

Nurses and other health professionals influenced by these theories and models developed within the empirical-analytical paradigm may in turn be influenced to accept and perpetuate these notions of loss and grief. The result can be prescriptive care through categorization and labeling of people's experience or behaviour where death or other cause of loss is the antecedent. For example, the researcher has observed carers being described as being in denial as described by Kubler-Ross (1969) and others. The researcher noticed that this label was often applied when people did not express their grief by crying, that is through catharsis, or when a person had not been seen to move through prescribed stages. On the other hand, the researcher has been exposed to carers' own bewilderment when they discovered that they did not fit the predicted timeframes for grief resolution. The researcher also has observed that many carers developed ways to live with their situation and did not

become swamped by grief and loss. They appeared to continue to lead fruitful and positive lives within their own beliefs and lifestyle. These observations seemed to indicate to the researcher that carers did not always react to loss, and particularly loss not related to death, in the manner theorists of loss and grief have suggested. Rather, carers appeared to interpret loss events differently, develop their own coping strategies and hence responded to loss and grief in different ways.

In 1996 the Department of Human Services in Victoria recognized the need to assist carers and launched "Victoria's Carer Initiatives, Strengthening the Partnership". The focus of this campaign was to support family carers. This support included providing increased respite options in order to reduce carers' workload and to give carers a break during times of need or crisis (Department of Human Services 1996). Whilst these initiatives are essential the researcher proposes that a deeper insight into the experience of carers and how carers cope in their specific lived situations, the partnership between the carer and the person being cared for, can be strengthened. In addition, partnerships between health professionals and people within their care could also be strengthened.

Possibilities for strengthening partnerships between spousal carers and their partners, and between health professionals and their clients, may be identified through understanding carers' experiences and concerns and by focusing on carers' strengths and abilities. As Perham (1995, p.39) argues "it is important not to underestimate the capacity of human beings to accept what life has dealt out to them. Our task is to

assist this process". In assisting this process it is important to understand carers' attitudes to caring, carers' ways of being in the world and carers' ways of interpreting meaning in their lives. Such influences in turn influence carers' ways of coping with their experiences of loss. Hence, the best way to explore how spousal carers live with loss is to understand their experience from their perspective.

## 1.2 STUDY AIMS AND PURPOSE

The aim of this study is to seek a deeper understanding of carers' experience of loss, particularly loss not related to death. By approaching the study of loss and grief from a phenomenological perspective the researcher hopes to offer new insights gathered from the perspectives of individuals experiencing loss. It is hoped that this study will provide new information that will raise the awareness of nurses and other health professionals about the context and meaning of loss for spousal carers, potentially improve their practice and provide a basis for developing strategies to help spousal carers strengthen their partnerships. In addition, new ideas for designing support programs for families with MS and impetus for future research might be identified and presented.

The purpose of the study is to present descriptions of spousal carers' experiences of facing loss and in so doing uncover categories, themes and patterns of meaning embedded in carers' experience of loss. In addition, the study aims to illuminate an understanding of spousal carers' ways of living and coping with loss.

### 1.3 ORGANISATION OF THE THESIS

Chapter two presents the literature review including stage models and theories of grief, the experience of loss and the experience of non-death related loss. Chapter three discusses methodology of the study. This chapter includes the theoretical framework underpinning the study, method, data collection and management, method and technique of analysis, issues of rigor and credibility of interpretation and ethical considerations. Chapters four to seven present the findings of the study. One chapter is allocated to each of the three relational themes that emerged from the data and one for the constitutive pattern. Chapter four presents experiencing the loss. Chapter five presents caring as worrying. Chapter six presents reinterpreting life meaning. Chapter seven presents the constitutive pattern, weaving through a web of paradoxes. Chapter eight provides a discussion of the findings with the literature. Chapter nine concludes the study and discusses the implications of the findings for the nursing profession, nursing research and health service delivery.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

Loss is a common human experience and grief is a human response to loss. There is a plethora of literature available on grief as a response to loss. During the last century, scholars particularly from the fields of psychology and medicine, recorded their encounters with patients, or studied people who were believed to be suffering from grief as a response to the death of a loved one. There is a tendency to draw from this literature to understand people who face loss not related to death. In recent years the importance of understanding the experience of loss from the perspective of those who have experienced the loss has been recognised. An understanding of individuals' experience is important to enable them to maximise their personal resources and give meaning to their loss. Increasingly scholars including nurses have challenged extant theories on loss and grief and have offered insights from phenomenological-interpretive studies that focus on understanding individuals' experience of loss, including loss not necessarily related to death. A phenomenological approach allows researchers to explore from the perspective of the person experiencing the loss and as such highlights what is important to the person.

This chapter consists of five sections that examine the general literature on loss and grief and other related literature. The sections are: grief as a response to loss; stage models and theories of grief; the experience of loss and the experience of loss not related to death.



## 2.1 GRIEF AS A RESPONSE TO LOSS

Terminology such as anticipatory grief, grief, chronic sorrow, chronic grief have been identified and defined to enable diagnosis and management of peoples' responses to loss. However, a clear definition of grief is very difficult to find in the literature other than that grief is a response to loss and is often said to be associated with depression. Lindemann (1944, p.141) wrote, "acute grief is a definite syndrome with psychological and somatic symptomatology". In 1991, after reviewing 74 articles on grief, Cowels and Rogers conceptualized grief as a "pervasive, highly individualized, dynamic process that often is discussed normatively within professional disciplines" (p.119). Normative is used to describe grief that is expressed acceptably within socially and culturally dictated boundaries (Cowels and Rogers 1991). This definition is also problematic as with other definitions. There is no reference to the individuals' perspective of their experience or the importance of the meaning of the experience to them.

There is scant literature that examines grief from the perspective of the individual or addresses grief as a response to non-death related losses. Some literature refers to grief related to divorce or loss of limb and as McKissock and McKissock (1995, p. 5) suggest:

The experience of grief, in response to loss, is known to all human beings, regardless of age, sex, creed and culture. Extremes of grief appear when one loses a close and meaningful relationship. Death, divorce, separation, abortion, the loss of limb or lifestyle, even forced retirement will precipitate this most painful human emotion.

However, having acknowledged other sources of loss and grief, McKissock and McKissock (1995) seem to suggest that responses to these types of loss would be the same and still offer timelines for grief resolution around days and weeks related to death.

Anticipatory grief was a term used by Lindemann in 1944 to describe a reaction to separation or a preoccupation with a perceived loss through death, that is an unconfirmed death. For example grief related to a presumed death in a war situation, rather than a known death. Siegel and Weinstein (1983, p.61) suggest that anticipatory grief is a "process in which an individual confronted with impending loss initiates the grieving process in anticipation of that event". Siegel and Weinstein (1983, p.69) also suggest that:

Widespread acceptance of anticipatory grief also may be traceable in part to a dynamic akin to a self-fulfilling prophecy. In other words, the fact that the concept is widely accepted is taken as *prima facie* evidence of its existence, which leads other clinicians to adopt it which in turn leads to even more widespread acceptance. The endurance of the concept is taken as additional evidence of its essential validity. Finally, clinicians' expectations may guide their perceptions. When confronted with clients facing the pending loss of a loved one, clinicians may observe what they expect to observe - initiation of the grieving process in anticipation of the loss.

In addition, Rando (1986, p.7) argues that anticipatory grief is complicated and involves "recognition of associated losses in the past, present and future." An individual cannot grieve in anticipation of a loss when the individual is unaware of or does not interpret the likely event as a loss.

Chronic sorrow according to Hainsworth, Burke, Lindgren and Eakes (1993, p.9) is a form of grief. It is "permanent, periodic and progressive in nature". Later "pervasive sadness" was added to this definition by Hainsworth, Eakes and Burke (1994, p.59). "Chronic sorrow is compared to the meaning of unresolvable grief and depression" (Lindgren, Burke, Hainsworth and Eakes 1992, p.27). Chronic sorrow is described as an ongoing emotional response to an initial tragedy. There is a recurrent and progressive change in levels of sadness as life events create the possibility of the recognition of further losses in terms of future possibilities, or recognition of a child's inability to achieve developmental milestones or future goals (Lindgren, Burke, Hainsworth and Eakes 1992, p.30-31).

## 2.2 STAGE MODELS AND THEORIES OF GRIEF

Stage models and theories of loss and grief have been developed to explain and predict the process of loss and grief to facilitate treatment, management and resolution of grief. These models and theories also serve to guide and facilitate the psychosocial adjustment of the person and their significant others whilst working through the grief process to achieve resolution. However, it is also noted that there is scant evidence to support the view that these models and theories with their inherent labels actually assist people to cope with their loss. This section will explore and critique models and theories of grief as ways of understanding responses to loss and grief.

Stage models and theories of grief and loss proposed by Kubler-Ross (1969), McKissock and McKissock (1995), Parkes (1987), and Worden (1991) generally attempt to formulate a universal process of grieving. These models describe a beginning and an end point with various tasks or stages in between. Some such models include time frames such as the first day, the third day, the seventh day, four to six weeks later and the first year after death to help the person get on with life in the absence of the lost person (McKissock and McKissock 1995, p.10). Others propose that normal grief consists of tasks or grief work that needs to be completed. For example, Worden (1991) suggests there are four tasks. They include acceptance of the loss, working through the pain, adjusting to the new environment and continuing on with one's own life. Overt expressions of grief such as crying are expected and are seen as signs that grief work is being accomplished. However, Shackelton (1984) suggests that catharsis is not necessary. He argues that the concepts of grief work and catharsis have been incorporated, unquestioningly into theories postulated by scholars such as Marris (1986), Parkes (1987), Raphael (1982) and Worden (1991) who have been influenced by empiricism and the work of Freud, Lindemann or Bowlby.

The underlying assumption of stage models and theories of grief is that a linear progression of emotional response and adjustment will occur culminating in resolution of grief with a return to normal pre-loss life patterns and behaviour.

“There is a pervasive belief among caregivers and helping professionals that such stages exist, and they are often used as a yardstick by which to assess a client's

progress" (Wortman, Silver and Kessler 1993, p.351). These stages and models encourage nurses and other health professionals to provide prescriptive care which may be inappropriate to the unique individual for whom they care (Walter 1994).

Expected behaviours of grief such as depression and denial are often used to assess and predict the stage of grief a person has reached. Scholars such as Clayton, Desmarais and Winokur (1968) and Levy, Martinkowski and Derby (1994) have used inventories and scales to measure depression as an indicator of grief and recovery. In addition, these inventories and scales are sometimes used to monitor the progress of the person through their grief and identify pathological depression. However, Siegel and Weinstein (1983, p.70) and Wortman and Silver (1989, p.350) argue that it is extremely narrow to equate depression with grief and that the inevitability of depression following loss has not been substantiated.

Grief work theorists, Marris (1986) and Worden (1991) propose that denial is a block to the process of grief and as such needs to be identified and treated to assist the person to come to terms with their loss. Kubler-Ross (1969) also identified denial as a stage that had to be overcome before progressing along the path to grief resolution and the resumption of life without grief. Worden (1991) suggested that the first task of mourning was accepting the reality of the loss and denial was a block to passing through this task. Other writers such as Aldrich (1963), Rando (1986), Walter (1994), and Wortman and Silver (1989) suggest that denial is an adaptive quality and should not be interfered with by believers of the cathartic model.

According to Shackelton (1984) much of the theory and research underpinning present beliefs about normal grief and its derivations are based on the perceived authority of the writer rather than validated evidence. Having identified various labels for grief, it follows that it may well be difficult to diagnose and label grief accurately. Cowels and Rogers (1991) acknowledge this and suggest that there is no consensus regarding definitions of grief or forms of grief. In addition, Cowles and Rogers (1991), Jacob (1993), Rando (1986), Shackelton (1984) and Siegel and Weinstein (1983) all argue that models and theories of loss and grief which were developed to identify, explain and predict behaviour in relation to loss and grief are not adequate.

### 2.3 THE EXPERIENCE OF LOSS

Many scholars such as Cody (1991), Cowels and Rogers (1991), Levy (1991), Rando (1986), Walter (1994), and Wortman, Silver and Kessler (1993) have questioned the validity of early literature on loss and grief. They have suggested the need for an alternative approach for researching grief. Rando (1986) identifies the absence of recognition of the experience of past, present and future losses as a limitation of much of the literature thereby preventing in-depth exploration and background understanding of individuals' grief experience. Levy (1991) identifies the need to focus on coping strategies while Wortman, Silver and Kessler (1993) propose that individuals' worldviews influence responses to loss. Cowels and Rogers (1991, p.124) argue that when supporting people during times of loss, care "is best directed

toward the determination of an antecedent loss and the individuals' self-reports of 'grief' and descriptions of their experiences". They suggest that there is "a need for additional research on grief that utilizes in-depth interviews as a primary source of data" (p.125). However, very few research projects have been conducted on loss and grief that focus on dialogue and resultant text as a source of data.

Phenomenology offers a broad philosophical framework as a starting point for exploring lived experience of phenomena to which people attach meaning and live their lives. A phenomenological-interpretive paradigm offers an alternative way of exploring people's experience that makes use of subjective data to gain deeper understanding. This paradigm focuses on individual's experiences described through dialogue with the researcher rather than observation and measurement. Researchers such as Brown and Powell-Cope (1993), Cody (1991), Gullickson (1993), Pilkington (1993) and Walter (1996) suggest that a phenomenological-interpretive paradigm allows for exploration of behaviour when meaning and understanding of experience is sought. The interpretation of text derived from individuals' interviews offers different views about loss and grief that challenge and/or enhance literature developed within an empirical-analytical paradigm. In addition, Rittman, Northsea, Hausauer, Green and Swanson (1993, p. 327, 328) argue that understanding lived experience will help achieve balance between technology and the human spirit and help bridge the research practice gap.

Walter (1996) in his biographical paper, which discusses the death of his father and the death of a dear friend, suggests that the clue to living with the loss of a loved one is to talk about the dead. Walter found that talking about his friend with different people who knew her well and within different contexts actually lead him to the realisation that he had, in a way, found his friend for the first time. He said, “What helped me were not the ‘*internal* dialogues with the *deceased* person’ but the *external* dialogues with *others who knew her*” (p.13). However, who to talk to presented problems because according to Walter (1996, p.16), “the overriding reality for many is that those encountered daily either did not know the deceased or did not know them at all well”.

Brown and Powell-Cope (1993) in their study of loss and dying among AIDS family caregivers found that carers tended to take one day at a time and put future goals and ideas on hold. They suggested that family caregivers were challenged to let go of their expected life-style and take on new ways of living. Some carers apparently found this easy and “others felt intense and difficult emotions, particularly anger, about a life-style that had been unjustly taken away” (p.185). Brown and Powell-Cope (1993, p. 185) suggest that:

As caregivers were challenged to let go of “the way life used to be”, they also proceeded to put the future “on hold”. Unable to find solace from current difficulties by turning to the future, they postponed short- and long-term plans and personal goals and devoted themselves primarily to care giving and day-to-day living.

It is clear from Brown and Powell-Cope’s interpretations that putting-on-hold is seen as a beneficial strategy to improve quality of life and living. Yet, the putting-on-hold



might also be seen as a form of denial if viewed from an empirical-analytical perspective and as such a block to grief resolution.

Pilkington (1993) identified three core concepts experienced by mothers after the loss of their babies at birth. These three core concepts were: anguished suffering in devastating void, consoling movements away from and together with the lost one and others and confidently moving beyond personal doubts (Pilkington 1993, p.132).

Pilkington (1993, p.130) believes that "meaning cannot be objectively designated by an observer". Pilkington (1993, p.130) suggests that:

While the meaning of any loss is personally and uniquely defined, grieving a personal loss is a universal human experience pertaining to health. The process of grieving pertains to health in that it influences one's way of daily living, sense of well being, feelings about self, and personal growth.

Cody (1991, p.65) identified the paradox of loss and gain as experienced by the participants of his study as "dwelling with the absent presence". Cody (1991, p.66-67) found that:

The experience of grieving a personal loss evolves dynamically in the living every day, as the individual propels self onwards, interrelating with others and choosing from among possibilities in light of what is cherished. Grieving a personal loss is seen as a way of living the now, the what was, and the not-yet all at once, a view that contradicts theories that specify grieving as a normative set of sequential stages.

The findings of Brown and Powell-Cope (1993), Cody (1991), and Pilkington (1993) suggest that individuals who experience a loss find ways of living with and coping with that loss. They do this by giving meaning to and making sense of their experience in the context of their world.

## 2.4 THE EXPERIENCE OF LOSS NOT RELATED TO DEATH

Gullickson (1993) studied the experience of people living with a chronic illness and identified that participants developed new ways of living with loss. Gullickson (1993) discovered meaning in the notion of possibility relevant to participants past, present and future. Participants identified that "the future presents the possibility of embracing the fruits of life as one journeys, not as a retirement benefit only to be enjoyed after enough resources have been ensured" (Gullickson 1993 p.1390). In other words participants uncovered possibilities by working with what they had and from where they were in their own reality. Wilson (1989, P.97) identified a carer strategy of "selective resourcing" which is in effect, filtering out what is needed. But, according to Wilson (1989, p.97) there are several obstacles that influenced carers' ability to do this.

Some caregivers are embarrassed and ashamed to tell anyone else what is happening, cutting themselves off from seeking help. Most caregivers report that an information gap separates them from getting help...Even when services are identified and accessed, they are perceived as generally inadequate.

In addition, there was always the problem of being confronted with a list of choices, none of which were satisfactory from the carers' perspective and involved a variety of negative side issues when balancing what is lost with what might be gained. Wilson (1989, p.95) reports that:

Family caregivers of Alzheimer's patients are constantly confronted with the problem of coping with negative choices. Negative choices are dilemmas in which all options represent "different degrees of impossibility."

Wilson (1989) argues that coping with negative choices involves taking it on, going through it and turning it over. Wilson (1989, p.96) states:

Taking it on occurs in a context of financial strain because many of the costs associated with home-based, extended care are not reimbursable and those that are require “going through all that red tape.” Yet, overriding the problematic conditions is a specter of horror stories about nursing homes (called by some “melancholy institutions”) and the caregivers sense of moral duty.

These issues are of paramount importance as health care is increasingly delivered in the home. People with complex care needs due to chronic degenerative diseases are often at home being cared for by family members who in turn face experiences of loss related to expanding carer roles.

Loss experiences for caregivers caring for people with chronic illness have been noted by some researchers such as DesRosier, Catanzaro and Piller (1992), O’Brien (1993), Robinson (1990), and Scholte op Reimer, de Haan, Rijinders, Limburg and van den Bos (1998). Whilst researching phenomena such as caregiver burden, caregiver stress and coping strategies, experiences of loss were also identified.

Caregivers reported loss of time to themselves, loss of lifestyle, loss of relationship and loss of self-esteem. Robinson (1990, p.793) noted that “caregivers who reported losing a greater number of relationships in the past year had significantly lower self esteem”. Walley Hammell (1992) and O’Brien (1993) documented negative effects on marital relationships and financial burden. They also described a negative impact on role issues as part of the burden of care giving, for example role change, role restriction and role constriction. Whilst these phenomena of marital relationship, financial burden and role change were seen as contributing to carer burden, they were not viewed in terms of loss experiences for the carer. This may have been because

indexes, questionnaires or rating scales were utilized to gather data rather than in-depth interviewing of the carers to understand their personal perspective.

## 2.5 CONCLUSION

Various definitions of grief and its derivatives have been offered and the difficulty with providing a single definition of grief has been highlighted. Much of the early literature was based on objective data and developed within the empirical-analytical paradigm. The findings of these studies, in the main, have been generalised to allow health professionals to predict, explain and treat grief. More recent literature framed within a phenomenological-interpretive paradigm has presented findings derived from the personal experiences of people living with loss. These findings enhance health professionals' knowledge of individuals' experiences of loss and grief and encourage understanding of the person and the context in which loss occurs.

Nursing knowledge and practice influenced by the empirical-analytical paradigm, according to Allen, Benner and Diekelmann (1986, p.24), invites regulation based on perceived laws without consideration of the context and situation or the role of experience and relationship. Therefore, it is possible that nurses, who accept literature influenced by the empirical-analytical paradigm and model their care accordingly, may well expect and predict specific emotional responses such as grief, anticipatory grief, chronic sorrow or chronic grief. Given the controversy over the accurate identification of each phenomenon, this in itself is fraught with risks of inaccuracy. In addition, the notion of health professionals' control and patient

compliance is perpetuated rather than allowing the patient to tell their own story and be supported according to their needs and resources.

During the last decade, a qualitative research approach has been increasingly utilized to explore the experience of loss and grief. However, very little phenomenological-interpretive research has been published about loss and grief. In addition, there is still a paucity of literature available that addresses the experience of loss for people where the antecedent of loss is not necessarily death. Hence, further research is required to explore peoples' experiences of non-death related loss from the person's perspective. Of particular interest is the experience of loss for carers, particularly unpaid spousal or family member carers, where their carer role impacts on their daily life. This is of fundamental importance in the health care industry due to increasing focus on home based acute and sub acute health care, where family members provide round the clock care with or without the assistance of health care organizations and adjunctive service providers.

Spousal carers of partners with MS are a unique group of carers who provide home based care for their partners. Due to the chronic degenerative nature of MS, spousal carers of partners with MS are confronted with long-term caring roles and face the possibility of loss in many areas such as employment and income, lifestyle and independence, future goals and relationships. The impact of their caring role, the ways in which these carers interpret their situations and their reality, and the ways they develop abilities to cope and live with loss remain largely unexplored.

This research study was developed to explore spousal carers' experience of loss whilst providing home based care for their partner. It is hoped that the findings of this study will shed light on understanding what loss means to these carers and so provide implications for improving health care provision for these people. The following chapter will discuss the methodology for this study in detail.

## CHAPTER THREE

### METHODOLOGY

Chapter three consists of three main parts. The first part explains the theoretical framework of this study. It discusses the philosophical underpinnings of hermeneutic phenomenology and provides the rationale for choosing it as the framework for this study. The second part of the chapter discusses the research design, the research method and procedures of participant recruitment, data collection and management including the technique of data analysis. Finally, the chapter includes discussion on issues of rigor and ethical considerations followed by a summary of the chapter.

#### 3.1 THEORETICAL FRAMEWORK

The theoretical framework of this study is hermeneutic phenomenology.

Hermeneutic phenomenology is a form of interpretive phenomenology originating from the philosophy of Heidegger. Heidegger's philosophy on what it means to be a person suggests that personal meanings determine individual's interpretation of the world in which they live. "Heidegger refers to human existence as Dasein, or being there, which emphasizes the situatedness of human reality" (Walters 1995, p.793).

Human reality involves what is important and according to Heidegger, people care about what is important in their world. "The most fundamental way of being-in-the-world, Heidegger says, is Sorge. This word is usually translated into English to mean 'care'. Care is about Being and it is about caring for things and other people" (Walters 1995, p.793). Heidegger's philosophy underpins much of Benner's research on stress

and coping. Benner and Wrubel (1989, p.407) translate being-in-the-world as describing "how people are involved in situations through their concerns, skills, and practical activity". A person's everyday social and culturally determined concerns, activity, knowledge, skills and coping are all aspects of their existential Being.

Heidegger's philosophy is also about existential Being. Individuals are seen as self-interpreting beings who are influenced by and influence the language and culture of their time (Allen, Benner & Diekelmann 1986, p.28). This environment forms the background from which we interpret our life world. For individuals "world is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (Leonard 1994, p.46) and according to Heideggerian philosophy, world is both shaped by and shapes the self. This background exists and cannot be ignored, hidden, made overt or bracketed and so research is always influenced by background knowledge. "Meaning resides neither solely within the individual nor solely within the situation. Meaning is a transaction between the two" (Allen et al. 1986, p.28). Meaning is explicated from the embodied being, a person, who is situated in a world and for whom things matter, are of value and have significance at a given time space.

Individuals interpret what matters as having significant meaning and hence concern brings out responses and action that according to Benner and Wrubel (1989, p.408) are necessary for life. "The goal of coping is restoration of meaning. Coping is always bounded by the meanings and issues inherent in what counts as stressful"



(Benner & Wrubel 1989, p.408). When meaning is shattered, for example through loss, coping strategies are initiated to restore meaning.

To gain understanding of how people cope during times of stress, Benner and Wrubel (1989) suggest that situation, embodiment and temporality are also relevant when exploring a person's lived experience. Situation takes into account history, culture and current existence – life worlds. A person's life world encompasses the environment in which living takes place, including factors of spatiality, context, temporality and awareness of the things in that world (Fjelland & Gjengedal 1994, p.15-17). Many things in the world are taken for granted and understanding of these things is often not explored or explicated. Stressors within such an environment impact on the person's perceptions of, and ways of coping with, concerns. Understanding of the entities of the environment and explication of such concerns becomes important and this impacts on the person as an embodied being.

Embodiment from a phenomenological view refers to the person being embodied rather than simply having a body. "Our bodies provide the possibility for the concrete action of self in the world" (Leonard 1994, p.52). That is, the way a person acts and behaves is expressed and experienced in the body in response to meanings, expectations, customs and habits that are socially and culturally determined.

Temporality is also an important concept when considering a person's behaviour and responses. Temporality refers to time in a life time rather than clock time. A person

caring for another person who has a chronic illness may develop an altered sense of time as a way of coping. The concept of the present or the now can be experienced as an eternity when living through endless commitments to caring. The concept of the future may be shortened to days or even hours depending on levels of uncertainty and unpredictability with which the person is living. Regarding temporality, Benner (1994, p.105) suggests "the experience of the lived time is the way one projects oneself into the future and understands oneself from the past. Temporality is more than a linear succession of moments" for it includes what has been before, what is now and what is anticipated for the future.

The phenomena of situation, embodiment and temporality contribute to the uniqueness of individual's interpretation, meaning and coping of their everyday life experiences. Such phenomena are embedded within a person's way of living and the intricacies of such notions can be explicated through the interpretation of text. A person's interpretation of meaning of experience can be illuminated using in-depth interviewing and through hermeneutic phenomenological inquiry. It is from this framework that the researcher aims to explore carers' being-in-the-world in order to develop an understanding of carers' lived experiences of loss, and their ways of coping with such experiences.

The phenomenon of investigation in this study is spousal carers' lived experience of loss. Van Manen (1990, p.11) defines phenomenology as an "attempt(s) to explicate the meanings as we live them [phenomena] in our everyday existence, our

lifeworlds". For this study it was assumed that concern, caring and coping were integral to the lives of spousal carers. These carers care because they have concerns about the people they care for. Their everyday experiences of being in their situations not only help them interpret what is stressful and what is not, but also help them to develop coping strategies. Phenomenological inquiry thus enables the exploration of the meanings of carers' experiences. Ray (1985) argues the purpose of phenomenological research is to seek a fuller, deeper understanding through description, reflection and direct awareness of a phenomenon to reveal the multiplicity of coherent and integral meanings of the phenomenon.

Within phenomenological inquiry, hermeneutics offers another dimension and is "concerned with the nature of understanding" (Draper 1996, p.45) through the interpretation of text. Transcribed dialogue derived from interview conversations between the researcher and each carer became the text for this study. The text from the narratives of the carers included in this study provides insight into carers' interpretation of loss and the meaning of loss. This enables the reader to gain enlightened understanding of carers' lived experience of loss.

## 3.2 METHOD

### 3.2.1 Research Design

A qualitative research design was chosen for this study to enable the researcher to collect data that captured the personal and unique experiences of spousal carers living with loss. To explore such experiences it is important to examine loss from their perspectives in order to illuminate understanding of the meaning and impact of loss upon their ordinary everyday lives that relate to their being-in-the-world, caring, and living. To uncover these hidden meanings and understand the essence of what it is like to live with their experiences of loss it is essential that the research design allows the participating individuals to interpret their experience and tell their story.

Qualitative research and in particular hermeneutic phenomenology offers a way of gathering and interpreting narrative text to gain understanding of meaning from the participants' perspective.

### 3.2.2 Access to, and Description of Participants

Spousal carers of people with Multiple Sclerosis were chosen as participants for this study in view of their long-term caring roles and their potential to experience continual exposure to loss. These carers lived with their partner, were aged between 40 and 60 years and spoke English. In addition, these carers provided at least one hour of hands-on care for their partner per day. Their partners had been diagnosed with MS for at least 5 years.

In order to seek volunteer participants the researcher approached the Coordinator of Research Services of the Multiple Sclerosis Society of Victoria (MSSV) who then presented the researcher's request to her senior colleagues at the MSSV. The MSSV Research Committee approved this study and agreed to contact suitable carers of clients on behalf of the researcher. All clients were registered with the Footscray Resource Centre of the MSSV. Carers of people with MS were chosen from this centre in order to reduce the likelihood that participants would be known to, or be familiar to, the researcher (in view of her previous employment with the MSSV at another centre). In addition, approval to conduct this study was sought and gained from the MSSV Research Committee and Victoria University Ethics Committee.

The MSSV Coordinator of Research Services contacted potential participants by an introductory letter. This letter informed carers of the study and acknowledged MSSV approval of the research. Included with this introductory letter was the invitation from the researcher explaining the study and inviting their participation (Appendix A). Carers were asked to contact the MSSV or the researcher should they wish to volunteer to take part in the study. Written consent was obtained prior to commencement of their participation (see Appendix B for the consent form).

Fifteen carers volunteered to share their experiences. Interviews were terminated after the tenth participant when information redundancy in carers' descriptions was considered evidence that a sufficient number of participants had been obtained. These participant carers, six men and four women, were aged between 40 and 60

years and had experienced lifestyle changes as their carer roles were established. A minimum of five years as a carer was considered adequate time, by MSSV Research Services, for such events to take place. However, some of the carers had been caring for their partners for around fifteen years.

Each carer provided 'hands-on' care for at least one hour per day for their partner, (for example personal care, meal preparation, shopping, housework or other activities that the person with MS would otherwise normally do themselves). One hour of care was considered an indication of a level of dependency as determined by a Disability Scale used by the Multiple Sclerosis Society of Victoria (MSSV) to estimate the care time required for individual people with MS. However, some carers provided care 24 hours a day. Even at night some carers provided assistance with position changing or toileting due to their partners poor mobility. As a consequence these carers slept lightly and remained "on call" around the clock.

Some of these carers originated from countries such as the United Kingdom and Greece. However, their cultural backgrounds were not the focus of this study. All carers had lived in Australia for many years and spoke English fluently. This was important to ensure that participants were able to articulate their experiences clearly in conversation directly with the researcher. A clear mode of communication enabled timely clarification of any doubts. This facilitated accurate interpretation of meaning during the interview process and later during data analysis.

These carers had lived with many losses in their lives which placed demands on their partner needs, their own needs, employment, children, household duties, recreation, finances, friends and family. For example Jim, George, Barry, Jenny gave up paid employment to take on the role of full time carer. Jenny and Andrew took on a role equivalent to that of a sole parent for their teenage children, in addition to their role as carer.

Each family lived in their own home. In most cases the home had been modified over the years in some way to meet the needs of the person with MS. Modifications such as handrails or ramps were often necessary to help the person with MS maintain some independence and to reduced the need for carer assistance.

Family cohesiveness within each household was generally strong and supportive relationships were evident. Some carers and their partners received help from older children not living at home. Some did not. However, there were often poor relationships with family members outside of the immediate household. For example parents and/or siblings of the spousal carer, parents and/or siblings of the person with MS, in the main, did not provide regular support and assistance.

### 3.3 DATA COLLECTION AND MANAGEMENT

Data were collected through face to face, unstructured in-depth interviews. The researcher commenced each interview with the leading question, “What is it like to care for (name)?” Subsequent questions were derived from the participant’s

responses. Refocusing questions were used when necessary to clarify meaning. For example “When you say [...], what do you mean by this?” or “How does [...], concern you?”. All interviews were tape-recorded and transcribed verbatim using pseudonyms. All participants were reassured that issues of confidentiality would be respected and that their identity and that of the people they referred to, would be protected by the use of pseudonyms.

Each carer was interviewed individually in the privacy of their home. All carers appeared to be relaxed, comfortable and willing to talk about their experiences. Some carers verified this by stating that they enjoyed talking about their lives and experiences and felt better afterwards. Interviews lasted for between one and two hours before it appeared that carers had exhausted their need to talk and that no new issues were left to discuss. Carers were interviewed once and no follow up to verify data during analysis was required.

The researcher recorded field notes after the interviews if pertinent conversation and information was not taped. This was done immediately after leaving the carer’s home. On two occasions carers talked about issues of concern after the tape had been turned off and this information was noted as accurately as possible at the time of conversation.

The researcher experienced some uneasiness during the interviews when the carers talked about very personal matters such as loss related to sexual issues and marriage



relationships. The researcher was surprised how open and honest carers were about such private matters and to hear how easily carers talked about their intimate relationship with their partner. Carers appeared to need to express these concerns as if debriefing, as if offloading to someone who would listen. Jeanne, Barry and Andrew cried during their interview when talking about very poignant and painful issues. The researcher felt particularly sad and experienced watering eyes also. Carers appeared to interpret responses such as this from the researcher as a sign of connectedness and understanding. Carers appeared to feel comfortable, and willingly shared their experiences with the researcher thereby enabling the researcher to remain “in-tune” with each carer and their story.

### 3.4 METHOD AND TECHNIQUE OF ANALYSIS

The data were analysed using hermeneutic analysis (interpretive phenomenology) as outlined by Diekelmann, Allen and Tanner (1989). This method was chosen for a number of reasons. Firstly it is a method that involves clearly defined steps by which subjective data can be analysed. Heideggerian philosophy underpins this method thereby guiding the exploration of lived experience and the explication of its meaning. The subjective data gathered in the form of text was interpreted through hermeneutic analysis. Through the process of hermeneutic analysis and interpretation, relational themes and a constitutive pattern were identified and documented. The relational themes and constitutive pattern provide new insight, illuminate understanding and identify new meaning supported by exemplars of lived experience extracted from the text. This method could be modified from seven stages

of analysis, managed by a research team, to five stages of analysis managed by the research student and her supervisor. The seven stages of analysis are documented in Appendix C. The modified method used in this study consists of the following stages:

**Stage 1:        Read transcripts as individual wholes**

All transcripts were read as individual wholes to gain an overall understanding about each carer's experiences of loss. This means that the researcher developed an understanding of each participant's specific circumstances. To this end the researcher listened and re-listened to the interview tapes. The researcher also visualised her interactions and interview with each participant in order to gain an appreciation of contextual and situational influences. The researcher transcribed the tapes and this provided another opportunity to become involved with the data. Each transcript was read at least five times in its entirety and the researcher recorded descriptive, explanatory or questioning comments in the margins of the transcripts. A summary of each transcript was documented to record a general overview of each interview. Words or phrases describing carers' experiences of loss were identified and preliminary ideas about ways of living and coping with loss were also highlighted.

**Stage 2:        Identification of categories and exemplars**

All transcripts were read, and re-read to search for categories of information. Categories of information were developed by grouping similar words or ideas that stood out to the researcher as being frequently present in all or many of the

transcripts. Initially thirteen broad categories were identified. These categories were refined and condensed to extract special or exemplary pieces of narrative.

Similarities and differences between transcripts regarding each broad category were noted. For example most transcripts included references to loss of family support but two mentioned family support being available even if only in a limited way. This difference was noted for future inclusion and analysis.

### Stage 3: Identification of relational themes

The thirteen categories were re-examined, reviewed, refined and condensed to ten categories. Then ten categories: loss, worry, living/coping, intimacy, cooperation, optimism, family and friends, career/finances, spontaneity/routine and system, were examined and explored for relational themes. "A relational theme is one that cuts across all texts" (Diekelmann et al. 1989, p.12). By reviewing the categories, common threads of information were identified that linked experiences described in all texts. There were three main threads of information and description that were explored. These were identified as three relational themes that occurred across all texts. They were interpreted as: experiencing the loss; caring as worrying; and reinterpreting life meaning. The relational themes will be presented in chapters four, five and six.

### Stage 4: Discovery of a constitutive pattern

After the three relational themes were identified, a constitutive pattern that clearly expressed the relationships of the relational themes emerged. This constitutive

pattern describes the ways in which participants' experiences of loss changed their way of living and their personal meanings. A situation is constitutive when it gives actual content or style to one's self-understanding or one's way of being in the world (Benner and Wrubel 1989). According to Diekelmann et al. (1989, p.12) the discovery of constitutive pattern forms the highest level of hermeneutic analysis. The constitutive pattern for this study was interpreted as weaving through a web of paradoxes. Within this constitutive pattern three main paradoxes were identified as loss/gain, limiting/enabling and vulnerability/strength. The constitutive pattern and the paradoxes will be described and discussed in chapter seven.

#### Stage 5: Final report

This consists of preparation and writing up of the final report which is presented in chapters four to seven. Exemplars of carers' experiences extracted from the interview material were used to validate data interpretation to achieve the goal of "discovery and understanding of meanings embedded in the text" (Diekelmann et al. 1989, p.13).

### 3.5 ISSUES OF RIGOR AND CREDIBILITY OF INTERPRETATION

To ensure accurate representation of carers' experiences each interview was tape-recorded as unobtrusively as possible. In addition, to the tapes, field notes were kept for later reference particularly when conversations or events were not tape-recorded. To enhance the accuracy of data collected and to maximise credibility of data, all interviews were transcribed verbatim. When data were explored a rigorous trail of data analysis was followed to establish trustworthiness in reporting. Koch (1994)

suggests that credibility, transferability and dependability are factors required to enhance trustworthiness of qualitative data analysis. Credibility is established when the researcher has developed self-awareness. This means the researcher has considered personal views and responses likely to be evoked whilst collecting data that may influence results. Credibility is increased by recording researcher reactions and feelings by way of journaling or by keeping field notes to record such events.

Transferability involves fittingness or applicability in different contexts.

Transferability suggests that the findings in one setting are applicable to other settings and so takes into account “the degree of similarity between two contexts” (Koch 1994, p.977). Koch (1994, p. 977) citing Sandelowski (1986) quotes that “a study meets the criterion of fittingness when its findings can ‘fit’ into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences”. The researcher believes that colleagues will regard the findings of this study as meaningful and applicable to their own situations caring for clients particularly with other chronic illness such as chronic obstructive airways disease, Parkinson’s disease, renal disease and so on. The researcher has also been able to apply the knowledge gained from this study in her daily work with carers of people receiving rehabilitation after stroke or other neurological and chronic conditions.

Dependability refers to being dependable and this relies on the notion of inquiry audit to authenticate the product. This process is reliant on the explication of the decision

trail when making analytical choices. Throughout this study, the researcher's supervisor provided regular surveillance of the data analysis process to ensure adherence to strategies to maximise trustworthiness of data analysis as detailed below.

Data were analysed through a number of stages as described by Diekelmann et al. (1989). Categories in the form of frequently occurring words, phrases or ideas were recorded in the margin of the transcripts and formed the beginning of the rigor trail to establish trustworthiness. Field notes were revisited. Written notes were also recorded on the identification of categories and emerging themes from the transcripts. Both the researcher and the principal investigator (supervisor) frequently revisited these data sources. This allowed the supervisor to follow the trail used in the analysis process and to act as an auditor to challenge the interpretations and ensure credibility. Pertinent and poignant interview quotes/excerpts were collected from each category to support interpretation and credibility of data analysis. Finally, each of the relational themes and the constitutive pattern were identified and documented. Some exemplars have been used in the completed report to validate data and to enhance trustworthiness of interpretation.

### 3.6 ETHICAL CONSIDERATIONS

It was believed that disclosure of private and confidential information might occur during the course of the interview process as each participant talked about his or her lived experiences as a spousal carer. For example issues regarding difficult family

dynamics or issues of concern that the carer felt unable to manage could become sensitive subjects. It was anticipated that discomfort, sadness or even anger might occur as participants talked about concerns, problems and issues that might have not been spoken about, resolved, challenged or perhaps even acknowledged. To minimise the risk of emotional distress the researcher ensured participants were well informed about the study verbally and via an invitation letter (Appendix A). This invitation letter indicated that there was no obligation to take part in the study and that participants could withdraw from the study at any time without concern. Each participant was interviewed privately in their home and was approached with respect and in a sensitive, caring manner. On one occasion a carer's partner was present for part of the interview. This was not a concern for the carer. At no time did any carer express any discomfort or desire to cease the interview. However, the researcher remained aware of the need to exercise professional competence and skill in order to observe and identify discomfort or distress and to act accordingly if they occurred.

Prior to commencing the interview process the researcher devised a plan of action should the participant show any sign of distress. The researcher planned to give the participant the opportunity to continue with the interview; cease the interview; seek assistance or any combination of these three options. Support/counseling was also made available to participants from the Multiple Sclerosis Society of Victoria either at the Footscray Resource Centre or via their 1800 telephone number. It was also made clear to participants, prior to commencing the interview, that they could withdraw from the project at any time without worry or fear of retribution or concern

that they could be identified as participants of the study. However, it was not necessary to engage the strategies formulated to respond to participant distress as no such events arose.

Issues of confidentiality and privacy were explained and clarified to the participants and respected by the researcher. All documentation related to the study and particularly the transcripts, was kept in a locked place and only viewed by the researcher and her supervisor. All transcripts were coded and people mentioned throughout the interviews were provided with pseudonyms.

### 3.7 CONCLUSION

This chapter presented the theoretical framework and discussed the philosophical underpinnings of hermeneutic phenomenology in this study. The chapter has also discussed the research design, research method, access to participants, the process of data collection and analysis and included discussion on issues of rigor and ethical considerations. Chapters four, five and six will address the relational themes and chapter seven will present the constitutive pattern and paradoxes that emerged from the data.



## **CHAPTER FOUR**

### **EXPERIENCING THE LOSS**

Three relational themes: experiencing the loss; caring as worrying; and reinterpreting life meaning emerged from data analysis. Chapters four to six will present each of these themes. Presentations will include exemplars of carers' accounts to support the interpretations offered. This chapter presents experiencing the loss.

Experiencing the loss was seen as a relational theme that occurred throughout each carer's story. Each carer spoke about and described many events or episodes in their lives that the researcher interpreted as loss experiences. These experiences are presented and discussed as follows: loss of the person, which was the major loss; loss of self; loss of companionship and partnership, loss of support; and loss of income and lifestyle.

#### **4.1 EXPERIENCING THE LOSS – AN OVERVIEW**

The relational theme, experiencing the loss emerged as the researcher became more involved with the text and her understanding of each carer's way of living and coping increased. Most of all, these carers missed the person they had married even though that person was still there, their partner had changed so much. Their partner had become a different person. These spousal carers had lost the partner they knew and understood.

People with MS are expected to live their normal life span, that is, whatever it might have been without the development of MS. Hence, spousal carers' of partners with MS did not worry about the loss of their partner through death, as might spousal carers caring for a partner with a terminal illness. However, the level of uncertainty in relation to disease progression and associated losses increased carers' feelings of worry about the future and increased their concerns about living and coping with a changed partner. Each carer tried to understand their losses and their situation and live with the difficulties that they, and their partners, faced.

It became clear that many experiences of loss were related to the taken-for-granted things of life and ways of living that were no longer possible. From these carers' descriptions it appeared that missing out on ordinary daily activities created voids within their lives, within their relationships and their partnerships. Sometimes carers expressed sadness about their situation particularly when talking about the things they missed such as going for a walk with their partner, supportive family relationships, and the life they had expected prior to the diagnosis of Multiple Sclerosis.

Many of these carers talked about the things they expected but did not realise the significance of them in their lives until they were gone. Les explained:

You don't appreciate what your wife is worth to you...[especially for] the things a man takes for granted. When I was working and Jill was healthy, I just took my breakfast, my lunch, my tea for granted, my supper for granted. I took having my clothes washed for granted and the house [cleaned]. You don't appreciate it. You don't appreciate it. You just take it for granted. You come home from work and you think your days work is done.

Others talked about a “dreamed of” future that was now no longer possible. For some carers, loss was experienced as restriction or reduction. They could still be involved in activities but they were aware that the need to cancel arrangements was highly probable due to their partner’s fluctuating state of health and ability – from able to disabled. The prospect of completing tasks or activities with a sense of satisfaction was often not possible and disappointment followed.

#### 4.1.1 Loss of the Person

Loss of the person was the most emotion evoking, heart felt loss experienced by these spousal carers. From the carers’ descriptions of their experience it appeared that their partner’s outward person, that is their visual body, was still essentially the same, whether disabled or not, but the person embodied within that body had changed. These carers talked about the person in the body they recognised, as being significantly changed due to the disease process or due to the person’s attitude to his/her changed body and changed capability. All of the carers spoke about the changed person they cared for - still their marital partner but different. The researcher interpreted this as loss of the person-in-the-partner. It appeared that these carers had lost the person they once knew and understood. They had lost the person they had married. Stan explained:

My wife was a very outgoing sort of person with a very bubbly and magnetic sort of personality. She used to attract people. She’s nothing like she was. She’s a very sick lady and when people come to visit there is nothing for them. There is never any good news. It’s always been, “Nothing’s improved”...She’s in bed most of the time. I’d say almost 98% of the time because of the way the MS has effected her through the nerves in her stomach and that makes her feel sick if she’s upright, so she tries lying down to lessen the effect...She gets

exhausted very quickly. If we do have a friend pop in she might get out of bed and come down to the lounge room. Just talking to them for about an hour and that's it. She's had enough and has to go back to bed because she's exhausted and she starts to feel sick in the stomach.

These carers experienced the loss of the essence of the person they once knew. They experienced difficulty living with, and caring for the changed person-in-their-partner. In addition, many of these carers experienced uncooperative behaviour from their partners who were resentful of, and had difficulty coping with, their changed self. Andrew said that his partner had changed and she did not like other members of the family enjoying outings that she was unable to attend. This created some resentment within the marital relationship. Andrew recognised this in his partner and explained that:

She was no longer the person that could be and would have otherwise been. She had become an observer and had to be an observer [even] as much as she'd like to be an active participant.

Another carer tried to describe this loss of the person he once knew by stating that his partner was not able to be interested. Many of the partners has lost their enthusiasm for life and did not have the energy, desire or motivation to be interested or sustain interest in previously enjoyed activities or entertainment. Stan thought he saw glimmers of the wife he once loved and enjoyed but he explained she was not able to be interested and the glimmer faded quickly. "Something had gone"; the wife he knew was not there.

In some cases the disease process also effected cognition. Often this meant that partners' abilities to respond and behave in appropriate ways fluctuated. Physical

limitations also impacted on partners' abilities. Both these factors created a changed person. Spousal carers appeared to accept changes in the visual image of their partner but had difficulty coping with the loss of the essence of the person they once knew and understood – the person-in-the-partner.

The loss of the person-in-the-partner also included the loss of a co-parent. The person with whom parenting was shared was lost. The person who fulfilled certain aspects of parenting that one parent finds difficult and beyond his or her experiences as a man or woman was gone. Participant's accounts illustrated that it was difficult to fulfil both the feminine or masculine roles of a mother or father. Andrew expressed his sadness about the effects of a limited feminine component of parenting for his daughter. He said this about his daughter Kate:

[She] hasn't picked up the idiosyncrasies that other girls may have from their mother and to know that that feminine side of things... There is a complement of womanness if you like that she has not been exposed to because Jane is simply stuck in a wheelchair... In other situations where a mother may be able to put some wind under her wings, it's more like lead weights around her legs.

Shared parenting was lost when the parent with MS was unable to carry out his or her expected role. Jane was unable to guide Kate with things like grooming and personal care. Instead the role was reversed and it was Kate who helped her mother do her hair, shower and dress. Andrew found he was unable to offer Kate the 'womanly' support that a daughter would expect from her mother and felt he has lost his co-parenting partner.

Likewise, this loss of co-parent in the partner was also experienced with sporting activities. For example both parents experienced sadness when playing football was not possible when the person with MS was unable to “kick a football with the kids”. The parent with MS was forced to seek other ways of spending meaningful time with children and the significance of football as a sport changed within the family. Gail faced difficulties with her children when their attitude to, and relationship with, their father changed as his physical abilities declined. Eventually Gail’s husband was only able to spend time with his children in sedentary ways. Gail said:

Simon the eldest, he’s the one with the ADD [Attention Deficit Disorder]. He’s felt it worst because his father was always active. [He played] cricket, football, and everything and all of a sudden that stopped. Where as with Don, he’s six and Colin has had [MS] since 1992 [Don was a baby] so Don’s never known his father to be active, so Colin reads books with him and that’s just normal. In Don’s mind that’s what a Dad does, but with Simon, [it’s different] Simon’s had all that and then it just stopped and there’s been problems with their relationship [ever since].

Spousal carers also experienced loss when games of football and shared outdoor family activities were no longer possible. Other less active and more accessible pastimes took on new meaning and greater significance in family life.

Loss of the person-in-the partner and loss of co-parent both influenced and were influenced by loss of companionship and partnership. Loss of companionship and partnership impacted on, and was interwoven throughout, daily life.

#### 4.1.2 Loss of Companionship and Partnership

Generally these spousal carers regarded their partners as their primary companions prior to the changes that occurred due to MS. Because these carers' partners had changed and become people whom the carers no longer understood, special connections of companionship and partnership that were expected in a marriage were lost. Andrew illustrated this when he talked about his wife and their relationship. He said:

You expect a partner in a lot of things, like, to go places or to do things together, or to work together in a situation. There is anticipation that that will be so, or that it is, but of course reality finally takes its toll and you realise there isn't a partnership anymore...the sort of partnership that [did] exist, its [now] not on equal terms. So it doesn't function, it can't function.

In some relationships the spousal carers were able to see their marriage as a religious bond and maintained a changed partnership but many talked about the break down of their marriage. They no longer had a partner to lean on, to rely upon for help and support, and to share everyday activities that people take for granted in life. For example not being able to walk along hand-in-hand was a loss. As Andrew said:

Just a simple walk together to the local park or the milk bar was not possible and that just seemed to take so much away.

Closeness and touch, as expressions of caring and partnership, from their partners became less frequent and carers struggled to live without the reassurance such gestures offered.

Intimacy of a more personal nature was also lost when companionship and partnership were lost. Both male and female carers talked about the loss of their

sexual partner. The female carers talked about missing intimacy at the level of hug and cuddles whereas the male carers talked openly about loss of sexual contact.

Barry said:

Because of the MS and the tempers and the relationship, the sexual side of my marriage disappeared completely. That was acceptable because I knew that person was sick and she wasn't the person I knew, so that was acceptable...and that's very, very hard. I think that's probably harder for a man than a woman and I can understand quite freely how some men just walk out. I think they miss that loss of physical contact with a woman and you just can't take it anymore. That's a major loss because we always got on very, very well.

The loss of a sexual partner was difficult for some carers to accept. The need for a sexual partner was also complicated by feelings of fear and guilt related to personal beliefs and social expectation. It appeared that carers felt that there were no socially acceptable options for the carer who lived with unfulfilled sexual needs. For example one carer felt the image of a young, stable man, walking out on his disabled wife would not be socially acceptable, nor would the idea of meeting a mistress or visiting a prostitute. Some carers felt restricted to a life with a person who was no longer their lover. Andrew said:

Our relationship has obviously suffered enormously, we still, you know, like each other etcetera. We still have a lot of things in common. But, there isn't a relationship there that normally is between a man and a woman. That's restricted because of paralysis [and] intercourse as such ... is very difficult. My options are very restricted therefore I've just taken the view that "Oh bad luck". You can consider all sorts of things and you can consider another relationship, a relationship with a mistress. I haven't taken that sort of option up. You just don't want those sorts of complications.

Andrew went on to discuss some possible solutions as he grappled with his loss. He said:



The general structure of society might be something to look at. We feel uncomfortable talking about it but other cultures don't. There has to be a half way position, where you acknowledge you don't throw people out. There may be ways that accommodate them, but that can't happen unless society accepts that it's OK, and polygamy is one thing. [Polygamy] ought to be looked at seriously in this situation for justice for everyone concerned. It's not really fair that it's so absolute. I really think most people, at this stage in my situation would have deliberately left [their partner].

Some carers were left wondering about the purpose and meaning of sharing a bed with their partner. Some were forced to sleep in different beds and even different bedrooms. This change obviously created barriers to intimacy. Such decisions were very difficult to make as carers realised the implications of such a move. One female carer said it was very sad when cuddles in bed were no longer possible. Another carer felt that leaving the bed she shared with her husband was a loss she could not tolerate. The marital bed was seen as a special private place for sharing with a loved partner. This meaning was shattered and lost when the couple was no longer able to sleep together. Instead, beds and bedrooms often became the place for administering nursing type care.

Whilst loss of intimacy was a very personal concern and loss, many other ordinary daily things that partners do for each other, which make them feel wanted and appreciated, were sadly missed by each spousal carer. Simply missing out on having a cup of coffee made by their partner was a loss. Giving and receiving of presents also took on a new meaning. Jenny said, "If you've got to buy it yourself it's not a present so you might as well not have it". The meaning of birthdays and other celebrations changed and became less important.

Feelings of loneliness occurred when the person with MS was unable to take part in previously shared activities. Leisure time together was lost. Time together began to revolve around caring duties rather than shared events. Even activities such as shopping became lonely, hurried tasks for the carer. Many couples indicated that before MS, shopping had been an enjoyable outing and included coffee together. However, Gail's husband, like many people with MS, was particularly reluctant to be seen in public if he needed to be in a wheelchair and so often opportunities for companionship were lost.

All these experiences, included within loss of the person and loss of companionship and partnership, are interwoven within the relational theme experiencing the loss. These losses also influenced how each carer experienced life as an individual. All carers talked about issues surrounding loss of individuality. This was interpreted as loss of self.

#### 4.1.3 Loss of Self

Loss of self is a sub theme of experiencing the loss. This theme centered on issues of loss of self-confidence, loss of self-esteem, loss of identity and loss of previous role.

Loss of self became apparent when carers experienced increased carer role demands and decreased time for themselves as individuals. Carers indicated that they began to feel less confident about their ability to do the things they used to do. Because of

missed meetings at clubs or social groups carers became socially isolated and less skilled in their hobbies. Many carers identified loss of practical skill with their hobby because they no longer had the time to spend on practice. George highlighted this when he said:

I'd like obviously to be able to do things myself, I miss being able to go off to do things, play golf, even go fishing, I haven't had a fishing rod in my hands for two years.

Most of the spousal carers had become fully occupied as a carer and as a result had reduced contact with people generally. Simply through loss of contact with people most of these carers experienced loss of social confidence and loss of self-esteem.

George also talked about his loss of self-confidence. He said:

Maybe the same degree of self-confidence I had [has gone because] I don't get the opportunity to mix with people the way I used to. Yeah, I think that's probably the biggest thing.

In addition, this loss of self-esteem was reinforced for many carers who believed that some people actually saw carers as lesser beings, as people with less status in society. This feeling of perceived inferiority tended to surface in situations where carers were involved in negotiating for support services or acting on behalf of their partner. Jim said:

At odd times I get a flash that somebody is regarding me in a lesser light because I don't work, [because] I don't have any sort of identity that they can respect, or relate to. There are occasions when you're talking to somebody and you'll get a feeling that what you're saying is being disregarded because you don't count.

These spousal carers felt that they were not valued as people in the same way as people with acceptable employment. They thought that there was no understanding by people in general about what it was like to be a carer. In addition, they felt their

commitment to care for their partner at home was not valued. No explanations were offered for this perceived lack of understanding about carers and undervaluing of carers' roles. Paid employment appeared to be valued and a boost to self-confidence. Hence, when access to employment was lost carers' self confidence declined. Jim talked about his loss of confidence to return to work. He said:

I'm very worried about the future. The way it is now, the future is really out of my hands. I've stopped worked and I'm virtually unemployable. I couldn't get back into [the type of] positions I was in. I'd get a little bit of part time work but that doesn't do much for us.

When situations like this developed, carers generally felt they had lost control over their own lives.

Having acknowledged a loss of control over their own lives, carers also began to acknowledge that they did not have any control over their own partners either. This had an impact on the way they saw themselves as couples. Some carers offered examples of occasions when they believed they were being judged for their partner's presentation and behaviour. For example George's wife, prior to being handicapped with MS, was a woman who took a pride in her appearance and was a smart dresser. George was proud of his wife. But according to George this smart well-dressed presentation was no longer evident and it appeared that George felt ashamed at times and did not want to be held responsible for the way his wife appeared or behaved. He was unable to control the situation. Jim also had similar experiences. He said:

I don't quite know how to explain how it is, how I see it. But, there are times that I feel it's me being judged rather than Jan. Jan's very off hand about the way she dresses, doesn't particularly worry about how she presents. I really have to talk to her for weeks before she'll go and

buy a new dress or something very smart. I like to see her going out looking better than she does. Jan doesn't particularly show any interest at all in the way she goes out. I'm losing it now [my influence to encourage her to dress smartly].

In situations like this carers generally felt they did not want to be associated with their partner any more and did not want to take responsibility for their partner's presentation or behaviour. Nevertheless, they felt society held them responsible.

Some of these carers stressed that they felt unhappy about the word 'carer' because the term 'carer' was a label with negative connotations in some cases, rather than being a descriptive word associated with positive caring activities and understanding. Some carers expressed their concern that the term 'carer' took away so much of their personal identity as individuals, as husbands or wives. They had become known as someone's carer, a possession, and an unpaid assistant who was considered responsible for their partner regardless of the situation and circumstance. They felt they had lost their individual identity. Jenny highlighted this when she described one aspect of her relationship with her husband. She said:

I didn't sign on to be [his] nurse. I mean I know I signed on, you know, in sickness and in health and all that but I didn't sign on to be [his] nurse. I signed on to be [his] wife and sometimes I feel that I'm more nurse than wife.

The need to be available at all times like nurses in a hospital was overwhelming for Jenny who felt she had lost one of the main attributes of her self-identity. Jenny primarily saw herself as a wife and she, like many of the carers, believed her status as a wife was the least recognised part of her life. These spousal carers appeared to have lost their main identity in their relationship with their partner and had become a carer.

The multiple roles of the carer and the need to constantly supervise their partner not only tired the carer but also limited and restricted their activities. It seemed that almost every minute of the 24 hours in the day was taken up with the need to provide care. This included the need to assist with personal matters, to entertain, to encourage, and to always be available to allay anxiety and fear. George said:

[His wife] had the phone with her all the time [so I'm on duty 24 hours a day] and I'm up probably on average, well, I'm probably up every hour and a half during the night" [to attend to her].

Spousal carers expressed their need for "time out" as they had lost time to be alone. Without this time, carers appeared to be consumed by their situation, restricted and limited, whilst they strove to find ways to feel a sense of self and self worth. It was difficult for these carers to meet their own needs as individuals when most of their time was taken up with caring for their partner. Jim talked about his loss of free time and about his efforts to meet his wife's needs. He said:

Jan has become very impatient and occasionally if I say I'm going to be home at 5 o'clock and I'm not home at 5 past 5, then she starts to ring around wondering what's happened. That irritates me a bit. I find [it] bloody difficult to live with, it cuts across the grain...I guess. I was once always able to walk in and walk out and not tell everybody what I was doing so I guess that's one of the things that doesn't sit very well. I resist that one always.

Another carer said, "Your life is not your own any more". For these carers the freedom to be an individual had become a luxury of the past. This was because their partners were controlling their activities through their demands for care and attention.

Care demands also meant that these carers found it difficult to maintain contact with their friends. If time became available to meet with friends, it was restricted and limited by their responsibilities to their partners. Jeanne said:

Once a month I meet with some friends, girl friends. We have lunch. So I give Ted an early lunch, get ahead on drinks (Ted has a catheter so fluid intake is important) and leave him for two or three hours. He can't fall out of the chair. He's tied in [with a] safety belt. Nothing can happen to him so he's quite willing for me to do that once a month. I don't always get there.

Time out to enjoy life independently required extensive planning and as Jeanne admitted, even then nothing may eventuate. Even last minute plans were subject to change. Nothing was certain. Sometimes, unexpectedly, these carers found they had to remain at home to care for their partner who was feeling unwell. However, often the energy and time taken to prepare, plan, organise and arrange was seen as too big a price to pay. Some carers stated it was much easier to just stay at home – at least everything was handy and available.

Loss of self-esteem was clearly evident in these carers' accounts of their experiences. Many talked about loss of confidence and loss of social standing which impacted on their daily lives and their feelings about themselves. These losses were compounded when appropriate and adequate support was not readily available.

#### 4.1.4 Loss of Support

The data revealed that the spousal carers of this study believed that family, friends and the government should be sources of support that could be relied upon during times of need. However, all these carers identified times when they needed help but insufficient or no help was received. It appeared that these carers perceived this lack of assistance as a loss because they believed assistance was available. Spousal carers recognised that lack of knowledge about the needs of people with MS and the work of carers impeded others' understanding. These carers also recognised that their support network, be they family or friends, have busy life schedules both at work and at home and therefore have little time to help. Some carers grappled with the notion that other people lacked the motivation and were perhaps too selfish to help. Fear of what to expect was also identified as a deterrent for people when they contemplated helping. Jeanne talked about one of her experiences. She said:

I said to my sister-in-law, you know, so and so is coming to sit with Ted today. "Oh, Oh," she said, "I'm too busy." She just went into a panic because she thought I was going to ask her and she just can't cope with it.

These carers identified their immediate family as an obvious source of help in all sorts of ways: practical assistance, emotional support, respite and finances. Some felt help should just be available, unconditionally from family members. When this did not happen many spousal carers found lack of family support a major loss. They struggled to understand how it could be that even siblings or their own parents or spouses' parents could not see, and perhaps did not want to see that they needed help. Andrew says that:



[My wife's family] never once in the 17 years picked up the phone and said, "Can we do something for you". Not once, and her sister is a [health professional]. I think it is just basically selfishness, and that they don't want to give up any of their time. Not even her mother.

Andrew was also very saddened by a close family member's lack of support because he felt she was a health professional and should therefore have the knowledge and ability to provide at least some assistance for his wife and children. Other spousal carers talked about special neighbours who used to visit almost every day to enjoy a chat and a cup of coffee. But, since MS had handicapped their partner, the frequency of these social visits declined to a point where no contact was maintained. The supports that these carers felt they should be able to rely on such as family and friends did not appear to be there. Not only did these carers learn to live with a changed person and to live with a changed lifestyle they often had to live with loss of support and assistance from their families. This was particularly difficult for the carers to understand.

However, there were carers who were grateful for family support but they also said that the availability of support declined over time. When their partner was first diagnosed with MS some carers did receive help from family members and friends but, unfortunately the ongoing, degenerative and changing nature of MS meant that their enthusiasm to provide support tended to fade. When the drug Betaferon became available as a treatment for MS that was marketed as a drug that could slow disease progress Stan said:

[My family] thought it was going to fix everything. They were all rallying around and that sort of thing, helping to the point where it seemed overwhelming at the time. It was a bit too much after a while

but after a while people seemed to think that nothing was happening [and so their assistance dwindled, they lost interest].

Stan's sister also offered to come over and stay whilst Stan went to the football and on one occasion she did keep Stan's wife company. But, it only happened once. Stan explained that for some reason his sister appeared to develop the flu when he needed help when other games of interest to him were being played.

There were also situations where the person with MS actually made it difficult for their spousal carers to care and friends to remain friends. Sam, like many people with MS, was his own worst enemy. His partner explained that Sam refused to go out in a wheel chair because he believed that once in a wheel chair he would never get out of it and walk again. Sam's partner said:

I can understand all that, but while he was struggling along, and using his wheel chair in private, all his friends and family were saying to me, "Why doesn't he use a wheel chair? It would be so much easier"...[But] at the time, because he didn't want them to know he was using a wheel chair and that he couldn't do what they were doing because he couldn't keep up with them, a lot of friends dropped off.

Sam, like many people with MS felt using a wheel chair instead of walking was being weak and giving in to the disease and so preferred to stay at home. However, the use of a wheelchair when needed could have been viewed as a useful tool to enhance independence, social interaction and to maintain some supportive contacts. At least it appeared that the carers believed this but were unable to convince their partners of the benefits.

Spousal carers sometimes felt inadequate when they recognised they needed help.

This seemed to be because they felt they should be able to manage on their own, that they should be able to cope. They did not want to ask for help. However, they wished others would recognise their needs, understand and offer help. Jenny said:

I have people say to me all the time. "I don't know how you cope. I'd never be able to cope with what you've done and as well as you've done." That annoys me. It annoys me when people say that because most of the people that say that don't ever say, "Is there anything you need?" or you know "Can I do anything" or "Do you need a break or anything like that.

These carers felt that they should not have to ask, it should be obvious that they needed help. Some carers appeared to crave for help but felt uneasy and unable to actually ask for it. Other carers felt unable to express their concerns about their deteriorating ability to cope and the feelings of pride, shame and guilt prevented them from seeking assistance. When asked about accepting help George said:

I have to admit that it's inevitable, and therefore, if somebody can help or if it is offered, I would accept. But, if it came to the point of physically having to go to somebody and say "Look I need help". I guess it hurts.

In effect, recognition of the need for help did not assist the carer in being able to seek help.

Not only did some spousal carers experience loss of expected support from family and friends; all carers experienced lack of support from governmental agencies and other such services in some way. Carers frequently spoke about the system, the bureaucracy and the difficulties they had in accessing appropriate and accurate information and gaining timely funded assistance not only for personal assistance but

also for equipment. Institutional care options were regarded poorly and often not considered until absolutely necessary. Time delays for any type of support caused much stress and worry. These issues will be discussed in chapter five, the second theme, caring as worrying.

#### 4.1.5 Loss of Income and Lifestyle

Loss of lifestyle is a sub theme that was identified within the theme of experiencing the loss and relates to loss of expected financial stability through loss of career and employment security. All the male spousal carers were employed on a full time basis, and three of the four female carers were employed at least on a part time basis prior to their partner becoming handicapped by MS. Most male spousal carers needed some time to adjust to their new domestic responsibilities as they took on a greater workload at home including cooking and cleaning. This meant that many male carers decreased or stopped their paid employment accordingly. Female carers, on the other hand, continued to provide care as they always did but tended to increase the degree and intensity of that role. One female spousal carer continued with part-time work and one was determined to return to the work force in some way. These women tended to identify loss of time to themselves as a major result of intensified caring roles. For both spousal carer and partner, their usual financial management within their partnership was lost.

Loss of expected family income could be partly replaced by the person with MS gaining a disability pension and their carer receiving a carer's pension. However the

acquisition of a disability pension depended on their spouses income. As two of the carers continued to earn a full time wage above the set threshold, this meant their partner was not eligible for the disability pension, either full or part. A carer's pension is also means tested and so engaging in part time or casual employment was not always beneficial financially. Gail's experience illustrates concern regarding loss of income issues. She said:

We've gone from two full time wages down to [two] pensions plus a part time wage so I'm scared, scared. Financially wise we were scared...I get a carers pension and I work 10 hours, so I only get a 100 dollars a week, a 100 dollars extra on top of the carers pension and Colin gets his pension [disability pension].

For George it is a different experience related to the same issue of finance. He said:

The only problem I have is that if I get another full time job Jan will lose [her disability pension]. She was on it once before and when I went back to work she lost that. At the moment I get the dole or part dole depending on how much I work.

Some carers found leaving the paid workforce a great loss and one that was difficult to accept. Jenny felt strongly about her right to work and have her own life but also recognized the futility of working whilst her husband required so much assistance.

As she lamented, other sources of support to enable her to work were not available.

She said:

I'd love to work. I hate not working. I hate it. I have worked in the hospital [system] for 14 years in catering and I once had my own business for a while. I've done everything. You name it. I've cleaned pubs. But this [is] the first time I've been unemployed since I left school, except to give birth. I liked it for the first couple of months. It was like a holiday. It was like being on holiday but now I'm starting to get real towy. I [stopped work because] it just got all too difficult. It got too difficult trying to do everything. I was exhausted but I still look in the paper every week hoping that some miracle job is going to turn up that would suit my hours...because I'd like to have my own life.

Giving up work to care for their spouse was a difficult decision for many of these carers because of personal loss related to individual identity and self esteem as discussed above under the sub heading loss of self.

Individual and shared lifestyle and recreational activities were restricted or lost through loss of income. All carers talked about loss of holidays and restricted family outings simply because of lack of money. However, there were other factors that inhibited holiday and recreational activities such as the equipment needs of their partner. Carers often needed equipment such as wheelchairs, hoists, ramps and handrails to enable them to care for their partner safely and comfortably. Many carers highlighted difficulties obtaining such equipment for use at home as documented in chapter five, caring as worrying, sub heading worry about lack of support. Essential equipment for holidays and outings was even more difficult to access or organise. Wheelchair access to public buildings and holiday accommodation including the availability of suitable toilet facilities for disabled people were practical concerns that had to be considered. Often it was simply not possible for carers to take their partners because of a lack of suitable facilities. Some carers stated it was easier to stay at home, even if they did have enough money. Even at home loss of adequate family finances also influenced other entertainment possibilities as Gail explained:

If somebody phones up Friday night and says we're going out to a restaurant tomorrow night "Do you want to come?" There's no way. We'd have to organise that two months in advance to be able to put a few dollars away every week to be able to go out. [Even going to Macca's (McDonalds) was often out of reach financially]

It appeared that loss of income impacted on lifestyle activities such as holidays and recreational opportunities for both carers and their partners. Carers' descriptions indicated that their lifestyles had changed and that they experienced loss in relation to these expected, taken-for-granted, activities.

## 4.2 CONCLUSION

Experiencing the loss has been presented under the sub headings of loss of the person, loss of self, loss of support networks and loss of income and lifestyle. Each carer's story illuminated that as their carer role increased in response to their partner's increased handicap so too did their experience of loss. With the increase in caring roles and responsibilities, carers experienced further losses. Carers identified losses in relation to their own identity, self-esteem, and confidence. Loss of employment and loss of income further impacted on lifestyle activities like holidays and hobbies. The experience of loss was intensified when little or no support was available from family, friends or government. This lack of support was also experienced as a loss in itself as such support was expected and anticipated. Even though loss was a constant part of each carer's life, most carers did not appear to be aware of when and how the next loss would present itself. Preparation for loss was not evident and none of the carers appeared to plan for the future in terms of living with loss. However, all carers expressed concern about their ability to continue to care for their partner and about their future. These concerns were experienced as worry and hence the second thematic pattern, caring as worrying was illuminated. The next chapter will present the second relational theme, caring as worrying.

## **CHAPTER FIVE**

### **CARING AS WORRYING**

Caring as worrying emerged as the second relational theme that represented another strand in spousal carers' experience of and ways of living with loss. The previous chapter illuminated and described loss experiences encapsulated in the relational theme, experiencing the loss. This chapter will expand on understanding carers' experiences of living with loss through caring as worrying. The chapter will provide an overview of caring as worrying and establish the relationship between concern, caring and worrying.

Within the relational theme of caring as worrying, three sub themes were identified that illustrated the main concerns the participant spousal carers expressed whilst caring for and about their partner. Caring as worrying will therefore be presented and discussed under the sub themes: worry about the future; worry about loss of partnership; and worry about lack of support.

#### **5.1 CARING AS WORRYING – AN OVERVIEW**

Worry was interpreted as a way in which these spousal carers expressed their concern in relation to their experiences of loss. The concerns and worries were manifestations of these carers' care and devotion to their partner. These carers appeared to worry because they had concerns about important things in their lives and major concerns about their cherished partner's future. In particular, they worried about possible



future losses such as losing their partner to institutional care. This aspect will be discussed later in this chapter.

Each carer expressed concern in relation to the potential deterioration of their health. They worried about their future ability to continue to care for their partner. Thinking about what would become of their partner, when it was no longer possible for them to provide care at home was a major source of worry. Uncertainty about MS disease progression added to these carers' concern. Most carers knew of the degenerative possibilities of MS and knew that their partner may experience acute disease exacerbation or a gradual general deterioration. However, despite knowing such changes were inevitable, few carers had readily available coping strategies for the potential challenges of loss that the future held. Hence these carers appeared to be worried with thoughts and concerns about their ability to care for their partner and the level of care their partner may need in the future. This dilemma confronted all these spousal carers and any changes in their partner's needs, abilities and behaviour heightened concern and worry.

In addition, the very sources carers anticipated for support, did not appear to be readily available. Worry was generally increased when support, be it from family members, governmental agencies or health professionals, for the maintenance of home based care, was not available during times of crisis or need and thus there were scant options for carers. This experience not only created worry for carers it also

represented a loss as discussed in chapter four and increased their vulnerability and feelings of isolation.

Worry was generated out of deep concern and devotion for their partner and centered around how best to meet their partner's needs. Such worry through concern and caring had become a daily experience for these carers and so caring as worrying, was identified as a relational theme that described part of the carers' way of living. Carers experienced worry about the future, worry about loss of partnership and worry about lack of adequate support. The following sections address these areas of worry.

#### 5.1.1 Worry about the Future

The experience of worry about the future for these carers occurred on a daily basis as their caring role expanded, as they became more aware of the nature of MS. Three major worries about the future emerged. Concern for their own state of health as well as their partner's health prompted thoughts about how to live in the future and worry about how they would cope. Carers struggled with an underlying fear that their partners would need to be cared for outside of their own home because of deteriorating health (either their own health or their partner's health) and insufficient support and resources. The fear that their partner may have to live in a nursing home or other such accommodation was a major worry because of previous bad respite experiences. These main worries about the future will be discussed as part of the relational theme, caring as worrying under the sub themes of worry about own health, worry about partner health, and worry about institutional care.

#### 5.1.1.1 Worry about own health

Many carers expressed concern for their own health and well being. They worried about the deterioration of their own health and were concerned about the

consequences of such that may limit their ability to provide care for their partner.

Carers' strove to provide loving, homely care for their partners but worried about the

maintenance of their own good health in order to do so in the future. Some carers

were at risk of back injury due to the frequency and type of assistance required by

their partners for moving even from bed to chair. Also changes in health occur

simply due to aging and so all these carers faced potential deterioration of health and

reduced ability to provide adequate care. Other problems such as tiredness,

exhaustion and lack of energy also impacted on each carer's general health.

However, these spousal carers constantly pushed themselves to the upper limits of their own ability and strove to remain strong for fear of letting their partner down.

These carers appeared to be unaware of their limits. They were, however, aware that a time could come when they would be unable to continue to provide care for their partner at home in a way that was acceptable, safe and appropriate.

Worry about not being able to continue to provide care for their partners in the future also created a secondary worry about who would care for their partner. Jeanne said:

I worry about something happening to me. What would happen to Ted? That's my biggest worry. If anything happened to me and he can see, like we've discussed the other night, [that] if I collapsed, he can't do anything to get help for me...My biggest worry is that I hope I outlive Ted. That's my ambition in life – to outlive Ted.

All carers expressed their concern that there would be no-one else available to care for their partner. Not one carer identified a family member who would be prepared to help or take over their role as carer. Concern revolved around deterioration of their own health and the potential for their partner to require levels of care that exceeded their ability to provide that care. These concerns created worry about how to plan for the future.

#### 5.1.1.2 Worry about partner's health

Each carer reflected that they had worried about their partner's health particularly in the period leading up to confirmation of the diagnosis of Multiple Sclerosis.

Uncertainty about how the disease would manifest itself in the future was a contributing factor. Many carers related incidents during the period leading up to the diagnosis of MS that worried them and created fear in their lives. Even then it appeared that these carers worried about the future. Factors that influenced carers' level of concern were the length of time it took to arrive at the diagnosis, the number of visits to a variety of doctors and the number of tests and investigations prescribed. Some were told that their problems were psychosomatic. Eventually the diagnosis of MS was often a relief to know that they were not "going mad" and that their partner really did have an organic illness. At this point, worry appeared to be alleviated somewhat, but when these carers began to realise what MS would mean in their lives they began to worry about the future again.

These carers worried about what aspect of independence their spouse was going to lose next and as a consequence, what impact that would have on their caring role and own independence. Mostly carers acknowledged that without a cure, their partners were not going to get better and hence they strove to accept their lot in life. George explained:

As she progressively gets worse and that is inevitable, there will be more and more that will have to be done for her. I worry about whether a situation will be reached where she cannot be left alone during the day. If she cannot, then how will we cope with that situation?

George, like all the other carers in this study, worried because he was concerned about his ability to provide the level of care his wife may require when her condition deteriorated. Deterioration of his partner's health signaled the potential need for nursing home care. Jim expressed his concerns and worry about not being able to care for his wife and the fear of institutional care but focussed on the loss this meant for him. He said:

I guess the planning and the not knowing exactly where you're going to be in another week or another day or another six months or whatever it is, [means] there's always the thing hanging over your head. That it's for nothing because eventually Jan will get that ill, that I can't look after her. She'll have to go [into a nursing home] anyway. And, I'll be on my own and lose in that sense.

The impact of the diagnosis of MS particularly in terms of unpredictability and uncertainty effected all carers. Living with the unknown, the prospect of future losses and further limitations on daily living activities became greater sources of worry. Worry escalated as more symptoms of MS became apparent in their partner and impacted on their partner's ability. Carers worried about how they would cope in the

future and continue to provide home based care. Uncertainty and planning was made even more difficult and frightening when their partners talked of suicide.

Worry about the possibility that their partner may suicide was a major concern for nearly half of the carers who were interviewed. Carers stated that their partners thought about suicide when they felt that their life was no longer worthwhile, such as when the need for a wheelchair was imminent, when future prospects with disease progression were bleak or when a sense of helplessness was felt. Whereas, Barry's wife regularly stated she wanted to kill herself. As a result of rapid onset MS Janice was severely handicapped and was unable to attend to her personal care or any activities of daily living without help. Janice had been a very active capable woman but now appeared to be helpless. Janice's behaviour confronted and challenged Barry on a daily basis as he struggled to attend to all of Janice's needs without help or support from anyone. Barry said:

[His wife] Janice would cry almost all day long, from the time she got up and the first phrase she would say was "I wish I was dead, I'm going to kill myself". So immediately, this is first thing in the morning [the first interaction between Janice and Barry for the day]. [It] knocks you right off your stride for preparing for that day.

But the daily routine continued regardless and despite Barry's personal feelings of despair, concern and worry. He went on to say:

You shower her, get her up, prepare her, dress her, and she spoke very little in that time, cried in the shower, cried when getting her breakfast. I'd get her comfortable in the main room and she'd settle for a little while, have a cigarette, cool down, and then she'd cry again.

This cycle happened regularly and Barry responded by trying to make his wife happy by being with her, by setting up the television by providing afternoon tea, or anything to divert her attention.

Such outbursts of despair and threats of suicide were very difficult emotional situations for these carers to manage. In one way such repeated references to suicide became part of the daily routine, with the carer believing it would not happen. Yet, at the same time there was always the possibility that the person with MS might in fact suicide. These carers struggled with balancing the unlikelihood with the possibility.

Some of these carers were concerned that their partners may suicide through overdose. Risks were taken regarding medication management. Some carers filled dosette boxes to enable their partners to manage their own medications. Sometimes district nurses visited weekly to fill dosette boxes. However, it was still possible for these carers' partners to access all medications in the dosette and even the source medication bottles. Strategies were not routinely in place to prevent overdose attempts. George felt helpless because his wife was often left on her own whilst he worked, and although unable to leave the house she was capable of taking her own tablets. George said:

My wife has taken the attitude on a number of occasions that when she reached the point where she is no longer capable of looking after herself, she would prefer not to be around and this is something which worries me that she would do something silly.

George felt sure that his wife was capable of overdosing on her tablets and was concerned that she may even 'stockpile' tablets from her dosette. Concern about the

possibility that his wife may suicide became a daily worry. Other carers knew that their partners were not physically capable of committing suicide even though their partners talked about suicide. In situations such as this, these carers still worried because of the intense unhappiness exhibited by their partners.

### 5.1.2 Worry About Institutional Care

The need to move their partner from home based care to institutional care such as a nursing home or other nursing home type residential accommodation was a major fear and worry for all carers. Concern about the standard of care that their partner would receive was a major source of worry. Many carers talked about very negative experiences with nursing home staff. The main worries were related to lack of understanding shown by staff, and their lack of caring, empathy and compassion, and their lack of respect for individuals. Some carers felt that nursing staff focused on tasks rather than the person in their care. Some carers felt their partners were dehumanised when they were in institutional care and left in conditions that were totally unacceptable. Jeanne said:

I came to visit [my husband] one day and the smell of urine was absolutely putrid. He was sitting on a donut, you know, one of those inflatable donuts, and I had one of my pillow slips over it. I can show you that pillow slip. It's stained with mildew. Ted was managing himself at that stage, using a bottle, he could use his hands [but he had accidents]. I said [to the nursing staff] "Look, you wouldn't leave a baby like that. Why would you leave somebody who can't help himself in that situation?" [They replied] "Oh, we just don't smell urine. We don't smell it any more. We just don't notice. We wouldn't know if anyone was wet or not".

Jeanne was disgusted and saddened to find her husband in such a humiliating state.



Some of these carers stressed difficulties associated with reporting unacceptable care to nursing staff. They and their partners were fearful of retribution if they complained. Some carers talked about staff who did their job without care and compassion, preferring to believe that they knew what was best for their patients. It appeared necessary for individuals in institutional care to insist and persist if they wanted and needed particular approaches or equipment to meet their care needs. Jeanne recalled staff being so bad tempered with her husband when he insisted on the use of a hoist that the staff caring for him “turned him on the side that they knew he wasn’t happy on and left him there”. Fear of and worry about more unacceptable ‘care’ prevented the reporting of such incidents.

Jim was saddened by the poor standard of care provided for his partner. Empathy was often a missing ingredient. Jim described some of the ‘care’ as unacceptable and dehumanising. Often when Jim visited his wife, who loved to talk about many topics with anyone (staff, visitors, other residents), he would find her isolated from other residents, sitting in her wheel chair facing a wall or lying in her bed, facing the ceiling. Jim just couldn't understand why this would be so. He knew his wife was keen and able to engage in conversation to discuss issues, yet it appeared to him that the staff who cared for her and "knew" her, were unaware of her needs and desires. Jim was very concerned and disappointed that the staff did not enhance and encourage the one activity that his wife was able to do and enjoy.

These carers and their partners expected to be able to live in their own home and enjoy the lifestyle they had anticipated and worked towards. When the viability of these important values and ways of life were at risk of being lost concern was generated about future options. In essence, these spousal carers cared about their partners and they worried about the potential need for their partners to live in institutional care facilities and be forced to forgo being cared for at home.

### 5.1.3 Worry about Loss of Relationship

Worry about loss of partner relationship and marriage breakdown was identified as a part of the sub-theme caring as worrying. Marriage partnerships and cherished relationships were at risk of being eroded or lost when these carers' partners became changed people who often behaved in uncooperative and unacceptable ways. This theme, worry about loss of relationship relates to caring for a changed partner.

From these carers' accounts of their experiences it appeared that their partner had become changed people with challenging behaviour which made living with them difficult. Whilst these carers recognised some of their partner's demanding, seemingly uncaring and self-centered behaviour was possibly a manifestation of MS, most carers were concerned about the effects of such behaviour on their marital relationship with their partner. Andrew suggested that his wife had made life a bit difficult for him and their children. He said:

I think she's been unrealistic in her demand and certainly not very generous about what we [the family] could do when the opportunity presented itself. She takes this negative justice view of things. If we do

something we like that she hasn't done she feels she's missed out, whereas if we don't do it, she feels fine.

Carers tended to remain patient and tried to tolerate their partners' poor behaviour but were disappointed because of lack of recognition from their partner for the care that they provided. Carers often felt frustrated with their role and some stated that feelings of resentment began to develop, particularly when they felt they were taken for granted and treated more like servants than caring husbands or wives. George struggled with his commitment to care for his wife and with the way she treated him at times. He said:

Jan has always been a person who has been relatively self-centered. That certainly has not changed. Sometimes you take her out in a wheelchair and the way she reacts to things [makes] you cringe. Sometimes you'd like to smack her backside but you know that you can't. Occasionally her reaction to things that you've done or when you're trying to help, is such that you sort of reel back and you could smack her across the face, but its not something that you can do. However, it certainly causes resentment and certainly puts pressure on [our marriage], no doubt about that.

These carers worried about how much they could tolerate before their marriage partnership deteriorated and was lost. In some cases feelings of frustration and restriction were magnified when partners refused to do for themselves the basic things that they could do. Jenny knew her husband could do certain things. She explained:

Like last night, I unbuttoned his shirt and went to get his pajama top and came back, he was still sitting there with his shirt on. He can take his shirt off himself but he was waiting for me to come back and do it. I said to him, "Why didn't you have a try to do it? He said, "Because its easier if you do it."

Behaviour, such as this, exhausted carers and was seen as unjustified by these carers.

Despite worrying about how to live with challenging behaviour, lack of cooperation and lack appreciation, these carers continued to provide care for their partner. Carers appeared to consider their commitment to their partners as important but at the same time had concerns about their ability to maintain that commitment. Carers worried about the detrimental effects of their partner's behaviour on their marriage partnership and worried about its viability in the future. These carers felt trapped at times and thoughts of divorce were common.

#### 5.1.4 Worry About Loss of Support

All carers talked about the worry of having to negotiate their way through health and social welfare systems that were available to provide assistance and support.

However, according to these carers, rather than provide enabling assistance, the people within these systems and the ways the systems were set up actually created worry, anxiety and frustration for both carers and their partners. These carers worried because the systems and the staff working within them appeared to be unable to understand carer needs or show any empathy regarding carer needs. These carers worried that their situations and requests for help and support would not be considered individualistically. As a result carers avoided or sometimes delayed seeking help.

Carers talked about two main hurdles that created barriers to actually seeking help. Waiting periods and excessive paperwork were encountered each time negotiations with care agencies or systems took place. These hurdles created immediate

frustration and ongoing worry about the future outcome of any applications for help. Frustration occurred because of the long waiting periods involved and worry occurred because nothing was guaranteed. Some of these carers worried that their requests might be denied. Even when applications for help were accepted these carers also experienced very long time delays between requesting help and receiving help, be it in the form of equipment or resources for personal support. Carers repeatedly expressed concern about all the "red tape" required when applying for assistance particularly in the form of pensions, help at home or equipment.

These carers expressed great concern and worry over the acquisition of essential equipment to improve their partner's independence and improve their workplace safety. Some carers felt that they had been struggling with extremely unsafe working conditions that health professionals would not work under. Carers identified hoists and wheelchairs as costly pieces of equipment that were difficult for people to purchase. Without this equipment carers risked injury whilst trying to lift or transfer their partners. These carers clearly expressed their concern for themselves and their partners wellbeing and safety. One carer indicated that nurses would not engage in such activities without the appropriate equipment. She explained:

[That her husband, Sam], had a wheel chair, a hoist, a shower chair and a monkey bar all on order through PADP for a year. [She said,] "We had to wait but when he had an operation and [all of a sudden] we had district nurses and people coming [and they had to use] this archaic equipment that I had borrowed from the MS Society. [For example] Sam had to pull down on [the hoist] to get it to go down, whilst I was releasing the thing, that's how bad it was. The visiting nurses said, "This is ridiculous, you can't use this equipment. Who has been helping you?" [I told them], nobody, I've been doing it all on my own. They rang PADP, the poor PADP person. She had about

20 phone calls in a week and in the end she said give him everything. I think she just didn't want to hear his name anymore. We got everything new within a week and it had been on order for a year. It happened just because of people with a bit of clout.

All carers stated the response time in obtaining equipment from the Program of Aids for Disabled People (PADP) was very slow and many carers stated that equipment had taken months, sometimes 12 months or more, to be delivered. These carers felt they were expected to manage and that no one understood their situation.

These carers also experienced dehumanising situations when seeking funded assistance for personal care and home help. Jenny explained:

We've been trying for five years to get Sam a carer. [Finally a personal care assistant started coming about a year ago] and that was because the MS society agreed to give us a carer after he had an operation because it was a lot more work. [Sam's MS symptoms had increased and he was less able post operatively.] Then a month ago Linkages just finally accepted us after the third application. And, we've been on the In-Home-Accommodation Support waiting list for about five years.

Assistance for carers appeared to be limited. Some of these carers highlighted the lack of services offered for people with disabilities and for carers. They also highlighted difficulties associated with finding and accessing services that did exist. There were always selection criteria, such as age, location, and diagnosis, to be met prior to even being considered for some forms of assistance. Sometimes people just did not "fit" anywhere. One carer stated:

[Despite] all these funding programs, he was too old for one and too young for another, and too sick for this and not sick enough for that. Excluded from one because he worked and one because he didn't work. There were all these criteria and he just didn't seem to fit into any slot.

These carers identified lack of flexibility and lack of client focus within the health care and social welfare systems. The systems and resources existed to varying degrees, but rather than help, they actually caused carers to worry about the future. They worried because of the lack of timely resources that impacted on their ability to maintain their caring role. These carers cared about the quality of the care they provided for their partners and it worried them when this quality was compromised by lack of assistance.

## 5.2 CONCLUSION

This chapter presented the relational theme caring as worrying. Caring as worrying was about carers' expression of their concerns related to loss experiences and the manifestation of their care and concerns through worry. To illustrate caring as worrying three sub themes, worry about the future, worry about loss of relationship and worry about lack of support systems were presented. There were also sub sub themes such as worrying about own health, worrying about partner health, worry about institutional care. Each sub theme and sub sub theme occurred in concert with each other and influenced carers' ways of living.

Whilst striving to live with these experiences, carers' accounts showed that they wished for cooperation from their partner. They also wanted non-judgmental, timely support from governmental and health care systems set up to assist carers and their partners. However, these wishes were rarely realised and the reverse often occurred. That is, lack of support and lack of support systems created increased worry for carers

whilst they endeavored to provide care at home for their partners. However, these carers appeared to cope and continue to be committed to caring for their partners at home.

Carers' ways of coping and living with caring for their partner with MS were also identified and will be discussed within the third relational theme, reinterpreting life meaning. Reinterpreting life meaning is presented in chapter six.



## **CHAPTER SIX**

### **REINTERPRETING LIFE MEANING**

Reinterpreting life meaning is the last of the three relational themes that emerged from the data and describes part of spousal carers' way of living with loss.

Reinterpreting life meaning encompasses carers' main ways of coping with loss. An overview of this relational theme is presented followed by the sub themes. These are: a renewed sense of self; understanding one's situation; and living in the present.

Finally a summary of the chapter is presented.

#### **6.1 REINTERPRETING LIFE MEANING – AN OVERVIEW**

The carers of this study showed that through their own personal life experiences they were able to redefine their situation and give new meaning to daily experiences.

These carers lived through losses and challenges. They struggled through periods of vulnerability and managed to gain strength. Some carers were able to change the way they did things. Some gave up old hobbies and commenced new ones. Some refocused their expertise to other areas of employment. However, all of these carers moved beyond the limitations of their situation by being aware of, and by taking the opportunity to engage in what was possible. That is, they were able to accept their situation and the limitations it created in their lives and at the same time they were able to recognise and grasp opportunities to develop and grow as individuals. In conjunction with this experience they reinterpreted themselves, their worlds and redefined their situation, leading to a strengthening of self and an acceptance (either

partial or whole) of their changed partnership and situation. In essence, through reinterpreting life meaning as they lived through loss experiences, these carers were able to recognize their strengths and to feel proud of their achievements, even though their life trajectory was not in accordance with their ideal plans or expectations. Reinterpreting life meaning emerged as a relational theme that further illuminated the lived experience of these spousal carers.

#### 6.1.1 A Renewed Sense of Self

These carers developed a new sense of self and a new sense of Being through seeing themselves as valuable, and by reevaluating who and what were important within their lives. These carers became more able to manage their lives, their situation, their space and their time. Their ability to do this came from a renewed sense of self. This sense of self was developed out of a sense of knowing where they had come from experientially and where they were going. These carers had developed a new sense of being in-tune with themselves through the experience of their carer role. Their ability to manage and live through many loss situations and their ability to understand themselves better helped them find new meaning, purpose and comfort in their lives. Stemming from this, carers were able to understand their situations more clearly and gain some sense of control within their lives as they refined what was important to them.

Feeling comfortable, feeling at home in their worlds was possible when these carers felt a sense of control over their lives. Most carers had developed strategies that

helped them maintain this sense of control and a sense of themselves. Fiddling about with wood, nuts and bolts, working on a computer, digging in the garden and going to work were some of the activities that helped carers renew and refresh their sense of individuality and sense of self. They were able to acknowledge their own identity and their needs as a person. This enabled them to maintain and build on their sense of self and self worth. The back shed or its equivalent was often regarded as a place to unwind, to let off steam and to seek refuge. Barry said:

When Janice's [behaviour] got on top of me and it was getting too depressing I would walk away from Janice and go to the shed. I'd go up there for an hour...I'd relax in that hour. I was able to control myself again, pull myself together...I've got a couple of little machines up there and I'd just potter about. There's always something to do; fix a garden tool, fix the barrow, tidy the garden, a nice big garden to keep busy...Anything to take my mind off things and relax and pull myself together.

Carers used time alone, their own space, whether it was in their shed or elsewhere, as a place to talk to themselves, to put things into perspective and to gain the strength to continue to live within their situation. Later during his interview Barry said:

You could talk to yourself inside your mind. "Say cool down, cool down, I've got a sick wife who is not as good as she used to be". I used to tell myself that in the back of my mind.

In addition, each carer developed their own way of reviewing their life and their situation. Most did this regularly by engaging in self-talk. A few of the carers confided in others. Les took time out to reassess his situation and search for meaning when alone at night. He said:

I do my soul searching when I go to bed at night. I put Jill to bed in her room and then I go to bed about a half-hour later and I just lie in bed and think about things.

Carers often sought a place of solitude to give themselves 'time out' from their role as a carer even if it only meant sitting in their car alone whilst parked at the end of the road. Time out enabled carers to revitalize their Being. That is to “recharge their batteries”. This was important to these carers as it enable them to “remain strong” in order to continue to care for their partner.

Some carers felt able to live with whatever life presented. Their ability to make choices and their ability to overcome difficulties relating to their role as a carer, created a sense of pride in some carers. Many carers stated that they had changed the way they lived and worked. They were proud that they were still able to care for their partner and cope with living in a changed way. Jim was proud when he explained his situation. Talking about a promotion offer Jim said:

[When my job was in question and an offer was made], at least that was a known choice and I did make the choice and said no. I felt a little bit robbed but it's something you just have to live with I guess. The other alternative was to get divorced, knick off and take the job.

Later Jim went on to say:

I've always felt it a bit rewarding about the way that we have stayed together and that Jan hasn't been sort of left [in a nursing home]. Generally I'm quite happy with the way things are going.

Being able to continue to support their partner was one of the positive aspects of these carers' lives. The realisation that they could cope was a boost to their self-esteem.

Some carers also felt that being actively involved in a job allowed the carer to develop and grow as an individual. This also strengthened their sense of self-identity.

Gail talked about her job. She said

God I'm tired before I start, you know, I get up, rush around with the kids, I take them to school, come back put a load of washing on, clean up the breakfast dishes and go to work. I think I've got to work another five hours here [at work] and it is difficult work but that keeps me going. If I didn't have that I think, I don't know, I think I'd be ill in a mental asylum. So that really keeps me sane. It really does but besides that I mean nothing worries me.

Andrew also felt that being active and working helped him maintain his sense of himself. He said:

I think I've done quite well. I'm happy with what I've done. I think I've been challenged, you know. I've changed career and swapped jobs a couple of times and managed mortgages and guided the kids. I've been forced to be a better person (laughs).

Carers developed their abilities and made the most of their lives by understanding their situation rather than trying to live a life they had expected or anticipated.

### 6.1.2 Understanding One's Situation

Each of these carers, in various ways and to varying degrees, learned new ways of living. They developed an understanding of their situation and their world as a spousal carer through being involved in their situation. Being involved encompassed concerns such as time, the context in which life was experienced, their partner, and personal issues, limitations, restrictions and resources. All these concerns have been identified in the carers' stories as contributing to the carers' ability to understand their situation and therefore gain some sense of control over their own lives. From this sense of control carers were able to assign new meaning to things of importance and

so start the process of reinterpreting meaning in their lives. This enabled carers to have a sense of purpose that in turn allowed them to be actively involved in their situation and develop ways to achieve what was possible in their lives.

By being involved in their situation these carers learned to understand how life was for their partner and to understand life from their partner's point of view. One carer suggested that putting herself in-her-partner's-shoes was a way to 'learn to know' what life was like for her partner. This in turn allowed her to accept what was happening, and so feel in-tune with her situation rather than battling to regain what was. She said:

I keep trying to put myself in his position and I think, Well what would I do? How would I cope? I mean there are times, when he gets an awful lot of pain and he copes amazingly well with the pain. I keep thinking, well, there is no way I would be able to cope as well with the pain that he feels. I suppose the thing that gets me out of it again [feeling overwhelmed] is trying to put myself in his position.

Being able to see the situation from their partner's point of view was enhanced when carers' were well informed about MS and its signs and symptoms, particularly relating to cognitive ability. However, carers still struggled with understanding and knowing when their partner's behaviour was attributable to MS itself or when their partner was just being uncooperative. Understanding these issues in relation to their whole life with their partner, including their time together prior to MS provided a basis for being able to understand their private, more intimate relationships with their partners. This ability was enhanced when marriage partnerships were cherished relationships.

Understanding life with MS within the context of married life appeared to be a helpful strategy to coping. Some carers stated that they had been married for many years and that the thought of abandoning their partner, who had treated them well, with love, respect and equality, was out of the question. Walking out or becoming divorced may have been contemplated by many, but generally, such options were not explored. The will to continue to provide for and share life with their partner who had provided for them and been a friend was of utmost importance. Jeanne's husband was totally dependent on her and this limited and restricted her individuality but she cherished her marriage. She explained:

You marry for richer or poorer, better or worse and so you can't enjoy 25 years of wonderful times together and just say, "Well, goodbye, I'm off, you're no good, so, I'm not going to look after you. I'm not going to spoil my life". That has never been in my thoughts whatsoever. As I say, we've got a very good relationship, loving relationship, and that's what we want, to be together. He's been too good a husband, too good a provider and father, to just say "Goodbye".

Carers felt proud of their commitment to care for their spouse and much of the time they did feel good within themselves.

With renewed understanding of their situation these carers were able to view life positively. This sense of positivity was apparent throughout the interview text particularly when carers talked about opportunities. Many carers stated that the situation they were living in actually created opportunity for personal growth and development. These carers enjoyed special relationships with their children that had become possible through a shared commitment to family life and a need to support each other beyond normal expectations. Andrew stated:

The fact that we've had to plan so much together, what we need to do has made us a very tight unit, I know my children very well and they know me very well. It is a plus. It is a plus. My relationship with my son for example is very very frank, a solid relationship and we've grown together over the last 18 years. It is the same thing with my daughter.

Children took on added responsibilities in order to manage some of the jobs their parent with MS might normally have been responsible for. Changed family dynamics in terms of who did what at home changed the situation for children. This encouraged sharing and increased awareness of others needs. Jenny was very proud of her children and explained:

I've only been getting home help probably for the last two years. Up until then I did everything. The kids had their chores, and probably more chores than the average kid but you know that's helped them along the way. My kids are very independent and they can fend for themselves. I was over next door. They've got 19-year-old twin girls. I went over the other day and they just told me they didn't know how to use the washing machine. I was horrified. My daughters were horrified. My kids could use the washing machine when they were 10 years old. So that's been good for them too, they've grown up, they had to be independent.

In addition, these carers and their children's views of people with disabilities were reinterpreted and redefined. This growth in experiential understanding was expressed when other people with disabilities were encountered. Such changes in personal growth and development grew out of an increased understanding and intuitive knowing about how to live with a partner or parent with disability.

Once in-tune with their situation and the limits inherent in their situation these carers were able to develop interests and hobbies. This was seen as positive. Jim was sad that his fishing boat had not been out of the drive in 10 years but he had taken on new



activities in an effort to maintain his space and not to become house bound. He explained:

Tennis and bowls took the place of fishing. The tennis courts are just across the road and bowls is just a couple of blocks up the road.

All carers sought this sort of balance in their lives in order to look after themselves and to be readily available to their partner should the need arise.

The above descriptions illuminate some ways in which the carers in this study developed understanding of their situation that enabled them to live more positive lives and identify personal achievements. By understanding their situation they were more able to feel comfortable within their worlds and tackle new opportunities or difficulties as they arose.

Understanding their situation and living in the present occurred in concert and both were sub themes within the relational theme reinterpreting life meaning. Living in the present not only involved renewal of one's sense of self and being able to understand their situation, it also involved carers' ability to live in the here and now.

### 6.1.3 Living in the Present

Living in the present is about living in the here and now. Living in the present involved a philosophical change in thinking about time. These carers developed an ability to understand and learn from the past and to make way for the future whilst dwelling in the now. These carers' attitudes to time in hours and minutes, days and years changed. Clock and calendar time were no longer relevant except to record

appointments and to put limits on activities. In other words clock time served as a boundary.

Rather than using dates and clock times, these carers recalled events as indicators of time. Such events were usually related to changes in their partners' state of health. Attitudes to time particularly in relation to when things and events should happen became more flexible. Most of these carers adopted a day-by-day approach to life, preferring to live in the now. This day-by-day approach reduced stress and anxiety and allowed carers to feel comfortable with their situation. Carers learned to do what they could at a given time and learned not to feel they had failed when events or plans were not completed. This approach was put in to practice with issues like shopping, outings and social engagements. Les stated proudly:

I know its an old cliché but I just do things day by day, that's all I do, I don't plan. As far as shopping goes, I don't have a shopping day. If I want to do the shopping Monday, [that's OK]. I will. It doesn't matter. I do the shopping when I feel like doing the shopping.

A day to day approach meant that an event, job or activity happened on the day that it was possible rather than perhaps a planned or more desirable day. Such a day to day approach was not the same as being spontaneous. Spontaneity was not possible when environmental friendliness was not assured. For example there was little point in these carers embarking on an outing with their partner on the spur of the moment, if MS 'friendliness' was not already established. Some outings required specific planning to accommodate the needs of both spousal carers and their partners. For example wheel chair access and special toilet facilities. Unfortunately, even with planning these carers acknowledged that they still had to live for today because there

was always the possibility that their partner might be experiencing a “bad day”. Bad days were always experienced in the here and now and hence whatever was planned was always cancelled on the same day. Jenny talked about her daughter’s valedictory dinner and was proud to acknowledge that her daughter understood that “her father couldn’t attend because he’d had a really bad day”.

Looking toward the future was an aspect of life these carers found difficult. They generally felt that thinking about the future or worrying about what might happen was not going to change what existed. One carer stated “I don’t worry about tomorrow because I have no control over tomorrow”. Sometimes plans were put-on-hold instead. Hobbies, seeking relationships with others, holidays and personal plans were all put-on-hold in some way for all these carers. From the way carers talked about this, it appeared they had made a decision to wait before attempting to realise any future dreams or take action regarding changing care arrangements for their partner. Some were prepared to accept that dreams or goals might never become realities and that they might remain a full time carer for the rest of their lifetime, or their partners’ lifetime. Putting-on-hold was attributable to these carers’ reinterpretation of what was important in the past and the present and what might be in the future. This allowed these carers to accommodate living in the present and assign new meaning to that which mattered in their present situation. Rather than adding more stress in their life by trying to accomplish something that was no longer a priority in their life, putting-on-hold gave carers the opportunity to concentrate on what was of concern and therefore important at the time.

All carers stated that there was no point in planning too far ahead because tomorrow was another day with the potential to be quite different. Jenny said her children would often say something like “Well I know you can’t answer this but what are you doing next Friday”. Andrew looked at his situation in a slightly different way. He said:

Knowing that I have to cope with the situation at least for the time being, things have been quarantined, because internally there is a need to see the kids become independent and those sorts of thoughts [about my future life] have been quarantined [put on hold].

Andrew, like the other carers, had many hopes and desires but he put his plans on hold preferring to provide for his wife and to dedicate his time to his children until such time that they were safely independent. Rather than planning for the future as one might in terms of a five-year plan, these carers appeared to remain open to what was possible on a given day. They were aware that change was inevitable and dependent on many aspects related to their partner’s state of health. They generally concluded that developing actual plans for the future was a source of anxiety and of no functional benefit. It was better to do and enjoy what was possible today. These carers did however, admit that some planning was inevitable.

Generally carers did acknowledge that planning particularly regarding the structure of their home was necessary to improve their situation and maximise their partner’s independence. These carers recognised that sometimes decisions were influenced, and at times predetermined by their partner’s level of disability. This meant that often issues were not discussed. Changes simply had to be made. Making their home

“MS friendly” was a focus for most carers to ensure life flowed as smoothly as possible. This meant that the need for modifications to the family home was acknowledged and plans were made to install handrails or ramps, or to renovate various areas to make way for wheelchairs and hoists. The timing of such plans was often difficult when the partner with MS was reluctant to admit such changes were needed. Some carers believed it was better to move to another home rather than struggle with limited options in their existing home. Gail was aware of her situation and stated:

[Our] house has a lot of steps so we’re not planning on staying here. At the moment we’ve got plans to make an MS friendly house with wider hall ways and everything like that, no steps leading in or out of the house or things like that so that’s as far as we look. We don’t look 10 years down the track or anything like that. We look maybe one or two years and that’s it.

However, looking forwards and considering what the future may present was a source of worry and anxiety and so the need to live for today was prioritised. The uncertainty of the future limited carers’ ability to stay in control. On the other hand, living in the present involved coping and managing with what existed at the time and so carers were able to maintain a sense of control over their lives.

## 6.2 CONCLUSION

Reinterpreting life meaning is a relational theme that involves thinking and being. This relational theme encapsulates the way these carers perceived their worlds and developed new personal meaning. Personal meanings about self and situation were established through lived experience and the reinterpretation of what was important. Reinterpretation of meaning as one’s situation changes and evolves is a way of

copied in response to what is of concern. In other words as a result of MS these carers' usual personal meanings, beliefs and values had been challenged and by discerning what mattered, what was of concern, these carers reinterpreted what was important in the present. The three sub themes, renewing one's sense of self, understanding one's situation and living in the present, illustrate the ways in which reinterpreting life meaning enabled these carers to cope through a new way of living.

## **CHAPTER SEVEN**

### **CONSTITUTIVE PATTERN: WEAVING THROUGH A WEB OF PARADOXES**

This chapter presents the constitutive pattern, weaving through a web of paradoxes that describes these spousal carers' overall way of living with loss whilst caring for their partner with Multiple Sclerosis. Three main paradoxes were pivotal in the lives of all the participant carers. These paradoxes are: loss and gain; limiting and enabling; and vulnerability and strength. All carers experienced and balanced the influences of either extreme of each paradox as they strove to live with and care for their partner. This chapter will present the three main paradoxes. Each of the paradoxes is intrinsically interwoven across, around and within each other.

#### **7.1 CONSTITUTIVE PATTERN – AN OVERVIEW**

The constitutive pattern, weaving through a web of paradoxes describes the ways in which these spousal carers' experiences of loss changed their way of living and their personal meanings. This constitutive pattern encompasses the past experiences of these carers that informed and shaped their present way of being. In turn, unique past and present experiences influenced future possibilities for each carer. It became evident that there was continual ebb and flow of coping as carers lived with loss and strove to meet the challenges of their changing situation.

### 7.1.1 Loss and Gain

All carers experience the paradoxical phenomenon of loss and gain. These carers experienced, recognised and identified losses in relation to parts of their lives that were valued, significant and importance to them. For these carers losses were experienced across a range of daily living activities including major losses such as the loss of their partner as they knew him or her and the loss of a co-parent which involved watching a child grow without shared parenting. These carers also recognised loss in relation to simple ordinary things in life such as missing having a cup of coffee made for them by their partner and being able to spontaneously arrange an outing. All of the carers in this study, expressed concern and worry about the effects of these losses on their partners and themselves.

Along with many losses carers also experienced many gains. These gains, some wanted and some unwanted, were viewed as a gain when these carers acknowledged the significance of the gain in their lives. Many gains created concerns and became sources of worry. The significance and effect of both loss and gain depended on how each carer interpreted their situation and what it meant to them in their lives.

The major loss and gain that each carer experienced was the loss of the person they knew and understood; their life partner, soul mate, lover and friend. These carers had gained a person to look after. All carers recognised that even though their partner had not physically died, they knew they had lost their partner as they knew him or her and that he or she was never likely to return. They worried about the future as they



struggled to live with, and care for, the changed person they had gained as their partner. This person often required care and attention, supervision and surveillance for up to 24 hours a day. The outward body of their partner was still recognizable as their partner despite obvious reduced functional ability such as being unable to walk or attend to their own personal care. These carers tended to still see their partner as they once were but at the same time continued to look after the different person they now cared for. They reflected on attributes such as the strong, capable, physically active, intelligent, fun loving person of the past whilst they prepared themselves to manage the uncooperative, often insightful, handicapped person they had gained to care for.

Barry was very clear about the loss of his wife and lover and he also acknowledged the person he gained to care for. He learned to live with the person he gained to care for by distancing himself from the person he once knew, by disconnecting himself from that part of his life. Barry's experience illuminates this paradox of loss and gain. He said:

At the beginning I was looking after a person that I had loved for 38 years, known for 38 years, since she was 17. And all of a sudden as time progressed I was no longer looking after the person I had courted, married and loved. I was looking after a person. I found if I kept trying to look after the person I loved, it just made things worse, it presented barriers. I had to become disconnected to that part of it. You have to break away from the person who was a lover to a person that you're caring for.

Most of these carers experienced this transition from husband or wife to spousal carer whilst still clinging to their status as husband or wife. Their intimate life partner, and the experiential connections that exist between two people, who knew each other

deeply, had been lost. These carers' had gained the role and status of carer and gained a person to care for.

These carers experienced loss and gain in many other aspects of life whilst becoming carers. Many roles and responsibilities normally carried out by these spousal carers' and their partners were increased or reversed for the carer and decreased for their partner. Carers who were initially employed decreased or stopped work and gained responsibility for domestic duties either partially or fully. Parenting generally became the responsibility of one parent, the carer, and financial matters were handled predominantly by the carer. These changes altered the dynamics of companionship and partnership including issues of power and control within the marital relationship.

These carers' situations were changed and challenged by an altered balance of power and control within their relationship with their partner. The degree to which the gain in control took place for the spousal carers, including having to make choices on behalf of their partner, depended on the degree of disease progression and how that affected their partner's health and cognitive ability. The increase in spousal carer power and hence control was particularly noted when their partner's cognitive state deteriorated. These carers generally developed ways to live with this gain in decision-making and allocation of responsibility. The smoothness and necessity of this transition was partially dependent on their partners' understanding of their own cognitive state regarding the soundness of their own decision making. Many carers found their gain in decision making responsibility and power difficult to manage

successfully, when they experienced a lack of cooperation and understanding from their partner. The possibility of joint decision making was often lost. Even with a gain in sole decision-making responsibility, these carers often expressed powerlessness to influence choice outcomes and talked about the disease process dictating many needs and changes. These carers were powerless when choices and consequent outcomes were dictated due to issues outside of the carers' control. For example, limited access to health services or exclusion from some services due to restricting admission criteria. Most of these carers appeared to experience this loss of control and were locked into their situations, feeling powerless to implement change, despite their gain in responsibility for making decisions. Jim explained:

So much is imposed and you don't have a great deal of control on the way it goes. I don't know myself how much I'm choosing and how much is imposed on me.

Because of factors outside of their control and because of poor support systems these carers felt they had to make major decisions alone. They had gained, and were constantly faced with, the challenge of making major decisions around life issues such as parenting, divorce possibilities, employment and potential institutional care for their partner.

### 7.1.2 Limiting and Enabling

Restrictions, limitations and inconvenience created by the multiple, increasing and ongoing care needs of their partners dominated the lives of these carers. As a result, over time, carers' eagerness for planning for the future was dampened and spur-of-the-moment, spontaneous outings and activities were often not even considered.

Enjoyment was hindered by having to be organised for every event or outing due to the need for special equipment and facilities including modified access to homes or buildings. These carers had to consider and balance the effort required with the potential benefit. Generally the effort was not considered worth the potential benefit especially when it was possible that their partner might experience a “bad day” and not be able to take part. This limited opportunity for social interaction and outings as a couple, with children or with other family members or friends.

Family harmony was also hindered, limited or lost when families experienced changed relationships and changed opportunities for family interaction, particularly with family members who lived outside of the couples’ home. This limited opportunities for family support from extended family members rather than the family encouraging and enabling carers to feel comfortable within their role as carer. Carers became less confident and hence vulnerable as they worried about how to cope without the expected help from family and friends. For most, this limited or loss of support was felt in very direct ways. Many describe episodes of obvious avoidance by family members and friends. All carers hoped that the immediate family in particular would be a source of encouragement and hence they felt bewildered and disappointment when such support was not freely available. Visits and support from friends were also noted to decrease to a minimum in most cases. Almost all carers talked about experiences of rejection by parents, siblings and friends. Generally these carers tried to understand why such rejection occurred. Some carers attempted to explain, or even justify, why family and friends appeared not be available. Fear of

getting involved, inability to accept the diagnosis of MS, inability to cope with disease and sickness, personal poor health, and being busy with their own lives, were common reason. Jeanne highlighted one of these reasons. She said:

[Some of our friends] have admitted that they can't handle seeing Ted in a wheelchair, and I've tried to say, "Well he's still the same person, instead of sitting in a lounge chair, he's sitting in a wheelchair". But they can't. They don't seem to be able to handle it, especially his ex work mates. Not one of them comes to see Ted and he was boss of 100 people, more than 100 at times.

However, Jeanne had overcome her feelings of sadness and regret about limited or loss of support from friends by changing her way of thinking about this experience.

She went on to say:

Well, I just think that it's their loss. If they can't come and see Ted in a wheelchair and picture him in a lounge chair, well that's [their loss]. I just feel sorry that they haven't got the ability to put their own feelings behind them and just think they might be brightening up Ted's life.

Enabling possibilities and opportunities for brightening up a friend's for family member's life by visiting were missed and lost through lack of understanding, distancing, fear of getting involved, poor family dynamics and limited family/friend support networks.

These carers also experienced limited assistance from support services. They talked about the health care system as though it was an unfathomable nebulous conglomeration of services. These carers' wanted a health care system that offered services that enabled them to care for their partners at home. However, these carers' experienced difficulties with many service providers that actually limited and hindered their situation. These carers experienced problems with services such as

Program for Aids for Disabled People, disability services, residential accommodation facilities, the Multiple Sclerosis Society of Victoria, local council and other sources of personal care and home help. In the main, these carers only contacted such sources of help and assistance when personal resources, be they physical, emotional or financial, were pushed to their limit. They were also encouraged to seek help through contact with people already receiving help and by word-of-mouth dissemination of information. However, whilst this was a step forward for most, it also presented more concerns and disappointments that reduced their faith in the systems and so limited their access to assistance.

According to these carers, often the health care systems and the people within them, made them feel inferior. In order to seek help and assistance, many of these carers had to go through repeated contacts with staff working in bureaucratically run and inadequately funded organisations where lack of understanding of carers' situations and lack of resources were obvious. These carers were marginalised and limited by inadequate and inefficient support services. The lack of timely responses to requests for help indicated to these carers that support services did not really understand their plight. For example one year's wait for resources, such as equipment through Program for Aids for Disabled People, was not uncommon.

Other resources such as respite care options to reduce carer stress and assist coping were rarely available at the time of a crisis. Generally respite had to be booked in advance to ensure accommodation particularly at a preferred facility. Even when

respite arrangements were possible, these carers stated that they felt uncomfortable leaving their spouse in the care of staff who lacked commitment to and understanding of the individuals in their care. Inevitably the respite was not a respite as these carers continued to worry about the standard of care their partner would receive. These carers negotiated their way, often on a tightrope-like-path, through limited and inadequate support options. These carers' personal values and resources were rarely considered and hence the likelihood of appropriate support was limited.

### 7.1.3 Vulnerability and Strength

The experience of loss and worry in addition to an expanding carer role exposed carers' vulnerability yet the experience helped them develop strength. These carers lived through periods of feeling lost, powerless, helpless and vulnerable but through reviewing issues of concern and determining what was important to them they learned new skills and became empowered and strong.

These carers usually took on sole responsibility for the family budget with respect to managing pensions and/or income from paid employment, including paying bills and general household expenditure. Decision-making regarding all life matters usually rested with the carer as discussed before. Without the back up of extended family members and friends these events were experienced in isolation. However, through experience, these carers learned and changed their way of living to cope with their evolving situation. For example, initially Jeanne felt vulnerable because she saw herself as a housewife supported by her partner but as her partner's health and ability

deteriorated she had to take on new responsibilities. She gradually gained strength and learned to manage these new responsibilities and to complement herself. She said:

When Ted was working I felt like I was about fourth [in the line of importance], his job came first, the children...and his interests...and I came after that I felt. Now I've got him all to myself, (laughs) but I'd rather go back to those days and have him up and doing [things] and so strong.

I felt my part of the partnership was for Ted to work...and I kept the ship afloat and stable [at home]...I felt I was leaning on Ted slightly and now he's leaning on me, very much.

Jeanne cherished their relationship and that gave her strength. Later in the interview Jeanne stated, "I'd say I'm handling things better now ... It was more frustrating 10 years ago". Through experience all these carers developed their skills and identified their abilities and strengths despite increasing care demands.

Twenty-four-hour-care needs in some cases increased carer isolation and exhaustion especially when external care services were not engaged. Developing strength even though they felt exhausted and vulnerable was a phenomenon shared by all these carers when facing loss, worry and change. A few carers stated that they felt they had to remain strong to keep their lives and partnerships together. Some carers amazed themselves. They were amazed about what they could actually do and fit into 24 hours. Gail, like the others, was constantly on the move. She said:

Running [that is driving] the kids to and from sport and school, and [my] work, and cleaning the house [inside] and now I've got the outside too. I never used to touch the outside of the house. Now it everything, mowing the lawn, trimming [edges] and [cleaning the] concrete. There are not enough hours in the day to fit in what you have to do. I do a physical job two days a week and when I come



home I'm exhausted and they're lucky if they get tea by seven o'clock and I finished [work] at four. Having said all that its fine, its fine but sometimes I wish I had another person to help me with the load [the outside things like lawns, the yard and the maintenance].

These carers gained strength to cope with their new situations through learning to be flexible, taking on new tasks, grasping opportunities as they occurred, focussing on the positive aspects of their lives and being proud of their achievements.

Remaining strong helped prevent displays of helplessness and counteracted feelings of fear about letting their spouse down. Jenny said:

I feel like I've got to be bright and bubbly...If I get all depressed too, we'll just fall apart and that can't happen. So I feel like I've got to be the one to be bright and bubbly all the time and be strong, emotionally strong for the two of us, rather than just myself...I've sort of had a philosophy for a long time and I try to live by it. I think, well, if, like falling apart isn't going to change it, why fall apart.

Some carers recognised that they did feel depressed at times but usually for only short periods while they struggled to recognise what was happening and what was important. Stan said:

I just put [my worries] at the back of my mind and try to do other things at home. [I] just try and get involved in the computer or something like that or have a look at the horse racing. I don't want it to sound like I've got a big sob story to tell or anything like that. There are other people in a similar situation and others worse. Feeling sorry for yourself doesn't help the situation. It usually makes you feel worse, a bit depressed. So you've got to snap out of it and do something. But I suppose it's sitting there near the surface. Still, it hasn't got control of me.

These carers remained strong and in control by being assertive. When feeling strong and assertive carers became more discerning and inquiring about information regarding their partner's health concerns and also about their rights as a carer. They

were more likely to question information and seek clarification. Carers remained strong and managed their concerns by speaking out. Speaking out, or voicing their opinion as a carer was particularly necessary when seeking support and resources for their partner and themselves. These carers, in the main, had become assertive, persistent and proactive in their efforts to achieve success in their quests.

## 7.2 CONCLUSION

This chapter has presented the constitute pattern, weaving through a web of paradoxes, that describes spousal carers' way of living with loss. Each paradox: loss and gain, limiting and enabling, and vulnerability and strength were interwoven and interlinked within the lives of each of these carers. The experiences that occurred in relation to these paradoxes were manifested simultaneously over time and described what life was like for these spousal carers.

## **CHAPTER EIGHT**

### **DISCUSSION**

This chapter will present discussion of the findings of this study in relation to current literature. In addition, the chapter will present significant aspects of the findings of this study, which broaden the information available on loss and grief and offer a different perspective for consideration. Hermeneutic analysis of the data lead to the identification of three relational themes: experiencing the loss, caring as worrying, reinterpreting life meaning and the constitutive pattern. The constitutive pattern, which describes the lived experience of loss for these spousal carers of partners with multiple sclerosis, is weaving through a web of paradoxes.

The three relational themes and the three paradoxes of loss and gain, limiting and enabling and vulnerability and strength, embedded in the constitutive pattern all occurred in concert with each other. They were inextricably interwoven across and within the lives of each of the spousal carers who took part in this study. This new information will add to the body of knowledge from which nurses and others practice. Practical relevance of the findings will be discussed under the sub headings of: grief as a response to loss and the experience of grief. The experience of loss will be presented under the sub sub headings of depression and catharsis, denial, loss of the person-in-the-partner, living in the present, a renewed sense of self and loss of support.

## 8.1 GRIEF AS A RESPONSE TO LOSS

The findings of this study support those of phenomenological-interpretative studies by scholars such Brown and Powell-Cope (1993), Cody (1991), Gullickson (1993), Pillkington (1992), Rittman, Northsea, Hausauer, Green and Swanson (1993), Walter (1996) and Wilson (1989). All these studies, including this one, illuminate experience from the perspective of the individual and so enable understanding of the individuals' lived experience. In addition, this study offers new insights to enhance practitioners' approaches to caring for their clients who have experienced loss. The findings of this study do not support stage models and theories of grief developed within the empirical-analytical paradigm. The perspectives of the carers in this study indicate that grief does not manifest itself as a series of events that occur in a predictable linear fashion as suggested by stage models and theories of grief. Rather, their experience of loss is manifested in changed ways of living as reinterpretation of meaning and allocation of importance leads to coping, well being and comfort in the context of the loss.

## 8.2 THE EXPERIENCE OF LOSS

The relational theme caring as worrying offers a new interpretation of how carers' live with loss. It describes how each carer, from their perspective, expressed concern and caring through worrying as they lived with loss and cared for their partner. Caring as worrying was viewed as a positive way of coping and living with loss. This interpretation of caring as worrying as a response to loss invites consideration and is a phenomenon that requires further research.

### 8.2.1 Depression and Catharsis

Whilst depression is often equated with grief in the literature, the findings of this study do not support this view. None of the spousal carers in this study talked about periods of depression and only one mentioned feeling depressed in relation to their experiences of loss of the person-in-their-partner. However, being depressed was seen as counterproductive and some of these carers suggested it was no use being depressed as that was not going to help their situation. Some carers did, however, mention or describe what could be identified as periods of sadness. Sadness was experienced when timely support was not available, when partners were uncooperative and when no relief was in sight.

Overt expressions of grief through catharsis, also significant in early writings and research were not identified in this study. However, one carer suggested that “having a good cry”, helped put things into perspective when life became too complicated. The data indicated that this response was more in relation to a feeling of being overwhelmed and perhaps out of control rather than a response to loss through grief or as a result of depression associated with grief.

Having acknowledged that these carers lived through many periods that were influenced by loss, depression and catharsis were not seen as significant in their lives. The researcher suggests that these carers had developed their ways of living with loss over long periods of time and had therefore become more familiar with and able to cope with their experiences related to loss.

### 8.2.2 Denial or Putting-on-Hold

Putting-on-hold was expressed by these spousal carers as a way of coping and living with loss. These spousal carers tended to put issues, plans and hopes on hold whilst living with the situation at hand. It was not worth worrying about what might happen when they were fully occupied with their caring role. They were prepared to wait until the time was right to embark on the pursuit of personal goals. This enabled carers to live their lives in ways that they could manage given the resources and supports available to them. Goals and tasks were prioritized. They were left for review at a more appropriate time when their situation and resources enabled other possibilities.

These carers also put-on-hold decision making with regard to how long they could continue to provide care for their partner at home and when the right time would be, if ever, to think of and plan alternative places for the care of their partner. Brown and Powell-Cope (1993, p.186) discovered that:

No one outlined plans for how they would handle a future of more intensive care demands if the PWA [person with aids] became more ill.

Brown and Powell-Cope (1993) also identified this phenomenon of putting-on-hold in their study. They suggested that family caregivers were challenged to let go of their expected life-style and take on new ways of living. Some carers apparently found this easy and “others felt intense and difficult emotions, particularly anger, about a life-style that had been unjustly taken away” (p.185).

Whilst putting-on-hold is seen as a positive coping strategy, it could also be viewed as denial and therefore labeled as negative and in need of treatment. This is possible when practitioners subscribe to the view of writers such as Kubler-Ross (1969), Marris (1986), McKissock and McKissock (1995), Parkes (1987) and Worden (1991). The role of nurses or health professionals is to predict, identify and explain their patients' responses to loss and guide patients to confront their loss and deal with whatever is being denied. The aim is to get over the hurdle of denial and proceed with grief resolution and to get on with life. However, if denial is interpreted as putting-things-on-hold as a way of coping and living then it is essential that support from nurses enable individuals to achieve what is possible.

### 8.2.3 Loss of the Person-in-the-Partner

Experiencing the loss of the person-in-the-partner was the major loss all these spousal carers experienced. Many described the need to move emotionally away from the person they had once loved and knew well, and the need to learn to live with, and care for a different person. Cody (1991, p.66-67) says that the findings of his study:

Indicate that the experience of grieving a personal loss evolves dynamically in the living every day, as the individual propels self onwards, interrelating with others and choosing from among possibilities in light of what is cherished. Grieving a personal loss is seen as a way of living the now, the what was, and the not-yet all at once, a view that contradicts theories that specify grieving as a normative set of sequential stages.

Cody (1991, p. 65) describes this paradox of loss and gain experienced by the participants of his study as "dwelling with the absent presence". Dwelling with the absent presence also reflects the way of living for the participants of this study. The

carers of this study learned to live/dwell with the absent presence of their partner, that is the person-in-the-partner had been lost yet had become a different person who looked the same.

#### 8.2.4 Living in the Present

Day by day living was adopted as a way of living with the unexpected and with the possibility that the future may represent further problems. Doing what was possible and making the most of what existed involved taking one day at a time. Brown and Powell-Cope (1993, p. 186) also discovered that day-to-day living became a way of living for the participants in their study as it did for the carers in this study. They suggested that:

Taking one day at a time became an anchor in caregivers' struggles for emotional equilibrium. This strategy was necessary because even the immediate future – tomorrow, this weekend – were contingent on the present strength and symptomatology of the PWA [people with aids].

Day-to-day living was not seen as a strategy within this study. Day-to-day living had become a way of life as these carers reinterpreted what was important. The similarity here is that spousal carers of partners with MS also resisted making specific plans for the immediate future but rather waited for the day and did what was possible. They were also prepared to cancel arrangements at the last minute should their partner's state of health at the time prevent such plans.

#### 8.2.5 A Renewed Sense of Self

Rittman et al. (1993, p. 329) described a theme "taking on a new understanding of Being". This theme is similar to the relational theme of this study, "reinterpreting life



meaning” and one of its sub themes “a renewed sense of self”. Rittman et al. (1993) suggested that the experience of the present became the normal way of life which was then described as “not much different”[from before], as a new understanding of Being was born. Rittman et al. (1993, p. 329) went on to say “as patients come to view their illness experience as a normal part of their lives, they take on a new sense of Being”. Rittman et al. (1993) suggested their participants took on a new understanding of being by maintaining hope and dwelling in their situation (in this case dialysis).

The changes that patients live with and eventually experience as normal become added to patients’ background meaning, assisting them to understand and live in the world of renal failure and dialysis (1993, p. 329).

Carers in this study also took on a new sense of being as they made sense of what was and learned to live with what is. They did this by remaining strong, by taking time out, engaging in self-talk, and by being active. Wilson (1989, p. 96) suggests that the caregivers in her study “confided that they talked to themselves in an attempt to muster their own inner strength in face of the decision to take on the caregiver role”.

#### 8.2.6 Loss of Support

Support, from family and friends, was sadly missed by most of the spousal carers in this study. These spousal carers provided various reasons for this that included guilt, being unable to cope, and other commitments. The importance of these supports, that highlight the significance of their absence, have also been identified and documented by Walter (1996). Walter (1996) suggests that the clue to living with the loss of a loved one is to talk about the dead. This belief may have implications for talking about the loss of the “person-in-the-partner” for carers of people with MS. Walter

(1996) found that talking about his friend with different people who knew her well and within different contexts actually lead him to the realisation that he had, in a way, found his friend for the first time. Walter (1996) also suggested that self-help groups offer the possibility of sharing experiences, and that sympathetic listeners or trained counsellors are also helpful sources of support. However, in this study it appeared that health and social welfare systems and programs developed to provide support and assistance often lacked the staff, funding, and equipment necessary to help spousal carers at home during times of acute need.

The spousal carers of this study, like the caregivers in Wilson's (1989) study, also identified difficulties with accessing resources and supports such as home help or in-home respite services. Carers developed strategies to seek appropriate help and assistance but carer embarrassment and lack of information were obstacles they had to overcome before being able to ask for help and assistance. Even when resources were found, carers also stated that they had to choose from a number of unsatisfactory options.

These spousal carers also appear to cope with negative choices. The suitability of options involved issues of quality, standards and personal values. Such personal requirements were often not met when making some choices. For example, most carers reported difficulties making choices about residential care, even for respite, for their partners because no options were completely suitable. Supportive home based care services, the preferred option, were not adequately available.

### 8.3 CONCLUSION

This chapter has provided discussion of the study findings with current literature.

Some new insights have been presented that add to the body of information available to nurses and other health professionals when caring for people who have experienced losses other than through death. These new insights, such as caring as worrying, loss of the person-in-the-partner and spousal carers' view of support, have bridged gaps in understanding the experience of grief from the perspective of spousal carers who have experienced loss. In addition, some similarities with other literature have been highlighted and discussed. These have been presented in a way that facilitates a different way of thinking to understand loss and grief. For example viewing denial as the coping strategy of putting-on-hold. This study also illuminates the benefits of exploring loss and grief from a phenomenological perspective in order to gain understanding from the perspective of individuals.

## **CHAPTER NINE**

### **CONCLUSION**

This chapter presents a conclusion of this thesis under the headings of limitations of the study, implications for the nursing profession, nursing research and health service delivery. Finally the summation of the study is presented.

#### **9.1 LIMITATIONS OF THE STUDY**

This study was conducted for a masters degree by research. It was a small-scale project that focused on a specific group of people. Each participant was a spousal carer who provided home based care for his or her partner who suffered from multiple sclerosis. The exclusivity of the participants is in itself a limitation simply because the data relates to one specific group of carers rather than carers who care for people with chronic illnesses in general or in other settings.

Six male and four female spousal carers took part in the study. However, multiple sclerosis affects more women than men in a ratio of about 2:1 and so the mix of female and male participants is not representative of this group of people (specifically spousal carers of people with multiple sclerosis). However, these participants were selected based on the selection criteria and their experience as spousal carers provided insightful information about loss from their perspective. This sample serves the purpose of this study.

Gender in general may effect the way people/carers grieve and live with loss. This is a phenomenon that was not focussed upon within this study. Current theories and models of grief, in the main, have been based on grieving women and as Walter (1996) suggests, women and men may grieve and respond differently to loss. Gender may also effect the way in which people establish and live with taking on a role as a carer, spousal or otherwise. Much of the literature about caring indicates that traditionally and historically caring is seen as women's work that has not been valued by society. It is also suggested that women generally perpetuate this notion and accept expanded caring roles (Carper 1979, Reverby 1987). Men and caring is an area that requires further research.

All participants had been living within a western society culture for many years, yet, occasionally, during the interviews there were references to cultural issues. Three families had connections with cultures from other countries such as Italy, Greece and Scotland. All the participants had strong relationships with their partners. The impact of religious, cultural or ethnic backgrounds on spousal carers' experience was not specifically explored because of interview time limitations.

All participants were selected on the basis that they spoke English, as funds for employing professional interpreters were not available. This limited the participation of potential participants from different ethnic backgrounds.

## 9.2 IMPLICATIONS

This study has provided some insightful findings and information to facilitate understanding of carers' lived experience of loss for nurses, health professionals and others. From such insight pathways can be forged to build partnerships between health care recipients and their carers as well as assist in the maintenance or improvement of health and well being. Implications of the findings of this study for the nursing profession and health service delivery will be discussed.

### 9.2.1 The Nursing Profession

The findings of this study provide insight into spousal carers' lived experiences of loss to enhance nurses' understanding of, and ability to work with carers who have experienced loss. All carers strongly expressed that they wished to be treated as individuals with individual abilities, resources and needs. Each carer wanted to be supported by health care professionals and health care services that understood, and were responsive to their needs and situation. They did not like to be told how to do things or what to do. They wanted to be provided with information and be able to have some input into their carer and support. However, many health care professionals continue to model their care practices on the tenets of the empirical analytical paradigm and popular dominant beliefs and theories about loss and grief. In addition, as a legacy of the manner in which health care systems operate and dominate over their customers, prescriptive health care practices still prevail.

The findings of this study indicated that carers often felt misunderstood and poorly supported. Because of this lack of understanding and therefore inaccurate assessment of their situation by health professionals, these carers experienced times when their needs were not adequately met or they were unsatisfied with the care planned. These carers sometimes had poor experiences when involved with the health care system. The implication is that nurses and other health care professionals are not in-tune with their clients and that health services need to be client focussed and be better equipped to meet the needs of their clients. They need to understand individuals' experiences and the contexts in which those experiences occurred. Adequate and appropriate care delivery could save much time and energy for all involved. This in turn would alleviate much carer stress, concern and worry.

Developing a philosophy of partnership is one way to improve understanding of clients' experiences. Partnerships between nurses and their clients and their families, based on in-tune understanding and connectedness, need to be established and fostered. From these partnerships, trust will grow and open channels of communication and information exchange will be nurtured. From this, clients will feel empowered and supported in their efforts to seek and engage in what is possible. Embedded in any such partnership is the need to understand clients' values, beliefs, strengths, weaknesses, resources, needs and connections with others in order to understand how to support and care for that individual client. This calls for nursing practice and the provision of care to focus on the client and their family in a cooperative and collaborative manner.

Nurses have been debating this notion of client focussed care for many years. They have recognised that task focussed nursing ignores the human element. They have also sought to define nursing and to develop nursing as a profession with its own body of knowledge. Despite this rhetoric and according to the findings of this study, client focussed care is still not being achieved. Hence, there is an immediate need for nurses and other health care professionals to evaluate, and be critical of what they mean by client focussed care. If client focussed care involves partnership between nurses and clients, then to strengthen such partnerships it is essential that all concerned (family, friends, nurses and others) understand each individual's way of living and their goals for the future. Understanding involves intuitive knowing to identify which losses are linked with the greatest concerns, identifying concerns and worries as important, and being in-tune with ways of living such as living in the present, taking things day-by-day and putting-things-on-hold. Embedded in this process is the need to be familiar with and understand the context in which care is delivered and received – acute, sub acute, community or home. Nursing practice framed and developed within the context of care delivery might promote in-tune partnerships that are client focussed rather than task based.

Nursing knowledge and practice traditionally was dominated by the medical model of patient care, and focussed on objective understanding and prescribed treatment with the view to a curative outcome. In some settings, this is still the case. However, over the last two decades and in particular since nursing education has moved from the hospital into the university arena, nursing has begun to develop as a discipline with a



unique body of professional knowledge and practice. In addition the discipline of nursing has begun to identify what it is that makes nursing care unique. Caring has been identified as an essence of nursing and nursing has begun to grow as a profession. However, the findings of this study indicate that nursing is still practiced according to the medical and scientific model. Nursing needs to be valued in its own right and further developed and promoted as a humanistic profession.

Many nurse scholars have studied nursing as an art and as a science. Carper (1979) suggests that nursing education involves learning to be human. She says that:

The possibility of the cultivation of the imagination and of compassion in dealing with patients, that is, the coming to know the uniqueness of the individual, is enhanced through empathetic acquaintance. A complete awareness of the meaning of another's life experience is never possible. But empathic understanding can extend our range of imagined possibilities. Empathy may be defined as the capacity for participating in or vicariously experiencing another's feelings. It requires one to imaginatively take the role of another in order to understand and accurately predict that person's thoughts, feelings and actions.

Nurses are in a unique position within health care services due to the personal, ongoing, and holistic nature of their work. This privileged and confidential position allows nurses to talk with their clients about personal and private matters and so "be with" their clients. Gullickson (1993, p. 1391) suggests:

Nurses are in a unique position to engage clients in this narrative as they care for them. Their conversations can change from discussions solely focused on symptoms to engaging dialogues that seek to uncover new meanings for each person living with a chronic illness. Their conversations will help recall the narrative of the individual's illness experience and, in so doing, may help re-create a future of possibilities. As nurses, our practice changes to focus on possibilities rather than deficits.

Both these nurse scholars highlight what appears to be missing for the carers of this study and that is client focused, empathetic understanding and compassion. Both papers were written between ten and twenty years ago and this indicates that nursing education still needs to promote the human aspect of nursing through “being with” clients if nurses are to be encouraged to maximise their relationships and partnerships with their clients. Excellence in nursing practice requires a melding of clinical nursing skill with humanistic, in-tune, client focused care through being there for clients.

However, Cheung (1998) in her recent research that involves Australian nurses’ views of caring identifies another barrier to the development of nurse client partnership. Cheung (1998, p.231) suggests:

On one hand, nurses choose to enter the nursing profession because they have a desire to care for patients. On the other hand, by practicing nursing, nurses learn how to become unconcerned and how to distance themselves from patients in order to protect themselves from burn-out. This paradox seems to suggest that the current philosophical orientation of nursing and of the health care system is incongruent with the philosophy of caring and the fundamental value of nursing.

From this it appears that it is not only important that nursing education encourages nurses to put themselves in their client’s shoes and understand their way of living, but also to lobby at societal and governmental levels to change people’s attitudes and views about caring. It is important that nurses are expert and skilled at a practical and clinical level with professional knowledge that is scientifically founded but it is equally important that nurses develop nursing as a way of understanding, as a way of being with their clients. By defining our role and changing our way of thinking about

our relationships with clients, nurses can help to break down the web through which clients and their carers travel. The findings of this study indicated that nurses are indeed expert and skilled at their nursing tasks but it appears education is needed to promote and encourage partnership as a way of nursing. Nursing in partnership with clients will be realised when nurses engage in intuitive nursing practice that is characterised by empathy, compassion, connectedness and a way of thinking that fosters the development of in-tuneness with clients. This takes time. Unfortunately, health care services continue to be funded according to tasks and measurable outcomes.

In addition, the need to provide care, based on understanding and partnership, not only applies to nurses but also to others who provide home based nursing care. As a part of the increase in home based health care, many other people such as personal care attendants, division two nurses, nursing assistants and of course family members such as spousal carers are carrying out nursing care. These people form professional relationships with clients and carry out nursing care with limited nursing knowledge and experience in relation to nurses who hold degrees. However, like nurses, these people are also likely to feel the effects of burnout and also deliver care based on tasks rather than partnership. It is important that nurses recognise this and take a leadership role to educate others who are performing nursing care in order to promote and facilitate the provision of client focused, holistic nursing care from other health care providers adjunctive to the discipline of nursing.

### 9.2.2 Nursing Research

The findings of this study complement existing literature regardless of discourse and offer nurses and other health professionals a view of living with loss from the perspective of spousal carers. Even so, further qualitative research that involves the narrative is needed to gain further understanding of loss. There is very little research literature that discusses carers' ways of living with loss particularly when the death of a loved one is not the antecedent.

Loss of expected lifestyle for carers was one loss that was identified in this study.

Loss of lifestyle for carers might well be a phenomenon that requires attention as more clients are being cared for at home. It is essential that health care providers understand and are prepared to minimise the demands of home based care on the carers and provide the support they need. Underpinning any caring role is a variety of issues relative to each individual. These may include religion, cultural background, age, gender and strength of relationship between the carer and the person receiving the care. All these issues require further research as they were identified in this study as potential factors that influence strength of partnership, coping and responses to loss. Because health care is increasingly being provided in the home, it is essential that these topics be researched in relation to carer roles and experiences of loss to ensure that service provision is mindful of carers' needs. It is through such research that nurses and other health professionals will be better educated and informed thereby enabling them to support their clients in appropriate ways.

There were three significant areas identified as warranting further research. The relational theme of caring as worrying is an area of interest that does not appear to have been explored in relation to loss or as a coping strategy. Worry is generally seen as counterproductive and is often associated with stress. However, it was through concern, caring and worrying that these carers reinterpreted what was important in their lives. Some things that were initially important to these carers were devalued whilst other things, often ordinary things, became more important. This appeared to give carers strength to live in new ways that were less stressful. Now that this theme, caring as worrying has been identified and described, it can be further explored as a research topic to further illuminate positivity in worry. One might wonder about the nature of worry and, if and how worry assists coping.

Secondly, loss of the person-in-the-partner describes the loss of the embodied person that was once the carers' partner, yet still having the partner present to care for. This was a difficult situation that these carers grappled with as they strove to care for the person they had once cherished. There are other times when the person being cared for is no longer the person who once was. People with dementia, Alzheimer's disease and other chronic degenerative conditions become different people embodied in the same body. It would be worth exploring how carers of people with such diseases live within their situation and how they cope. It would be interesting to discover if this notion of loss of the person-in-the-partner is relevant in other situations. Again this would have implications for nursing practice.

Thirdly, the phenomenon of putting-things-on-hold was also identified as a way of living with loss for carers to reduced worry and stress. Putting-on-hold was seen as a positive way of living in the context of this study but if given the label denial, it becomes an avoidance strategy. This requires further research.

### 9.2.3 Health Service Delivery

The findings of this study indicate that there was a lack of knowledge about available services to these carers. There were also issues of accessibility, affordability and responsiveness of services available to meet carer needs. Many talked about informal networks that kept them informed about changes in various support systems or the introduction of new ones. Some carers suggested that to get help one needed to know someone in the system to hasten the process. This indicated that carers were skeptical about seeking help as an ordinary carer without the support of a contact or a professional in the system. However, the main difficulty appeared to be identifying what help was available. Perhaps a government supported public awareness campaign about the needs of, and services available to spousal carers would be one way of increasing public awareness at a macro level. Such a campaign could also target family and friends of people who are “carers”. Such a campaign could disseminate information to break down barriers of misconception about disease and the value of caring (as identified by some carers in this study) and so encourage the development of family and friend support networks.

However, even when carers were aware of the services, these services were not always available when they needed them or in a manner that was acceptable to them.

Brown and Powell-Cope (1993, p.189) assert that:

Health care services may need to be reoriented to become more responsive to families who do not engage in future preparations and instead live “one day at a time”. If nurses were more accessible on an “on call” basis in family-centered primary care models, families could access services on demand at times of greatest need.

If this were possible, and given that a day-to-day approach to living was adopted by many of these carers, perhaps the need for respite services and residential care facilities would decrease. Also carers may feel more valued and enjoy better health.

The findings of this study also indicated that some carers benefited from self-help groups for support and dissemination of information. One carer in particular identified a need for participant driven self-help groups where there was access to expert skill and knowledge through a health professional. It is important that services offering such groups ensure that the groups are accessible and affordable. For example it may be necessary for the organization running the group to also provide staff to care for the attendees’ partners thereby enabling the spousal carers to leave their partners and attend support groups.

### 9.3 SUMMATION OF THE STUDY

At the conception of this study, it was hoped that the findings of this study would offer a view of loss and grief that embraced individuals’ unique experiences and provide new insights into their experience to increase the awareness of nurses and

other health professionals about loss and grief. It was intended that greater understanding of these carers' experiences would lead to the development of nursing care practices based on understanding and connectedness; assist in the development of 'in-tune' support program for families living with Multiple Sclerosis and provided impetus for further research into loss and grief. Hence, the purpose of this study was to uncover and describe spousal carers' lived experience of loss. The aim of this study was to seek a deeper understanding of these carers' experience from their perspective.

In addition, it was hoped that the findings of this study would provide insightful information to encourage discussion about, and questioning of the dominant theories and models of grief that encourage prescriptive care practices. The researcher believed that with this new information nurses and other health professionals would be encouraged to position themselves within the context of their clients' situations and so gain understanding about their clients' strengths and resources. Hence, a qualitative research design was chosen for this study in order to explore spousal carers' unique experiences of living with loss.

A phenomenological approach and hermeneutic analysis of the text derived from interview transcripts enabled the researcher to explicate existential-ontological description and meaning of spousal carers' experiences of loss. The findings showed that carers reinterpreted the meaning of taken for granted daily activities and situations that occurred within their lives. Through the experience of loss and



through caring as worrying, various activities and situations gained new personal significance for each carer as they took on a new way of being in their world. Some carers' new way of being in the world was dramatically different from their previous way of being in the world. For example some carers had become full time carers with total domestic responsibility having previously been full time employees and the household 'breadwinner'. A deeper, richer understanding of the meaning of such experiences for carers can be developed and achieved when nurses and others become in-tune with the carers and acknowledge these meanings and the importance of them to the individual. Once nurses have experienced the benefits of interconnected in-tune partnerships with their clients they will question the reasoning behind, and need for prescriptive nursing practice.

It is hoped that the insights gained in this study will enhance nursing knowledge and understanding of their clients and carers responses to loss and needs related to loss. Nursing practice that is based on being with, doing with, talking with clients rather than keeping a professional distance, doing for and instructing clients, fosters an environment in which trusting partnerships can be developed to maximise possibilities for improved health and well being. It is hoped that nurses will be encouraged to change their way of thinking thereby facilitating a change in nursing practice based on in-tune, connected relationships and partnerships with their clients.

Gullickson (193, p.1391) suggests that:

Nurses are able to restore the healing power of the narrative as they care for clients. It is through the type of caring that 'leaps ahead' of itself that they engage their clients in meaningful dialogue. Each

individual's past experiences bring forth understandings and determines the range of what is possible in the present.

In summary, one way in which nursing can gain a deeper understanding about carers' ways of living with loss is through talking with carers to unveil lived experience and common practices in order to see new ways of being.

The evidence of this study shows that human relationships, personal meanings and concerns give people the courage to weather illness and adversity in life. If nurses are committed to providing individualised client focussed care, then their role is to help and enhance people's (clients and families) ability to maintain health and well being. To fulfil this role, it is essential that nurses understand their clients' values, priorities, concerns, worries, past experiences, hopes and dreams, and their connections with others as fundamental to their way of coping. With such insight, nurses will be better informed and able to critique the dominant view of grief and loss thereby enabling them to provide support and care which are tailored to clients' situations and their concerns. This approach to support and care provision based on clients' strengths and resources is particularly important when designing support groups and information seminars aimed at informing, enabling and empowering individuals such as carers. In so doing, nurses can look ahead with renewed energy and creativity to improve our practice and strengthen our partnerships with clients and carers in our care.

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## **APPENDIX A**

### Department of Nursing

#### INVITATION TO PARTICIPATE IN A RESEARCH STUDY

My name is Peta Harten. I am a Registered Nurse currently undertaking a research study as part of the Master of Health Science Course at Victoria University of Technology, Footscray Campus. I am interested in talking with people, like you, who are involved with caring for their spouses who have Multiple Sclerosis. My research is focused on gaining a better understanding of what your experience of caring is like.

I would like to arrange a time to meet you at a mutually convenient time and place, so that we can talk about your experience as a carer. Our discussion will be tape recorded and later transcribed. I wish to emphasise that the interviews will be treated with total confidentiality and that no identifying information will be used in my completed project. The actual interview should take about one hour.

You are under no obligation to participate in this study. If you do choose to participate you are free to withdraw at any stage if you feel you need to. If at any time you feel uncomfortable about our interview we will stop, discuss your concerns and decide to a) continue, b) to withdraw, c) to seek assistance or any combination of these three options.

I would be please to discuss any questions you may have regarding my research. You can contact me in the evenings before 9.30 pm on (03) 5265 6124. If you are willing to participate please contact either myself or Dr Lindsay Vowels at the Multiple Sclerosis Society on (03) 9828 7222.

Thank you for taking the time to consider my request

Peta Harten  
RN, Grad Dip Com Health, Grad Dip Nursing





APPENDIX B

Department of Nursing

CONSENT FORM

I,.....  
of.....  
.....

certify that I am at least 17 years old and that I am voluntarily giving my consent to participate in the research study entitled:

Exploration of spousal carers lived experience of loss.  
being conducted at Victoria University of Technology by Peta Harten.

I certify that the objectives of the study, together with any risks to me associated with the procedures listed hereunder to be carried out in the project, have been fully explained to me by Peta Harten, and that I freely consent to participation involving the use on me of these procedures.

Procedures:  
Face to face unstructured interview for approximately one hour  
Tape recording of interview

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from the study at any time and that this withdrawal will not jeopardise me in any way. I have been informed that the information I provide will be kept confidential.

Participant:  
Signed: ..... Date: .....  
Witness other than the researcher:  
Signed: ..... Date:.....

Any queries about your participation in this study may be directed to the researcher Peta Harten, Ph.No.: (03) 52656124 or her supervisor Jenny Cheung, Ph. No.: (03) 96884654. If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box, 14428 MCMC, Melbourne, 8001 or Ph.No.: (03) 9688 4710.

**APPENDIX C**  
**SEVEN STAGE METHOD**  
**OF DATA ANALYSIS**

This methodology is presented in *The NLN Criteria For Appraisal of Baccalaureate Programs: a Critical Hermeneutic Analysis* by Diekelmann, Allen and Tanner (1989).

Stage One. The purpose of this stage of interpretation was to examine all three documents as a whole. Each member of the research team read each of the documents to obtain an overall understanding of the documents.

Stage Two. In this stage, each member of the team summarized sections of the documents and identified categories. Weekly sessions were held during which the investigator would first read his or her written interpretation of the categories, then provide excerpts from the texts to serve as supportive data of the interpretation. Similar analyses by other members followed. Dialogue among team members clarified the analyses and the evidence provided by the text. Group consensus was the ultimate goal.

Stage Three. This stage involved further independent analysis of each document. Each team member's interpretation of the categories was compared with the investigator's for similarities and differences. Any discrepancies in interpretation were clarified by referring to the text.

Stage Four. The purpose of this stage was to identify relational themes. A relational theme is one that cuts across all texts. Texts generated in previous stages were re-read and studied to see if similar or contradictory meanings were present in the various texts. During this stage, whenever conflicts arose among the various meanings within the texts, extensive documentation was provided to support the choice of relational themes.

Stage Five. During this stage of interpretation, constitutive patterns emerged. These patterns were present in all the documents and expressed the relationships of the relational themes. Constitutive patterns are the highest level of hermeneutical analysis.

Stage Six. The purpose of this stage was to validate the analysis by persons not on the research team but familiar with both the content and the research method. In this stage, the investigator provided the opportunity for review of the entire analysis to members of the research team and to two interpretative nurse researchers who were not members of the team.

Stage Seven. The last stage involved preparation of the final report using sufficient excerpts from the interview to allow for validation of the findings by the reader. The multiple stages of interpretation provided a means of bias control. The purpose of the multiple stages was to expose conflicts and inconsistencies by allowing for reappraisals and comparisons. The goal was to expose unsubstantiated meanings and inaccurate interpretations not supported by the text. Expert consensual validation was also included in this process.

The goal of hermeneutics is the discovery and understanding of meanings embedded in the text. Initially, this method was utilized for the interpretation of biblical texts, classical literature, and legal documents. The process involves moving from the parts of the text, to the whole and back to the parts again (Diekelmann et al. 1989, pp.11-13).