

MARRIAGE PATTERNS OF ADULTS WITH MULTIPLE SCLEROSIS
LIVING IN EXTENDED CARE

by

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ABSTRACT

Title: Marriage Patterns of Adults With
Multiple Sclerosis Living in Extended Care

Having a serious illness can create a major threat to the marital relationship and may lead to a disruption of the family unit. In a long-term disabling illness, emotional adjustments are complicated and may cause more distress than the physical effects of the disease. This study attempts to develop a framework, by analyzing individuals with MS stories of illness and to examine some of the factors that are unique to marriage and illness (specifically multiple sclerosis). Six individuals, three males and three females between the ages of 45 to 60 years of age, who are currently married and residing in an extended care facility were interviewed using an interview schedule. Data were analyzed using grounded theory.

The study was an exploratory one. Using a qualitative design, the study sought to understand the experiences of individuals with MS and the effect their disease has had on their marital relationship, particularly with regard to the factors that have contributed to the constancy of the marriage.

Factors influencing the perseverance and longevity of the marital relationship were examined. The data indicated that there were four marriage patterns specific to maintaining a marriage, having a disease, and living in an extended care facility. These marriage patterns were

described as: marginal, functional, companion and romantic relationships.

These findings are discussed in relation to the relevant clinical intervention strategies for social work practitioners.

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CHAPTER ONE

INTRODUCTION

The serious illness or disability of a spouse generally constitutes a major threat to the marital relationship of couples. Often a debilitating illness will lead to a disruption in family functioning. While it is usual for the illness or disability of a spouse to constitute a serious loss, the intensity, duration, and expression of the loss is quite difficult if not impossible to predict. In some ways, the illness and resulting disability of a spouse may be experienced unconsciously in much the same way as an impending death (Agnes, 1979). Yet, the chronicity of the problem and the continued existence of the relationship pose additional dilemmas for the family, and particularly, to the couple (Fagan & Wise, 1986).

Having worked with individuals with multiple sclerosis (MS) for many years, several clinical observations became apparent to me. Couples where one spouse has MS have special difficulties in coping and adjusting to this debilitating disease. Apart from coping with the day-to-day physical strains, it seems difficult to know where to strike the balance between cheerful denial and over-protection. The variability of MS symptoms can give rise to many misunderstandings between the MS individual and their spouse. When the spouse with MS can no longer live at home

and must be admitted to an extended care facility because of extreme debilitating symptoms, it is not surprising that many marriages break down and end in divorce. However, there are some marriages that persevere, in spite of the stressful factors associated with a chronic long-term disease. It becomes intriguing to speculate why some marriages are able to sustain the MS experience while others end in divorce.

The research questions addressed in this study include: Are there factors particularly unique within the relationship between couples who remain married and identify themselves as a couple, even with one spouse having MS and living in an extended care facility? Are there similarities within the marriages of those spouses who remain together in spite of the many losses resulting from chronic progressive multiple sclerosis? What are the beliefs, perceptions, stories and thoughts of individuals with MS living in extended care about their experiences of having this disease, being disabled, and being married?

One purpose of this study is to address these questions by examining the effects of multiple sclerosis on marriage. Specifically, since the research covering individuals with MS experiences of their disease and their marriage is very limited, this study will attempt to identify some of the major themes of individuals' experiences of having MS, being married, and living in an extended care facility.

A second purpose of this study is to explore and

describe persons with MS experiences of marriage while residing in an extended care facility, with particular emphasis on what aspects of the relationship supported the relationship.

There are few studies that have examined the effect of illness on marriage from the perspective of the individuals with MS.. Furthermore, it appears that the focus of much of the previous research in this area has been on why marriages do not survive. Much of the research has focussed on *what is wrong* with marriages when a devastating illness or condition such as MS befalls, rather than examine the strengths that some marriages possess. This study will be relevant in developing a beginning understanding of how some individuals with MS cope and deal with their disease, disability and resulting losses while continuing to preserve a marriage.

The findings of this study will be useful for social work practice because of the clinical and theoretical implications. Theoretically, this is significant as it contributes to the development of a model or framework which seeks to understand the human experience more fully. This study will focus on what individuals have to say, in their own words, about the experience of marriage and disease. As social workers working in the field of health care, it is important to understand the dynamics of what happens to marriages when people develop debilitating conditions such as MS.

The meaning of several terms are defined below for the purposes of this study.

Spouse: A marriage partner, usually ones wife or husband (Penguin Canadian Dictionary, 1990).

Marriage: A legally recognized personal union entered by a man and a woman (Penguin Canadian Dictionary, 1990).

Couple: Two people, especially a man and a woman, considered as partners or mates (Penguin Canadian Dictionary, 1990).

Multiple Sclerosis: A chronic disease of the central nervous system, usually progressive in nature. Symptoms occur singly or in combination and commonly include malfunction in vision, speech, coordination, sensation, use of extremities and control of bowel and bladder (Hashimoto and Paty, 1986).

CHAPTER 2

LITERATURE REVIEW

The Nature of Multiple Sclerosis

The effect of a neurological disease on a marital relationship can be immense. Those caring for a spouse in an advanced, debilitating state of disease often encounter tremendous strains, major restrictions on social roles, increased financial burden, social stigma, and increased stress throughout the family system (Kerns & Curley, 1985). These family units often include a well adult living in a committed relationship with an ill family member, in this case, a spouse. Couples in which one partner has advanced multiple sclerosis face challenges in interpersonal relationships and strain on the bonds of commitment (Catanzaro, 1990).

Multiple sclerosis (MS) is the most common cause of neurological disability that affects men and women between the ages of 15 and 55 years of age. Approximately 90% of those who experience the disease onset are in this age range (Shulman & Schwartz, 1988). After trauma and arthritic disorders, MS is the most widespread cause of severe disability in adult life (Shulman & Schwartz, 1988). Often individuals are affected as they have just embarked on establishing a family and/or a career (Webster, 1989). When MS becomes too much for the individual or the family to deal with, there may at times be no choice but to move the person

to an extended care facility. This present study is concerned with what happens to the individual's marriage when the multiple sclerosis and resulting disability become so severe that the individual can no longer live outside of a hospital setting. Specifically, how does the relationship or marriage survive, even when one spouse is living within an extended care hospital? This selected literature review is divided into two parts. The first part will examine the general theoretical and empirical research that contributes to understanding the effect of illness upon relationships. More specifically, it will focus on studies pertaining to multiple sclerosis, the issues associated with MS, and how couples cope with this disability. The second part of the literature review will explore the theoretical and conceptual framework. A general review of the theoretical conceptualizations of social support illustrates the connection to the conceptual framework. Also within this second part will be a general exploration of "*stories*" which are important to the methodology of this study.

Theoretical and Empirical Research

People with disabilities have traditionally been regarded as human beings who are not "whole" (Goffman, 1961). Individual differences, interests, and personal history disappear behind the disabled status. Due to stigma, others cannot deal with the person except to see him or her as a disability, and then only in regard to its stigmatizing features (Jones et al, 1984). Similar to this

self-fulfilling prophesy, the individual with a disability may respond and act at a level well below his\her level of functioning (Howe-Murphy, and Charbonneau 1987). In addition, society's negative response toward a disabling condition has resulted in the social and physical segregation of many of the population with disabilities.

People with disabilities often express a wish to isolate themselves, and research shows they are far less likely to have a level of social involvement equal to non-disabled individuals (Sigelman, 1991). In one study conducted by Agnes (1979), when one spouse contracted MS, most couples opted for dissociation by turning away from former friends and associates and seeking a new peer group among others with a similar disease. Individuals with MS must struggle with being viewed as "abnormal" and learn to live with rejection and disapproval (Pavlou et al, 1979). This tendency toward isolation does not appear to only affect the spouse who is afflicted with this debilitating illness but it seems that the couple as a whole becomes isolated.

The couple involvement with illness can sometimes precede the period of diagnosis of MS. Patterns of communication, sexual relationships, and even power may be affected by the threat of illness or disease (Mishler, 1981). The couple may be involved by observing and assessing symptoms and suggesting a course of action. The ways in which individuals interact throughout this pre-diagnostic phase can be revealing, as they may present

patterns of interaction that persist throughout the illness (Doka, 1993). In this period, the couple may have to cope with considerable anxiety and uncertainty. There may be concerns about the effect of the disease upon the health of the non-ill spouse. Such concerns can exist even when a disease is not infectious (Nathan, 1990). Their responses may portray coping mechanisms that will be utilized throughout the illness. Some people may deny symptoms or the implications of these symptoms, while others may fear the worst. The couple may experience other emotions as well. Often there may be guilt associated with their fears. It is not unusual for the non-disabled spouses to worry about what the illness will mean for the spouse with multiple sclerosis and what it will mean for them (Cousins, 1979). Such thoughts, when perceived as selfish, can become a source of guilt.

People will find their marital lives radically changed when the diagnosis of MS has been made. The spouse they knew is replaced by a person with more complex needs. There are numerous issues related to this disease, and the effects on the individual and the couple occur in a myriad of ways. Recently, people with MS have identified sexual dysfunction and changes in feelings of sexuality as a major problem to their relationships (Barret, 1982). As a life force, sexuality is evident in each of the dimensions that comprise the total person. Men and women with MS are no different than other people in their desire to fulfill the sexual

aspect of their lives.

A chronic illness can have a tremendous impact on sexuality and marriage. Shapiro (1987) reported that over 90% of all men with MS and over 70% of all women report some changes in their sexual life since the onset of their disease. Physical disability may interfere with the motor and urinary-bowel control areas, and can alter one's self-image, leaving them feeling sexually unattractive (Szaz, 1989). The psychological feelings associated with coping with an illness such as MS may interfere with the sexual expression and desire inherent in an intimate relationship. As well, the partner can experience a similar range of feelings which may interfere with his/her sexual ability and interest (Crewe and Krause, 1991).

Emotional reactions can often be an issue both for the disabled person and his/her partner, as anxiety, guilt, anger, depression, and denial are the natural consequences of coping with a chronic illness (Shapiro, 1987). It would seem that the numerous physical problems that are part of multiple sclerosis set off a whole range of other dilemmas. Based on the above studies, it is not merely the presence of physical symptoms that creates difficulties in the marital relationship, rather it is how these physical symptoms seem to affect the psychological and emotional responses of the persons involved that has more of an affect on the relationship. For instance, neurological problems caused by MS may accompany or cause psychological problems, problems

that exacerbate the already fragile dynamics of the family system (Fagan & Wise, 1986).

Knowing this, it is not surprising that many marriages break up as a result of the increased stress. Vischer and Clark (1981) stated that relationships where one spouse had MS were more likely to be divorced than married couples where the debilitating disease of MS had not been present. Robinson (1988) found a high correlation between MS and divorce or separation, especially if the couple was young at the onset of the illness.

Beyond the mere stress of multiple sclerosis as a disease, couples are often on an emotional roller coaster; they are affected by the ill individual's health as well as the reaction and responses of that individual and their own responses. The spouse may feel anger over the disease and the sick person's demands, over the effect of the disease on his/her own life, and at the cost of the treatment both on the individual and the relationship (Sanders, 1983).

Conversely, there are relationships that not only survive but transcend and flourish in the presence of the disease and in which the illness seems to consolidate the partnership (De Souza, 1990). Several researchers have speculated on how it is possible for some relationships to grow even stronger in spite of a devastating illness. There have not been any studies that have actually examined what factors are associated with marriage survival when one spouse has MS and is living in an extended care facility.

Ironically, there have been studies that have attempted to explain, either theoretically or empirically, why most marriages end in divorce when one spouse has a debilitating disease and/or disability. However, one need only look around to witness that marriage is a weakened institution (Glenn, 1987), and that high levels of divorce seem to have become a standard part of contemporary society, with one's stability in the community being the best predictor of aggregate divorce rates (National Council on Family Relations, 1990).

Theory on divorce is a relatively underdeveloped area and little is still known about how divorce is related to social-psychological factors, relationship quality, or family structure. Albeit, when theory is invoked, it is usually in some form of cost/benefit, or exchange theory (Martin & Bumpass, 1989). In an exchange theory model, reconciliations are more likely to occur when the costs of divorce are high and benefits are low (Morgan, 1988). Therefore, due to a lack of reciprocity and failure to fulfill role expectations (sex, affection, companionship, money), the non-disabled spouse may deem it necessary for his/her psychological well-being to end the relationship. Furthermore, a couple's financial state is likely to be adversely affected by the primary and secondary costs of illness. Often the demands of the illness as well as any social or financial consequences may curtail social interactions with others (Bluebond-Langner, 1987). Once

again, the above research focuses primarily on developing an understanding of divorce, particularly in the context of illness.

There are additional ways to explain the effect of illness upon marriage, as indicated by Pearlin's research (1980) on marital distress. Pearlin, (1980) identified three types of marital problems that correlate highly with marital distress including:

- 1) the non-acceptance by one's spouse of one's essential self,
- 2) failure to fulfill role expectations and,
- 3) lack of reciprocity in the give and take relationship between husband and wife.

When illness impacts all three of these areas, Pearlin concluded that the couple may find it psychologically more beneficial to end the relationship rather than to continue under these conditions.

There are other factors associated with how some marriages in the face of illness end in divorce. In the literature review, these have been identified along developmental theory and general systems theory. Timing of the illness in the life cycle, nature of the illness, and the openness of the family system all affect the degree of disruption in the marital relationship. Bowen (1976) defines openness as the ability of the couple to be "nonreactive to the emotional intensity in the system" and to communicate his or her thoughts and feelings to others

without expecting others to act upon them. Several researchers working with the population diagnosed with MS have discussed the significance of a stable yet flexible relationship as a defence against premature institutionalization (MS Society, 1990 ; De Souza, 1990). Assessing the life stage of the individual may hold part of the answer to this dilemma. Intimacy versus isolation, generativity versus stagnation, and integrity versus despair demonstrate that a marital symptom may be a more convenient focus for the couple than the larger issues of burden, chronicity, uncertainty, fear, and responsibility. As well, both individuals careers and life plans may have to be changed or postponed as there may be new and additional responsibilities, demands upon time, and financial effects (Fagan & Wise, 1986). This suggests that the couples' developmental life stages can play an integral part in helping the clinician aid the understanding and resolution of the marital problem(s).

However, another way of understanding the effect of illness upon marriage is through an understanding of relationship dynamics between individuals. General systems theory postulates that a change in one part of the system effects change in other parts as well (Buckley, 1967). Using this premise, it would be natural to assume that the effect of MS will influence the spouse and the marriage to some extent. Uncertainty, anxieties about the past, present and future, and frustration with a declining physical body

may all lead to changes in attitude and behavior toward the relationship (Grant, 1986). Although this does not really explain why some marriages end in divorce while others (a minority) become strong, it does indicate why multiple sclerosis or any disease would have a tremendous affect on people's relationships with one another.

There are other researchers who have studied the effects of illness upon families. The findings drawn from these studies can assist in facilitating certain understandings of how this may effect couples. Throughout the entire course of life-threatening illness one needs to be sensitive to the effects of the illness upon the whole family. Families are always trying to maintain a dynamic balance, constantly adapting to the continued changes brought about both by internal changes such as the development of the relationship and external, societal pressures. Dyads in families, such as the couple, are also continually adapting to the changes brought on through internal and external life pressures. Life-threatening illness with all the extensive financial, interpersonal, social, psychological, and spiritual changes that it brings about can seriously threaten that required balance. This is evident in all stages of the disease, particularly at crisis points such as the diagnosis, and times of marked deterioration in health (Slaby & Glicksman, 1985). And yet, Rando's research (1984) tells us that we need to look at the marital relationship from two perspectives. First, each relationship is comprised of

individuals. Reaction to the spouse's illness will be affected by a wide range of variables such as personality, coping abilities, age and maturity, gender, intelligence, education, mental and physical health, religion, fears, knowledge of and experiences with illness, and formal and informal supports. Second, the couple as a whole has its own unique structure and characteristics such as values, norms, expectations, beliefs, flexibility and patterns of communication. The illness will also affect the couple's responses in such areas as the meaning of the illness, the way the illness presents itself, the stigma associated with the illness, the related stresses and strains, and the timeliness and course of the illness (Shneidman, 1978).

A further influence was related to gender differences. This was noted by Weinert (1988) who found that middle-aged wives of husbands disabled by multiple sclerosis spent much more time assisting with activities of daily living and other tasks than husbands of disabled wives. Wives reported feeling an increased sense of isolation and participated in significantly fewer group leisure activities than husbands.

In reviewing the literature, little attention has been paid to the social relationships of marriages where one spouse has MS or their perceptions of marriage. There have also been gaps in the literature with regard to institutionalized partners with the majority of studies focusing on the geriatric population. However, recently there has been an increased emphasis placed on the

importance of stories in the family with regard to patients' illness narratives. Through these narratives the "patient" can achieve a sense of empowerment, and feel anchored and more connected to those around them thus helping to strengthen the family system (Cole-Kelly, 1992). Chronic illness stories are of particular importance in that they treat the whole person and help to give a coherence and meaning to the illness event, marriage, being expressed (Kleinman, 1988). The process of relating a story may serve ritualistic benefits that give meaning to the marital relationship and provide a formal process usually associated with significant transitions (Cole-Kelly, 1992). This notion of "story" will be elaborated further below.

Conceptual Foundations

Coping with multiple sclerosis on a daily basis in a residential facility presents a complex set of experiences to both the marital partners. Social support has been shown to play an important role with coping and psychological adjustment in individuals and families where multiple sclerosis is present (Weinert, 1988). At best, the phenomena of social support has always been comprised of a diversity of conceptual definitions which ultimately reflect the difficulties in understanding this complex concept.

The role of social support in determining how couples cope with multiple sclerosis is a useful conceptual framework (Kerns & Curley, 1988). The concept of social support uses the social environment as the salient factor to

explain the forces that facilitate the survival of human beings (Lin, 1986). Social support can be especially useful in studying adults with partners who have multiple sclerosis because of such issues as social stigma, social isolation, and the influence of the disease on social roles of the disabled spouse.

Caplan's (1974) conceptualization of social support included three elements in which the significant other:

- (1) helps mobilize the individual's psychological resources in order to deal with emotional burdens;
- (2) shares tasks; and
- (3) provides the individual with supplies of money, materials, tools, skills, and cognitive guidance to improve the individual's ability to handle the situation.

Using this understanding, social support provided to spouses with multiple sclerosis might include emotional or instrumental aid, or the provision of goods or information, all of which serve to improve the non-disabled spouses ability to provide support to their husband or wife. Caplan (1974) claimed that:

"....such support may be of a continuing nature or intermittent and short-term, and may be utilized from time to time by the individual in the event of an acute need or crisis" (p. 5-6).

Aside from instrumental aid as such, Cobb (1976) identified support as consisting of three types of

information. The first related to the person believing that he or she is loved and cared for. This information would occur in a situation of mutual trust whereby the person's needs for affiliation and nurturance would be satisfied. This kind of support is often referred to in the literature as *emotional support*. The second type of information related to the person's self-worth and has been referred to as *esteem support*. This kind of support would occur in situations where the person felt needed and valuable, and able to contribute in some way to another's well-being. The third type of information within Cobb's model (1976) has to do with the person believing that he or she belongs to a network of communication and mutual obligation, thus, this is a *belonging form of support*.

Weiss (1974) conceptualizes support as the quality of feeling sustained through the gratification of needs. Weiss investigated newly divorced people, and women who had recently moved to accommodate their husband's employment. What he discovered was that different types of relationships provided different kinds of support. For example, the loss of intimate relationships resulted in the "loneliness of emotional isolation" (p.20) and could not be reconciled through friendships. The loss of friendships resulted in the "loneliness of social isolation" (p.20) even though the spouses were happily married. In applying these findings to this study the potential exists for a spouse whose marital relationship has deteriorated due to the advance of multiple

sclerosis, to experience "the loneliness of emotional isolation", and social isolation if their spouse is institutionalized. This would also apply to the spouse with the disease.

The notion of reciprocity is another theme that arises within a particular conceptualization of social support. Shumaker and Brownell (1980) state that a norm of reciprocity operates within our culture and that people usually return the benefits received from others. In cases of chronic illness where help is often needed over an extended period of time, "the recipient's inability to reciprocate fully may become increasingly apparent and asking for help may become especially difficult" (Shumaker & Brownell, 1984, p.14). If reciprocity cannot be fulfilled, then relationships between the people involved may disintegrate.

Although definitions of social support vary considerably, the underlying assumption of this phenomena is that "supported people are physically and emotionally healthier than non-supported people" (Shumaker & Brownell, 1984, p.22). Many studies have provided evidence of the relationship between support and well-being; however, there is a lack of agreement about how social support promotes well-being.

Repeated research shows that spouses, when available, willingly assume the responsibility of supporting their disabled partner (Cantor, 1983; Johnson, 1983). Cantor

(1983) describes the hierarchical nature of support in which friends and neighbors assist only when the spouse is not available. Eggert and associates (1977) found that in severe chronic conditions, family supports become eroded over time. Presumably then, a spouse providing support for their disabled counterpart, will not only assume major responsibilities in many areas of their partner's life, but may find it difficult to find others to assist should they be unable to fulfill their role.

Although the link between social support and physical and mental health has been briefly discussed in this review of the literature, there is little mention of how the concept of social support relates to people diagnosed with a debilitating illness. More specifically, there does not appear to be much connection made in the literature between the concept of social support and marriages that survive, even when one spouse has MS and is living in an extended care facility. This thesis hopes to discover more about the concept of *support* when examining factors involved with how some marriages survive.

Another concept to be explored within this study is the notion of persons' with MS "stories", and in particular, stories pertaining to their relationship with their non-disabled spouse. Several family researchers have studied the notion of "family stories" in order to obtain more information on family experiences and family themes. Stone (1988) contends that family stories are beginning to get

more notice among social workers because there is an increasing awareness of how profoundly these narratives can affect what we see and therefore how we live.

Thomae (1968) emphasizes that thematic units of experience relate to the meaning of events. By remembering family stories, individuals might well give themselves points of orientation. Askham (1982) states that family stories can be categorized into particular themes (such as work- or health-related experiences) and one can analyze generations within the family that share similar themes, which thus orient individuals in regard to their own life path. Hagestad (1984) identified certain themes that pervade human experience: views on social issues, work, education, money, health, daily living, and interpersonal relations. Such themes may in fact be reflected in individual stories.

In this study, "story" reflects the way people describe or talk about an event of the past, whether it be a situation, another person, a particular time period or anything else. What is important in terms of this specific kind of definition is that a story does not necessarily reflect "concrete facts" of what has happened or occurred, rather it refers to an individual's interpretation or experience of the event.

Important studies have looked at illness and marriage from a macro position, or from the point of view of the couple, however none have dealt specifically with MS and the

marital relationship from the clients' point of view. This study is concerned with the subjects' own experiences of marriage.

Multiple sclerosis is a devastating disease that can have among its range of disturbances the physical and emotional domains. To date, little research has been done with regard to clinical intervention models on what the factors are of those marriages that have persevered despite one spouse having MS. This study attempts to explain the factors that keep a couple together and are unique within a marriage, even when one spouse has MS and is living in an extended care facility.

CHAPTER 3

METHODOLOGY

The research design is exploratory in nature. There are numerous studies that have been done on multiple sclerosis as a disease, or multiple sclerosis from a professional perspective, but very little has been done in the area of multiple sclerosis and its effect on marriage.

Particularly, although some studies have focused on some of the challenges and problems individuals with MS must confront, there do not appear to be any qualitative studies on what people with MS have to say in their own words about their own experiences with this condition. Arkava and Lane (1983) suggest that when a research topic is poorly understood it is appropriate to engage in "exploratory-descriptive research (pg. 190). This study is qualitative and is the method used to gather and interpret the data.

Through this kind of research design, many aspects of participants' experiences are explored offering a richness and breadth. The individuals' experiences are validated and recognized as significant and valuable. This design gives participants' experiences a voice, and an opportunity to express in their own words what it was like to have multiple sclerosis and be in a marital relationship while living in an extended care facility. Since there had been few studies in the literature giving the individual with MS this voice, an exploratory, qualitative research design was selected.

DATA COLLECTION

Data were collected during a one-to-one in-depth interview between the participant, individuals with multiple sclerosis living in extended care, and the primary researcher. The interview lasted from one, to one and one half hours. Each interview was audiotaped and subsequently transcribed for analysis. All interviews were conducted in the participants' residence, George Pearson Centre, in Vancouver, British Columbia. This provided an opportunity to observe environmental factors pertinent to this study. Open-ended questions were asked, following a general interview guide (Appendix A) that was divided into three parts. Part one of the interview guide focussed on demographics. Part two focussed on questions pertaining to the time surrounding the MS diagnosis. Part three focussed on questions pertaining to the marital relationship.

The interviews were unstructured and although initial questions originated from an interview guide (Appendix A), subsequent questions evolved out of the accounts provided by the participants. There was no attempt to problem-solve or counsel the participants, although at times this was difficult due to the researcher's greater familiarity with the role of clinician rather than researcher. To encourage further exploration of a topic, prompts such as, *"Tell me more about that"* were used.

George Pearson Centre is part of the British Columbia Rehabilitation Society consisting of an extended care

facility with a resident population of about 190 with the mean age being 53 years of age. Approximately one third of the clients have a diagnosis of multiple sclerosis. Other wards within the Centre include a ventilator-dependent unit, a traumatic brain injury unit, and an outpatient clinic. The remaining clients within the residential component include spinal cord injuries, cerebral palsy and other neurological conditions.

SUBJECTS

Six individuals were interviewed, three males and three females. All subjects participating in the interview met the following pre-determined criteria:

- (1) be residents of George Pearson Centre,
- (2) have a confirmed diagnosis of multiple sclerosis,
- (3) be currently in a marital relationship,
- (4) have no concomitant medical disorders (such as an amputation, or a psychiatric condition),
- (5) understand and volunteer to participate in the study,
- (6) be able to sustain a level of alertness and attention to complete the 60 to 90 minute interview, and
- (7) state that one is not currently in a "crisis situation" (such as being depressed or suicidal).

To ensure these criteria were met, the Medical Records Department of George Pearson Centre provided this researcher with a list of clients in the Centre whose primary diagnosis was multiple sclerosis. The total number of clients identified was 64. Having determined no known concomitant

medical problems, participants were sent a letter of initial contact (Appendix B). When respondents agreed to participate in the study, a consent form (Appendix C) was signed.

PROCEDURE

The constant comparative method of analysis (Glaser & Strauss, 1978) was used to formulate categories for coding the data. Codes were inductively generated, compared to others, and examined for emerging themes. Passages were coded and compared to each similarly coded text passage to ensure consistency within each category. Using these steps in data analysis, each interview was examined separately and in relation to the other interviews. Eventually an organizing framework emerged that reflected perceptions of marriage of spouses who have multiple sclerosis and who live in an extended care facility (Appendix D). Analysis continued until unique categories no longer appeared.

MEASURES

The sampling design was purposive. A face-to-face interview was chosen to collect the data in this study as the most appropriate way of disclosing and discussing emotionally laden subjects (Sellitz, Wrightsman, & Cook, 1976, pg. 298). Having the subject talk about their perceptions of the marital relationship could potentially evoke strong emotions and, therefore, only face-to-face interviews could allow for the emotional needs of the subject to be adequately addressed, if needed. A general

interview guide was used rather than a standardized list of questions since the interview guide could offer more flexibility in terms of wording and sequence of questions. Furthermore, the interview guide could be used as a basic checklist (Patton, 1980) ensuring that all the relevant areas would be covered, and encouraging clients to talk about their experiences in their own way.

Prior to interviewing individuals for this study, the interview guide was pre-tested on an individual with MS who met the pre-determined criteria but would not be participating in the study. This pre-testing was to assess if the interview questions were clear and concise, and if there needed to be changes or modifications. The results of the pre-testing indicated that no changes were necessary.

DATA ANALYSIS

Following each interview the audiotape was transcribed. This process of transcribing fostered greater familiarity with the data and therefore facilitated data analysis. Following the transcriptions, the researcher read the transcript in tandem with listening to the audiotape to get a more complete sense of the whole. The transcripts were then re-read more thoroughly to identify categories of complete thoughts expressed by the participants. The categories were considered and themes were identified. At this stage the researcher began to take the data and abstract them into the language of social work.

In a qualitative study the credibility of the statements

made by interviewees is important (Glaser & Strauss, 1967). In regard to reliability, one might wonder if participants would give different responses in an interview due to different experiences or because the questions had been asked in an inconsistent fashion. Standardization of format was increased by using one interviewer which increased the likelihood that the interview was conducted in a similar way than if there had been more than one interviewer. Reliability was enhanced by audiotaping the interviews to avoid selective recording of the responses. During the interview, the researcher was attentive to possible key factors that influenced subjects' report of subjective data. Some factors included the wish not to disclose memories of their personal experiences, fears of being judged, and the desire to please the interviewer. This researcher attempted to facilitate an open and non-biased discussion with the participant, as well as ensuring that comments were made and questions asked with as non-judgemental an attitude as possible. It was anticipated that due to this effort, the participants would find it easier to share non-biased statements of their own experiences. The participants' stories and descriptions of their life was accepted as having "face validity", (Stanley & Wise, 1983, pg. 53). All six of the interviews were transcribed into the written form and subjected to the constant comparative method of analysis (Glaser & Strauss, 1967;1990).

ETHICAL CONSIDERATIONS

The researcher obtained permission to conduct this study from the University of British Columbia Behavioral Sciences Committee For Research And Other Studies Involving Human Subjects (Appendix E) and from the Chief Executive Officer of The British Columbia Rehabilitation Society (Appendix G). Participants who met the selection criteria and who expressed a willingness to participate in this study were provided with an information letter (Appendix B) and were contacted by the researcher who met individually with each participant at the long-term care facility at preset times. During this meeting the ethical concerns of confidentiality, the right to refuse to answer any questions, and the right to withdraw from the study at any time without jeopardizing care at the facility or at The University of British Columbia were explained by the researcher. A written consent form (Appendix C) with this information was obtained from each participant and signed in the presence of the researcher prior to conducting the interview. Participants all received a copy of the consent form.

The names of those who chose to participate were kept confidential. The audiotapes and transcripts were coded and stored in a private area. Names and identifying information were removed from all written material. Access to the audiotapes and transcripts were limited to the researcher and the primary research advisor. Upon completion of all

written work in relation to this study the audiotapes and computer discs will be erased and the transcripts will be destroyed.

CHAPTER 4

RESULTS

Whether or not the marriage and/or relationship survives when one spouse has multiple sclerosis and must live within an extended care facility appears to depend on several factors, according to this study. These factors or influences play a part in either supporting or not supporting the marriage. Some of these factors existed long before the diagnosis of MS came into being, and in this way, they are informative to us in that they tell us something about the individual with MS and the marriage apart from the intrusion of the disease. Of course, since this study is in part retrospective, it is difficult to know with certainty about anything apart from the MS experience because the research method depends on individuals' memories of events. In spite of this obvious limitation, the factors which seem to have an effect on marriage survival do reveal something about the past as well as the current present-day relationship.

The purpose of this chapter is to examine each of the categories identified and their properties. What are the general marriage patterns of couples who stay together when one spouse has MS and is living in an extended care facility? What are the factors or situations that contribute to the survival of the relationship? What are the stories, experiences, and perceptions of MS persons

living in extended care about their experiences of having MS and being married? The research questions will be addressed using *grounded theory* analysis. This approach will provide examples from the data, allowing the richness of individuals' own words to punctuate the trends and themes that have emerged from the data analysis. Analyses will focus on the connections between the categories.

Five main categories emerged from the data analysis. The categories reflected the individuals' with MS past and present *experiences* with the disease and these in turn appeared to have an effect on how they experienced their present day relationships with their spouses. The categories were Person's with M.S. Experiences of;

(1) *Self* (2) *Spouse* (3) *Medical System* (4) *Support Systems* (5) *Present Relationship*.

Person's with M.S. Experience of Self

This first category emerged as individuals with MS described how their personal ideas, perceptions, thoughts, emotions and beliefs seemed important to how they had coped with this devastating disease. For most of the individuals with MS interviewed there was an emphasis on how their self-images either helped or hindered them cope with having this disease. In their own words, some individuals described certain beliefs arising from their cultural or religious backgrounds that existed prior to them being diagnosed but it was through the diagnosis that these beliefs became more pronounced and salient in their lives. It was as if having

MS, for some individuals, propelled them to connect back to past beliefs that had either been forgotten or had been somewhat dormant. Of course, other individuals described new perceptions/beliefs they developed through having MS, such as certain notions of spirituality or God. The common area for all of the people who spoke about experiences of self was that these experiences somehow enabled them to *cope better* with the disease, and this inevitably helped their marriage. This first category was comprised of five main areas of the experience of self, or rather, properties, and they were as follows: (A) self-concept (B) cultural/ethnic affiliation (C) spiritual beliefs (D) emotional experience (E) psychological well-being.

Self-Concept

The notion of self-concept as an experience of self occurred whenever the persons with MS commented on what they thought or felt about themselves. Through their descriptions of themselves and their stories, it became apparent whether they had positive or negative feelings about themselves. For example, the following quote illustrates this quite well:

".....like, I always felt that I'm not a bad guy, well, you know, decent, and that having MS was going to be a challenge, but that it wouldn't change me, I mean, it wouldn't change that basic good guy inside...."(Male)

The impression from the above passage is that this individual found a way to continue seeing himself as a "good

guy" in spite of having multiple sclerosis. Although this may not appear to be surprising in itself, research has shown that people with long-term illness often have very negative self-images. One could speculate, by this person's choice in words of how he describes himself, that he liked who he was as well. This was in contrast to the individual quoted below whose way of seeing himself was not as positive:

"When I see myself being all dependent on people, on strangers really, well I wonder then what X sees in me. Because I ain't the person I was, I ain't really a whole person anymore, I just can't see what she would see in me." (Male)

From this person's perspective, having multiple sclerosis has taken away from his personal image and made him less than he was before the disease. There has been a metamorphosis to a new, unwhole person. This individual assumes that his spouse also must perceive him differently. One can speculate that there is a relationship between the self-image and self-esteem of this individual and the nature of his relationship to his wife. Although this query can not be explored thoroughly in the context of this thesis, it will remain a factor that will be considered as the data are presented.

The following passage illustrates how closely connected one's self-concept is with psychological wellness:

".....on a given day, depending on how I feel about

myself, that's how I handle living here and having multiple sclerosis. I guess on those days where I feel real shitty, well, real down on myself, then everything else seems to go bad also, like how others see me, and how X and I get along...."(Female)

This idea seemed to come up as a re-occurring theme in the sense that *self-concept* either enabled the person with MS to cope better with the disease or not cope as well. Thus, as the client above articulated, it was the feelings about himself that appeared to have an influence on his relationship with his spouse.

Cultural Affiliation

The second property in the category Person's with M.S. Experience of Self had to do with the cultural and/or ethnic affiliation of the person with multiple sclerosis. These cultural experiences, for the most part, existed prior to being diagnosed with the disease but somehow came more "to life" once there was a diagnosis. In other words, it was as if the cultural identity to which one was born into took on a new meaning with a debilitating disease. For one person, the cultural affiliation in her life not only enabled her to cope better with the disease in general, but it somehow added a deeper meaning to her life. Yet prior to having multiple sclerosis, this person's cultural experiences had not meant as much to her. In her own words she said:

"I don't know if being French-Canadian really has helped me or not, but in my family, we grew up with a

joie de vie, and that means that we love life and we do the best we can with what we got. So when I find out that I have multiple sclerosis, then even though I am down, I know that I must still do the best I can do and that I must look for the joy in life." (Female)

Clearly the above person appeared to draw some support from her heritage of having grown up in a French-Canadian family. When she spoke about the diagnosis of multiple sclerosis and her relationship with her spouse, what emerged was a deep connection to her cultural background. Through this connection it appeared as if she searched for lessons about life within the culture of being French-Canadian that could possibly offer her some guidance with her current life situation. It is almost as if this woman relied on the *joie de vie* notion to help her cope with the fact that her life had changed with having multiple sclerosis. As she emphasized:

"...I still must do the best I can do and I must look for the joy in life."

Thus, her cultural background taught her something about how to survive in the face of adversity, and in this way, her experience of self was defined in part with being French-Canadian.

Spiritual Beliefs

For some of the individuals interviewed, having a connection to religion or God enabled them to cope better with having a debilitating disease. Interestingly, a few of

the people spoke about how they had been born into a particular religion but that it had not been tremendously meaningful to them until their diagnosis. Although it is difficult to speculate about the nature of this theme without more data, it appears evident that being diagnosed with a chronic long-term disease such as multiple sclerosis propels people to examine their lives on a deeper level, look for more avenues of support, and strive to develop new meanings:

"....although I was born Catholic, it never really meant much to me because I guess I was so busy with my life, I mean going here and there, working, achieving, buying things, you know, the fast-paced life of most people and then bang, I suddenly have this terrible disease and there is no cure and wow, it stops you dead in your tracks, you know? So I guess I started reflecting on the meaning of my life, or something like that, and I started thinking about God and what it means to be Catholic and I found that it helped me deal with all the uncertainty of what was ahead." (Male)

This person appeared to re-discover what it meant to be Catholic during the onset of the disease and somehow it enabled him to face the uncertainty of what was ahead in a new way. It is almost as if his life "slowed down" once he found out that he had multiple sclerosis and this in turn gave him an opportunity to re-examine the meaning in his life. Another person commented:

"I think X saw that I had become more spiritual after having this condition for a few years. It's not something I planned, but it just happened and we could now share it together." (Male)

The above individual had described in the interview that his wife had always been more religious and connected to "spirituality" than he had been. After having multiple sclerosis for a few years and ending up in an extended care facility, he began to question *"the meaning of it all"* and so looked toward religion for some answers. Though he did not find specific answers as to why he had been stricken with this disease, this individual described how in searching for some answers, he no longer felt so alone and in despair but somehow felt more hopeful and optimistic toward life. This enabled him to connect to his wife in a new way as he elaborated in the following:

"....even though I wish I wasn't in this condition, you know, that I wish that I was healthy, I think that our relationship has grown, we're even closer and that could be because I'm different, like I'm more into this religion thing and that was always my wife's thing." (Male)

It is difficult to know if this person and his spouse would have grown in their relationship to one another had he not become interested in religion or if they had not found something to share once he started living in an extended care facility. What is evident is that he found a way to

connect to his wife in a new manner which he had not done when he did not have multiple sclerosis. Thus, this person's *experience of self* in terms of becoming more spiritual appeared to affect the general marriage pattern in the sense that the marriage not only survived from the person's with MS perspective, it became closer.

Emotional Experience

The fourth property was called *Emotional Experience*. All of the individuals in this study described, at some point in the interviews, how they had emotionally responded to having multiple sclerosis. Aside from the immediate responses to the diagnosis, which ranged from crisis to complete denial, the emotional experiences to having this disease had developed over time. For some individuals, living with fear had become a way of life for them. Although difficult, the emotional experience of fear enabled them to connect to others, especially their spouses, in an even deeper way than before. Another person with MS described how having MS had allowed him to transcend the mundane in life and actually become more spiritual and connected to life around him. For all of these people interviewed, however, the emotional experience of MS seemed to play a part in their overall relationships with their spouses. The following person elaborated:

"I was never the kind of person to talk a lot, you know? Like I really was not into talking about feelings and stuff like that. But when I got this MS,

well, everything just bubbled up inside me and it got to be too much so I started talking a bit to the wife and in a weird way, we got closer." (Male)

For some individuals, the emotional experience was characterized by the concept of sharing with their spouses, and this in turn seemed to be positive for the marriage in general. As the above person elaborated, there was a certain *emotional intensity* that grew upon learning that he had MS and it was this overflow of emotions that propelled him to begin sharing more with his spouse. Other individuals also referred to the intensity of the emotional experience as can be seen in the following two passages:

"I was really angry in the beginning, when I found out, I was so angry I couldn't think about anything, I couldn't talk to anyone, nothing, I was just gone. But now, as I look back, I think that maybe that's how I survived in the beginning, you know? Being angry helped me survive." (Male)

"I cried and cried and cried. I don't remember much about that time period except that I spent all the time crying. And then one day I decided I had to get on with my life." (Female)

The above passages describe two stories of survival. Although the stories are different, the message about surviving in both of them is clear. The man in the first passage responded to the diagnosis of MS with confrontation

(anger) whereas the woman in the second passage responded through grieving, (crying all the time). Though one could speculate that these are gender differences, this needs to be examined more systematically from a gender perspective. It seems that both ways of responding relate to grieving. In the first passage one is able to imagine the intensity of the emotional experience of this person. Although it may not be fully clear what all of the anger may be about or what the person was thinking about at the time, it is clear that his emotions are intense. Although he is not able to share these feelings with his spouse in the beginning, at a later point in the interview he discloses that they were eventually able to talk about the multiple sclerosis. In the second passage the individual with MS describes an emotional experience that is also very intense and all consuming. Once again, although it is difficult to know what she was thinking about at the time, there is the understanding that somehow the intensity of the emotional experience was part of a larger process in coping. In other words:

"And then one day I decided I had to get on with my life",

may not have been possible had she not withdrawn into herself and experienced the grieving response as fully.

Person's with M.S. Experience of Support

The second category focussed on the person's with MS experience of support systems. As could be expected, the

perceived support that individuals with MS had seemed to have an effect on their relationship. The notion of "perception" has been specifically noticed because from the data, it did not seem to matter how much *actual* external support was available (ie, how many friends came to visit) but rather, what seemed important was whether or not the individual with MS felt supported. In his own words, one person described how much the support systems made him feel that he was not isolated, and this in turn, allowed him to be able to "give" more freely to his relationship with his wife.

This second category *person's with M.S. experience of support* had four dimensions; (1) spouse, (2) family, (3) friends, and (4) medical system. All of the individuals interviewed made reference to one or more of these areas which they felt had been supportive during the diagnosis of multiple sclerosis and throughout the experience of this disease.

Spouse

Respondents indicated that there were a variety of ways in which his or her spouse's reaction to the diagnosis of the disease was experienced. For instance, some individuals experienced their spouse's anxiety, whereas others experienced their spouse's confidence and logic. And still others experienced their spouse becoming more talkative or increasingly withdrawn. Regardless of the emotional reaction, what appeared to make a difference to the person

with multiple sclerosis was whether or not they experienced their spouse's reaction as being supportive:

"When he learned that it was MS and as I said earlier, that diagnosis came after a certain time had passed, my husband was pretty calm about it. He doesn't get excited about things really easily. He was pretty calm.of course, I was very fearful and nervous and excited and so his way of being was the best for me because I looked to him for strength, and for support and it was there. Somehow, he was able to be strong for me and I found that it helped." (Female)

We learn through the above passage that this woman found something in her husband's response to her to be supportive, even though it was very different from her own responses. We will never know what the above husband did or said to "be supportive" but what is significant is that this woman found something about her husband's response or "way of being" to be supportive during a time of great crisis to her. Somehow his quietness which she viewed as inner strength helped their relationship survive beyond the time of the diagnosis. In her own words she emphasized:

"I think that his support was a quiet, almost invisible kind of support, you know? Like he never was into talking too much, that's just his way, but he was always there, ready to let me lean on him if I had to....and believe me, I had to some of the time! And when I got stronger, well, I tried to be there more for

him also. Somehow we've managed to be together all these years." (Female)

The value of reciprocity is evident in that she found her husband to be supportive when she first learned that she had MS, and it also becomes apparent that she found a way to return this support at a later time in their lives.

Another person with MS described how he experienced his spouse's support when he discovered the disease:

"I mean, upon discovering that I had MS, she was very supportive in the sense that she simply let me talk and sat there and told me that whatever happened, we would handle it together as we had always done with other things in our lives. You don't know, but just her saying that made a huge difference on me, like somehow, I did have more strength after sharing all that I had been feeling with her." (Male)

Similar to the previous person, the above individual spoke about how his spouse appeared to put her needs and feelings on hold while he was initially in crisis upon learning about the MS. Support can be a response that is passive, as seen in the above passages, yet conveys a willingness to "be there". Both of the above individuals with MS perceived their spouses as being fully present, even when no active response was given.

As another individual stated below:

"She put on hold all her own stuff so that she could be with me completely. This is what I really

needed to survive that first two years. But after some time, things did change and she was then able to share with me some of what she had been feeling, her disappointments, and I am very glad that she did because I do not think it would have been good for our relationship if she was never able to be herself, so to speak." (Male)

Support, in some ways, is reciprocal. Although the sample size in this study is too small to generalize, there does appear to be a pattern in the relationships where spousal support was experienced in that the person with MS wanted also to be able to offer support to the spouse. This appears to be an important factor since it was mentioned by most of the individuals interviewed. As one person stated so eloquently:

"I guess what I am saying is that it would have been more of a struggle if I were alone, without a close and supportive relationship that I can draw some strength from. My only hope is that somehow I have managed to give something back to her so that she finds that the relationship in some way enhances her life as well." (Male)

One could speculate that perhaps what contributes to the overall marriage pattern is reciprocal support, and although one spouse may require more support during a time of crisis, there is the implicit understanding that support is reciprocal.

Family

The experience of support came from family members of the person with multiple sclerosis. From parents, siblings, and extended family members, the support that they offered was important and remembered as the individuals in this study described how they had coped with having this devastating disease. For some, the support that came from family was offered in terms of a world view, or rather, a way of seeing life in a general sense. One woman spoke about this:

"My mother visits here once or twice a year. And her philosophy of life that I grew up with, it's funny how it only became real to me with having MS, but her philosophy in life is that you find the strength to do what you have to do in bad situations, and that you don't choose a lot of what happens to us....I think her philosophy is that you do the best you can do with what you have. You don't give up. You don't lose hope. No matter what, you keep on trying, and life is still precious." (Female)

It is almost as if the above woman has found a way to cope and make a life for herself by accepting the gift from her mother. This gift can be seen as a deep form of psychological support that not only informs her how to be in the moment, it also offers her a vision of how to live her life and make the best of each day as possible. To perceive that "life is still precious" enables this woman to live

beyond the terror and disappointment in having multiple sclerosis and appreciate all that is still present in her life, all that has not been taken away by the disease. It is evident that the mother of the above woman has provided the kind of support that will most probably have an influence on other relationships in her daughter's life as well. We get the impression that the above woman grew up having been infused with this "world view" and the diagnosis of MS tested this world view.

Another person with MS described how a sibling had been immensely supportive:

"....we were never really close, like, my sister and I we're just very different people, you'd almost think that we came from different families. So anyway, something happened when I got MS, we suddenly started talking more and something changed. I don't know if she felt sorry for me or what, but she was suddenly very supportive, very interested in being a sister, and it couldn't have come at a better time." (Female)

As illustrated in the above passage, for some people the crisis of MS served to reunite them with family members in a new way. It was almost as if MS became an opportunity for some individuals to become better connected to family members with whom they had been previously distant. Another person referred to the support he had received from his brother in the following quote.

"The next person who I really shared stuff with was my brother, and he came over a few days later and sat with me and we talked about everything under the moon, including my diagnosis of MS and being my older brother, he was very supportive and let me know that he would be with me every step of the way - you know, just hearing those I loved say those things made a difference in my outlook after that point. I think I was able to handle it better in some way." (Male)

It is clear that part of the experience of support had to do with being able to talk about the diagnosis and all the aspects of having multiple sclerosis. At various points in the interviews, everyone mentioned how important it had been for them to have someone, outside of their spouse, to be able to talk about what was happening. It appeared that an aspect that was considered valuable by all six individuals interviewed was being able to talk without the fear of being judged. An example of this was stated in the following excerpt.

"What was really important for me was talking to my sister. Even though talking to my wife was great, I needed someone outside of our relationship, just so I could vent, and I didn't have to worry about making someone else feel bad." (Male)

Another individual expressed how she felt that knowing her father was there somehow helped with her relationship to her spouse. Part of this had to do with knowing that her

spouse would not be alone in dealing with the stress of multiple sclerosis. She explained in the following:

"He (husband) was fabulous, I mean, I couldn't have asked for more support. But having my father around, knowing that I could talk to him at any time and knowing that he (husband) could also talk to him made a difference. I guess its like knowing that we weren't all by ourselves, that there was someone else we could both lean on." (Female)

The experience of support from family members appeared to have an influence on the relationships of individuals with MS and their spouses. This influence was positive in two main ways; (1) it provided a certain "respite" to the partner who did not have MS (2) it enabled the person with MS to not become too dependent emotionally on one person (the spouse) and to have other supportive people around as well. There appears to be a connection between *family support* and a positive affect on the marriage. The implications of this will be discussed toward the end of this chapter.

Friends

The third dimension in the category *experience of support* was related to the support of friends. The following passages by two individuals with MS relates to friends:

"You really find out who the friends are, you know? Like, before MS I have lots of people to talk with, and

after MS, well, I only have a few, but the few that I have, they are with me all the time. Les vrais amis, we say, real friends." (Female)

"I imagine it was difficult for them to see me in the psychological state that I was in, and it was difficult for me to see myself at that time because even though I was being so moody, it was like I could not stop myself so I had some awareness of how challenging my close relationships were at the time, for me and for others. But what was wonderful, and is almost a positive thing that has occurred through having MS is that relationships have become stronger, and they have endured, and in this way I am even closer with my wife, my brother, and some of my friends."

(Male)

As can be seen, there are several aspects to the support experienced from friends. Both of the above comments are linked to the idea that the relationships that have endured through the disease of MS have become stronger and perhaps even more rewarding. As the individual in the first passage emphasized, *"you find out who the friends are"* which refers to the idea that support from friends really only occurred from a few people, or rather, only people who could be considered real friends were able to offer support. One gets the impression that although this individual may have been disappointed because it appeared as if he had more

friends prior to being diagnosed with MS, one learns that the support he receives from a few true friends goes a very long way.

In the second passage, one also gets the impression that the friendships that have survived the ordeal of MS have been extremely supportive. In fact, the individual in the second passage explains how perhaps a positive outcome of having MS has been stronger and better relationships with those close to him. Although we learn how difficult it was for him to cope, it also became apparent that his friendships offered him tremendous support and it is something which he has not forgotten.

Another person with MS spoke about how a friend offered support by simply not treating her any differently than when she did not have MS. In this example, the fact that her friend continued to see her as the same person she had always been was perceived as very supportive:

"It was kind of weird, realizing that she (friend) didn't think anything different about me, once I became bed-ridden and all that. I mean, for me, there was a big difference but for someone like her, such a good friend, it never seemed to matter to her what I looked like or what was wrong with me. She really lifted me up." (Female)

Another person with MS mentioned that what was most supportive to him was being able to have a good time with his friend. The emphasis here was on "feeling good again"

and we get the impression that this was what made the relationship even better:

"He really made me feel good again. Our friendship didn't change for the worse, if anything, it got better. Between guys, having a few laughs." (Male)

Person's with M.S. Experience of Spouse

The category *Person's with M.S. Experience of Spouse* was related to how the person with multiple sclerosis had experienced the relationship prior to and throughout the diagnosis of this disease. In other words, all those aspects that had to do with how the couple had met, the ideas and thoughts they had about marriage as an institution, as well as their history together in the relationship became part of this third category. Other aspects of this category also included the spouse's reaction to the diagnosis and the possible role and identity changes that went along with this change. It must be pointed out that all of these aspects or *properties* of this third category are the MS person's *perception* of these events. Thus, we do not really know if the spouse would share the same perceptions, memories, or experiences of the relationship, nor do we really know if the spouse actually reacted to the diagnosis as described. What we do know, however, is that the person being interviewed has experienced the relationship with his or her spouse in a particular and unique manner, and it appears that this experience contributes in some way to the overall marriage

pattern. It appears as if the person's with MS experience of his or her spouse prior to and during the diagnosis of MS may tell us something about whether or not the relationship survives once the person is living in an extended care facility. These experiences will be described and presented within the following properties.

Ideas of Relationship and Marriage

As the individuals interviewed were asked to talk about their relationships prior to being diagnosed with multiple sclerosis, some of them responded by talking more generally about their beliefs and ideas on what it meant to be committed in a relationship. Others talked about what it meant for them to be married. All of these ideas and notions about the relationship with the spouse were considered to be part of the larger category *person's* with M.S. *experience of spouse* because they seemed to reflect a philosophy that had been developed while in a relationship to the spouse. Although we do not know if the spouse shared these same ideas or philosophy, it nonetheless seems important for the person with multiple sclerosis to have experienced these notions in the presence of such an important relationship. The following are some examples of this property:

"....our relationship is a bit of a romantic relationship. It always has been. I think that relationships like marriage must never lose their romance." (Female)

In this first passage, what is emphasized is the notion of romance. At an earlier point in the interview this person described how she and her husband had always celebrated birthdays with flowers and went out for dinner by themselves on special occasions. What added to her ideas about "marriage" was the concept of romance which she had described as "going out of your way to do something special". She particularly emphasizes that marriages must never lose their romance, and this idea seems to have helped her and her husband survive the effects of a long-term illness:

"...you talk about everything, you know? Like, when you're married for a long time, you grow really close to each other and you can not let the other person go because the spouse becomes part of you." (Female)

In the second passage, we learn about the importance of communication for the person with MS. Although it is not described in depth, we do get the impression that for this person, being involved in a long-term relationship involves spending time talking about life experiences and events. Interestingly, we get an indirect impression that "leaving" the person is not really an option because of the closeness that is developed. When the person with MS states, *"...you can not let the person go because the spouse becomes part of you"*, perhaps we are getting a small glimpse of an idea that will enable the relationship to survive the adversity of the future:

"In long relationships, like ours, well, leaving is not something that's done, because you've been there for each other for a long time, and well, you are committed to the relationship. You find a way to make it work." (Male)

In this passage the person with MS, in very simple words describes the dedication that needs to happen in a long-term relationship. She is stating that marriage entails a commitment, and in that commitment is the understanding that leaving the relationship is not an option when problems arise. *"You find a way to make it work"* are words that potentially give both partners the strength to face what others might consider unimaginable.

What all of the above passages have in common is that they speak to a value-based philosophy that these three individuals with MS have with respect to marriage. All of them refer to marriage as being a long-term relationship. Whereas one person emphasizes romance, another highlights communication, and yet another talks about commitment. The common thread connecting these narratives is that they inform us about the person's notion or idea about what a marriage is and what makes a marriage work. The premise here is that all people have assumptions, known or unknown, about their relationships with others. The above passages illustrate some of the assumptions of these individuals about their experiences with their spouses. This seems to be important in terms of our understanding about the nature

of these relationships.

History of Relationship

This property emerged in the data as individuals told stories about how they had met and how they had come to be a couple. All of the marriages of individuals' with MS interviewed appeared to have a rich and long history as demonstrated below:

"It was a very romantic courtship. And our marriage always stayed romantic. ...we never forgot birthdays, never forget special dates or anything. Both of us always planned trips around special dates, that sort of thing. We travelled an awful lot for many years." (Female)

"We did everything together. She went everywhere with me. She was almost like my wife 4 or 5 years before. She was always with me. I mean I think a lot of people probably assumed that we were married because we did everything together." (Male)

"Actually we met, I worked as a part-time tourist guide. We kept running into each other, he was in my group and then we met in the discotheque. We were together six years, no seven, before we had kids. We had an exciting life together." (Female)

All of the above passages refer to the history of the couple, as remembered or experienced by the person with

multiple sclerosis. Once again, the common areas in this part of the data have to do with *time* and *years* together. Prior to the diagnosis of MS there appears to be a rich period that the couple shares, either in the activities they chose (ie, traveling) or in the actual lifestyle (ie, exciting time). Also what was observed with the three people above is that several years were shared with their spouses prior to MS. These people spoke about doing things together, doing things that were exciting, and having a lot of time in which to do them. Another person with MS elaborated in much more depth about her history with her husband in the following:

".....when you're sick, you sometimes think about everything of the past as perfect. It wasn't like that for us. We had our arguments like everyone. But we had a more normal life than now. We experienced a lot together, positive and negative. A very full life."
(Female)

Perhaps the above passage so eloquently spoken really captures the importance of the history of a relationship. What has an influence on the survival of the current relationship is not only an idealized past, but a past that had its share of problems and dilemmas. In fact, all six people interviewed spoke about a history that was robust in the sense that it included dreams and struggles. Some people referred to the past as being "more normal" because it included some aspects (such as health and independence)

that the present did not include in the same way. Others spoke about how the past provided them with memories that they could sometimes hold onto when difficult moments arose in the present. Although for some, the past was described as "exciting" and "romantic", these same individuals mentioned that the present had some exciting and romantic times. What seemed to be an emerging theme within this property was that all six individuals had what they perceived as a full life prior to being diagnosed with this disease. Of course, it is difficult to determine in any objective way if these individuals really had a "full life" prior to MS or if having the disease had influenced how they now looked back upon the past. However, as has been emphasized throughout this study, it is the individuals' impressions that are important more than the actual events themselves. So the fact that some of these people remembered a past history with their spouses that gave them "*lots of time together*" and enabled them to "*go everywhere together*" has perhaps served in some way as a foundation in their current relationships. It is the remembering of a period in their lives in which they developed roots together that has propelled them to find ways of "*making it work*" in the present.

Spouse's Reaction to MS

As the individuals with MS spoke about their relationships and the diagnosis of the disease, there appeared to be importance in how they perceived their

spouses had responded during that time. Some described the various feelings they believed their spouses had experienced, such as sadness and anger. Another person spoke about how his spouse was supportive. And another person stated that her spouse continued as usual and did not want to talk about it. What emerged as important for two of the people with MS was knowing that somehow their spouses would be able to cope with all that was going on. The following are some examples:

"X would stay there hiding by himself. And I think there were probably times he became bitter. Not getting answers, and you know, with the time, what we learned, we learned from other patient, you know,....so he was bitter and I think he stayed like that for a while." (Female)

"We were both angry. That's all I can remember. I think she may have been even more angry than me." (Male)

"He doesn't want to talk about it, not even now, after so many years. Even then, when he found out, he did not want to talk about it." (Female)

As can be seen in the above passages, the spouses of the people with MS responded with different feelings. Some of the individuals interviewed mentioned that they were glad that their spouse had been able to respond to the diagnosis

in the way they did. Although this is a confusing idea, one person elaborated a bit further:

"I felt alone, because he didn't want to talk about the MS, and that's all I wanted to talk about. But I knew that he was really with me, he just couldn't talk about it the way I wanted, so I guess I'm glad that he handled it in the best way for himself." (Female)

What seemed especially important in the property *spouse's reaction to MS* was that the person with MS acknowledged that the spouse needed to experience his or her feelings or reactions to the diagnosis. Whether or not these reactions were perceived as supportive at the time or not was not as important, it seemed, as the need to express them. The individuals with MS seemed relieved that their spouses had been able to express their feelings, even without words.

Person's with M.S. Experience with Medical System

Within this fourth category, person's with M.S. experience with medical system, three main properties emerged; a) history of diagnosis b) relationship with doctor c) notions of health and disease. It appeared as if the person's with MS experience with the medical system in general was related specifically to how the disease of multiple sclerosis was diagnosed and treated at its onset. All six people interviewed spoke about the history of the diagnosis and how integral this was to their relationships with their doctors and their personal concepts of health and

disease. Thus, these three properties were interrelated. For instance, one individual commented that the way in which he was diagnosed not only influenced how he felt about his doctor, it also had an effect on his ideas about health and healing. Another person emphasized that she trusted her doctor tremendously and that this experience of faith somehow enabled her and her family to cope better with all of the ramifications of the disease. More than any other category, this fourth category was comprised of properties that were closely linked together.

History of Diagnosis

Individuals' with MS stories about the diagnosis seemed important in terms of their perceptions of their relationships with their doctors and the medical system in general. It was almost as if the experience of the diagnosis played a large role in their overall experience with the disease and living in an extended care facility. For most of the individuals interviewed, the time period of the diagnosis was a confusing one at best, with much anxiety and uncertainty. Yet the ways in which the diagnosis was experienced and its effects varied for each individual:

"I found because I was only diagnosed with a tumor, I had doubts right from the beginning but the doctors seemed absolutely sure. I went into the operation, which was life or death...and then I was very angry, and the doctors dropped me like a hot potato." (Female)

The above person referred to a mis-diagnosis, and it is

evident how very difficult it had been during that time. In the beginning, it appeared the doctors had suspected that she had some form of cancer, and only after intrusive surgery did they come up with a new diagnosis which turned out to be multiple sclerosis. However, the history of this diagnosis - particularly the amount of time and work it took to discover that it was MS and not cancer - left this person feeling as if she could not cope well with the disease. Although it is not clear how this happened, there does seem to be a connection in this one example between the history of the diagnosis and this person's relationship with her doctor. She stated that her "confusing diagnosis" got in the way of her being able to trust the system and her doctor after that.

Another person spoke about her diagnosis of MS in the following:

"It was always up and down, up and down. The doctors, well, when you ask the doctors, what will happen? Will I improve? They always say, we don't know." (Female)

In this example the uncertainty expressed by the medical system influenced this woman's ability to cope. "It was up and down" referred to her emotional life, and her relationship to significant others, particularly her husband. Another person had a different experience with the diagnosis:

"Nine different doctors confirmed my diagnosis, but

it took a very long time. Nine different opinions, but they all said the same thing." (Male)

The above individual referred to the length of time it took to confirm that he had MS, however, the fact that there had not been a misdiagnosis had been somewhat re-assuring to him. Also, it appeared from this individual's viewpoint that the medical people involved were working well together and this made the diagnosis easier. In his own words:

"I felt that was probably the best thing that happened to me... I mean nine people agree like that, all who are specialists, most of whom I really liked, I admired them. There's no point in asking another question because there is your answer." (Male)

This person felt with a diagnosis that was clear and confirmed, that he was able to cope better and to develop a positive relationship with his doctors. This is an example of how the properties of the category *person's with M.S. experience with medical system* are interrelated. In this example, the history of the diagnosis clearly enabled the person to develop an "admiration" for the doctors involved with his case.

Relationship with Doctor

All of the individuals made either a reference to, or a comment about, their doctor. This relationship seemed to be connected to the history of the diagnosis. Because of the chronic nature of their disease and inasmuch as they were all living within an extended care facility, the

individuals' with MS relationships to the medical system in general were considered important to these people. Several people with MS expressed that they felt that the most important aspect for them was having a doctor with whom they could communicate. Others emphasized that they felt it was good to have a doctor who took an interest in them and their families, not just the disease:

"Well the positive things I remember about it the most was the doctor, initially, what a great guy he was. The way he diagnosed it, and the way he told me, and the way he told the wife." (Male)

The above passage reflected this person's positive relationship to his doctor, which began with the diagnosis. Also evident in the above passage is the importance of the doctor taking the time to communicate, and being able to relate to the family (spouse) of the person with MS. Once again, it seems that when the diagnosis is clear, there is more of a possibility of a good relationship with the medical system. This might have to do with a foundation of trust being established right from the beginning, or perhaps the notion that the disease of MS is less scary when the diagnosis is clear. Another person commented on this notion of trust:

"He did all these tests... so I thought O.K., it wasn't that he made a mistake, like, uh, there was no way I could fault anything he did so he must be right. So I trusted him, and then, acceptance was simple."

(Female)

The above person emphasized that she was better able to cope with the diagnosis because her physician was very thorough, performed many tests and did everything in a timely manner. She did not have to wait for weeks after each test, but rather, her doctor made an "extra special effort" to get her answers as quickly as possible. She was therefore able to place her trust in him and was confident that he would do everything possible. Someone else elaborated on this idea:

"They investigate. I get the answer, and then, O.K., let's investigate some more. And they do really whatever they can do. So if they can help me, that we don't know, but they try their very, very best."

(Female)

This quote reinforced a similar idea that has been emerging in the data. It was her belief that her doctor was "doing everything possible" and was continually investigating her condition to see if anything could be done. The doctor's efforts were noticed by the patient which in turn helped build a relationship based on trust and hope. This helped her cope generally better with the disease. The following person had a different sense of the efforts made by her doctor, and she had difficulty in her relationship with him:

"I didn't get any help from the health professionals. I didn't get any help in case I wouldn't be able to walk. What kind of help is available to me? The only thing they would probably

tell me is the husband has to look after you. So I would say that we absolutely didn't get any help."

(Female)

Although it is unclear what exactly happened during the time of the diagnosis, what is evident is that the above person did not perceive there to be help available from her doctors. She also said at another point in the interview that the doctors had "not been able to figure out what was wrong" with her for a very long time, and finally, through a process of elimination, they diagnosed her with multiple sclerosis. This person remembered vividly how the doctors seemed to shake their heads, as if in resignation, when they finally told her that she had MS. Her dramatic memory of the diagnosis and feelings about the doctors "not doing enough" are indicators once again that these two properties are closely interdependent on one another. In order to understand the person's current relationship with the medical system, it is necessary to understand the history of the diagnosis and all the memories that go along with it. It is this process that made the above person lose faith in her doctor, and hence, the medical system. Trust and hope translated to either positive or negative feelings toward medicine.

The two properties, history of diagnosis and relationship with doctor are related in terms of how the person with MS copes with the disease, however, an in-depth analysis of this connection will be examined in part two of

this chapter.

(C) Cultural Expectations of Health and Disease

Part of the person's with MS experience and understanding of the medical system was related to the individual's personal impressions or cultural expectations of health and disease. All of the people interviewed spoke about or referred to in some way what they considered health to be in terms of a state of well-being. Whether these ideas were formed prior to the diagnosis of multiple sclerosis or after having had the disease for a while is difficult to say. Either way, it seemed important for the individuals with MS to describe their experiences with health and how they saw themselves in terms of living healthy lifestyles. For example, one person described how in spite of having MS, he was able to maintain an active and involved way of life which included going outside the hospital to participate in activities with his wife. Another person mentioned that having a debilitating disease like MS had in many ways forced her to think about her health more often, and make decisions about how to live in a way that would maximize the health that she did have, in spite of MS. She described that ironically, it had only been in the face of disease and fear of disease that she then became more interested in health. In her own words:

"It's funny how with MS, I suddenly think about health somehow more. It was not something that I ever really thought of much before, maybe before going

to the dentist or so, but you realize that you can never take anything for granted, and so I try to do things so that I can stay as healthy as I can." (Female)

The above woman's notion of health in a paradoxical way became more defined once she became ill. This idea of what health was, more generally, was reinforced for her by the doctors who cared for her. This in turn helped her feel that she was supported by the medical system, as she said in the following:

"I found all of the staff here, and my doctors, when I was first diagnosed, to really be good when it came to helping me remain as healthy as possible." (Female)

The property "notions of health and disease" emerged quite vividly within the category, "person's with M.S. experience of medical system". It seemed for some individuals, that the experience with medical staff was defined in part by how the staff treated them, and whether this treatment was based on health or on sickness. The following woman explained this:

"I found this one nurse to really be supportive in helping me and my family cope with this terrible condition. I am not sure what she did so much, but I think that it was her attitude. She treated me like I was still healthy, not just like a person who is sick with MS, but as someone who was healthy in a lot of other ways." (Female)

It was important for this woman to have others be able to see beyond her disease and be capable of relating to her as a whole person. This idea was referred to by a few of the other people interviewed. For example, one man mentioned that "staying well" meant that he needed other people, primarily the medical system and his family, to help him see life past having MS. Another man stated emphatically that the worst aspect of having multiple sclerosis was not the disease as such, but the way some people were not able to see anything but sickness and despair. He elaborated a bit further:

"I see health and disease to all be part of the same spectrum, so to speak. If the system responds to people as people, and not just as sickness, despair, and gloom, then I think we'd all be better off."

(Male)

When speaking about support from the medical system, this man mentioned that he had experience searching for support but had not received what he had hoped he could receive from the doctors. He emphasized his struggles over the years in the following passage:

"I have been fighting a long time with them, the doctors, to not treat us like big diseases. I have found that I need to deal with MS like it is part of my life, but the mistake comes when we see MS as someone's whole life, as if there's nothing else. Unfortunately, when you live in a place like this, it's easy for

people on the outside and on the inside to see you and your life as just being about one big disease." (Male)

Not everyone interviewed was as eloquent and articulate as the above man, however, the central ideas expressed by him were reflected by most. The main ideas pertaining to health and disease tended to be (1) that these two notions were part of a continuum, meaning that they were not static states, but rather they were fluid and changing, (2) that multiple sclerosis was not a way of life but rather an aspect or a part of an individual's life, (3) that people with MS have a desire to be treated like people who possess health in other ways, and that they wish the focus of treatment to be on the whole person and not simply the physical disease. This last idea was expressed well by the following woman:

"I think my experience with the medical people has been best when they were interested in all of me - my emotions, my spirit, my psychological, and my physical. Then I feel like I'm being treated like a real person. If they only deal with MS, the disease, then how can you ever have health?" (Female)

It appears, that when the focus is on the whole person and not just the disease, then the person with MS experiences support from the medical system. It is almost as if the medical system's notions of health and disease are crucial to the well-being of the people with MS. In other words, if the system only focuses on disease, the person

with MS tends to not feel supported, whereas if the focus is more holistic, then the person has a more positive experience with the system. Although this is only a tentative hypothesis emerging from this study, this pattern of a relationship was evident in the data. Another person referred to this idea in the following:

"I think the staff here could offer us the most support if they encouraged us to live beyond our own beliefs, and believe in ourselves more, and our abilities, even if we are all physically disabled."
(Female)

This powerful statement captures the essence of this property. One's notion of health and disease may be more limiting or debilitating than the actual disease. Perhaps it is one's cultural expectations of health and disease that will determine how well one will live, even in the face of such adversity as multiple sclerosis. Clearly what emerged was this sense that support from the medical system was closely related to the person's with MS perception of being treated as a person with real emotions and other abilities, and not simply as someone with a disease. All of the people interviewed believed (to some degree) that disease was not just a physical state but a psychological reality. In other words, these individuals expressed that it was important to pay attention to the whole person, and not just the disease.

Person's with M.S. Experience of Present Relationship

This fifth and final category, person's with M.S.

experience of present relationship, was comprised of three important properties; (1) creating new ways of being together, (2) re-defining the parameters, (3) balancing the past, present, and future. The fifth category also exists as a result of the other four categories previously discussed, pertaining to the person's with MS experiences with self, spouse, medical system, and support. Thus, it is interdependent with the other categories and is the main focus of this study. This section is divided into two parts. In part one, the properties will be presented and highlighted, much in the same way that occurred with the other categories previously presented. In part two, the data that makes up this category will be analyzed in the context of the data from the other categories, and in the framework of the main questions examined throughout this study.

This last category, "*person's with M.S. experience of present relationship*" is different from the other categories in that it is an accumulation of all of them. Consequently, person's with MS experiences of self, spouse, medical system and support all contribute to an overall marriage pattern which is the individual's experience of the present relationship. The person's with MS ability to cope with the disease and with living within an extended care facility was related to certain experiences throughout the diagnosis and progression of MS. These experiences were organized into four categories which were then further divided into

different properties or dimensions. It appeared that the person's with MS experience of the present relationship with the spouse was connected to the coping experiences and the perceived support received during the diagnosis and progression of the disease. This connection will be examined further during the analysis.

Questions and discussion surrounding the person's with MS relationship with the spouse accounted for most of the time in the individual interviews. The six people interviewed talked about their relationship prior to the diagnosis, such as the story of when they first met, and what their life had been like when they were first married. These individuals also spoke about how their relationships had changed with the onset of MS, as well as what their experiences with one another had been after that point. Much of the discussion focussed on what some individuals referred to as lost dreams or disappointments. A few individuals spoke about some of the positive changes that had occurred in their relationship with the diagnosis of MS. All of the people interviewed appeared very interested in talking about their marriages, and one person even commented that he felt it was wonderful to be asked to talk about something that was so important to him.

All six individuals interviewed had very unique and distinct relationships with their spouses. The individuals' experiences with coping and support, as evidenced in the first four categories, had an influence on their

relationships. Although one can not make any general conclusions based on such a small sample size, it is clear that the pattern of these relationships was influenced by these other experiences.

Creating New Ways of Being Together

This property was comprised of several main ideas. The first main idea was the individual with MS realizing that certain things were no longer possible to do as a couple because of the effects of multiple sclerosis. With this realization came also the understanding that new ways of being together could be created:

"We can't do the things we used to do, not in the same way, but we still find ways of being together, new ways for our present life." (Female)

This woman illustrated that some of the old routines could no longer happen whereas the couple's "new life" together was still something that they could look forward to. Other people interviewed, when discussing their present relationship, also spoke about being creative in terms of activities they could participate in as a couple:

"You have to look for stuff you can do together....like we still go out, you know, to Stanley Park or whatever, but well, now, it takes a whole day to plan, that's all." (Male)

Part of the concept of creating new ways together emerged as individuals described how even the same activities they used to do were now different and they had

to be willing to make adjustments. Also, one person with MS spoke about how "new routines" were created once she began living in an extended care facility, and she felt very positive about it:

"He came over for dinner almost every day, sometimes to join me, and other times to help me eat. So we now have dinner together, almost more now than we did before I got MS, so I feel good about that, there are some good things that happen." (Female)

Another person was also able to see some of the positive patterns that were created as a way of adjusting to the implications of MS. She described it in this way:

"We talk about more now than ever before. They all come over and tell me what's been happening, if there are problems with the kids or something, he tells me all about it, so I feel satisfied, I'm still the mother in the family, having MS hasn't changed that." (Female)

What came out as a common theme among the individuals who spoke about how it had been necessary to create new ways of being together was the recognition that certain activities could not continue (one person mentioned backpacking trips) whereas those activities that could continue would inevitably be different (such as taking more time). Another theme that emerged for some individuals was the desire to continue searching for ways to enhance their relationships with their spouses and to create ways for them

to do things together:

"I think you really have to try hard, and no, you can't do everything that you used to do before getting sick, so you go out and do some things that you have never done before, that is what makes the relationship interesting." (Male)

Finding new ways of being together was about keeping the relationship alive by being able to adapt to the constraints and changes brought on by MS and continue spending time together as a couple. Throughout the interviews, all of the persons with MS spoke about the changes and adjustments they had to make with their spouses because of the disease. Much of the time, these comments were indirect, and emerged when the individual was talking about something else. There were some differences between the people interviewed in terms of the *number* and the *intensity* of ways that were created to enable them to be together, and this appeared to be connected to how well they were able to re-define the boundaries or parameters of their relationship. This notion emerged as the next property within the data.

Re-defining the Parameters

Part of the person's with MS experience of the present day relationship with the spouse included "changing" or "modifying" the boundaries or structure of the old relationship. This notion of the old relationship emerged when people spoke about how "things used to be" prior to the diagnosis of MS, and prior to all the physical and emotional

changes that went along with a long-term disability. The property re-defining the parameters emerged as people spoke about the changes that they had adapted to in order for the relationship to persevere. From the small changes, (such as having dinner together) to the larger changes, (such as separate residences), the structure of the relationship was re-defined so that the marriage could survive in a new form. Some of these changes had to do with time, as is illustrated below:

"We are more flexible, like, it might take all day for us to go to Stanley Park, but whether it's an hour or all day, at least we get to go. We have had to adapt to things being slower now, otherwise we would maybe not be able to go anywhere." (Male)

The concept of flexibility was mentioned throughout the interviews as one of the ingredients that had helped the relationship survive the adversity of MS. Time as a concept was recognized as one of the structural changes of the old relationship as indicated in the following:

"We used to pick up and go, foot loose and fancy free, so to speak. Now, we have to plan and plan and spend more time planning, like transportation, and medical supplies, and comfort things and on and on. But you accept that. There's no choice. Your time is no longer yours, but you work with what you have." (Female)

Along with the re-defining of time, was also the re-

defining of place. As individuals spoke about how they had to adjust and adapt to the time constraints, they also mentioned that there were limitations in terms of where they could go. For instance, one man spoke about how he and his wife had met one another while hiking in Vermont and that until the diagnosis of MS, they had spent much of their time backpacking and hiking in the mountains. Now, they were no longer able to go to the same destinations (mountains) because his condition had deteriorated and he became fatigued quite easily. He mentioned how it had been important for him and his wife to find new places to go, ones that were feasible given the nature of the disease. In his own words:

"A trip to the woods, in the real sense, just ain't possible, given my condition. So we take a trip to the beach. Not the same, no way, but we're still together, trying to do some things together. It's disappointing, but it's better than not going anywhere together."

(Male)

Another person spoke about a similar limitation in the following:

"Sometimes, because of the way I am feeling, I can only go for a walk around the block, and not to the beach, the way we used to when he came to visit. So we are gradually, maybe every few years, having to get used to something instead of being able to do or go to where we always did." (Female)

When speaking about limitations or boundaries of the relationship, one person spoke about how his sexual relationship with his wife had changed:

"It's different now, than it used to be, you know, how we are as man and wife. It's O.K., don't get me wrong, but it's not like we chose to have it this way. It's better than not having sex at all." (Male)

Another re-definition of the parameters of the relationship for one person had to do with having to accept that other people needed to be around some of the time. She said:

"There is always someone else around. My husband can't always lift my chair or help me up, so we often have to have a health care worker around. There's a crowd sometimes." (Female)

Although the property "re-defining the parameters" was similar to establishing new ways of being together, what was expected was that most of the changes or modifications that occurred were not seen or experienced as ones that would have been chosen. Rather, they were imposed by the nature of the disease itself, and though they were accepted, it was always with some reluctance. However, as several people pointed out, had these changes or limitations not been accepted, there would have been more strain on the relationship since there may not have been anywhere else to go. As indicated in a previous passage, something was better than nothing at all.

Balancing the Past, Present, and Future

Individuals' with MS experiences of their present day relationship seemed to be influenced to some degree by their ability to balance the past and the present. The term "balance" related to whether the past experiences with the spouse had been integrated with the new experiences of the present. Although "balance" and "integration" are subjective terms, the persons with MS were able to speak about whether or not they felt that their past life prior to MS was recognized and in some way honored in their current life.

One person, for instance, mentioned that mourning the past (prior to MS) occupied more of the present than did anything else:

"All I can think about is how good everything was before I got MS. It's very hard for me to think about the present when all I want is what I used to have. My husband and I always talk about back then." (Female)

For another person, living in the moment was all that mattered for her, and as such, the past did not hold as much meaning as it once had. She emphasized:

"I had a wonderful life before being diagnosed with this disease. But I don't think about it, I haven't thought about it in a very long time. I appreciate every moment now, when my family and friends are around, and I live for these moments. Nothing else matters." (Female)

Another person with MS mentioned how he was able to remember all of the good times of the past so that he and his wife could create new good times in the present. Although this wasn't easy, he described the past as being similar to an anchor, enabling him to remain stable in the turbulence of MS. He described:

"The past helps keep me sane. You can go crazy in a place like this, all these sick people, and everything. The wife and me, we laugh about all those times we had, and sometimes it helps us keep everything in place." (Male)

Another woman stated that in order to survive in an extended care facility and deal with the on-going challenges of having a disease such as MS, she needed to remain focused on the future. Subsequently, it was her opinion that she and her husband never spoke about the past, nor ever focused on the present, but rather spent most of their time planning the future for their children. She explained:

"All we have is the future. Past is dead, and present, well, there is no present. All we have is our children and how to help them have the best that they can in life." (Female)

This woman stated at a later point in the interview that the only thing that ever connected her husband and herself to the past were the children. It was as if, for this individual, the past brought up too many memories of

what was missing in the present, and so it was safer to remain future-focused. She elaborated:

"I choose not to think about the past. I don't know if I could live anymore if I thought about the past. Our children are all we have that connect us to the past, but we look to the future with them. I live in the future, in my mind of course. That's the only way that I can be now." (Female)

For this woman, balancing the past and the present happens by remaining focused on the future. The future for her emerged from a past in which her family was created and a present that had become unbearable in many ways. As she describes, there has been an active decision made about keeping the past truly in the past. How this translates into her relationship with her husband is influenced by this decision and is the focus of discussion in the next section.

CHAPTER 5

Discussion

Marriage Patterns

The five categories identified in this study as outlined in the conceptual model (Appendix F) include: person's with M.S. experience of self, perception of spouse's experience, experience with medical system, experience with support systems, and experience of present day relationship.

All of these categories relate to the individual's experiences of different systems, both past and present, in his or her life. For example, in the category "Persons' with M.S. Experience of Self", it became clear that as the participants spoke about themselves, the main ideas that continued to arise were of self-image, culture, spirituality and emotions. A further example was when the individuals with MS spoke about their experiences with the medical system. What emerged most frequently and with the most emphasis pertained to the history of their disease, the relationship to their doctors, and their personal ideas about health in general.

Each of the six people interviewed spoke of experiences that fell within the first four categories of the conceptual model (Appendix F) and these categories influenced their experiences of their present day relationships. The "Present Day Relationship" category became the fifth

category and was influenced by the four other categories. From data that were gathered in the interviews, the persons' with MS experiences in all the categories contributed to the definition of a general marriage pattern with his or her spouse.

What happens to the marriage when one spouse has MS and resides in an extended care facility, and how does a marriage survive when faced with a chronic, long-term, debilitating disease, were the primary questions studied. Some of the general themes that arose from the results in comparison to the literature review are examined here.

A general theme that emerged was that the person with MS felt isolated in her/his everyday life and did not feel he/her had as much of a social life as prior to the diagnosis of MS. This theme corresponds to Sigelman's findings (1991) that people with disabilities often felt more isolated and were far less likely to have a level of social involvement equal to non-disabled individuals. Four of the individuals interviewed spoke at length about how their ideas and perceptions about themselves had transformed since having the disease. These individuals stated specifically that they struggled with seeing themselves as whole people capable of living within the normal, mainstream society. This central theme is in agreement with Pavlou et al.'s (1979) research results which emphasized that individuals with MS continually struggle with being viewed as abnormal and learning to live with rejection and

disapproval.

The history of the diagnosis, a property of the category "Person's with M.S. Experience of Medical System" turned out to be an important theme pertaining to the marriage in general. When speaking about their relationships to their spouses, all of the individuals interviewed had a story or a recollection to share regarding how they discovered they had MS. It became apparent in the data that the way in which the person with MS and his or her spouse handled the time of diagnosis influenced the period after the diagnosis. This is similar to what Doka (1993) found in his research which stated that the ways in which people interact throughout the pre-diagnostic phase can be revealing, as they may present patterns of interaction that persist throughout the illness.

Another theme that emerged involved the inevitable changes in the marital relationship due to the debilitating nature of MS. An important change that several of the participants described was how their sexuality and sexual relationships were now different. Shapiro (1987) reported that over 70% of all men and women accounted for some changes in their sexual life since the onset of their disease.

Throughout the interviews, there was reference to the emotional experience over the time of the diagnosis and history of the disease. Shapiro (1987) also confirmed this theme by emphasizing that emotional reactions such as anxiety, guilt, anger, depression, and denial are the

natural consequences of coping with a chronic illness. Another aspect of the emotional experience discovered in this study was intensity. Persons with MS spoke about feeling as if they had to continually adjust to the plights of the disease. This was perceived as stressful and relates to Sander's findings (1993) that couples where one spouse had MS are often on an emotional roller coaster, affected by the ill individual's health as well as the reactions and responses of that individual.

Some of those interviewed spoke about how their roles with their spouses had changed through the course of the illness, and this had caused distress in their marriages. For instance, there was reference made to the spouse who did not have MS becoming a "caretaker" to the disabled spouse. Pearlin's (1980) research identified failure to fulfill role expectations to correlate highly with marital distress. However, although the individuals interviewed for this study spoke of an inability to meet the same role expectations as they had prior to MS, for the most part they did not report marital distress. Thus, Pearlin's (1980) research did not examine what factors contributed to the marriages surviving, in spite of the roles of the spouses changing. In fact, in reviewing the literature on the subjects of multiple sclerosis and on marriage, the similarities correlate with the challenges and changes brought on by MS and the distress this placed on the marriage. No known study on how marriages survived in the face of such adversity was

uncovered in this review of the literature. Many of the previous studies tended to center on why or how marriages failed when one spouse had a chronic disabling disease, rather than on how they survived.

In this study, all six participants interviewed were married and considered their relationships with their spouses to be good. The range of reactions that the individuals with MS experienced around their illness varied, including such emotions as anger, sadness, and fear. When these individuals described the reactions of their spouses in connection with their illness, they described several variables that affected their spouses' reactions, which included personality, coping ability, religion, fears, and formal and informal supports. This finding is similar to what Schneidman (1978) found regarding the reactions to the spouses' illness, which included characteristics of the couple including values, norms, expectations, beliefs and patterns of communication. Schneidman (1978) however, like others who have studied the effects of long-term illness on marriage, concluded that most marriages ended in divorce.

This study sought to understand marriage patterns in couples whose marriage had survived the diagnosis of multiple sclerosis and subsequent institutionalization. Four patterns of marriage emerged within this study, based on the interviews with six individuals with multiple sclerosis (Appendix G). The four marriage patterns were categorized as, (1) marginal, (2) functional, (3) companion,

and (4) romantic.

Within each of these types of marriages, the person with MS described having a good relationship with their spouse prior to being diagnosed with MS. Another area that all six individuals had in common was having been married for seven years or more prior to the diagnosis. For all the individuals, there was a strong connection to the past and to their relationships with their spouses. Although the manner in which they described their current relationships varied, all of the individuals experienced their past relationships with their spouses as positive. And yet, their present day relationships were described differently. It was through these differences that the marriage patterns became apparent.

Marginal

Marriage patterns were discovered when individuals spoke of their experiences within the present day relationship. Two individuals (one male, one female) described experiences of their present day relationship with their spouses which would be classified as a "marginal" marriage pattern. These relationships were considered routine by these individuals with no focus on the present or the future and only a loose connection to the past. What is meant by this is that these relationships, as experienced by the persons with MS, existed out of "convenience" and "habit" and they described their connection to their spouses as being weak. Both individuals reported that their spouses were involved in

intimate relationships with other people. One person stated he did not mind that his wife was involved with someone else. The other participant said she did not care if she never saw her husband again. Both individuals stated that if it had not been for the fact that they had children, they would have nothing in common with their spouses, in terms of their present day relationships. The individuals in a "marginal" marriage pattern described not having had much support from family and friends throughout the period of the diagnosis, in addition to not having any confidence in the medical system or the extended care facility in which they lived. When they spoke about themselves, images such as being a "freak", "abnormal", and "hating oneself" were described. Although their past relationships with their spouses had been described as positive, they felt their only connection to their spouse in the present was through their children. Generally, what appeared to characterize these "marginal relationship patterns" for the persons with MS were factors such as low self-image, a negative or distrustful perception of the medical system, and a belief that they had little or no social support.

Functional

Two males with MS described "functional" present day marriages. In these relationships, there was a tendency to focus more on the past (pre-diagnosis) with some link to the present. The present day connection related to practical matters, such as finances, property, and other functional

matters. Unlike the marginal relationships, persons with MS in a functional relationship emphasized they felt their marriages were necessary so that "things in their lives would run smoothly". This indicated that their connection to their spouses in some way enhanced their lives, and they remained married for reasons more than simply having children. When they spoke about the period of the diagnosis and throughout the progression of MS, it became apparent that they felt there had been some support from family and friends. Though their perception of the medical system was not positive, these two individuals had the belief the doctors and staff at the extended care facility had done their best. When they spoke of themselves, their self-images could not be described as positive, nor was it as negative as the two previously mentioned individuals. For these two people in the functional relationships, there was the sense they had some acceptance of their current situation with MS.

Companion and Romantic

The next two marriage patterns were referred to as "companion" and "romantic". The primary factor that differentiated these relationships from the first two marriage patterns was an ability to focus on the present and the future, as well as the past. Within both these marriage patterns, the individuals with MS spoke of how they had created new things to do and new ways of being together, in spite of the difficulties associated with MS and living in

extended care. Words like "enjoyable", "wonderful", and "supportive" were used to describe the present day relationship. Another characteristic of the two relationships related to the "companion" or "romantic" categories was when the persons with MS stated that they "loved" their spouses, and there continued to be much "joy" in their experiences of the present. Although both individuals with MS had children in addition to financial responsibilities together, what they spoke of in their present day relationship was finding "new meanings" in their lives, and discovering ways of being a married couple even though there were external changes.

Other characteristics of the "companion" and "romantic" relationships noted support in terms of relatives, friends, and the medical system. In fact, there was the understanding of both individuals in "companion" and "romantic" relationships that the medical system, particularly the doctors and staff at the extended care facility, had been extremely supportive throughout the progression of the MS. This theme was perhaps the most divergent from the other persons interviewed, the perception of support from many places. The primary differences between the "companion" and "romantic" relationships were the person's with MS experience of self. In the companion relationship, the person with MS described having accepted the changes and feeling "O.K." about herself at the present time. In the romantic relationship, the person with MS

described not only accepting herself, but feeling better in some ways than prior to MS. This individual described feeling "sexy" in spite of the MS and enjoying a more romantic relationship than before.

The differences between companion and romantic relationships were a matter of degree in the areas of experience of self, perception of support, and experience of the present day relationships. It appeared that the chief difference in the romantic relationship was the addition of a sexual relationship.

Although tentative, these findings on marriage patterns are partly supported by Caplan's research (1974) on social support theory which suggested that social support helped mobilize the individual's psychological resources and provide some assistance in dealing with emotional, physical and financial burdens. This might explain, or at least begin to illustrate, why there seemed to be a pattern of marriage closeness and perception of support.

The findings in this study can be further understood in relation to Cobb's (1976) research which suggested that support consisted of three types of information. The first type was emotional support, the second was esteem support, and the third type of information focussed on a support of belonging. All these supports differ only in degree, thus what differentiated one from another was "intensity" which can best be understood along a continuum. For example, esteem support, according to Cobb (1976), related to an

individual's complete identity, whereas emotional support was inclined to focus primarily on emotional reactions. Belonging support included the whole person in his or her environment. Essentially, Cobb was describing that support included a progression of events, from the emotional, to the whole person and their environment.

In this study on marriage and multiple sclerosis, individuals who reported having had support not only in terms of their self-images but from the medical system and staff, were generally more accepting and better able to cope with the disease. There is some evidence in this study that when there has been the perception that support existed on a societal level for individuals with MS, they were better able to deal with the effects of the disease. This in turn enabled them to have improved skills in working on their marriages.

It is difficult to comment on why the six marriages in this study survived, when the literature review suggests that most marriages in which one spouse has a debilitating disease and is living in extended care, will end in divorce. However, all participants in this study had at least seven years of marriage prior to the diagnosis of MS and reported having strong relationships with their spouse prior to MS. Furthermore all six individuals had some support throughout the progression of the disease, and to some degree, the extent of this support had an influence on the general marriage patterns of the relationships.

Limitations

There are a number of limitations to this study beginning with the retrospective nature of the design. The spouses interviewed in this study had all been diagnosed with MS and been living in an extended care facility for four to fourteen years. These individuals were asked to relate their experiences about the effect of their disease on their marriage. It was probable that these individuals' perceptions of themselves and their relationship had changed over time. Given the retrospective nature of the narrative, one could anticipate that the stories spouses told today might in fact be different from the stories they would have told previously about the same time period in their lives.

Although the retrospective nature of this study could be perceived as a limitation due to one being unable to obtain original results of spouses recollections around the pre-diagnosis and diagnosis of MS, this aspect could also be deemed a strength. With time, spouses have been able to reflect on their experiences, as well as gain more information which might allow them to put their experiences into clearer perspective and integrate their experiences into a cohesive whole. This in itself allowed the individuals with MS to acquire some emotional distance on these time periods, particularly if an initial crisis period had occurred or if the experience had been painful. The individuals' with MS stories of their relationship could be thought of as constantly changing or evolving, thus allowing

for the full range of perceptions, thoughts, feelings, and interpretations to emerge within the description. This coincides with previous studies done on narratives that state that the meaning of stories is enriched over time (Stone, 1988).

A second limitation of this study was in the nature, composition, and definition of marriage. All participants were in a heterosexual relationship. Contemporary relationships are not constrained to male/female or ecclesiastic boundaries and thus examining the full range of relationships may have lead to different results.

The individuals with MS were all Caucasian, and did not include members of ethnocultural communities. Other cultural values may have placed a different emphasis on the role of the relationship and the participation of both spouses in the marriages.

The sample size was small and purposive in nature (six individuals diagnosed with multiple sclerosis). This limits generalizability. The purpose of a small sample design which is exploratory in nature is to gather information to better define variables for further investigation and/or conceptual clarity.

Other factors may bias the development of an encompassing conceptual model. Even though there were differences among the individuals with MS interviewed, there were similarities which limited generalizability beyond a certain group. The individuals were all from a middle

socioeconomic group and had been living in Canada for at least two decades. This had been the first marriage for all the couples and no previously divorced and remarried couples were interviewed.

Although preliminary, these findings are important in that they inform the clinical and research fields of social work about the factors involved in long-term relationships for those with a chronic progressive disease in a long-term care facility. Salient features included factors such as self-perception, support systems, and experiences of past and present relationships. All of the marriages in this study were "successful" simply because they survived, in spite of the challenges of multiple sclerosis. Although they were categorized into four groups, some marriages were inherently better than the others, and this was based on differences due to distinct variables.

In the marginal relationships, the individuals experienced themselves and others negatively and had little faith that this could change. Having had children was the single connection they felt they had with their spouses, and even that was tenuous. In the functional relationships the focus was more on the everyday practicalities of two people sharing their lives, and though their experiences were not as "negative" as the marginal relations (in terms of their experiences of the medical system and support from others) they could not be described as positive. Their connection to their spouse was based on more than simply having had

children together, but on how, because of their functional connections (such as finances, etc.) their lives were enhanced. In the companion and romantic relations, both of which were experienced by women, there was more of a focus on the present and the future than the other relationships. Because these two women's experiences with the medical system, and support from others, were quite positive, they had more optimism that their present relationships with their spouses could also be positive. In the companion and romantic relations there was an open expression of love toward the spouses and more of an experience of self-acceptance on the part of the individuals with MS. The addition of a sexual relationship was the principal distinction between the romantic and companion relationships.

In reviewing the variables that differentiated the relationships from each other, it is important to remember that all of the individuals had been married for at least seven years prior to the diagnosis and had at least one child. One could speculate that these factors in themselves contributed to a more solid foundation in the marriage prior to the onset of the disease. However, more information would be required about the marriages that did not survive before being able to confirm this hypothesis. As social workers in hospitals , it would be useful to know more about the ways in which people experience support through the medical system since this appears to play a large part in

their psychological healing. Thus, if we knew more about how marriages survived with individuals requiring long-term extended care, we might be able to assist in building the internal and external supports needed for this to happen.

CHAPTER 6

CONCLUSIONS

The relevance and implications of this study for social work practice are numerous when considering how these marriages survived. An awareness of these variables ; self-image, experience of the medical system, perception of social support, and experience of present day relationship, would enable social workers to better identify and assess potential stressors and challenges individuals with MS face. It also allows the professional to intervene before the relationship becomes unmanageable. These variables have formed the conceptual model that has emerged from the data and has become the major finding of this study (Appendix F). To fully understand the implications for the field of social work, more should be said about the conceptual model and the interrelation between categories (Appendix G). The model is about how persons' with MS experience of: (1) self, (2) spouse, (3) medical system, and (4) support systems, all contribute and determine the persons' with MS experiences with their spouse in the present, the 5th category in this conceptual model (Appendix F).

It is the combination of these variables that influence the experiences of the present day relationships. For example, the persons' with MS experiences of self emerged as self-concept, cultural affiliation, and spirituality.

Although these "properties" determined the experience of self, they also influenced the individuals' experiences with the spouse and others around them. These present day experiences with the spouse were determined in part from the past, as well as other variables previously mentioned.

The findings of this study suggest a number of implications for social work practice, education, and research. When working with married couples where there is a combination of disability and institutionalization, one needs to evaluate how such variables play upon the experience of marriage. One should also assess how the experience of the present is influenced by critical key periods of the past, in particular the time period surrounding the diagnosis of the disease. These findings are consistent with non-chronic patient management in social work and are applicable to anyone experiencing change.

Moreover, with the knowledge of this conceptual model (Appendix F) professionals would be better able to make assessments about how well individuals were coping psychologically with the disease, and whether or not they were isolated from others. With increased knowledge about the different marriage patterns, hospital social workers would be in a better position to understand some of the factors contributing to unconventional marriages and perhaps be able to work with those individuals desiring their marriage to be distinct. For instance, if an individual in a marginal relationship desired to move to a more functional

or companion relationship, we would know what some of the important factors were and work with this individual (or couple) on increasing support or developing more positive present day relationships. It is important to note that during the interviews there were no "values" ascribed to the marriage patterns in terms of better or worse, only a sense that there were differences between them. However, in retrospect the respondents were clearly happier in the companion and romantic marriages. This study allows us, at a very early stage, to work with the differences within marriages.

Apart from being able to assess and support individuals and their relationships in extended care facilities, social workers could enhance and strengthen the different components related to these relationships. This in turn could re-define the notion of support to include being able to see the whole person in relationship to others, instead of merely focussing on the disease, an already present attitude in social work practice. Other changes to social work practice would include:

- (1) Understanding the importance of a supportive medical staff toward the overall health of the individual with M.S.
- (2) Developing a model of practice that emphasizes people's strengths and abilities and facilitates their connections with family members and friends.
- (3) Understanding that services, such as counselling,

which could be introduced at the time of diagnosis (a highly stressful period) may enable some marriages to persevere instead of deteriorate due to the intensity of that time period.

(4) Developing a model of practice that would focus on enabling individuals to have a companion/romantic marriage. As such, practitioners would have to become more aware of the variables that emerged within the conceptual model such as self-image, history of diagnosis, family support, etc. More research would be required to examine, in greater depth, the interplay between these variables and to examine such questions as; What is the relationship of self-esteem to support from friends? And what is the relationship of a supportive medical system to support from a spouse?

The results of this study provide direction for social work practice. Of primary importance is the need for social workers to recognize the ever increasing emotional demands placed on marriage when one spouse has a chronic illness. Due to the deteriorative nature of MS, social workers must ensure adequate and regular assessment of the support needs of both the person with MS and their spouse. Therefore, one approach would be to offer self-help groups for individuals with MS to share their concerns while simultaneously allowing the non-disabled spouse time out from marital responsibilities.

This study provides direction for client education in that it focuses on the ways and means of accessing and using

professional services. Support and self-help groups related to the development of self-awareness may lead to the recognition of personal and common concerns related to marriage.

Education of the professional social worker should include information on chronic illness as an event that involves both members of a marital relationship. Awareness of marriage patterns and the unique qualities of the marital experience can lead to a better understanding of the support needs of the individual with MS. Social work education that focused on marriage patterns would ultimately lead to respect for the couple's ability to make informed decisions suitable to their own best interests.

This study has concentrated on the perceptions of marriage of individuals with multiple sclerosis. It is a beginning in the understanding of marriage patterns and there remains much for future research. In order to build on this knowledge base, further research could explore whether marriage actually promotes psychological wellness in individuals with MS. The question remains whether those individuals who remained married were "healthier" than those who did not. Is there a connection between "psychological wellness" and the companion or romantic marriage patterns, or are marginal marriages worse than those marriages that ended in divorce? The question arises about how people with chronic progressive disabilities manage to cope with the challenges and adversities of this kind of disease. For

some, it may be that remaining married at all costs is better for their physical and psychological health. For others, unless their marriages are the kind that are companion or romantic, divorce may be the best solution.

Whatever the marriage pattern, marginal, functional, companion, or romantic, individuals that wish to maintain their relationship with their spouse should have the opportunity. Not only does the MS individual have to contend with the challenges of disability but with the deterioration of the institution of marriage as well. If, as social workers, we are to assist and empower individuals to cope with their social environment, this is the first step in achieving that goal.

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Appendix A

Interview Guide

(1) Demographic Information

Present age, sex, age at diagnosis of MS, age of spouse, number of years married at time of diagnosis, where did participant reside at time of diagnosis, any children? Occupation? Place of birth? Ethnicity?

Number of years at Pearson Centre? How much contact with spouse (daily, weekly, monthly?) How much contact with extended family (daily, weekly, monthly?) How much contact with children (daily, weekly, monthly?)

(2) Questions Pertaining to Diagnosis and Experience of MS

A. Could you tell me the story of how you first learned you had multiple sclerosis?

B. Who did you talk to in the beginning about your feelings/reactions to having MS?

C. What were some of the challenges you remember confronting in the beginning? Have they changed over time? In what way? How did your life change in the beginning? How did it remain the same? What are some of the negative and positive things you remember experiencing in the beginning of MS?

D. Do you remember how your spouse responded to learning about your multiple sclerosis? How did this response change or remain the same over time? How has this response helped or hindered your own feelings and thoughts about having MS? Was your own response to learning about your MS similar or dissimilar to that of your spouse?

E. Do you think you have learned anything more about yourself and /or your spouse in having MS? As challenging as having MS may be, are there aspects about yourself or others that you have acquired insight about as a result of MS? Would you say that there are new understandings/perspectives that you have about the world that you may not have developed had you not had MS?

F. Looking back upon the time when you first learned about your MS, how do you think you imagined you would be now?

Were your thoughts about yourself then different than they are now? How have they changed? How have they remained the same? Who do you think has had the most influence in your own thinking and reflecting upon the multiple sclerosis experience?

(3) Questions Pertaining to the Marital Experience and Relationship

A. Do you remember the story of how you and your spouse first met?

B. How would you describe your relationship prior to having MS?

C. What are some stories you have of what that relationship was like in the beginning? After a few years of being married? Upon discovering your MS?

D. What kinds of special activities/events/outings did you and your spouse do in the past prior to having MS? Are their special activities events/outings that you do now, in the present? How are they different/similar to the past?

E. How would you describe your relationship currently? Do you think your ideas and thoughts about your relationship with your spouse have changed over time? In what way or how have they stayed the same?

F. How has having MS changed or influenced your relationship? What challenges do you think you have faced together?

G. As with all life transitions, having MS may have brought some changes in your relationship with your spouse. What did you tell yourselves at the time of diagnosis of MS about the effect on your relationship? What do you tell yourselves now?

H. There are many couples, when faced with life transitions, who break up or do not seem able to remain together as a couple. What do you think has made a difference in your experience from these other couples?

I. Can you tell me any stories about you and your spouse that might give me more of an understanding of how you have been able to meet the challenges of MS as a couple? Can you think of any other stories about your relationship, either about the present or the past?

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Appendix B

Initial Letter of contact to MS residents at George Pearson Centre

Dear Mr. or Ms.,

As a candidate in the Masters program in social work at the University of British Columbia, I am about to begin a research study which will involve persons who have MS and are married, and who currently live at George Pearson Centre.

Although there is much written on multiple sclerosis as such, there is very little written about the experience of people who are married and have MS. The purpose of this study is to better understand the experiences of people who, like yourselves, have this condition and are currently involved in a marital relationship. How have you and your spouse managed the challenges presented through MS?

By sharing aspects of your own personal experiences of having MS and being married, you will help broaden the understanding of issues in this area. This will lead to more effective and responsive services to persons living in an extended care facility and being married.

If you agree to participate in this study, this would entail being interviewed by Samuel Greenspoon for approximately 1 to 2 hours. The interview will be audiotaped to ensure accuracy in recording your responses. The tape will be transcribed into written form and then the tape will be erased. Your confidentiality will be protected in that at no time will your name, address, phone number, or any other identifying information appear on any of the research material.

Please note that your choice not to participate will in no way jeopardize any future contact or service with George Pearson Centre, the British Columbia Rehabilitation Society, or the University of British Columbia, or any other agency.

Thank-you for taking the time to read this and for your consideration. I will contact you within a week to answer any questions that you may have and to inquire if you

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Your confidentiality will be protected in that at no time will your name, address, phone number, or any other identifying information appear on any of the research material. The interview will be audiotaped to ensure accuracy in recording your responses. The tape will be transcribed into written form and then the tape will be erased.

If you consent to this interview, you are free to withdraw at any time or to refuse to answer any of the questions. Any such choice will in no way jeopardize any further or future contact or service that you may have, either with the George Pearson Centre, the British Columbia Rehabilitation Society or the University of British Columbia. This interview will take approximately 1 to 2 hours.

As you are aware, talking and reflecting about a past event or time period that may have been problematic or a crisis can sometimes be difficult, even painful. If at any point in the interview, strong emotions are evoked for you, these can be addressed with the interviewer as they arise, or after the interview has finished, whichever is preferable for you. Please feel free to ask any questions as well.

Please indicate your formal consent to being interviewed and to the utilization of the interview material for the above noted research study. Your signature also acknowledges your receipt of a copy of the consent form.

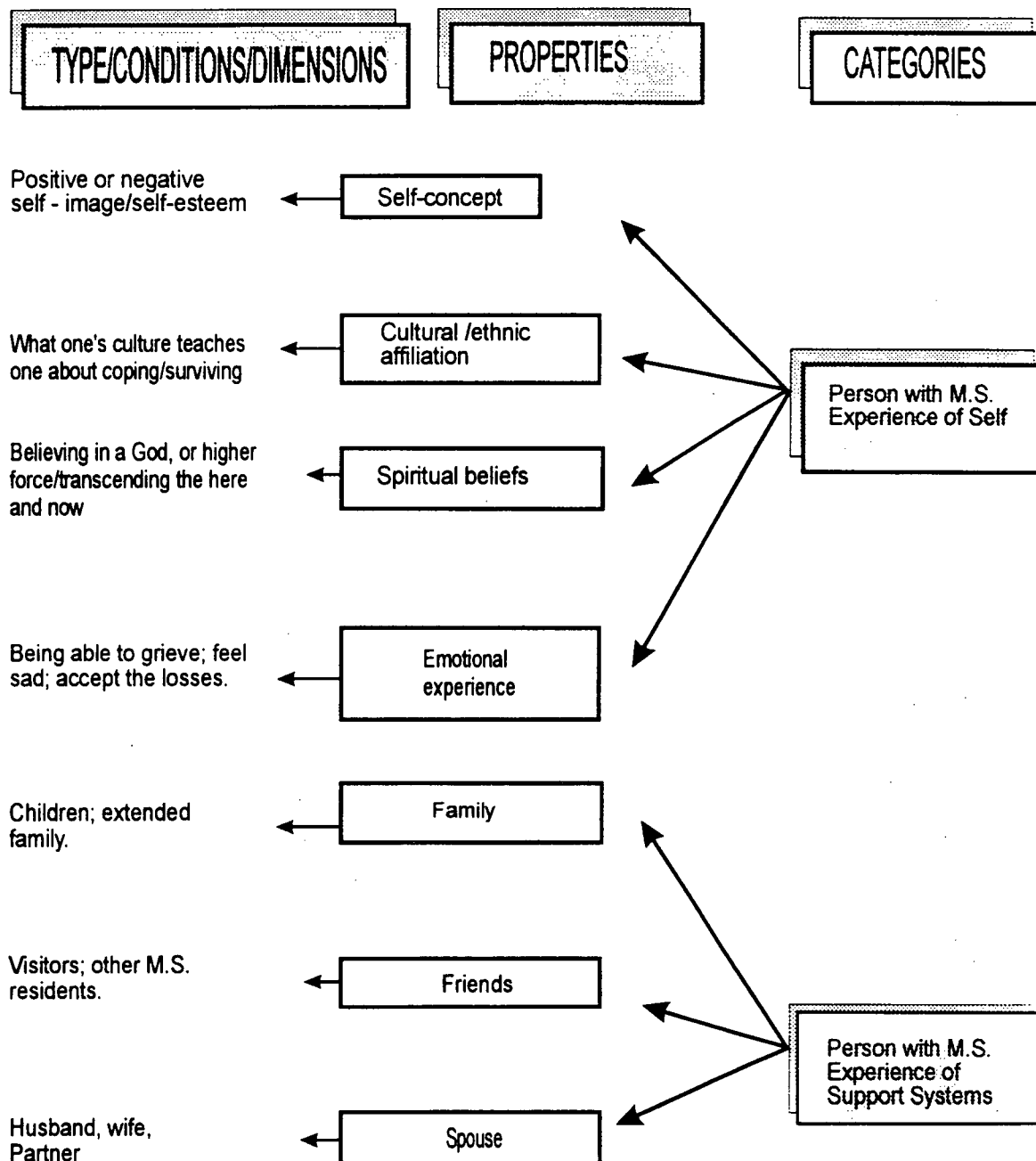
Participant: _____

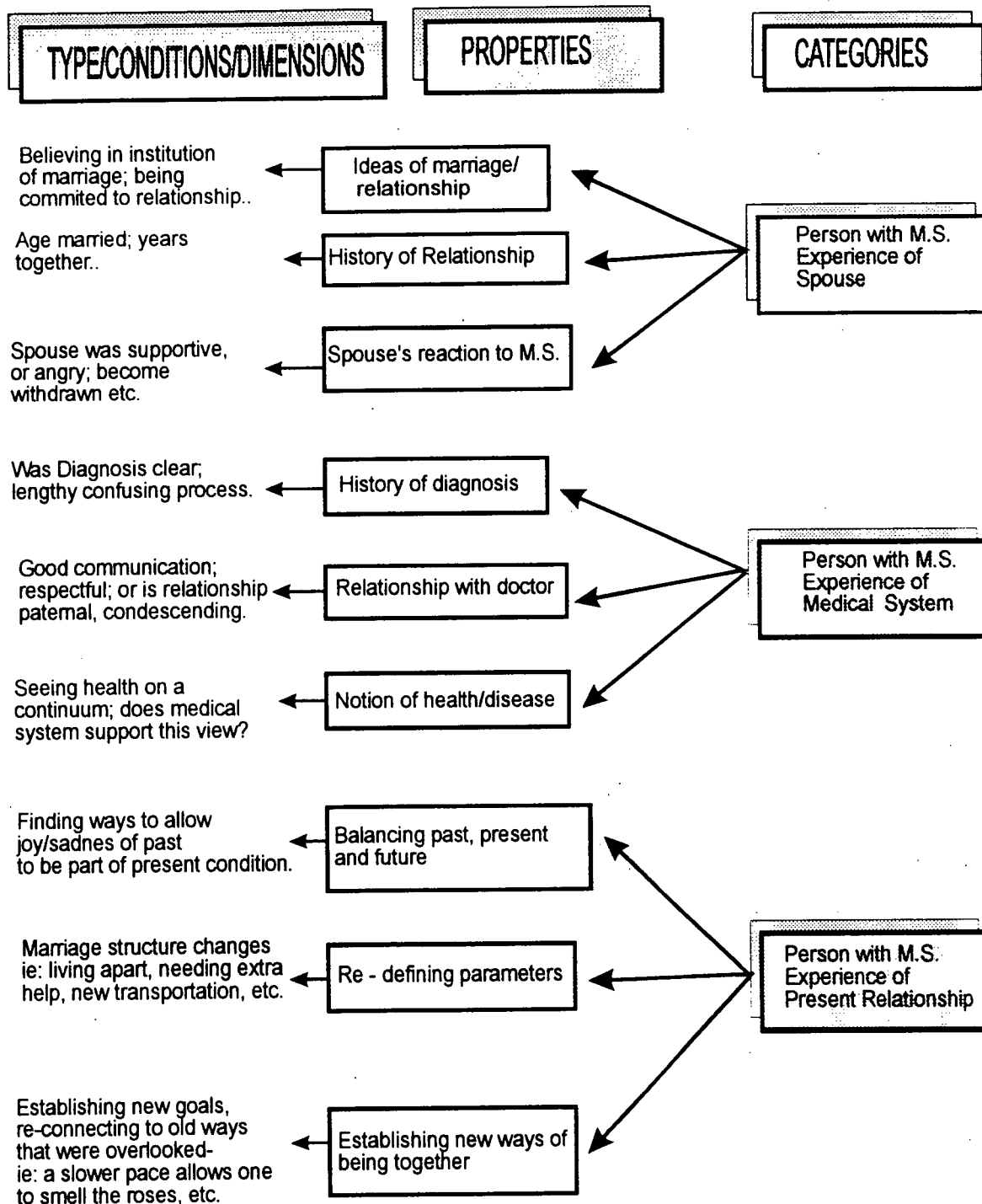
Signature(interviewer): _____

Date: _____

Appendix D

**FRAMEWORK FOR UNDERSTANDING
FACTORS INFLUENCING MARRIAGE PATTERNS
WHEN ONE SPOUSE HAS M.S. AND IS LIVING
IN EXTENDED CARE**





Appendix H

THE INTER RELATION BETWEEN CATEGORIES

