University of Alberta

Impact of Disability on Couples' Sexual Relationships Focus on Multiple Sclerosis

by

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Dedication

To my family who are the most important people in my life. My wife Yashmina without her astonishing patience and support I would not have completed my work; my wonderful children Samir, Azan and Zianna who always put into perspective what is important in life and provided me with daily rejuvenation while working on my graduate program.

ABSTRACT

Disability significantly impacts both the individual's life and the life of their spouse or partner. A literature search confirmed the clinician/researcher's experience that health care providers often feel ill prepared to deal with the issues raised by their clients regarding changes in their sexual relationship as a result of a disability, and that there is a lack of resources to assist them in doing so. The personal experience of couples impacted by disability in regard to their sexual relationship is a fertile area for research. Knowledge and understanding of the couple's perspective is essential in order for health professionals to provide relevant and timely support and intervention. For this study, the research was undertaken by an occupational therapist using a hermeneutic phenomenological approach within a human ecology framework. The purpose of the study was to understand the "lived experience" of couples in which the female partner was diagnosed with MS during the relationship.

Data were gathered by means of an in-depth semi-structured interview ("conversation") with each partner separately. Transcripts of the conversations were subjected to a 10-step interpretative thematic analysis, grouping data by females only, males only and then with all data aggregated. All the participants identified the primacy of communication in coping with the effects of MS. The women with MS live with the unpredictable course of their disease and doubts about their worthiness, attractiveness, and identity. The male partners of these women with MS perceived little impact on the women's sexuality, likely because the women went to great lengths to maintain their customary roles and to buffer their male partners from the full impact of the disease. Using the PLISSIT model, suggestions for intervention strategies are provided based on

the "lived experience" of the couples in this study, including guidance regarding when to refer on to a specialist. Because sexuality is a value-laden subject, a limitation of the study is that only couples who were comfortable talking about sexuality chose to participate. There was no attempt to factor in causality or other quantitative considerations. The couples' stories were allowed to speak for themselves.

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Introduction

What's the Problem: Disability and Couples' Sexual Relationships

Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled (World Health Organization Homepage, 2004).

We are all sexual beings from birth to death (Spica, 1989). Our needs and manner of expressing our sexuality are unique to each of us based on such factors as gender, age, personality, socialization and ethnicity. Sexuality includes behaviours, emotions, as well as an individual's knowledge and beliefs. Integration of these aspects of sexuality contributes to the overall health of individuals (World Health Organization, 1975).

Sexuality is a broad concept that incorporates both behaviours and emotions and their interplay within the context and environment of a relationship. Considerable effort has been invested in the sexual health care curricula for health professionals of all disciplines, resulting in more effective sexual rehabilitation services and programs for clients (Chipouras, 1979; Neistadt, 1986). Despite these improvements and greater acceptance of health care professional involvement (McAlonan, 1995), surveys continue to show that most health professionals do not consider themselves competent to provide sexual health counseling and intervention. Many are unsure of their role in such services and many more neglect the area entirely (Anderson, 1992; Chubon, 1981; Conine 1984; Dicker-Friedman, 1997; Ducharnme & Gill, 1990; Gamel, Davis & Hengeveld, 1993; McAlonan, 1995; Wilson & Williams 1988). Health care providers often feel ill prepared to deal with the issues raised by their clients regarding changes in their sexual relationship as a result of a disability (Ide, 2004).

Clients report varying degrees of satisfaction with the sexual health services they receive, many stating that they were not asked about their sexual concerns during rehabilitation (McAlonan, 1995; Rodocker & Bullard, 1981). Even more neglected is the issue of sexuality from a couple's perspective where one partner has a disability (Miller, 1994; Milligan & Neufeldt, 1998; Rolland, 1994).

Sexuality and disability are both intensely personal experiences and highly variable among individuals. In contrast, to date research exploring the impact of disability on couples' sexual relationships has been impersonal and quantitative in nature, describing the rate of separation and divorce, or establishing casual links for the "observed reality", for example, that a more severe disability produces a more severe impact. As such, the literature does not reflect the personal experiences of people with disabilities and their partners. Their voice is absent in the literature.

Knowledge and understanding of the couple's perspective is essential in order for the health professional to provide client-centred intervention. With an enhanced understanding of the clients' "lived experience", the health care professional may be better able to assist them to cope with their situation by providing more relevant interventions.

Scope and Focus of the Study

The majority of studies in the area of disability and sexuality have focused on individuals who have sustained sudden-onset, traumatic injuries such as spinal cord injury (SCI) and traumatic brain injury (TBI). This study focussed on couples in which one partner was diagnosed with MS during the relationship, i.e. couples in which both partners were able-bodied before the onset of MS. Multiple sclerosis (MS) is a disease of the central nervous system with onset during adulthood usually during the third or fourth decade of life (Speziale, 1997), but may strike at any age between ten and 59 (Sanders, Foley, LaRocca & Zemon, 2000). Unlike SCI and TBI, which are stable conditions, MS is a degenerative disease with a fluctuating course of exacerbations and remissions.

The aim of the current study was to get to the essence of what the individual with MS and their partner are experiencing with respect to their sexual relationship, where "essence" is understood to be a true description of the phenomenon. Specifically, this study was designed to acquire an understanding of the following:

1. each partners' perceptions of the impact of disability on their sexual relationship
2. what gives each partner/couple meaning in their sexual relationship
3. what each partner/couple considers to be important disability-related factors impacting their sexual relationship
4. the coping strategies the couple are using and how these have changed since the onset of MS.

Definitions Used in the Design of the Study

Couple

For this study, a couple was defined as two people in a committed relationship, including but not exclusive to heterosexual married and cohabitating couples.

Disability

Disability was defined "as a loss or deviation, in either a qualitative or a quantitative way, of the ability to perform an activity or behaviour, taking into consideration age, gender, and physical, social and cultural environment" (de Kleijn-deVrankrijker, Heerkens & van Ravensberg, 1998, p. 16).

Sexuality

This study used Dailey's definition of sexuality (1984), comprising five components: sensuality, intimacy, sexual identity, reproduction, and sexualization. **Sensuality** relates to our awareness of and acceptance of our own body through all five senses. **Intimacy** is our need and our ability to experience emotional closeness to another human being, and to have that emotional closeness predictably returned in kind. Our **sexual identity** is a major component of who we are as individuals which involves a continual process of unfolding and self-discovery. **Reproductive aspects** of sexuality deal with fertility, conception and child rearing. **Sexualization** is the term used by Dailey to describe our use of sexuality to influence, control and manipulate others. Sexuality takes place in and is affected by an environment which contains sociocultural influences such as family, ethnicity and religion. It is important to look at the five components as an integrated whole. Each component influences and is influenced by all other components. The greater the integration of the five aspects in an individual, the more positive his or her "sexual beingness" (Dailey, 1984). (For a more comprehensive description of Dailey's definition of sexuality see Appendix A).

Multiple sclerosis (MS)

Multiple sclerosis (MS) is a demyelinating neurological disease, characterized by breakdown of myelin and development of sclerotic plaques through out the brain and the spinal cord (Hatzichristou, 1996). Typical symptoms at the onset of the disease are weakness in one or more limbs, optic neuritis and paraesthesia. (Hatzichristou, 1996). Impairments due to demyelination include cognitive, motor, and sensory dysfunction depending on the area of the brain or spinal cord involved (Bezkor & Candeo, 1987a; 1987b; Sanders et al., 2000). In the majority of individuals, cognitive changes are not severe, but may include impairment in memory, conceptual reasoning, visuospatial perception, language skills, to severe dementia (Speziale, 1997). According to the MS Society of Canada, Canadians have one of the highest rates of MS in the world. Every day three more people in Canada are diagnosed with MS. There are approximately 2.5 million people worldwide with MS. In Canada, women are twice as likely to develop MS than men. Worldwide, the ratio is approximately three women to two men (Sanders et al., 2000).

Human Ecology: The Ideal Theoretical Framework

Human ecology is "... the study of human kind in the ordinary business of life; it deals with everyday problems of living" (Westney, Brabble & Edwards, 1988, p. 130). The fundamental premise of human ecology is to help human beings manage their lives in an effective manner, and to understand themselves in relation to forces (e.g. disease) that interrupt their capacity to be fully functioning (Westney et al., 1988). Sontag and Bubolz (1988) identify human ecology as the study of humans as social, physical, biological beings in interaction with each other and with their physical, sociocultural, aesthetic, and biological environments. They state that "the uniqueness of human ecology lies in its focus on viewing humans and their near environments as integrated wholes, mutually influencing each other"(p.118).

Human ecology theory, its definitions, concepts, principles and approach, provided the broad framework for this study on the impact of disability on couples' sexual relationships. As such, the participants in the proposed study were seen as social / physical / biological beings who are both influenced by and who influence their environment. The participants and their perceptions were examined from a broad perspective structured around themes and assumptions of human ecology theory. Specific concepts of human ecology were used to frame and focus the research process, as follows: environment, holism, values, and spirituality

Environment

A basic premise of human ecology is that human beings cannot be studied in isolation from their environment (Bubolz & Sontag 1993). Broadly defined, the environment consists of human built, social-cultural and natural physical-biological environment (Bubolz & Sontag, 1993). The near environment can be defined as the environment with which the individual or couple interacts directly (Sontag & Bubolz, 1988). The attitudes and behaviours couples are exposed to in their near environment have a significant impact on a couple's sexual expression (Milligan & Neufeldt, 1998), and indeed sociocultural inhibitors may have more of an impact than the physical limitations caused by the disability itself (Baum & Gray, 1998). For example, the disabled population tends to be systematically asexualized (Fifield & Esmail, 2000).

The Family Ecological Perspective

When a family ecological perspective is contemplated for application to couples sexual relationships impacted by disability, a key concept is the "unit of analysis". The question that arises is how should the family be viewed? Is the family a unit in itself - living and functioning in the environment? Or is the family an environment within which individual family members interact (an ecosystem)?

Human ecology is the study of human interaction and interdependence with the environment (Sontag & Bubolz, 1988). Family ecology is a general theory that can be used to study a wide range of problems related to families and their relationships with various environments including diverse levels and kinds of external systems (Bubolz & Sontag,1993, p. 424). To fully understand the intricate relationships of the family and their relevant contexts, an ecological approach is required (Wright & Herrin, 1988)

Sexuality is a fundamental aspect of family life (Sussman, 1983). A couple's sexual relationship is an essential element of the couple bond on which a family unit is based. In addition, as identified by Badir, (1993) the family is the environment within which members' needs are met. The family helps establish gender roles identity and is the structure for acceptable role behaviours (Maddock, Neubeck & Sussman, 1983). Clearly, both the "family within environment" and the "family as environment" are applicable when a family ecological perspective is contemplated for application to couples sexual relationships impacted by disability.

Family/Couple as Environment (Ecosystem)

The family viewed as an ecosystem "reflects the belief that family life and its immediate environment – its space, food, clothing and artifacts – form a complex, dynamic, living system of which family members are a part"(Badir, 1993, p.9). Using the ecosystem perspective allows for understanding the natural and social environments of the family and reciprocal interactions that occur among the systems and subsystems (Wright & Herrin, 1988). There are relationships and specified roles each individual plays and usually they have an area that they consider their own. Here, the family is seen as an ecosystem within which the family lives, functions and interacts. Viewing the couple/family as an ecosystem allows for understanding how for example a disability may influence how the couple changes and evolves through interaction within itself and within the environment.

Every ecosystem contains niches (Klein & White, 1996); interdependences in an ecosystem are not between specific individuals but between specific niches occupied by individuals. The idea of niches is seen as helping to clarify the dynamics that occur in a couple impacted by disability, seeing members as occupying one or more niches that achieve certain functional tasks.

When a family is impacted by disability, it disrupts the niches in the family-as-ecosystem and the interdependencies that have been established between the niches, including those interdependencies affecting the couple's sexual life. For example, the bread-winner niche may be suddenly unoccupied and their function lost to the family. A new niche is created, called "caretaker". The immediate environment may be unexpectedly inaccessible by the disabled partner -- how to move from wheelchair to bed?

Both individuals have certain roles and expectations (interdependencies) they need to fulfil to allow their relationship, including their sexual relationship, to function and evolve. The literature has shown that pre-injury expectations and role definitions (niches) may be impossible to meet (fill) in the presence of a disability (McNeff, 1997; Rolland, 1994). Miller (1994) reported that the longer a non-disabled partner continues to perform the caretaker role, the more difficult it becomes to return to the pre-injury level of intimacy. Couples also need assistance to clearly outline what self-care activities can be done independently and which activities require assistance from the partner and which require professional help (Rolland, 1994).

Disability has also been shown to increase stress and affect the roles and personal boundaries experienced by couples (Feigin, 1998; Kester, Rothblum, Lobato & Milhous 1988; Rolland, 1994). Early intervention to help couples identify and address all of these factors (e.g. renegotiate roles) may help avert a crisis (McNeff, 1997; Rolland, 1994).

Couple/Family in Environment

The ecosystem that is defined as a family does not live independent to the environment it is situated in (Badir, 1993). As Badir put it, the family is an environment situated within a larger environment of the society.

Role definitions are influenced by what society states a partner's role should be. The couple/family occupies a niche within the larger community or society. They participate in many local community activities etc. A family is influenced by events and activities in their society, and at the same time the family influences various aspects of the environment with which it interacts.

The attitudes and behaviours couples are exposed to in their near environment have a significant impact on a couple's sexual expression (Milligan & Neufeldt, 1998). For example, the disabled population tends to be systematically asexualized (Fifield & Esmail, 2000). The near environment is quite different for someone with a disability. They may have to use assistive devices and prostheses to enhance their ability to function and interact with people and objects in their environment - whether it is in a functional, social or sexual manner. Sontag's (1986) description of the three dimensions of human comfort - physical, social and psychological - is relevant to couples functioning in today's society. Many individuals with disabilities have to develop an acceptance and comfort level with who they are, and how they function and interact with their environment.

Using a family ecology perspective, the current study encompassed both an ecological study of the couple-in-environment, as well as a study of the couple-as-ecosystem, that is, their perceptions and problems were investigated within the context of societal influences and expectations as well as their own inter- and intra-personal factors.

Holism

Westney et al. (1988) state that human ecology is a holistic study of human beings and by nature human beings are a composite of physical, social, intellectual, emotional and spiritual components. Similarly, Young (1991) emphasizes holism in human ecology in that it accepts the full range of human interactions at all levels of complexity.

The study of sexuality also requires a holistic approach (Dailey, 1984; Rathus, Nevid & Fishner-Rathus, 2002; Sipski & Alexander, 1997). When a disability exists within a couples context, a holistic perspective is imperative to ensure comprehensive understanding of the resulting impact on the couple's sexual relationship.

Real problems of society do not come in disciplinary shaped blocks (Klein, 1985). Steiner (1995) states if scientists transcend the borders of their own disciplines and try to understand other disciplines relevant to the human ecological context, integration can be achieved. Contributions from a variety of disciplines are especially useful when studying a topic as broad as sexuality which is of clinical interest to a large number of disciplines (Rathus et al., 2002). As human ecology is an eclectic discipline (Westney et al., 1988) a research study conducted under the human ecology umbrella allows for a more interdisciplinary and trans-disciplinary approach (Jungen, 1986; Strauss, 1988). A trans-disciplinary approach may help overcome the negative effects of specialization and help form effective problem solving frameworks (Firebaugh, 1995). Strauss (1988) discusses the emergence of human ecology as a meta-discipline that challenges the traditional role and authority of specialists over certain prescribed domains of knowledge. Using a meta-disciplinary approach within the human ecology perspective allows a skilled generalist (Strauss, 1988) to integrate the knowledge base generated by specialist contributors to the study of sexuality. "What we need today is to relate the sciences to each other, and we lack the specialists in generalization to do this" (Lord Brain as cited in Strauss, 1988, p. 14).

Values

Values are human conceptions of what is good, right and worthwhile (Bubolz & Sontag, 1993, p. 435). Values underlie the choices and behaviours of individuals, groups, and organizations. Sexuality is value-laden as well. Sexual behaviours and lifestyles vary greatly from culture to culture and on an individual basis. What is acceptable for some is unthinkable for others. Attitudes towards sexuality are influenced by factors such as education, laws, ethnicity, family, peer groups, personal experience, and religion. Personal values will be most affected by whichever of these factors are most important to the individual (Rathus et al., 2002).

Values are important in directing human ecological research (Steiner, 1995; Wang & Ye, 1991). The grounding of family ecology theory in values places an important responsibility on researchers and practitioners (Bubolz & Sontag, 1993) to do research that will make a difference and improve human existence. Research in human ecology should be assessed in terms of its contribution to improving quality of life and well being of the participants, and of society more generally.

McGregor, (1997) discusses value reasoning, which involves arriving at decisions on how to deal with problems by not only using the facts but also considering values. Values ensure the special problems of less abled groups are dealt with (Bubolz & Sontag, 1993). Individuals with disabilities may be included in this group as they often lack power, self-determination, access to resources and are often the target of discrimination (McColl & Bickenback, 1998). Acquiring a disability has a profound impact on overall quality of life and well being (Kreuter, Sullivan, Dahllof & Siosteen, 1996). Well-being may be defined as the level of satisfaction or happiness in terms of the perceived fulfillment of needs and wants which may be physical, psychological, spiritual, etc. (Stanley & Cheek, 2003; Westney et al., 1988)

Spirituality

Human ecology and occupational therapy both embrace spirituality as a significant component of the human experience (Young, 1991; Egan & Delaat, 1997; Westney, et al., 1988). Egan and Delaat (1997) describe spirituality as relating to our thoughts, feelings and actions concerning the meaning that we make of our daily lives. Meaning is constructed through our relationships with ourselves, other humans, and other inhabitants of the earth, the earth itself and for many individuals, a higher power or Creator.

Spirituality plays a key role in the way individuals deal with disability (McColl, 2000). Individuals attempt to find meaning in what has happened to them. For example, some will see their disability as a reminder of their humanity, as a mission, as a punishment or a warning (McColl, 2000). Spirituality is the part of us that connects with other people, it can be thought of as the force that dissolves the boundaries between the self and others (Canadian Association of Occupational Therapists, 1997; Lindsey, 1996; Soeken & Carson, 1987). Spirituality plays a role in shaping how people interact with each other and function in everyday life (Young, 1991). Turner, Center & Kiser (2004) suggest that spirituality must be considered when dealing with the sexual concerns. They found that efforts to link sexuality and spirituality have brought considerable benefits for couples. By considering the meaning individuals and couples place on their sexual relationship counselors can better understand the couple's perspective as well as enhance their ability to achieve positive therapeutic outcomes (Turner et al., 2004).

Occupational therapy

> The occupational therapist is a professional in the area of health responsible for prevention, cure and rehabilitation of physical, mental, social or developmental dysfunction, through specific use of expressive, recreational, professional, arts and crafts and self-care/daily living activities. Occupational Therapy aims to promote and support health, to restore and/or reinforce functional capacities, to facilitate the learning of essential functions and to develop adaptive skills aiming at helping the individual to reach the maximum autonomy possible in social domestic, work and leisure environments. (Lopes & Hahn, 2004)

Although I used a human ecology framework for this study, I brought my consciousness as an occupational therapist to the study. Occupational therapy and human ecology have many points of commonality. Both are holistic in their perspective and view the individual in the context of a multi-faceted environment. Occupational therapy is fundamentally client-centred; that is, the individual, and in particular what activities give one meaning and purpose in life, is the primary focus of occupational therapy. The human ecology perspective is more concerned with the individual-within-environment, and thus has a more externalized point of view.

Occupational Therapy and Sexuality

Occupational therapists are specialized in assessing and treating aspects of a disabled individual's functioning which interfere with their performance of the activities and roles which give their life meaning and purpose, one of these being sexual activity (Kennedy, 1987).

When I first began practicing as an occupational therapist I observed that patients were at a loss on how to deal with the emotional and physical impact a disability can have on their sexuality. Intuitively I felt it was important to deal with sexuality as a couples issue however I felt ill-prepared and was not sure of the appropriateness and level of my intervention and how to handle the partner's perspective. Resorting to the literature, I found a lack of useful or practical information to assist couples in their sexual relationships, finding instead primarily statistics on break-up and divorce. These statistics are cold comfort and of limited utility to both clinicians and clients, simply confirming the negative influence of disability on the long term survival of couples' relationships. Now, as an educator and a clinician with several years of experience as well as additional training in the area of sexuality and disability, I can see sexuality is a significant issue which most healthcare professionals are ill-equipped handle.

Client-centredness is a driving value of occupational therapy. With experience and training I have become a skilled observer and an active listener to couples whose sexual relationships are affected by disability. As a clinician I am aware of how valuable the right information at the right time can be to a couple who is struggling with their sexual relationship after the onset of MS. I value information-sharing as an essential clinical tool. I also strongly endorse one of the fundamental assumptions of human ecology, that practice should inform the research process.

Occupational therapy as a profession is undergoing a paradigm shift in which positivist empirical science is no longer viewed as the only legitimate contribution to knowledge. Interpretive and critical social sciences are on the rise as it becomes increasingly clear that empirical science cannot answer all the questions (Canadian Association of Occupational Therapists, 1997). This perspective is ideal for completing a study of this type where the client's voice is heard.

Sontag's (1986) description of the three dimensions of human comfort - physical, social and psychological - is relevant to couples sexual functioning in today's society. Many individuals with disabilities have to develop an acceptance and comfort level with who they are and how they function and interact with their environment. An understanding of the barriers and facilitators in the environment can help to promote successful adaptation and restore a new balance in the couple's sexual relationship. Human ecology theory provides a broad framework within which research on this topic can be conducted. Combined with the occupational therapist's consciousness of the individual's experience, the marriage of the two perspectives allows for a thorough examination of factors that will help determine how such adaptations and balance can be achieved.

Chapter #2

Literature Review

Disability and Couples' Sexual Relationships

Considerable effort is expended in rehabilitation programs on improving a client's physical, cognitive, and emotional status, as well as in dealing with vocational, leisure and self-care functioning (Dicker-Friedman, 1997; Kennedy, 1987; Miller, 1994). However, sex, love, intimacy, and relationships are often not addressed (Miller, 1994; Rolland 1994). When it comes to the experience of the non-disabled partner the literature is "virtually silent" (Milligan & Neufeldt, 1998). With a few exceptions, the sexuality of couples facing illness and disability remains a neglected topic in the literature (Abrams, 1981; Kreuter, Sullivan & Siosteen, 1994a; Rolland, 1994).

Impact of Disability on Sexuality and Couple Relationships

Acquiring a disability has a profound impact on overall quality of life and well being (Kreuter, Sullivan, Dahllof, & Siosteen., 1998). In one study, sex was reported to be the most serious problem in marriages where one of the partners had a disability (Yim, Lee, Yoon, Song, Rah & Moon, 1998). People with disabilities are less likely to marry (DeVivo & Richards, 1996) and if they do marry or are already married, they have almost twice the risk of divorce (DeVivo, LaVerne, Hawkins, Richards, & Go, 1995). Urey, Viar, & Henggeler (1987) point out that divorce rates among individuals with spinal cord injuries have been estimated as high as 85%. The majority of individuals who have acquired a disability report a decline in frequency in sexual activity following disability (Sadoughi, Leshner & Fine, 1971). In the same study, more than half of the subjects indicated they had to change their pattern of sexual activity following disability and sexual satisfaction and interest also declined following disability. Sadoughi et al. (1971) also found that 36% of individuals with disability they surveyed indicated a desire for more sexual satisfaction in their present relationship and 42% believed that their spouse presently desired more satisfaction.

The literature also provides several explanations for why disability has the impact it does on a couple's sexual relationship. Disability-related physical limitations was the most frequently cited reason for fear and feelings of discomfort in participating in sexual activities (Cohen, Wallston & Wallston, 1976; Sadoughi et al., 1971). Other problems found to affect relationship development and enhancement include frequency of activity, perceived constraints on attraction and societal barriers (Rintala, Howland, Nosek, Bennett, Young, Foley et al,, 1997). Generally, when a partner has a disability problems have been reported in the frequency of sexual activity, who initiates (communication), amount of pleasure experienced and limitations or alterations in the types of behaviors they would like to participate in (Kreuter et al, 1994a; 1994b).

Disability has been identified as a stressor which affects roles and personal boundaries in couples (Feigin, 1998; Kester, Rothblum, Lobato & Milhous, 1988; Rolland, 1994). Kester et al. (1988) reported a significant occurrence of adverse health consequences as a result of being married to, or living with a partner with a spinal cord injury. When compared to the general population, the non-disabled partner had significantly worse scores on every health measure and the health problems were largely stress related.

Self-esteem

Sexual esteem, sexual satisfaction, and body esteem were strong predictors of overall self esteem of individuals with disabilities (Taleporos & McCabe, 2002). People with more severe physical limitations due to their disabilities were found to have lower levels of self esteem and sexual satisfaction and higher levels of sexual depression as compared to able-bodied individuals and individuals with mild impairments (McCabe & Taleporos 2003). Parker (1993) found that the guilt of having a disability and the restrictions it placed on their partners was a significant cause of decreased self-esteem in the disabled individual, and in turn, this affected a couple's sexual relationship (Barak, Lamp, Sarova-Pinchas & Achiron, 1999; Bianchi, 1997). Bianchi (1997) found that decreased self-esteem was positively related to sexual preoccupation in disabled individuals. Individuals with disabilities commonly believe they are less sexually desirable then able bodied individuals and their disability greatly limits their sexual life (Taleporos & McCabe, 2001; McCabe & Taleporos, 2003). Taleporos and McCabe (2003) also found that relationship status was strongly correlated to sexual wellbeing, where individuals in a relationship reported higher sexual satisfaction and self esteem than individuals who were not in a relationship.

Pre- versus Post-Disability Relationships

Some researchers have examined the difference between pre-disability relationships (relationships between couples that formed prior to the disability) and post-disability relationships (disability was already present when the relationship formed) (McNeff, 1997). In this regard, Crewe and Krause, (1988) found that couples in post-disability relationships reported greater satisfaction with their sex lives, living arrangements, social lives, health, and emotional adjustment than did couples in pre-disability relationships. In contrast, Kreuter et al. (1994a, 1994b) found no significant difference in the level of satisfaction with current sex life, emotional attachment and satisfaction with the relationship as a whole when comparing pre-disability and post-disability relationships. They did describe certain differences concerning sexual aspects of the relationship, all of which favoured post-disability relationships, including frequency of sexual activity and variety of sexual expression, which were lower in the pre-disability group. In general, Crewe (1993) found that pre-disability marriages that survived demonstrated "strength and commitment but also included noticeable areas of loss and regret" (p. 146). Spouses in these relationships were more likely to have an increased caregiver role (Crewe, 1993; Rolland, 1994). Individuals in post-disability relationships were more likely to be employed, socially active and have a higher level of education (Crewe & Krause 1988).

Changes in Roles and Expectations

The task of confronting and accepting the disability is not limited to the affected partner (McNeff, 1997; Miller, 1994; Rolland, 1994). A woman reported having difficulty becoming intimate and taking the role of a lover immediately following helping her husband with his bowel routine (personal communication, 1998). Similar reports are common (Milligan & Neufeldt, 1998; Yoshida, 1994). Pre-injury expectations and role definitions may be impossible to meet in the presence of a disability (McNeff, 1997; Rolland, 1994). Miller (1994) reported that the longer a non-disabled partner continues the caretaker role the more difficult it becomes to return to the pre-injury level of intimacy.

McNeff (1997) reported that gender socialization may also affect how men and women cope with their partner's disability. Men and women have different strengths and skills which affect how they deal with disability (McNeff, 1997). He found that women were more likely to accept their disability than males and that the disability can provide an opportunity to reexamine traditionally held roles. Couples also need assistance to clarify what self-care activities can be done independently, which require assistance from the partner and which are best managed by hired assistance (Rolland, 1994). Early intervention to help couples identify and address all of these factors (e.g. renegotiating roles) may help avert a crisis (McNeff, 1997; Rolland, 1994).

Intimacy

Sexuality involves interplay between physical and psychological elements (Sipski & Alexander, 1997). Sexual rehabilitation and research often focuses on the mechanics of sexual intercourse rather than on the process of regaining closeness and intimacy (Blackerby, 1993 as cited in Miller, 1994; Yoshida, 1994), whereas the physical aspect is only a small component of a couple's sexuality (Dailey, 1984). While sexual performance is important, it is the intimacy in the relationship that provides the foundation for meaningful expression and experience of sexuality (Miller, 1994). From the perspective of non-disabled partners, feelings of emotional closeness, mutual concern and willingness to participate in a variety of sexual activities are more important for sexual fulfillment than the physiological aspects of sexuality (Kreuter et al., 1994b, Kreuter et al., 1996).

In disabilities that involve cognitive impairment, the capacity for intimacy may be lost and a "new" relationship (with the same partner) must be developed (Rolland, 1994).

In general, non-disabled partners report having greater difficulty dealing with cognitive changes as opposed to physical impairments that affect sexual functioning (Peters, Stambrook, Moore, Zubek, Dubo & Blumenschein, 1992; Sandel, 1997).

Couples who can redefine intimacy and nurturance in terms of valuing mutually caring companionate relationship with shared interests and pleasurable activities rather than purely sexual terms can successfully adapt to losses in the sexual components of their relationship (Rolland, 1994). If the individuals have sufficient cognitive and emotional capacities there are other ways of establishing intimacy besides intercourse (Miller, 1994).

Couple Characteristics that Predict Successful Adjustment

Urey & Henggeler (1987) found that with few exceptions, the same characteristics were associated with successful marriages for couples affected by disability as for able-bodied couples. They found that the strongest predictor of positive marital adjustment for couples affected by disability was the number of recreational and social activities they participated in with others. Couples with the most problems were found to participate in fewer activities alone or as a couple (Urey & Henggeler, 1987). Not surprisingly, the authors suggest that education programs offered in rehabilitation settings should emphasize the participation of disabled individuals outside the home or institution.

Another key predictor of successful adjustment is the disabled individual's attitude and adjustment to his/her own condition. Those with a positive attitude were more likely to maintain or develop long-term relationships (Brown & Giesy, 1986; Milligan & Neufeldt, 1998). As identified by Milligan & Neufeldt (1998), characteristics of partners of disabled individuals that predict greater marital adjustment are: the degree to which the person is open to a relationship with someone with a disability; prior experience with disability; flexibility regarding role performance; acceptance of the disability; willingness to accept help; and an attitude which fosters their partner's independence and resiliency in spite of social disapproval. In another study, Vargo (1983) found six factors that were of primary importance for satisfactory adaptation to a partner's disability: adequate support systems; commitment to the marital relationship; hope; health care staff attitude and advice; architectural and societal barriers; and positive contribution of having children.

Counseling and Intervention

Although the literature is very limited in the area of counseling and intervention for couples affected by disability specifically on the topic of sexuality (Rolland, 1994), it is quite consistent in the strategies recommended to enhance couples' sexual relationships. Counseling and intervention strategies which have shown to be effective include mutual responsibility, education, facilitating communication between partners, facilitating attitude and behavior change, and prescription and provision of aids, prosthesis and resources.

Efficacy

Sexual counseling and intervention have been shown to be effective tools for couples dealing with the changes and stress due to a disability (Bernardo, 1981). A study conducted by Perlesz & O'Loughlan (1998) found that the stress experienced by disabled individuals and their caregiver was reduced with counseling. Hoch (1977) found that a mutually rewarding sexual relationship can be obtained and developed by individuals with a disability and their partner through use of strategies which are similar to those used in therapy for couples not affected by disability. Each couple-disability combination will have its own unique characteristics and effects, and as such will require an individualized form of education and counseling (Rolland, 1994). For example, some individuals reported not being ready to deal with their sexuality during the early stages of recovery (McAlonan, 1995), therefore the timing of counseling may be a key to successful adjustment and participation in sexual activities (Bernardo, 1981).

The P-LI-SS-IT model

The model cited most often in the literature for dealing with disability and sexuality is the PLISSIT model developed by Annon, 1975 (Dicker-Friedamn, 1997; Sipski & Alexander, 1997; Neistadt, 1986; Thorn-Gray & Kern, 1983; Whitehead, 1993). Using a learning theory framework, Annon (1975) developed, tested and refined a conceptual scheme for organizing intervention in the area of sexuality consisting of four levels: Permission, Limited Information, Specific Suggestions and Intensive Therapy (P-LI-SS-IT). The first three levels of intervention are appropriate for use by most health care professionals, while the final level, intensive therapy, should only be provided by an expert in the area of need (Dicker-Friedamn, 1997; Neistadt, 1986; Thorn-Gray & Kern, 1983; Whitehead, 1993).

At the ***permission*** level, the health care professional should seek permission from the client to address sexuality, as well as give permission for the client to discuss sexual matters with their partner. ***Permission*** can also be given indirectly, by involving the partner in all aspects of the care and education of the client (Anderson, 1992; Urey et al., 1987). The ***permission*** stage may also be the best level at which to facilitate communication between the couple and dispel the idea that sexual expression is appropriate for only young, healthy and physically able-bodied individuals (Thorn-Gray & Kern, 1983).

The level of ***limited information*** involves providing both partners with general information regarding the etiology, pathology and complications associated with the disability (Esmail, Esmail & Munro, 2001). This level is also useful to begin to dispel myths the couple may hold regarding disability and sexual activity. By simply providing information, the clinician may be facilitating attitudinal and behavioural changes (Dicker-Friedman, 1997; Esmail et al., 2001; Thorn-Gray & Kern, 1983).

At the third level the clinician offers the couple ***specific suggestions*** on how to cope with the disability. Before progressing to the ***specific suggestions*** level of intervention, the health professional must first complete a full evaluation including completing a sexual history of the couple. By gaining all the pertinent information, the clinician has greater confidence that the intervention prescribed will be appropriate for the couple (Dicker-Friedman, 1997). Goals may be set regarding new strategies for sexual activity (Dicker-Friedman, 1997; Thorn-Gray & Kern, 1983). Specific suggestions may include positions for sexual activity (Thorn-Gray & Kern, 1983), or adaptive devices and orthotics (Miller, 1994). This is also an appropriate time to discuss boundaries and roles that are acceptable to each partner. Attitudinal changes can also be addressed at this level of intervention. If necessary, the clinician can assist the couple to explore and discover a wider range of intimate activities they both may enjoy (Rolland, 1994; Schuler, 1982). Couples can also be given options to broaden the scope of activities that they consider acceptable (Dicker-Friedman, 1997; Miller, 1994; Schuler, 1982; Thorn-Gray & Kern, 1983). This level of the PLISSIT model is much more demanding of the clinician with respect to time, experience, and knowledge (Dicker-Friedman, 1997; Thorn-Gray & Kern, 1983).

Intensive therapy is beyond the scope and expertise of most health care professionals. The treating therapist must honestly assess his/her own expertise in relation to the couple's needs and then recommend an appropriate referral. If the problem the couple is experiencing pre-dates the disability, it may require intensive counseling or more specific medical intervention, in which case appropriate referrals should be made (Dicker-Friedman, 1997; Thorn-Gray & Kern, 1983).

Mutual responsibility

The person most affected by the disability other then the person with the disability is their partner (Williams, 1993). Optimal couple functioning depends largely on the willingness of each partner to take responsibility for the relationship, that is, the disability cannot be defined as exclusively the domain of the disabled partner (Kreuter et al., 1994a, 1994b; Rolland, 1994; Williams, 1993). By introducing the issues as "our" problem, the clinician is able ensure that each partner examines their own values, beliefs and attitudes (Rolland, 1994). Responsibility for sexual adjustment must be shared by both the disabled individual and his/her partner (Rolland, 1994; Schuler, 1982). For this reason, the partner must be involved in the care and education of the disabled individual (Anderson, 1992; Urey et al., 1987). Similarly, if both individuals share in sexual pleasuring, the increased satisfaction experienced by the partner will increase the satisfaction of the disabled individual (Comarr & Vigue, 1978, as cited in Schuler, 1982).

Education and Information

Nothing is more helpful and reassuring to patients and their families than clear explanation and education regarding the disability (Miller, 1994). Williams (1993) found that with increased information imparted to the spouse, there was less negative impact of the disability on marital satisfaction. The education component should include helping the couple understand the disability itself, the prognosis and any complications (Miller, 1994; Rolland, 1994). Specific information on sexual anatomy, physiology and function should also be covered (Schuler, 1982). Other areas that should be addressed include fertility, pregnancy, contraception (Bernardo, 1981; David, Gur & Rozin, 1977; McAlonan, 1995), and bowel and bladder management (Thorn-Gray & Kern, 1983).

Facilitating Communication between Partners

Communication is a crucial element for facilitating healthy couples' functioning (Bernardo, 1981; McNeff, 1997; Rolland, 1994). Assisting the disabled individual and the partner to develop and maintain good verbal and nonverbal communication may be one of the most important challenges faced by a therapist (Miller, 1994). Both partners must be encouraged to discuss their sexual needs openly, including issues of intimacy (Miller, 1994). Without open communication, the sexual experience becomes a gamble and satisfaction cannot be guaranteed (Schuler, 1982).

Attitude and Behaviour Changes

Often societal myths and attitudes create inhibitions that interfere with a couple's ability to satisfy their own sexual needs (Schuler, 1982). Sexuality can be redefined in broader terms as any activity that is mutually stimulating and pleasurable for the couple (Rolland, 1994; Schuler, 1982). Couples can be given options for activities that they may consider acceptable to learn about their new sexuality (Dicker-Friedman, 1997; Miller, 1994; Schuler, 1982; Thorn-Gray & Kern, 1983). Another area of attitude change is the establishment of healthy roles and boundaries (Rolland, 1994). Couples are encouraged to accept the disability and establish new boundaries, which may be different from societal norms or their personal expectations (Rolland, 1994; Samelson & Hannan, 1999).

Prescription of Aids, Prosthesis and Resources

Miller (1994) suggests that when the disability is physical, one of the first options to consider is the use of orthotic and assistive devices which are acceptable to the couple. Assistive devices may help in positioning, overcoming functional limitations, or for enhancing sexual pleasure (Kennedy, 1987; Miller, 1994). Clinicians must also have available a list of resources in the form of literature and other professionals who are trained to deal with the specific needs of the couple (Dicker-Friedman, 1997; Kennedy, 1987; Thorn-Gray & Kern, 1983). Assisting couples to develop resources in the form of support systems both at a personal and community level can prove very valuable (Strauss & Finegan, 1990).

Multiple Sclerosis and Couples' Sexual Relationships

Sexual dysfunction in multiple sclerosis

Activities of daily living, including sexual activity, are impacted by MS (Bezkor & Candeo, 1987a; 1989b; Speziale, 1997). Although there is a correlation between the severity of MS and the severity of the sexual dysfunction, sexual dysfunction can occur at any point during the course of the illness (Smeltzer & Kelly, 1997). Sexual dysfunction often accompanies MS, significantly interfering with the social life of individuals and detracting from their quality of life (Zorzon, Zivadinov, Bosco, Bragadin, Moretti, Bonfigli et al., 1999). Prevelance reports indicate that 50 - 90% of individuals who suffer from MS report changes in their sex lives after the onset of symptoms (Barak et al., 1999; Zivadinov, Zorzon, Bosco, Bragadin, Moretti, Bonfigl et al., 1999). Approximately 70 – 75 % of individuals under the age of 50 with slight impairment due to MS reported having disturbances of sexual function, with almost 20% reporting the disturbance to be serious in nature (Minderhaud, Leemhuis, Kremer, Laban & Smits, 1984).

Foley developed a three level conceptual module, (primary, secondary and tertiary sexual dysfunction) to describe the sexual symptoms in MS (Sanders et al., 2000). ***Primary sexual dysfunction*** occurs as a result of neurological impairment that directly affects sexual response. For men this may include impaired genital sensation, decreased libido, erectile dysfunction and decreased intensity of ejaculation. For women, it includes decreased libido, altered genital sensation (including numbness, pain, burning or general discomfort), decreased physical response in terms of vaginal lubrication and decreased frequency or intensity of orgasm. (Foley, LaRocca, Sanders & Zemon, 2001; Sanders et al., 2000). ***Secondary sexual dysfunction*** refers to non-sexual physical changes which may affect sexual response such as fatigue, spasticity, bowel and bladder function, pain, and incoordination producing general impairment in mobility and function. Cognitive changes in the form of apathy, confusion and diminished interest in activity are also common (Smeltzer & Kelley, 1997). Secondary sexual dysfunction also arises from the side effects of medications taken to deal with the various symptoms of MS. These include cognitive difficulties and atypical sensory responses (Foley et al., 2001; Sanders et al., 2000). ***Tertiary sexual dysfunction*** refers to psychosocial and cultural issues that may interfere with sexual satisfaction or performance (Foley et al., 2001), which may include changes in self-image, mood, body image, depression, anger, general identity, and fears of isolation and abandonment (Foley et al., 2001; Sanders et al., 2000).

Very few MS sufferers considered having a chronic illness like MS as a reason to reduce activity or interest in sex (Minderhoud et al., 1984). However, many couples placed sexual activity on hold in order to deal with the chronic symptoms of MS (Koch, Kralik & Eastwood, 2002). McCabe, McDonald, Deeks, Vowels, & Cobain. (1996) found a dramatic decrease in frequency and satisfaction in couples' sexual activity after the onset of MS.

Sexual disturbance constitutes an important aspect of the disease (Minderhoud et al., 1984). Sexual dysfunction was found to be one of the most distressing aspects of having MS to the individual and their family (Zoron et al., 1999). However, Rodger & Calder (1990) found substantial variation in perceived importance of the sexual relationship in a marriage. Their results indicated that individuals who had sexual problems had a tendency to downplay the importance of sex but did not deny it was a problem area. Similarly in another study looking at the impact of MS on couples' sexual relationships, McCabe et al., (1996), found that the majority of their participants did not express concern about their sexual problems. It was thought that individuals with MS accept sexual dysfunction as a symptom of their disorder and feel there is nothing that they can do about it and therefore do not attempt to change the situation. This was also seen as the reason for their low level of sexual activity.

Relationship - Quality

A few researchers have assessed the effect of MS on sexuality and interpersonal relationships (Garden, 1991; MaCabe et al., 1996). In a study by McCabe et al. (1996), one third of respondents reported relationship breakdown or a relationship that grew distant after the onset of MS, one third reported no change and one third reported the relationship became much closer. Rodgers & Calder (1990) found a strong association between marital adjustment and the emotional adjustment of couples impacted by MS. Overall, marital quality of couples affected by MS was significantly less favorable when compared to a normative sample. MS was blamed for marriages that deteriorated post-diagnosis, however, in marriages which were rated as well-adjusted; MS was not considered a contributing factor to that adjustment.

Couples impacted by MS reported that the demonstration of affection was a very important aspect of a relationship, however, this was strongly correlated to sexual activity. Problems in sexuality also showed up in decreased demonstration of affection and intimacy (Rodger & Calder, 1990).

McCabe (2002) found a strong relationship between sexual satisfaction and relationship satisfaction, and in general, couples affected by MS reported decreased sexual and relationship satisfaction.

Partner Often Ignored

It has been established that couples react to disease as a unit (Pakenham, 1998) and the literature consistently emphasizes that the partner must be involved in the evaluation and management of problems due to disability (McCabe et al., 1996). Sexual function and expression frequently relies on the presence and cooperation of a partner

(McCabe et al., 1996). Disability is known to place significant strain on a relationship. Despite all this, partners have been consistently ignored in most of the studies of the impact of MS on couples' sexual relationships. No studies have been done to determine how the partners' sexual desire and responsiveness are affected (Dupont, 1995). In one of the few studies that looked at the impact on couples' sexual relationships, McCabe et al. (1996) only studied the partner with MS and did not gather the views of the non-disabled partner. In studies of marital satisfaction of couples impacted by MS, the non-disabled partners were generally less satisfied with their relationship than the partner with MS (Dupont, 1995).

Caregiver Stress and Role Shift

MS is a disease of adulthood, tending to have its onset in the third and fourth decades of life when individuals are at their peak in terms of educational attainment, career development and family and economic responsibilities (O'Brien, 1993). The progressive nature of the illness and its unpredictable course contributes to a substantial degree of uncertainty in the lives of victims and their families (McCabe, 2002). Individuals with MS experience a decrease in their ability to engage in activities of daily living, and, if in a relationship, the spouse assumes these responsibilities (O'Brien, 1993). Caregivers can experience severe impacts in terms of changing roles, restriction in time, freedom, economic burden, and loss of employment (O'Brien, 1993). Caregiver stress may arise from their unmet needs, disruption of family relationships, need for physical care and supervision of the person with the disability, role conflict, and adverse impact on employment status (O'Brien, 1993). Stress is further increased when there is lack of support (O'Brien, 1993). Women tend to suffer more distress whether they suffer from

MS or as a caregiver. Women tend to assume a greater burden of caring for the needs of others and provide more physical and emotional support to their spouse (Steck, Amster, Küppos & Burgin, 2000). MS has a significant effect on family dynamics. The increased dependence on the spouse for basic personal care can place a huge strain on the relationship.

Relationship - Enhanced

Most of the couples studied reported that MS seemed to strengthen the marital commitment even though problems existed (Rodger & Calder, 1990). McCabe et al. (1996) directly studied the impact MS had on sexuality and relationship using a relationship questionnaire. Their findings indicate that MS was most likely to have a negative impact on sexual function both in terms of decreased frequency and increased dysfunction. However, although most of the couples they studied expressed strong negative emotions regarding their illness, they considered their marital relationship to be a strong source of support (McCabe et al., 1996).

Relationship - Intervention

McCabe et al. (1996) and Dupont (1995) both found that couples affected by MS were less likely to seek advice or assistance, were more likely to express negative emotions and to not communicate their difficulties to their partners. Intervention strategies to promote communication are very important. Individuals with MS and their partners need to feel comfortable discussing sexuality and changes in sexual function with their health care providers. In addition, they may need assistance and encouragement to discuss sexual concerns with each other (Smeltzer & Kelley, 1997). It has been shown that effective healthcare intervention in terms of communication and counseling can greatly improve relationship satisfaction, problem solving, and effective communication in individuals with MS and their partners (Foley et al., 2001). Because there is a strong correlation between emotional health and perceived marital adjustment, the spouse should be included in treatment from time of diagnosis (Rodgers & Calder, 1990). Psychological intervention for couples with MS should include both individuals (Pakenham, 1998).

Summary

Although not extensive, the literature in the area of disability and sexuality as it affects couples provides some key points which can be summarized as follows:

- the impacts may be different on pre- versus post-disability relationships
- the presence of a disability results in stressors including changes in roles and expectations, caregiver burden, and neglect of the non-disabled partners' needs
- in addition to the physical aspects of the sexual relationship, disability also impacts the expression of affection and intimacy
- successful adjustment to disability in a couple's relationship is associated with the ability of both partners to take responsibility for the necessary changes in attitude and acceptance of the disability, and the participation by both partners in activities outside the relationship
- information, education and communication are important components of intervention with couples affected by disability; the PLISITT model is a useful guide for clinicians in this regard

- MS is a degenerative neurological disease which has a negative impact on sexuality activity in terms of frequency and satisfaction as well as overall quality of the relationship for some couples.

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Chapter #3: Methods

To arrive at a method for this study I used the four factors outlined by Depoy and Gitlin (1998), as follows:

Factor 1)	paradigmatic framework – relationship of investigator to that which is being studied (what is the approach or conceptual thinking)
Factor 2)	research problem - question or query (the nature of the research question)
Factor 3)	design type – naturalistic or experimental (what type of data do you need to answer the question)
Factor 4)	practical limitations – money, time, access to research populations.

Paradigm

Before committing to a method, congruence between the project design and the overriding paradigm of the study needs to be ensured. Kuhn was one of the first to discuss paradigms (Kuhn, 1970), describing them as functioning as maps or guides. They tell us the kind of problems or issues that are important to address, the sorts of theories that are acceptable, and the processes that will solve the problems defined. As in other "ways of knowing", paradigmatic knowing imposes its own limitations on what is being studied and what can be known (Pratt, 1993). I understand paradigms as providing a context, matrix, filter or way of perceiving and making sense of phenomena. Kuhn identifies that science and scientific "data" are not absolute fact, but are instead relative to the paradigm and period in which it was described. He also illustrates that paradigms are influenced by history, culture, human nature, etc. (Nielsen, 1990), as Kuhn put it, explanations are grounded in worldview, (Kuhn, 1970).

Given that the intent of the study was to expand the present knowledge base and augment the overall understanding of the impact of disability on couples' sexual relationships, an inductive approach was judged to be appropriate, in that it would allow generalizations to emerge from the enquiry. Below, other considerations regarding the ontology, epistemology and study method are presented, structured after Guba, (1990).

Ontology - the Nature of the Information or Reality

Each individual and couple operates from a unique reality when it comes to sexual relationships. The problems and issues they face in their relationships become routinized within their present reality (Berger & Luckmann, 1966). However, when disability strikes, a couple faces new problems and issues which they may have never considered previously. They do not leave their reality but attempt to incorporate new knowledge and skills required to deal with the problems into their original reality (Berger & Luckmann, 1966). As noted in the literature review in Chapter 2, relationships that began after one individual acquires a disability (post-disability relationships) are very similar to relationships that are not impacted by disability (Crewe & Krause, 1988; Kreuter et al., 1994a; 1994b). However, relationships that started before one partner acquired a disability (pre-disability relationships) tend to be quite adversely impacted in terms of level of satisfaction, quality of life, and increased risk of marital breakdown (Crewe & Krause, 1988; Kreuter et al., 1994a; 1994b). These differences between pre-disability and post-disability couples may be related to the former's inability to deal with the new reality imposed by the disability (Crewe & Krause, 1988). Their previous reality is not able to accommodate the changes and, as such, the couple must embrace a new reality, either together or separately.

Clearly, each couple impacted by disability has different experiences, knowledge and values -- no one reality exists. Each couple has a unique "lived experience". An understanding of the lived experience of couples' sexual relationships impacted by disability is the researcher's objective. A relativist understanding of the multiple realities of these couples was appropriate for this study.

Epistemology - the Nature of the Relationship between the Knower and Known

For this study, a modified objectivist approach in which objectivity remained an ideal and could only be approximated was combined with a subjectivist approach, in which values mediated the inquiry (Guba, 1990). The goal of the researcher was to remain objective. However, sexuality is a highly personal and subjective experience and it was imperative that values mediate inquiry. The researcher was respectful of and responsive to participants' values and sensitivities.

Standpoint epistemology may be useful to gain a fuller understanding of the impact disability has on couples' sexual relationships. It holds "that less powerful members of society have the potential for a more complete view of social reality than others precisely because of their disadvantaged position" (Nielsen, 1990). Although societal attitudes and resources have improved significantly over the years, individuals with disabilities still tend to be in a disadvantaged position. Using Nielsen's (1990) argument, the partner with the disability due to his/her disadvantaged position may be more able to see viewpoints of both partners ("double vision – double consciousness") thus their understanding may be more complete (Nielsen, 1990).

Another epistemological contribution is the concept of "pathos" as a way of knowing. This knowing comes to us through feelings, which are understood to be more than emotions or sensations (Taylor, 1993). As in standpoint epistemology, couples impacted by disability are in a better position to be able to describe their own experience than a researcher not affected by disability. The information gathered from them has greater salience than information from individuals not directly impacted by disability.

Taking into account the relevance of standpoint epistemology and the importance of pathos, a limitation of this study becomes apparent. I have not been directly impacted by a disability and therefore do not have the benefit of "double vision"(Neilsen, 1990) or intuitive feeling (Taylor, 1993) as does someone who is experiencing the phenomenon. To partially compensate for this limitation participants in the study played an active role in all aspects of the study from planning to implementation.

Methods - How the Inquirer Goes About Finding Out the Knowledge

I strongly endorse the view of Palys who states that "methods are vehicles to an end, not an end in themselves. Your research question and research objectives come first, and all else, including the methods you pick to address those questions and objectives follows from there" (1992, p. 2).

Method is based in a paradigm and in the ontological and epistemological assumptions discussed above, for example where along the positivist → constructivist continuum the research is situated. Deductive approaches tend to fall more toward the positivist and post positivist end of the continuum. Inductive approaches tend to be used in the critical theory and constructivist approaches.

Inductive versus deductive approach. To acquire an understanding of the impact of disability on couples' sexual relationships, both deductive and inductive approaches are valuable. Both approaches allow one to describe, explain, and predict phenomena, however cause and effect is usually determined using deductive approaches, while generalizations tend to emerge from using inductive approaches (Depoy & Gitlin, 1998).

In the deductive approach, the researcher formulates a theory and develops some hypotheses to test the theory. If the hypotheses are supported by the results of the research, knowledge is born; if not, the theory may be revised and the process reiterated. In this approach, theories and hypotheses are usually based on some observable reality and the research is focused on quantifying information to determine casual links for the reality observed. This is the approach that has been used in the majority of research on the impact of disability on couples' sexual relationships, establishing that there is an association between disability and higher rate of marital breakdown.

To be loyal to only one approach may prevent one from discovering relevant information (Depoy & Gitlin, 1998). Although the information derived from deductive approaches is valuable, it does not give a complete picture of the impact of disability on couples' sexual relationships. Deductive approaches provide no information on the couples' perceptions of how the disability has affected their sexual relationship, how the couple constructs meaning in their sexual relationship and what they consider to be important factors in their sexual life together. An inductive approach, on the other hand, would facilitate investigation of "the lived experience" of couples affected by disability.

In the inductive approach, data is first gathered and then a theory, descriptions or generalizations are developed based on the data gathered. The topic of sexuality is so broad and multifaceted that research conducted to date has taken place without the benefit of a theoretical framework (Gamel et al., 1993). Using an inductive approach in the current study may contribute to the emergence of a theoretical framework for understanding the impact of disability on couples' sexual relationships.

In applying an inductive approach to studying the impact of disability on couples' sexual relationships, the inquiry framework for this study flowed along a continuum from the post-positivist to the constructivist. Most of the literature reviewed followed a positivist -- primarily deductive -- approach, and focused on quantifying the problems (e.g. divorce rates, frequency of activity). By placing a greater focus on inductive approach, a richer understanding was reached of the experience of couples whose sexual relationship is impacted by disability.

Phenomenology

Phenomenology has been referred to as a paradigm, a philosophy, a perspective or as a synonym for qualitative research (Patton, 1990). According to Creswell "Phenomenological study describes the meaning of the lived experiences for several individuals about a concept or phenomenon". (1998, p. 51)

Accepting that the research objectives should determine the approach (Guba, 1990), a phenomenological approach is the most appropriate for data collection and analysis when attempting to understand the lived experience of couples' sexual relationships impacted by disability. The phenomenological approach is inductive, relying on the participants as "experts on their own sexuality" (Richard, Tepper, Whipple & Komisaruk, 1997).

In the current study a hermeneutic phenomenological approach was applied in the data collection and analysis process. A hermeneutic, dialectic approach was used; that is, an attempt was made to reconstruct the world "at the point it exists: in the minds of the constructor" (Guba, 1990, p.27). As Moules, Simonson, Prins, Angus, & Bell (2004) states, hermeneutics without phenomenology is interpretation without context. Concurrently, hermeneutics adds to phenomenology, in which objects are not fixed or given, they are interpreted. "Interpretation gives phenomenology its alethia" (truth) (Moules et al., 2004, p.7).

Deploy & Gitlin (1998) explain that phenomenology differs from other forms of naturalistic inquiry in that phenomenologists believe meaning can be understood only by those who experience it. They add that phenomenologists do not impose an interpretive framework on data but look for one to emerge from the information they obtain from the informants. Phenomenology helps clarify the participants' inner voices and understand their experiences in the world that surrounds them (Iannone, 1997).

> The method of phenomenology is such that it posits an approach towards research that aims at being presuppositionless; in other words this is a methodology that tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would govern the research project (van Manen, 2001, p.29).

In short, the aim of phenomenology is to "transform lived experience into a textual expression of its essence" (van Mannen, 1997, p.39), where the "essence" may be understood as a true description of the phenomenon.

The Continuum of Phenomenological Research

One way of describing phenomenological study is to locate it on the continuum of philosophies that dictate how the study should be conducted. Caelli (2000) distinguishes between traditional European phenomenology at one end of the continuum, consisting of the philosophies of Husserl and Heidegger, and the American tradition represented by some of the more contemporary researchers at the other end of the continuum.

In the European tradition (Husserlian), it is thought that a person's experience can be examined and that an objective, universal reality can be described (Caeilli, 2000; Lowes & Prowes, 2001). Any preconceptions and beliefs must be acknowledged then put away in a process called reduction (Lowes & Prowes, 2001). Lowes & Prowes (2001) also describe the differences between the philosophies of Husserl and Heidegger, which are generally categorized under the European tradition (Caelli, 2000). According to Husserlian tradition the researcher must acknowledge and then put away any preconceptions, while Heidegger's philosophy holds that the participants' experiences and interpretations can only be understood and interpreted by another being in the world – the researcher (Lowes & Prowes, 2001).

The process of reduction and bracketing is important in the European tradition in order to arrive at an awareness of the researcher's consciousness. The process of reduction involves rediscovering our original awareness of a lived experience through bracketing. "Bracketing involves a researcher exposing his/her presuppositions about the phenomenon under study making them apparent so that the researcher can abstain from them" (Beck, 1994, p. 500). Van Manen, describes reduction as a phenomenological device which permits us to discover the spontaneous "surge of lifeworld" (1997, p.185). Reduction involves several steps as described by van Manen (1997), 1) having a sense of wonder and interest about the topic, 2) need to overcome one's own subjective or private inclinations 3) need to strip away scientific conceptions and thematizations which may overlap the phenomena 4) see through the particular lived experience toward a universal essence.

The more contemporary American tradition does not require researchers to put aside their perceptions and interpretations but rather to include them in data collection and analysis (Caelli, 2000). Other people's experiences and reflections on their experiences are "borrowed" so that the researcher is better able to understand the deeper meaning or significance of an aspect of human experience (van Manen, 1984, as cited in Beck, 1994). In addition, the American tradition does not attempt to describe a universal reality but instead to describe the lived experience of the participants within the context of culture and setting (Caelli, 2000).

Formulating the Phenomenological Research Question

The phenomenological research question must be carefully constructed in order to guide the process of seeing, reflecting and knowing (Moustakes, 1994). "A phenomenological question must not only be made clear, understood but also 'lived' by the researcher" (van Manen, 2001, p. 44). It cannot just be written down but must be a description of what is planned, so it pulls the reader into wondering and questioning what the nature of the phenomena must be (van Manen, 2001). From a phenomenological point of view to do research is to always question the way in which the world is experienced (van Manen, 2001). Phenomenological research begins in the "life world" which is defined as the world of lived experiences (van Manen, 2001).

In summary, after using the four factors suggested by Depoy and Gitlin (1998), the phenomenological research question for the current study was formulated as follows:

The purpose of the study is to understand the lived experience of a couple in terms of their sexuality where one partner has a disability.

Summary Statement of Method

In approaching the proposed research, the use of more than one paradigm is envisaged. Paradigms are understood as both a worldview and a way of knowing (inquiry). My worldview is as an occupational therapist using a human ecology framework to generate knowledge that is of value to both couples whose sexual relationship may be impacted by disability and to front line therapists assisting such couples. My way of knowing falls more toward the constructivist end of the continuum which is subjective and interpretive (Annells, 1996).

To answer my research question, I used a hermeneutic phenomenological approach which I consider to be especially valuable in exploring "the lived experience" of couples affected by disability. It is also consistent with the ontological and epistemological characteristics of the subject under study. Ontologically, reality exists in the form of multiple mental constructions on the part of the couples impacted by disability. Epistomologically, my method was similar to the American approach which is more subjective. An ontological orientation of multiple realities and a subjective epistemology is consistent with hermeneutic phenomenology (Annells, 1996). This approach is both descriptive (phenomenological) which is attentive to and allows things to speak for themselves, and interpretive (hermeneutic) as it claims there are no such things as uninterrupted phenomena (van Manen, 2001). Any apparent contradiction is resolved if one accepts that all phenomena are in someway meaningful (hermeneutically experienced) by someone and are captured through language, which is in itself an interpretive process (van Manen, 2001).

Emic and Etic Approach – Interpretive Paradigm:

I approached this research with the goal of combining both the emic and etic perspectives to achieve a more comprehensive description of the true impact of disability on couples' sexual relationship. McColl (2000) describes how the meaning individuals attribute to their disability impacts their perceptions and motivation in daily activities. Some see disability as a reminder of their humanity, or as a mission, or as punishment or even as a warning (McColl, 2000). The emic perspective contributes the insider's view of how the individual or couple "experiences the disability".

The etic perspective was provided by me, an occupational therapist with several years of experience working with individuals and couples with disabilities. Extensive preparatory work was done in planning for this study, including discussion with stakeholders and an extensive review of pertinent literature.

As suggested by Deploy and Gitlin (1998), the proposed study began with an emic perspective where the focus was on the voices of the participants. Although I have not directly been impacted by a disability, as health care professional I played an important role in integrating the participants' perspective with my own clinical experience and with related information from the literature to present a more comprehensive understanding (the etic perspective).

A hermeneutic phenomenological approach was ideal for gathering data from both the emic and etic perspectives. It allowed the participants to describe their experience (emic) and for emergent themes to be identified from their conversations (Depoy & Gitlin, 1998). Further analysis resulted in a higher integration of the themes (etic perspective) into thematic patterns. A summary of the themes was reviewed by the participants for accuracy and to ensure congruence between the emic and etic perspectives.

Chapter 4

Research Design and Procedures

Accommodating Subjectivity

In experimental design, the purpose of data collection is to learn about an "objective reality" and the investigator is considered separate and removed from that which is known (Deploy & Gitlin, 1998). The data are made more "objective" by the assignment of numerical values which are submitted to statistical procedures to test relationships, hypotheses and descriptors (1998). This applies readily to quantitative research however is difficult to apply and indeed may be unwarranted and invalid when doing qualitative research. Because both an emic and etic perspective was used in the current study research, there was a need for both closeness to and distance from data (Richards, 1998). Closeness maybe defined in several ways, eg. that the researcher either has full knowledge of the data or has access to the data (Richards, 1998).

In qualitative research the researcher focuses on experiences of people in their everyday lives. It is used to understand naturally occurring phenomena in their naturally occurring states (Mayan, 2001). Specifically the goal of phenomenology is to study and describe the essence of the lived human experience where the phenomenologist must attempt to bracket or put aside pre-conceived notions or ideas before collecting data (Mayan, 2001). Berg (1989) describes that many investigators avoid, omit, or obscure their feelings, since emotions are not typically considered capable of independent verification by others. In his view, highly "objectified", nearly sterile methodological accounts of field-work efforts are not complete descriptions of the research. "Mention of researchers' personal feelings are not wholly absent in the research literature, but are relatively rare and are frequently made anecdotally rather than with a substantive purpose in mind" (Johnson, 1975, as cited in Berg, 1989, p. 58)

Our assumptions predispose us to interpret the nature of the phenomenon and thereby to clarify our ideas and assumptions (van Manen, 2001). Similarly, Strauss and Corbin (1998) describe a constant interplay between the researcher and the research act. Because this interplay requires immersion in the data, by the end of the inquiry, the researcher is shaped by the data, just as the data are shaped by the researcher. This does not imply that the researcher has "gone native"; rather, he or she is sensitive and attuned to the issues and problems of the persons or places being investigated (1998). Strauss and Corbin discuss the dilemma faced by the researcher who desires to be both objective in the pursuit of accuracy, and sensitive so as to not miss any of the subtleties. They suggest that a state of complete objectivity was never achievable, and with that awareness, the researcher is in the position to minimize the impact of their subjectivity on data gathering and analysis (Strauss & Corbin, 1998).

The objectivity aspired to by positivists may not be achievable, whereas understanding one's own conceptual baggage may allow one to minimize the negative or unconscious influences one may have on the study. Conceptual baggage is defined by Kirby and McKenna as "the record of the experience and reflections of the researcher that relate to the focus of the research"(1989, p. 49). This is a vital aspect of doing research. It requires a researcher to record their account of the study, as well as their own reflections as they are going through the research.

Keeping a record of one's conceptual baggage also allows the researcher to see if the objectives of the study have started to influence the quality of their participation.

Using a process called layering (writing new ideas over old perspectives) can further assist with this. It can also be done several times over the same material (Kirby & McKenna, 1989).

Alternatively, some hermeneutic scholars and researchers embrace the idea that "truth" is not only not possible but not desirable, that the generative nature of hermeneutics lies not in a claim of accuracy but in the attempt to offer the most believable and useful interpretations and extend knowledge (Moules et al., 2004).

Although I made every attempt to maintain objectivity, my training as an occupational therapist and my clinical experience working directly with individuals affected in a similar way to those in this study cannot help but be reflected to some extent in my interpretations. Therefore I had what Gadamer (1989) would say was a preunderstanding or even prejudice (Heidegger, 1996) when I conducted this study. Consciously and unconsciously, my matrix of training, the experience may have resulted in my perceiving meanings and nuances that might have escaped the notice of a more "naïve" researcher. This background both informed and guided me in my interpretations, allowing me to produce the believable and useful interpretations, which were cross-checked with the participants, step which is generally not taken in pure hermeneutics.

Trustworthiness and Credibility

The primary focus in a study of this type is to gather a comprehensive and truthful representation of the phenomena (Depoy & Gitlin 1998). Several strategies were used to ensure the trustworthiness and credibility in this study. These included a form of triangulation, partial saturation, member checks, peer debriefing, personal reflexivity and audit trail. Although I necessarily entered the study with some preconceived ideas based on my clinical work as an occupational therapist, the use of personal memos and revisiting data in various ways as well as comparing field notes with actual interview transcripts all helped to minimize and at times enhance any influence I may have had on the actual data collected.

True saturation was never achieved nor was it ever a true goal. A constant comparison method was used as part of the procedure for data analysis where each subsequent interview was compared to previous interviews. Each new interview was added to the previous interview until a point was reached at which new themes and categories were not emerging. Also, later interviews were found to fit within the categories and themes already established. At this point I felt that sufficient information had been gathered to give a good representation of the phenomena.

Departing from a pure hermeneutic approach, I contacted each participant and they reviewed a summary of their story as well as the categories and themes that emerged from their story. Participants were also given the opportunity to add to and refine their story to ensure it accurately spoke their lived experience.

Peer debriefing was done at two levels to ensure the analysis completed would be considered to have good "truth value". The first was to review the data and themes and categories with a content expert, a nurse who works clinically with individuals with MS and has conducted studies on sexuality and MS. Debriefing was also done with a colleague who did not know the content area however is considered an expert in qualitative research analysis.

Reflexivity, the practice of self examination (Depoy & Gitlin 1998), was also used during all parts of data collection and analysis. When conducting analysis and interpretation it is important to understand that one is entering into the process with a set of experiences, prejudices and expectations. Moules et al., (2004) describes this process as entering the hermeneutic circle, in which the researcher, understanding their own pre-understanding and prejudices, enters a process of interpretation with a back and forth inter-play which is necessary for this generative process. In an attempt to become more aware of my own perspective and how it might influence my analysis of the data (Depoy & Gitlin, 1998), I maintained a reflexive journal in which I wrote notes during and immediately after all interviews as well as during all phases of the research process. These notes were reviewed for any bias or preconceived notions, emotions and experiences that occurred during the various stages of the study to ensure what is reported is a true representation of the participants' lived experience, not my perceptions of it.

The final strategy used was to adhere to a set route for data collection and analysis. Adherence to a set path allowed me to back track and check various ideas and thoughts. It also allowed me to review and reflect upon my reasoning for decisions I made.

Inclusion and exclusion Criteria

At the onset of the study the initial plan was to recruit volunteer couples in which one partner had been diagnosed with multiple sclerosis for at least 1 year and not more than 10 years, and who were between 18 and 50 years old. The age range and time lines were chosen because of the significant changes associated with sexual function that occur normally as individuals age (Monga & Kerrigan, 1997) as well as to account for the period of adjustment that most individuals require to come to terms with their diagnosis (McNeff, 1997). However due to difficulty in recruiting subjects the age and timelines were widened. Ethics approval was received to broaden the criteria, to include couples in which one partner was diagnosed with multiple sclerosis for at least one year and not more than 20 years, and is between 18 and 60 years of age. In addition, all the initial volunteers were women with MS and their partners. Preliminary analysis revealed some significant gender-related phenomena. It was decided to focus the study on the emergent sample of women with MS and their partner. A future study is envisioned to focus on men with MS and their partners. Later, the data from both studies can be combined to develop a more comprehensive understanding and possibly expanding the theory formation on the impact MS has on couples' sexual relationships.

Participant Recruitment and Selection Procedures

The primary method of recruitment was contact with agencies that commonly deal with individuals with MS. Recruitment information was given to the MS Society of Canada – Edmonton Chapter, the MS clinic at the University of Alberta Hospital, homecare offices, as well as various rehabilitation offices across Alberta.

An article on sexuality and MS was also published in the monthly news letter published by the MS Society. Recruitment information for the study was provided at the end of the article.

The volunteers for the study are referred to as participants rather than subjects, to reflect the active nature of their participation throughout the study. The aim of qualitative sampling was to understand the phenomenon of interest as opposed to quantitative research where the aim is to generalize finding to the population from which the sample was taken (Mayan, 2001). Therefore the task of phenomenological research and writing is to construct a possible interpretation of the nature of a certain human experience. The key is to call upon the experiences of several people as opposed to those of only one person (van Manen, 1997). Generally, the participants in a hermeneutic research study are selected as those who best exemplify the phenomenon under study and offer the richest possible data (Moules et al., 2004). The subjects recruited for this study were volunteers who had a story to tell or felt strongly enough about the topic of sexuality to be willing to participate. The number targeted for this study followed the general trend for a phenomenological study of this type where information is collected using in-depth interviews with as many as ten individuals (Creswell, 1998). Milligan et al. (1998), for example, used a grounded theory approach and eight participants to study women's perspectives on making a commitment to men with spinal cord injury. Vargo (1983) studied ten women using a phenomenological approach with the goal of describing adaptation to disability by wives of men with spinal cord injury. Another study by Richard et al. (1997) also used a phenomenological approach to describe fifteen women's experiences with spinal cord injury, sexuality and relationship issues. Pure hermeneutic inquiry is not validated by the number of participants but by the completeness of the examination of the topic under study and the fullness and depth to which the interpretations increase understanding (Moules et al., 2004). Keeping all of this in mind, I aimed for about 5 – 8 couples with the idea that I would continue until I had achieved the desired fullness and depth. As it turned out, after about five couples I was starting to get a good, in-depth understanding

In total nine couples inquired about the study. Two couples did not meet the inclusion criteria and one couple chose not to participate after reviewing information regarding the study. This left six couples to participate in the study. In each couple the female partner had been diagnosed with MS after the relationship was established and both partners defined themselves as a couple who saw a future together. Table 4.1 illustrates some of the information on the couples. The description is necessarily broad to protect the anonymity of the participants. All the participants were from the Capital Health Region which includes Edmonton and Sherwood Park. All couples were in heterosexual married relationships. The level of impairment was not formally assessed to ensure level of impairment would not interfere with the true goal of the study which was to understand the lived experience of these individuals and not to quantify their stories by attempting to quantify their level of impairment. There were no unique ethnic variation of note.

Table 4.1.

Participant Description

Description	**Range**		**Average**
	Minimum	**Maximum**	
1) Age – female – with MS	32	58	46.1
2) Age – male partner/husband	43	58	49.6
3) # of years in relationship	11	37	25.8
4) # of years married	7	36	21.8
5) # years since diagnosis	6	20	9.1
6) # of year in relationship pre-diagnosis	4	28	15

Ethical Considerations

Recruitment

No participants were directly approached without their consent or initiation. The recruitment procedure allowed the potential participants to initiate the first contact either directly to the principle investigator or though an intermediary such as the MS Society or healthcare professionals at various institutions. Once participants had contacted the principal investigator, information was provided to them about the research project in oral or written format. Exclusion criteria were described, allowing any participant to withdraw without sharing personal information. The participants were free to resign from the study at any point. (See recruitment notice - appendix B and letter of support MS society Edmonton Chapter – appendix C)

Benefits of Participating in the Study

As embodied in the PLISSIT model, having permission to talk about their sexual life in relation to disability can be beneficial, in and of itself. Participation in this study may have facilitated subsequent dialogue within the couple. Putting words to their experiences may have allowed participants to come to a new level of understanding or insight. It may have heightened or clarified their awareness of what is important to them in their relationship. Through asking questions, participants may have accessed resources or information previously unknown to them. Many participants in research studies feel good about having the opportunity to help others.

Risks of Participating in the Study

Some of the same opportunities also presented risks. Discussion of the impact of MS on their intimate life may have forced participants to confront or recall losses and changes that could give rise to emotional distress. Some participants may have felt awkward or uncomfortable talking about such personal issues. Care was taken when debriefing to not compromise the privacy and confidentiality of the content shared by each partner. Nonetheless, there may have been some pressure between the partners to reveal what they said to the researcher that could lead to discord. Old emotional wounds could have been revisited such as childhood or sexual abuse that might require intervention.

If and as indicated, participants were provided with contacts for various agencies as well as professional services for assistance with issues that may have arisen from talking about their experiences with disability (see Appendix D).

Based on the researcher's own experience working with many couples impacted by disability as well as preliminary discussions with several couples, the probability is low that issues requiring intervention arose from engaging in the interview, debriefing session and reviewing the narratives.

Privacy and Confidentiality

The privacy of the participants was ensured with the customary diligence for clinical intervention and FIOPP requirements. Through the informed consent process participants were made aware of how their information and identity would be protected. Participants were informed that any information collected would not be shared with their partner. The researcher undertook to answer any questions with regard to privacy and confidentiality. Once a couple agreed to participate in the project specific personal information and data were gathered. All data collected was assigned a code number to protect the anonymity of subjects. All data was pooled to ensure anonymity. Identifying information was stored in a locked secure location which only the principal investigator has access to. This information will be destroyed after 5 years.

Informed Consent Procedures

An appointment was set up to conduct the interview, and the participants informed the investigator of their decision regarding their choice of location for the interview. Prior to beginning the interview the investigator again provided a detailed description of the entire research process and answered any additional questions.

Consent forms were signed at face-to-face interviews. The Standard Consent Template suggested by the Health Research Ethics Board was adapted for use in the study (see appendix E). In addition to the consent form, participants were given an information sheet (see appendix F). (See letter of ethic approval appendix G)

Pilot Interview

A pilot interview was completed with a couple to assess the quality and relevance of the questions and methods. The couple that participated in the pilot interview was known to the researcher and had contributed to preliminary discussions regarding study design and approach. This couple was not included in the actual study.

Data Collection

Choosing a method is like choosing a language. Like language and other signifying codes, methods structure a certain kind of experience, in this case empirical scientific discourse. Thus a method is a way of talking about reality while at the same time a way of constructing reality (Tseelson, 1991, p. 299).

Semi-structured Interview

The data collection method used for this study was an in-depth semi-structured interview. Interviews were conducted with each partner separately as a means of gathering their individual perspectives. An in-depth interview with both partners was not conducted, so as to avoid forcing either individual to discuss issues they might not want to reveal to their partner. Interviewing as a method of data generation for phenomenological studies has been increasing in popularity (Lowes & Prowse, 2001). The interview approach used can best be described as a conversation structured by a list of prompts (see appendix H) that were used if and as necessary. The objective of the interview was to enter into a conversation with the participants in which they would have the opportunity to share their stories. The role taken by the interviewer was one of a "traveller" as opposed to a "miner" (Kvale, 1996). A **miner** digs and probes to unearth information, some seeking objective facts and others seeking "nuggets" of essential meaning. The miner uses specific tools and strategies to uncover the data. The **traveller** begins a journey that leads to a story to be told on return. The traveller explores many domains and unknown territory (with or without the aide of maps). The traveller may deliberately seek a specific site or just roam freely discovering new and unique things (Kvale, 1996).

For this study the role of the interviewer was primarily as a traveller. The task was to listen and to understand what the participants said and to capture their experience in their words. This was accomplished by entering into a conversation with the participants that had structure and purpose (interview guide). As the researcher and interviewer, my responsibility was to be an attentive listener, not to offer reflection, paraphrasing, interpretations or therapeutic suggestions. Because the goal was to discover the couples' lived experience, this format minimized my influence on what the participants offered as their experience. The conversations varied between fifty-five minutes to two hours in length depending on the comfort and the experiences shared by the participants. All the wives' interviews were longer than their partner's interviews. After each interview the tape recorder was shut off and each participant was given an opportunity to express any concerns and to have them addressed. Participants were also asked if they had any questions or concerns they wish to raise. A list of resources was made available to the participants to access if required.

Recording and Transcription

Before beginning the interview, consent was obtained along with permission to tape-record the interview. During the interview, I made field notes, recording my observations, thoughts and perceptions as well as any emerging themes. Later, I played the tape recording and made additional field notes. I also made note of ideas related to emerging themes and on how the interviews could be improved. I added my own thoughts and feelings to the field notes to ensure that my experiences and understanding did not bias the data collected.

Each interview was transcribed immediately after it was conducted while it was still fresh in my memory in order to ensure that the transcribed data was free of error and accurate (Morse & Field, 1995). Transcription was done by a professional service provider with appropriate attention to confidentiality. After reviewing the transcriptions as well as the field notes, a concise summary of each interview was written.

All material and content from the interviews such as field notes, recorded content, personal information, consent forms etc. have been stored in a secure location accessible only to the primary investigator.

Data Analysis

"The purpose of the qualitative research interview is depicted as the description and interpretations of themes in the subjects' lived world" (Kvale, 1996, p.187). In keeping with the overall methods of the study I used what would best be described as an interpretative thematic analysis. This process was developed by adapting a fourteen-stage approach described by Burnard (1991), as well as a six step guide to analysis as described by Kvale (1996), and a general approach described by Maykut & Morehouse (2001). The new ten stage process (Table 4.2) was used to analyze the transcripts and field-notes. Rather than use one standard method of evaluation, instead a free interplay of techniques was used for the analysis, including condensation, categorization, narrative and interpretation (Kvale, 1996). The data collected from the participants was analyzed in three groups – group one comprised the women participants diagnosed with MS, group two comprised the male partners of the women who had MS, and group three was an amalgamation of all the participants.

Phase one Analysis: (Steps 1-4)

The first phase of analysis involves four stages in which the data is filtered and categorized. During the first phase notes were written immediately after the interviews. After each interview the tape recording was replayed and more notes were made. Memos were also written about ways of categorizing the data (Burnard, 1991). During the second stage, the transcript was reviewed again and put in table format. The transcript was read while listening to the tape recording of the interview to ensure accuracy as well to gain a general "feel" for the interview and a better understanding of some of the larger themes (Beck, 1994; Finlay, 1999). Some quick notes were made using sticky notes as well as in a column on the left side of the interview transcript. In the third stage, each transcript was reviewed again. Detailed notes on general themes and major categories were recorded in the right column of the table. In the fourth stage, the transcripts were read again and as many headings and themes as necessary were written down. Any information that was deemed unrelated to the topic ("fillers") (Burnard, 1991) was crossed out. During this stage, which is referred to as open coding (Burnard, 1991), four basic guidelines described by Berg (1989), were followed. These were: (1) asking the data a specific and consistent set of questions that are related to the research question; (2) analyzing the data minutely; (3) frequently interrupting the coding to write a theoretical note; and (4) never assuming the relevance of any traditional variable until the data shows it to be relevant.

Phase two Analysis: (stages 5-7)

Stages five to seven involved condensing, organizing and integrating the data. In the fifth stage, the headings and themes found in stage three were narrowed down and similar or repetitive ones were removed. During the sixth stage, the remaining headings and themes from stage five were grouped together under categories and higher order headings. For the seventh stage, the transcripts were reviewed again using the categories and higher order headings. Colored highlighters (one color for each category or higher order heading) were used to ensure all aspects of the interview were covered except for the fillers marked off in stage four. Throughout the second phase of analysis a constant comparison method was used in which all data coded were simultaneously compared to each new unit of meaning and then compared to all other units and subsequently grouped (Maykut & Morehouse, 2001). This allows all data to be compared to all categories and themes to eliminate overlap and repetition. Any unit of data that was found not to be related to a previous theme constituted a new category.

Phase three Analysis: (stages 8-10)

Stages eight to ten were used to gain an understanding and meaning from the data. In stage eight a discovery page was developed on which all the categories were listed and the themes that had emerged were grouped under the most related category (Maykut & Morehouse, 2001). Then a short narrative was written, briefly describing the primary themes under each category. During this stage comparisons were made between interviews. By referring back and forth between interviews, general ideas as to the meaning of the data were identified. The written narratives also allowed for the data to be "brought to life". In stage nine these categories and themes were shared with the participants to ensure congruence between what they said (the emic perspective) and what I heard (the etic perspective). Individual participants were also given an overview of the types of categories and themes developed from the data allowing them to confront and refine the data (Guba, 1990).

The goal of my approach was to produce constructions that are as informed as possible. To achieve this, the channels of communications were kept open to ensure substantial consensus on the constructions that were generated (Guba, 1990). In the final stage (ten), the narrative under each category was linked up to and compared with what has already been described in the literature about the impact of disability on couples' sexual relations and how the narrative relates to the research questions. See table 4.2 for summary.

Table 4.2.

Data Analysis Summary

PHASE	STAGE	PROCESS
1 Filtering and categorizing	1	- Notes are written immediately post interview - Memos are written about ways of categorizing data
	2	- Each transcription is read to gain a better understanding of some of the larger themes - Quick notes are made
	3	- Each transcript is read again and detailed notes on general themes and major categories are recorded
	4	Open coding - Transcriptions are read again and as many headings and themes are recorded - Fillers deleted
2 condensing organizing and integrating (constant comparison method employed)	5	- Condensing, organizing and integrating the data - Headings and themes are narrowed down and repetitious ones are removed
	6	- Heading and themes are grouped under higher order headings
	7	- Transcriptions are reviewed again using the categories and higher order headings
3 understanding and meaning	8	- Discovery pages developed - Short narrations briefly describing the primary points are written - Comparisons are made between interviews
	9	- Narratives are shared with participants
	10	- Narratives are linked up to what is found in the literature and how it relates to the research questions

Chapter 5

Research Findings

The ten stage content analysis described in the previous chapter yielded a number of themes, described in detail below.

Group One: Women with MS

The themes that emerged from the interviews of the women with MS were as follows:

1. Communication is the key
2. Patterns of Denial & Acceptance of MS
3. Impact of MS on sexual activity
4. Partner's needs take precedence
5. Impact on established roles
6. Partner's support and love are imporant.

Theme 1: Communication is the Key

All the women who participated in the study felt communication was vital in maintaining and improving their sexual relationship with their partner.

> ***...communication. To me, that is the most sexual thing,...***

> ***Now, the communication, I mean, that's a big part of life, anyway, in any relationship, but I think more so when one of the two has a disability.***

> ***The big thing is the communication. I know at the beginning when I was first diagnosed, I was afraid to talk to [my husband]. I wouldn't. He'd say, "What's the matter?" "Nothing." But I think the biggest part, if you can be open and honest with your partner, it helps everything. It makes you feel more at ease.***

The majority of women experienced their partners' lack of understanding of the impact of MS on their sexual function as a barrier in the relationship. They felt that their partners were unaware of how the MS interfered with their ability to make "a connection" and at the same time there was an expectation that the partner should understand without being told.

> ***I think the biggest thing for me, though, is that my partner still doesn't really understand the impact of the illness on me. He has a very good understanding of the illness itself, but he doesn't really understand why I'm limited with so many different things.***

> ***....it would help if the partner knew more about how it can affect the person with MS.***

Even though all the women felt communication was important, many found it difficult to discuss sexual matters with their partners and were concerned about the reaction their partner might have.

> ***I guess to be honest, I don't always tell my husband that it's not as good as he thinks it is. I just figure, "One of us may as well be having fun!" [laughs] I often think I should probably be more honest with him, but then, on the other hand, I don't really want to spoil things for him.***

Some women reported that at times they were afraid to talk to their husbands. They felt like they had no control in the relationship and if they attempted to gain some control they feared it would lead to conflict. At times all the women held back information feeling it was better for the partner not to know. The women also attempted to deal with things themselves or to suffer through things in silence. Some of the women went so far as avoid intimacy because it might lead to sex which would cause discomfort which they were not able to discuss with their partners. The women at times were at a loss for how to enhance communication with their partner. Others felt that the effort was not worth making because they believed nothing would change whether communication took place or not.

> ***I didn't really want to talk about it. I held everything inside, and that didn't really help things....And really trying to communicate with my partner as to what's happening. That can be a big challenge.***

> ***I don't tell my husband everything about what I'm feeling at that particular time because I don't want him to worry, I don't want him to feel bad.***

> *I find it hard sometimes to discuss things, especially things that we get into feelings, without him getting angry. Then I shut right down; I don't want to talk any more.*

> *No, not really; I don't feel guilty about it, I just feel that [pause] I feel sometimes that I should be more honest; then I think, "Why should I?" because he can't do anything about it.*

Theme 2: Patterns of Denial & Acceptance of MS

Initially when recently diagnosed, all the women had attempted to maintain the status quo and described this as a form of denial.

> *When you're in denial and you have a burst of energy and you think that you're as normal as everybody else, and you think you can do the housework, the cooking, the cleaning, the working, and go to the party, and come home and have a really good night, you're sadly mistaken.*

However, over time many of the women described coming to a level of acceptance that they were not able to do the same things as they had done previously. All the participants with MS expressed the need to accept the disease.

> *Admitting that I have MS is the biggest thing.*

> ***Be prepared for changes. Don't expect to be the same. Be prepared for what's coming or what you're experiencing. It's normal, it's okay, it's part of it. It'll all be fine.***
>
> ***I don't try to convince myself I'm Wonder Woman and I can do everything, because I can't.***

The degenerative course and unpredictable symptoms of MS symptoms made the disease harder for the women to deal with and accept.

> ***I think the hardest part is the not knowing — not knowing where things were going to lead and not knowing the changes that would happen.***
>
> ***But there are still times where, emotionally, it's difficult, because you want to be able to experience what you've experienced before, and you don't know; you don't know until you get into the moment whether it is going to be a good experience or not. I find that very difficult.***
>
> ***That's very much true for me, too, because even though you may want to have it end up with intercourse, at the same time, there's that resistance because you know that it may or may not cause pain and it may or may not be pleasurable. So that's always that hesitancy.***

Universally, the women defied MS to affect their lives. There were two patterns to their defiance: one was to attempt to maintain the status quo and to set even higher personal expectations and standards; the other pattern was to try new strategies to overcome the limitations they faced from their disability. Either way, although the women accepted the fact that they were not the same, there was a resistance to change because they were unwilling to let the disease get the better of them. Although all the women described elements of both patterns of defiance, half the women strove to maintain the status quo. They described accepting the MS, however they would not allow the disease to control them.

> ***Well, I guess I try to ignore it as much as I can...I try as much as I can to live as I always have lived.***

These women also described setting high personal standards in order to meet their own expectations as well as their perception of others' expectations of them.

> ***But in my mind, it's like, No!, because I can't function like a normal person, or — not a normal person; a person without MS — 'cause I am a normal person. But it's like, No!; I've got to prove to myself and to [my husband] that, yes, I can still do all that.***

Typically, they sacrificed other aspects of their lives or lived with increased symptoms and discomfort just to defy the disease. They reported knowing the consequences but pushing themselves nonetheless, at times to the point where their partners had to step in and tell them to slow down. Acknowledging the fact that they have a disability, many have realized that they can not do everything they used to but still continue as best as they can to keep things as "normal" as possible. At the same time all of the women realize intellectually that things had changed and they were not the same functionally that they were before their diagnosis.

> ***Yeah, but I don't think I would have ever admitted either that it was probably the MS and not feeling good and being overtired. I never would have admitted that before; now I can admit that.***

The second pattern of defiance described by all the women as important but not universally implemented was a willingness to try new things to overcome limitations imposed by their disability. The key element they described was being open and trusting of their partner.

> ***So it's like you have to get to the point within yourself that you can accept who you are and be willing to open up and even — like, [my husband] used to say, "Show me what you want me to do." "Oh, yuck, no." Now, it's like, "Okay, fine, I'll show what I want you to do," because it changes every time. What might have worked the last time won't work the next time. So being very open really helps.***

These women also described the need to experiment and to rediscover their bodies. Because of all the changes in their bodies from the MS, what may have been pleasurable in the past may now be uncomfortable.

> ***.... [laughs] you have to experiment more, you have to figure out what works for you,...***

Getting to the point of open experimentation with their partners was very difficult for the women who took this route. Several women described arriving at a precipice where they had to do something or their relationship would end. Attempting to do things the way they used to was not working. For many women it meant stepping outside the values they had maintained with respect to sexual behavior and activities. Sexual activities that they may previously have felt were outside their realm of acceptable behavior were now something they were willing to consider and experiment with.

> ***Yeah, different positions, toys, oral sex — I wasn't into that before. It's, like, "Ew, no." Now, it's like, "Okay!" I've finally accepted what my body is changed to, and it is definitely more fun.***

> ***But taking the time to experiment and be — I can't stress that enough — being open, not being afraid, and not — 'cause I know I did it! [laughs] — you feel like "Oh, my God, if I tell him that, he'll think I'm just disgusting," or if I say, "Don't do that; that hurts," he's going to not want to be with me. I think once you accept everything, be honest, open, say, "No, that doesn't feel good. Wait — we need more greasy stuff," then it all kind of comes together.***

All the women who took this route reported that their sex life not only improved but became better then before they were diagnosed.

Theme 3: Impact of MS on Sexual Activity

All the women in the study described that MS has had a negative impact on their sexual activity, including specific problems with physiological and physical functioning as well as changes in the overall quality and quantity of sexual activity. They are not having sex as often as they used to and the quality had changed. The most frequently identified problems were fatigue, sensory changes, and a reduction in the intensity of their sexual response, i.e. level of arousal, as well as their general sexual response including less intense orgasm.

> ***....I just don't have really good orgasms [laughs] any more. It's not that I don't ever have them, but they're not — they're just not as good as they used to be.***
>
> ***Number one, I don't think we have sex as often as we used to, and it's probably more to do with me [laughs] than it is with my husband. I definitely have reduced sensation, and you don't really look forward to it as much. I don't know; ....but I think my husband would probably like me to be a little bit more forward when it comes to sex and initiate it, but it's kind of hard sometimes when you don't [laughs] —you can't look forward to it being as good as it used to be.***
>
> ***I guess one of the things when it comes to physical problems, that is that the MS has caused either a lack of sensation or change of sensation. So things that were pleasurable before may be painful now, and that's hard***

> ***on me because [pause] it's hard for me because I don't get the same pleasure from sexual encounters as I once did.***
>
> ***Part of it, as I said earlier, is change in sensation; the fatigue level. I don't think either of us were ever prepared for the changes that it would bring. I think, too, that there was very little, though — that was something that wasn't talked about, and a lot of it has been trial by fire, I guess you could say.***

Fatigue was the most frequently reported barrier to sexual activity. Most of the women reported that fatigue would prevent them from initiating or responding positively to sexual advances by their partners. In addition, they had decreased endurance which prevented them from sustaining sexual activity for the same duration or intensity that they were used to in the past.

> ***...but I just never had the energy to really act on it, because if I had an option of that or sleeping, I would probably — I would definitely take the sleeping over the two.***
>
> ***I would fight with [my husband] all the time, and say, "You're going to find someone else, someone that can be more awake," because at the beginning, that was the biggest problem, to stay awake. "Do you want to do anything?" "Sorry, honey, I'm sleeping."***

> ***I don't feel that my sex drive has decreased, or my desire to be intimate with my partner emotionally as well has decreased, but my ability to sustain that has, because it just takes so much out of me, and then I'm so exhausted after the fact. So I'm not able to keep it ongoing for a long period of time.***

> ***I think it has impacted our sexual relationship in the sense that I find that, especially when I'm close to having an exacerbation, I'm not getting as much enjoyment out of having sex as well. With all of the fatigue and other issues — the hidden issues, I call them, because they're not visible to my partner — I think it sometimes will interfere as well, too, with us making an emotional connection as well***

Although the women understood that they could overcome the fatigue barrier by engaging in sexual activity earlier in the day, they were faced with scheduling problems and the interference of other roles and responsibilities.

> ***And then fatigue is part of the MS. Part of it is just sort of the daily lifestyle and not being able to — by 10 o'clock at night, there isn't a hope, some days, that I can do anything. But with my husband, he's got an 8:00 to 5:00 job, he's gone by 7:00 in the morning and doesn't usually get home till 7:00 at night, so we get kind of caught up in a tangle that way, as well, where you just don't have the same opportunity. I found if we get an opportunity to go away for a weekend or something,***

> ***that works out a lot better for us, because we can curl up and watch TV, and things go where they go, and that seems to be okay for both of us.***

Some of the women are hesitant to engage in sexual activities because it aggravates some of their MS symptoms, or makes them too tired to do other things.

> ***... after making love, lots of times, too, I get worse***

> ***Everything, for me, basically, has to be timed. I mean, not to that degree, but if I know I'm going to a party, I know I have the next day off. So I don't go to very many parties, so I don't have a huge social life.***

Aside from affecting specific sexual activities and behaviors, the MS was also reported to influence many of the related social activities that the women participated in before they were diagnosed. Fatigue and other barriers (some self imposed – avoiding – knowing better) caused a change in the frequency of activities they previously found enjoyable. These activities were also felt to be important in maintaining and enhancing the emotional bond between the couple and setting the frame of mind (mood) for sexual activity.

Many of the women acknowledged the negative impact that MS had on their sex lives and were quite regretful of the impact.

> ***But the fact remains that we are having sex less frequently, and that has impacted me not only physically, but emotionally as well, too. Because***

> ***for me, having sex makes me feel that I'm being loved and I'm nurtured and I'm important and so forth.***

Given the choice they would definitely consider making changes however some reported feeling lost and not sure where or how to begin to make things better.

Theme 4: Partner's Needs Take Predence

The women all reported that although sexuality was not as pressing an issue for them as other barriers imposed by their disability, sexuality took increased precedence by virtue of the fact that they are in a relationship.

Within the context of the relationship, sex was reported as an important component of their lives. The effects of MS on their sexuality had a definite impact on their quality of life and self-esteem. They felt guilty about not being able to engage in their usual range of sexual activities, or for not wanting to have sex. One woman felt that sex was part of her obligation in a relationship.

> ***I just felt really guilty, I think is what it is. I felt guilty as well, because I knew that it had been a long time.***

> ***For me, I know that just hugging and holding and kissing and just having it go no further than that, but just having that contact is more than enough. But on the other hand, I know that's not always enough for my husband, so there's always that constant tension when it comes to the relationship.***

All the women in some way reported that their partner's sexual needs were more important then their own. Half the women went further describing how they forced themselves to have sex to meet their partner's needs fearing that they may lose their partner if they didn't.

> ***I'm not even so much worried about my satisfaction or my pleasure, but I gain satisfaction knowing that he's been satisfied, both emotionally and physically,***

> ***My husband's needs are more important than mine.***

> ***....you were meeting your husband's needs as opposed to your own.***

> ***But I thought, "No, I will do whatever it takes, even if I just have to kind of lay there and pretend." The fear of losing everything, it didn't make it fun.***

Some also felt they were less of a sexual being, They questioned their desirability and their ability to perform sexually compared to pre-diagnosis.

> ***And then sometimes you just can't be what they want you to be, right? I couldn't; I didn't feel sexual.***

> ***The emotional part of it, not feeling like a total woman, that is the hardest part to go through.***

[pause] Yeah. Yeah. Sex out of fear. Or even guilt, too, because you don't feel like — well, at least I didn't — that you're living up to what you used to be. 'Cause I felt like less of a human being.

I would try so hard, whether I felt like doing anything or not. I was terrified of losing him. I thought, "Oh, no, I don't care. If it's going to kill me, I don't care. I'm keeping him."

I think that one of the reasons that I do as much as I do for (husband) as well too and want to make sure that he's happy and satisfied is umm fear of abandonment as well too umm cause I don't want him to leave me.

Theme 5: Impact on Established Roles.

Although the semi-structured interview questions focused on the couple's sexual relationship, interestingly most of the participants linked that to other roles in the relationship. All the women with MS attempted to maintain the same roles as before their diagnosis and in all cases their male partners were willing and did take on some of the household and caregiving responsibilities when the MS symptoms worsened or when there was a relapse or exacerbation.

He has also had to take on very much a caregiver role at times.

> ***When I was first diagnosed, every time I'd relapse, he had to assume both roles, mother and father, because I couldn't do anything. A lot of pressure was put on him, I think. Now that I'm starting to feel a little bit more [pause] no, no, not normal — a little better — I always say "normal" and I shouldn't. So now it's going back to the Dad role, the Mom role, the husband role, the wife role,...***

> ***... I'm still fairly independent, but not always. When I've had exacerbations and that, there's been times where he's had to brush my teeth, he's had to comb my hair, 'cause my arms got to the point where I couldn't use them. That was very difficult. He had to learn to give me injections; he had to learn to catheter.***

Although the women accepted that they were not able to fulfil some of their responsibilities, most of them felt guilty and did not like having to burden their husbands with tasks and roles that were once theirs. Many of the women questioned their self worth in the context of these role changes.

> ***...because of my health and in case I end up not being able to satisfy him to say that I [with]drew more emotionally that at least ... he won't leave me because I can I overcompensate in other areas, such as you know taking care of him, doing laundry, cooking, and stuff. So there's a big fear of failure and abandonment that he's going to leave me.***

> ***My husband does take on some extra things when I'm not feeling well, which he is really good about doing. He doesn't question things, he doesn't always expect supper on the table, and so forth. But it makes me feel that "What's wrong with me, because I should be taking care of him in that role, and why is he having to take care of himself?" Like, it gives me pleasure to be able to do things for him, even though I bitch and complain about it otherwise. [laughs]***

When asked about changes in their sexual role behaviour, the majority of women reported that things remained the same. One woman discovered that disturbing their established roles in sexual activity caused more conflict so she reverted to how they had always proceeded.

> ***He likes to be the boss, ... I often find if I do initiate and he's not in the mood, then I feel rejected, and then I begin to [pause] what's the word I'm looking for? Over [pause] build it up and make a mountain out of a molehill in terms of "He doesn't love me, he doesn't care about me, he doesn't find me attractive," and so forth ..... So I just don't initiate any more.***

Theme 6: Partner's Support and Love are Important

All the female participants stated that the most important factor facilitating their adjustment to life with MS and to continue having a sexual relationship was the love and support of their partner. For these women to feel confident enough to begin redefining sexuality and how they see themselves they needed to trust their partners.

> ***Well, I think for me [it] has been that my husband has been able to be so supportive all the way around, whether it's to do with [sighs] with the sexual relationship where I'm not able to meet the same standards.***

> ***First of all, I guess the biggest thing if you talk about sexuality to me is also talking about love and commitment***

> ***...he tries to boost me up in every way.***

> ***We have a very, very good relationship. There's, I think, a hundred percent, or very close to a hundred percent, trust. Yeah, I love him to bits, and I think the feeling is — I know the feeling is mutual. He's my best supporter.***

> ***The most helpful? [pause]...... Sexually, I guess it's my husband's understanding.***

Although the love and support of their partner was key to maintaining the relationship, sex was identified as important in maintaining the bond and intimacy with their partner. Sex was viewed as more than just a physical act but as an expression of love and intimacy between the couple.

> ***We just seem to always get along better when we have sex. Like most people, you just feel closer.***

> ***...it's important to have a physical act occur, because it allows me to renew the emotional bond I have with my partner.***

> ***I think because emotionally, it's better. I think it's the emotional end that makes it better.***

> ***I think even if you don't do anything, even if you just lay in bed together and just hold each other, the intimacy part, knowing that you're loved.***

Group two: Male partners of women with MS

The themes that emerged from the interviews of the male partners of the women with MS were as follows:

1. Communication is the key
2. No perceived impact of MS on partner's sexual activity
3. Impact on establish roles
4. Intimacy and closeness are more important than sex
5. Partner's emotional response to MS is the problem

Theme 1: Communication is the Key

The male partners of women with MS also felt that communication was a key component in their relationship. For the majority of these men increased communication did not come easily. Often it took frustration and open conflict to force them into talking about things. For the men, the primary goal of communication was to understand what their female partners with MS were experiencing.

> ***The biggest one is for the spouse to understand what the other one — the one with the disease — is going through. If they don't have an understanding of that, they can't understand.***

The men found that having to cope with their partner's MS also resulted in more open and exploratory communication with them.

> ***Basically, just our own communication and testing to see what's acceptable and what's not acceptable, and trying to think — trying different kinds of things to see if that would work.***

> ***The communication part, we do talk more in detail about different things than we did before.***

Theme 2: No Perceived Impact of MS on Partner's Sexual Activity

In this study the majority of the male partners of women with MS did not know or understand how or if the MS had affected their partners' sexual response. In their eyes their partner's sexual functioning had not been affected. Even when asked directly most of the men felt that MS had not affected their partner's sexual response in any significant manner except for decreased frequency due to their fatigue.

> ***I can't honestly see any effect that it's had on her. She seems to be quote, "normal," unquote, as far as I'm aware, as far as I've observed in terms of her sexual response or things of that nature.***
>
> ***[pause] I don't know; maybe fatigue, it could very well — maybe it has. I mean, come the end of the day, she's finished; doesn't matter what happens; there's no night-time activity. Maybe that's the one thing that has changed; we just don't get very amorous or anything.***
>
> ***We have sex maybe once a month — if. Maybe, maybe on a good month, maybe three times, but that's about it. It might be once every two months depending on how it's going.***
>
> ***I don't think — things haven't changed, I don't think. I don't think they've changed.***

[Question: Do you think the MS has affected your wife in any way to how she responds sexually?] [pause] Not at this time, not that I can [pause] no, I don't think so.

The men did perceive that their partner's MS had impacted other aspects of their lives together, if not the sexual aspects.

— but the problem — and I italicize "problem" — is that she hasn't really been affected much by the MS, as far as I'm able to see, other than the heightened sense of emotionality and the reduced level of physical activity,

So when you look at sexuality, look at the whole issue of what's happening, not just that part, 'cause it's all tied together, and if one part's not in tune, you're in the wrong direction.

About half the men felt that having to deal with their partners' MS may have actually improved their sexual relationship. For one participant it allowed him to gain a greater respect for his partner because of the way in which she dealt with her disability.

— I look at [my wife] and say, "You're really a great lady. [laughs] I'm a pretty

> ***lucky guy to have got — to be with you." Because — just because of the way she's been able to deal with this and some of her other problems, too. [sighs] She works harder, and I think that's probably what it's done for her.***

Those who reported a positive impact of the MS felt it had improved their communication and strengthened the relationship.

> ***In our case, yeah. It's made us communicate more, and to try and delve deeper into understanding what's going on, so it's made us closer together, I think, in a lot of cases. I think if it had been a normal relationship, and things turned out, we might have parted our ways, but it's made us a little more committed to each other.***

> ***On the sexuality end of it, she's lost probably all the sensations from about the waist down, so we've had to learn different techniques to figure out those kinds of things. The last 3 years, it's been more of a touch, feel, talk kind of thing, rather than the actual physical doing it kind of process. So that way, it's probably deepened it, the relationship.***

> ***Positive effects? [pause] Yeah, sometimes we work together a little bit more, I think, because of the MS. I think I'm a little bit more understanding; I can attribute some of the things to her MS.***

Theme 3: Impact on Established roles

Similar to their female partners with MS, the men in this study saw their sexual relationship in the context of other roles in the relationship. The majority of these male partners reported taking on more of the household work when the MS symptoms were worse. Blurring of the traditional roles was not a significant issue for the men, rather, it was just part of dealing with the situation of having a partner with MS.

> ***It changed when she has [pause] I wouldn't say "attacks," but when — yeah, I guess it has, because I clean the house more often, and I try and get things ready for her when she comes home. If I'm home.***

> ***Yeah. I [garbled] the home. She does some stuff, too, but I do the majority of the cooking, the majority of the cleaning, those kind of things; the grocery shopping,***

Theme 4: Intimacy and Closeness are More Important than Sex

For the majority of the men in this study the intimacy and closeness of sexual contact was more important than the physical act or frequency of sexual relations with their partner. Having a strong bond with their partner was more important.

> ***No, no, really, it's not the amount. In our relationship, it's really the closeness and an understanding between the two of us. Like my best friend; really, she's my best friend. So I guess it's the closeness. There really isn't a day that we're not together that we don't hug or kiss.***

> *[Question - What's the most important thing when it comes to your sexual relationship?] Having physical contact as far as touch, feel, more than the other (sex).*

> *For the most part, being happy with one another. I mean, the rest all falls together. If she's happy, I'm happy, however we work it out, however it happens, kind of thing, as long as it's something that we're both doing together, kind of thing.*

Theme 5: Partner's Emotional Response to MS is the Problem

The majority of male participants reported that their partner's emotional reactions were far more difficult to deal with than the physical limitations of MS. Many of the men voiced their frustration at the seeming irrationality of their females partners' attempt to be "miss perfect" when it was not expected of them.

> *Mentally, the way it made her feel. Like I said, it's on her brain all the time and everything else. If something happens, she attributes it to the MS or whatever. She feels that she can't do something with the kids or whatever, that she can't move or whatever, it's just everything just kind of triggers and then she starts feeling sorry for herself kind of thing. Then that comes back in an argument kind of thing, that I'm not doing my part or whatever.*

> ***Well [pause] not real conflict, but I just say, "Start taking care of" — like, fatigue is the number one symptom, and she's tired lots of time, then I say, "Take it easy. Don't try to take everything on, everybody's problem. Do you have to be perfect on everything? You don't."***

The men felt that their partners were trying to be "superwoman", sometimes at the expense of taking care of themselves. The mens' complaints fell into two categories 1) their partner was working too hard and not resting; 2) their partner does not take care of herself, (eg. not eating right or taking medications as prescribed).

> ***Well [long pause] we have arguments — not arguments, disagreements — that she works too hard and always puts too much on herself all the time — well, that's my opinion — and try to slow down a bit, and take care of yourself instead of worrying about everybody else. Stop worrying about everybody else and start worrying about yourself, make yourself important every once in a while instead of everybody else.***

> ***Oh, yeah, absolutely. I have to constantly remind her that when she's tired, it's time to go to bed, and not to overtax herself. She's hard headed.***

> ***What causes me the most grief is her — maybe she's in denial, but is her inability or unwillingness to do anything about it (the MS).***

> ***Part of it is I think it's got a lot to do with her acceptance of what's happening. Don't get me wrong; I mean I still get ticked off here when she's not doing what she's supposed to be doing. Like, her diet's off, and sometimes suppers around here aren't exactly what you'd call a nutritious supper, but they're still supper. So when she's not eating right, that's when I get ticked. I don't think that answers your question.***

Some of the men reported a perception of their partners as more emotionally needy with respect to having sex, the inference being that they needed to feel reassured that they were still loved.

> ***...but from the emotional point of view, it's almost like, if there's an absence of sex for any period of time, the emotional discourse — her edginess, her moodiness — seems to increase. It's almost like, when the sex act takes place, it's almost like a relief for her, and her emotional level tends to drop back. Then it builds again, and it seems to have that cycle to it.***

> ***I think it's affecting her ability to control her emotions, so she over-emphasizes, over-responds, I guess, when she doesn't get things that she thinks she needs. For example, if she doesn't get sex in a timely manner, she draws adverse inferences from that because of her heightened sense of emotionality; like, because she's not getting sex, she's not being***

> ***loved. So I think that's a major response that MS might have incurred on sexuality, but it's an indirect one.***

Group three: All Participants

The common themes that emerged from the interviews of both the females with MS and and their male partners were as follows:

1. Communication is the key
2. Impact of MS on sexual activity
3. Impact on established roles.

Common theme #1: Communication is the Key

All the participants identified communication as the key to ensuring their relationship survived the diagnosis of MS. In one sense, their communication needs dovetailed nicely: the men wanted information so that they could understand what their partner was experiencing, and the women with MS wanted to be understood by their male partners. There was a tendency for the men to want communication for the purpose of acquiring information about how MS was affecting their partner, whereas for the women communication fulfilled more of an emotional need.

> ***I think they need to talk to the partner who doesn't have the MS; in a lot of cases, it's the male, and explain to them what kinds of things are really happening, and that it's not — you hear that that will happen, but it doesn't necessarily have to. Just sort of what might happen and how to prepare for it. For the male.***

> ***Oh, yeah, drastically. Like I said, the whole mental part of it and everything else, just the conversations we have and everything else. We used to have all kinds of arguments about lots of things; it was part and partial [sic] to do with me not understanding what she was going through. Sometimes way back then, I thought, "Okay, you're just being lazy or whatever. Why don't you not walk with that limp? It looks like you're trying to attract attention to yourself or something." Things like that. Not knowing how much it does affect the body and things like that.***

Both the men and the women knew that they needed to "talk" but many did not know how to start or were afraid to open the discussion. Although all the couples acknowledged the importance of communication, not all had been able to positively communicate with their partners. For some couples conflict was required to precipitate a dialogue and there was a sense that they wished they could just deal directly with the issues as opposed to being forced to through to conflict. The couples who described being able to openly discuss the impact the MS had on their relationship and sexuality actually reported their relationship had improved to the point where it was better than before the diagnosis.

Common theme #2: Impact of MS on Sexual Activity

The men and women in this study had significantly different perspectives on how MS had impacted their sexual relationship, although they both identified that they were having sex less frequently. The reasons for the reduction in frequency were different for the men than for their female partners with MS, with the only rationale in common being fatigue caused by the MS.

Common theme #3: Impact on Established Roles

Both the men and the women reported that MS did affect their established roles in the relationship when it came to home management and maintaining the daily routines. They all reported that the men took on many of the women's responsibilities when their MS became worse, although the women and men diverged substantially in their attitudes to this shift in role responsibilities. The men were less concerned than the women about maintaining their traditional, pre-diagnosis roles, whereas the women felt guilty, obligated or fearful of being abandoned if they did not fulfil their pre-diagnosis role in homemaking and caretaking. When directly questioned about roles in their sexual role behaviour all participants reported no change in their established roles.

Chapter 6

Discussion and Conclusion

The Lived Experience: Two Solitudes

The purpose of this study was to understand the lived experience of couples with respect to how MS has affected their sexual relationship in order to assist clinicians to work with these couples more effectively and provide some insight for the couples themselves.

Inevitably, stereotypes will fill in the gaps in a clinician's understanding of sexual issues. The results of the current study both uphold and negate some of the common stereotypes.

The impact of MS on their sexual relations was primarily an emotional issue for the women with MS, whereas it was largely a practical issue for the men who were their partners. Indeed, some of the men were more frustrated with their partner's emotional response to their MS, than with its actual impact on their sexual life.

The women with MS in this study live in a world of uncertainty because of the unpredictable course of their disease. They expressed a range of conflicting feelings such as: "MS has made me weaker" versus "it has made me stronger"; "it has made me more dependent" versus "I've had to become more independent"; "I don't like who I've become" versus "I like who I am"; "I am abnormal" versus "I am still normal"; "I need to talk about it versus "I cannot talk about it".

To a greater or lesser extent, having MS has raised doubts in some of the women in this study about their worthiness, attractiveness, and identity and they have adopted corresponding defenses to maintain their self-esteem or sense of security in the face of these doubts. One common defense was to attempt to maintain the status quo in all their roles, until the fatigue or other symptoms overwhelmed them. Another was defiance of the disease, refusing to let it change their life. Guilt or fear (of abandonment) motivated some of the women to have intercourse with their partners in spite of discomfort or fatigue. Thus, the outward behaviour and appearance of women with MS in this study did not necessarily reflect their inner state.

In this study, the male partners of the women with MS tended to respond with pragmatism, approaching the effects of MS more as an inconvenience, just something to be dealt with. Their strategy was to continue to fulfill their responsibilities and commitments. A common theme among the men was frustration that their partner with MS was not doing more to take care of herself. The men found it irrational that their women partners with MS had such unrealistic expectations of themselves and consequently made mountains out of molehills, emotionally. Many men felt that the women just needed to relax and move on. Universally, the men did not perceive much of an impact on their sexual relationship or on their partner's sexuality.

It appears, therefore, that the women with MS were quite successful in their efforts to buffer their partners from the full impact of the disease. In this context it is not hard to understand how a communication gap could easily arise, and thus potentiate feelings of isolation and being misunderstood in the women and frustration or bewilderment in the men.

The emotional - practical dichotomy may be partially gender-based, but may also reflect the fact that the impact of a disability is felt more personally and keenly by the individual affected, which in this study were all women.

The men and women who participated in this study all instinctively constructed meaning in the sexual relationship in terms of their life as a whole. Although the interview questions focused exclusively on their sexual relationship, both the men and the women framed their responses in the context of their other roles within the relationship, in particular their effort to maintain their established roles despite the MS. Always the pragmatists, the men willingly assumed some or all of the traditional role tasks of their partner when the woman's condition worsened or they were experiencing an exacerbation. Conversely, the women tended to experience these changes in roles as a personal failing or a threat to their identity, which in turn affected their self-perception as a desirable or worthy sexual partner.

Interestingly, among some of the women it was only in the context of having a man in their lives that the impact of MS on their sexuality was a pressing issue. Had they been single, their sexuality would not have been as much a concern to them. The fact that they were in a relationship made sex an important component of their lives and was reported to have a real impact on their quality of life and self esteem.

All participants felt that sexuality was a critical component in maintaining their relationship. The love and support of their partner was identified by the women as one of the most important factors in allowing them to deal with their MS and continue being a sexual individual. Without that support they would probably avoid sexual activity. The majority of the men in the study felt that the intimacy and closeness of sexual contact was far more important than the physical act, the specific sexual activities, or frequency.

For a variety of reasons all the participants in this study felt sexuality was a very important component of their relationship. The is consistent with a study conducted by

Taleporos & McCabe, 2001 where their clearest findings was that individuals with disabilities had a strong interest in and a desire for sexual expression – this is very important to them.

Sexual Dysfunction in Multiple Sclerosis

All the women in the study reported some changes in their sexual lives. This is consistent with studies which indicate that fifty to ninety percent of individuals with MS report changes in their sex lives after the onset of symptoms. (Barak et al., 1999; Zivadinov et al., 1999).

The experiences shared by the women in this study encompass all three levels of sexual dysfunction described by Foley et al. (2001). These levels are: primary (neurological impairment that directly affects sexual response); secondary (non-sexual physical changes which may affect sexual response such as fatigue); and tertiary (psychosocial and cultural issues that may interfere with sexual satisfaction or performance).

The most common primary sexual dysfunction described by the women in this study was decreased or altered genital sensation (including numbness, pain, burning or general discomfort), decreased libido, decreased physical response in terms of vaginal lubrication and decreased intensity of orgasm. A common cause of secondary sexual dysfunction was fatigue, as well as specific functional limitations unique to each woman such as bowel and bladder function, movement and mobility and cognitive and emotional changes. Tertiary sexual dysfunction arose from fear of abandonment, questioning their desirability, and self esteem and body image issues.

Similar to other studies (Koch, et al., 2002; Minderhoud et al., 1984), the participants in this study did not feel that MS should be a reason to reduce activity or interest in sex; also consistent with the literature was a reported decrease in frequency and satisfaction of sexual activity post-onset of MS symptoms (Gagliardi, 2003; McCabe et al., 1996; McCabe, 2002).

Coping with MS as a Couple

The couples were not very articulate when asked directly about what strategies they used to cope with MS in their sexual relationship. However they universally spoke of communication and coming to terms with having a chronic disease like MS as very important in dealing with their life together, post-diagnosis. Although the men and women approached communication differently, they all felt that it was a vital element to being able to cope with the MS and improving their sexual relationship.

Although accepting their diagnosis was identified as critical by all the women participants in this study, many also reported resistance to doing so, going through such defensive strategies as maintaining the status quo or setting higher standards thereby refusing to allow the disease to control them. There was a sense that the unpredictable nature of MS made the disease harder to deal with and accept because they could not be sure what to expect or how their bodies would respond.

Communication is the Key

The objective of this study was to describe the lived experience of couples where one partner was diagnosed with MS re: sexual relationship. No attempt was made to develop any theories or causal links however a clear link between communication and overall view of sexuality was found.

Even though the consensus was that communication was important, the majority of the participants also reported that increased communication did not come easily. Some were not able to fully open up with their partner for various reasons, others were at a loss as to how to begin, some felt it would not change anything so why bother, and for many communication was a last resort when conflict and frustration brought matters to the breaking point.

Couples who described their relationship as having good communication also talked more positively about their overall sexual relationship. The couples in the study demonstrated similar patterns where initially they were more likely to express negative emotions which lead to conflict. Some continued having difficulties expressing their concerns with their partner while others moved forward and described having no choice and being forced to increased levels of communication. The couples who described having good communication with each other also described their relationship both emotionally and physically as very positive. This is consistent with Gagliardi's (2003) finding that individuals who had negative emotions about sexuality reported little communication with their partner. McCabe et al. (1996) and Dupont (1995) both found that couples in which one partner had MS were less likely to seek advice or assistance but were more likely to express negative emotions and not communicate their difficulties to their partners.

Couple Characteristics that Predict Successful Adjustment

All the women in the study spoke of the need to come to terms with the MS and accept it so they could deal with it in their way. Other researchers (Brown & Giesy, 1986; Milligan & Neufeldt, 1998) have found that disabled individuals with a more positive attitude and acceptance of their disability were more likely to continue in a strong positive couple relationship.

The attitudes and behaviours couples are exposed to in their near environment have a significant impact on a couple's sexual expression (Milligan & Neufeldt, 1998), and in this study society's gender-based role expectations seemed to be quite influential. The women in the study were quite intent on meeting their expected role demands even if their capacity to do so was limited by MS. Concurrently, the husbands felt it was their role to be supportive and "be there" for their disabled partner.

From the perspective of family-as-ecosystem, all the couples described various forms of adaptation and patterns of interdependency. They had to redefine their relationships, reframe their self-perception, and learn to relate in new ways. For some couples communication was a key component of this adaptation. Many couples described learning by trail and error what helped them adapt to their new reality and to deal with the changes in their sexual relationship as a result of MS.

Impact of Disability on Sexuality and Couple Relationships

Consistent with the findings of this study, Taleporos & McCabe (2001) found that some individuals felt their disability lessened their value as a sexual partner, others felt it did not have an impact and still others felt that their disability forced them to be more creative and versatile.

Similar to Gagliardi's (2003) findings, some participants in the present study experienced their sexuality after MS in a positive way, while others felt negatively about their sexuality after MS, in that it created distance between themselves and their partners; they also reported limited communication with their partners.

Self-esteem

Parker (1993) found the guilt of having a disability and the restrictions it placed on the non-disabled partner was a significant cause of decreased self-esteem in the disabled individual. This in turn affected a couple's sexual relations (Barak et al., 1999; Bianchi, 1997). Bianchi (1997) found a decreased self-esteem was found to be positively related to sexual preoccupation.

The women in this study were found to have much more preoccupation regarding sexuality then their male partners. Some of the women reported having sex primarily to meet their husband's needs and fulfill their obligations. Others expressed a fear that their husbands might leave them if they were not able to satisfy their needs. Similar to what was found by Taleporos & McCabe (2001 & 2003), the women in the study described feelings of inadequacy and decreased desirability and felt the MS greatly limits their sexual life.

Pre- versus Post-disability Relationships

In the planning of this research project it was decided to use pre-disability couples where one partner had been diagnosed after the relationship had been established. This was done as previous research showed that pre-disability relationships were more adversely impacted by the disability then post disability relationships, Crewe (1993). The couples in this study demonstrated similar characteristics to what Crewe (1993) found where pre-disability marriages that survived demonstrated “strength and commitment but also included noticeable areas of loss and regret”.

Relationship - Quality: (in MS)

Reporting on marital satisfaction of couples impacted by MS, Dupont (1995) found that the non-disabled partner was generally less satisfied with the relationship than the partner with MS. In contrast, in the present study the male partners of women with MS reported for the most part that their sexual relationship had not been greatly affected by their partners’ illness. In fact some reported the sexual relationship has actually improved since the diagnosis. This is in line with what McCabe et al. (1996) concluded, that the majority of their participants did not express concern about their sexual problems. It was thought that individuals with MS accept sexual dysfunction as a symptom of their disorder and feel there is nothing that they can do about it, therefore they do not attempt to change the situation.

The women with MS in this study were more preoccupied than the men with the sexual problems associated with MS. Perhaps this was because the women also tended to put their partner's sexual needs ahead of their own. Thus, their concern about sexuality was due more to the fact that they were in a relationship rather than related to their own sexual needs.

The "lived experience" shared by the couples in this study was that couples who could communicate openly had a better quality of relationship than those who could not.

Caregiver Stress and Role Shift

Similar to what was reported by Crewe (1993) and Rolland (1994), the male partners of the women with MS in this study were more likely to have an increased caregiver role. All participants reported that the men did take on many of their female partner's roles when the MS worsened or when there was an exacerbation.

Disability has also been shown to increase stress and to affect the roles and personal boundaries experienced by couples (Feigin, 1998; Kester et al., 1998; Rolland, 1994). For the men in this study, care giving and role shift was a practical matter. They felt it was part of having a partner with a disability and that they just needed to get the job done. The women were significantly more emotionally troubled by the impact their MS had on their customary roles in their relationship. The women in this study tended to take on the burden of their disability, to suffer in silence and to minimize its impact on their roles and relationships. This was consistent with the finding that women tend to suffer more distress whether they have MS or are the caregiver. They also tend to face a greater burden of caring for the needs of others and to provide more physical and emotional support to their male spouse (Steck et al., 2000).

Intimacy

Contrary to the stereotype of men as interested only in the physical gratification of sexual activity, the men in this study confirmed Miller's (1994) finding that intimacy in the relationship provides the foundation for meaningful expression and experience of sexuality (Miller, 1994). This was consistent with other studies that found that for non-disabled partners, feelings of emotional closeness, mutual concern and willingness to participate in a variety of sexual activities were more important for sexual fulfillment than the physical sex act (Kreuter et al., 1994b, Kreuter et al., 1996, Miller, 1994). Although couples impacted by MS reported that the demonstration of affection was a very important aspect of a relationship, this was strongly correlated to sexual activity. Problems in sexuality also showed up in decreased demonstration of affection and intimacy (Rodger & Calder, 1990).

Half the couples in this study were good examples of couples described by Rolland (1994) who are able to redefine intimacy and nurturance in terms of valuing mutually caring companionate relationship with shared interests and pleasurable activities. He found that these couples can successfully adapt to losses in the sexual components of their relationship (Rolland, 1994).

Relationship – Enhanced

Consistent with what Rodger and Calder (1990) reported, most of the couples in the present study felt that MS had strengthened their marital commitment despite the problems it presented. This was similar to a study in which McCabe et al. (1996) found that although MS had a negative impact on sexual function and most of the couples they studied expressed strong negative emotions in relationship to their illness, they nonetheless considered their relationships to be a strong source of support. Through mutual discussion and growth some of the couples in the present study were able to move their relationship to a point where they achieved a positive level of satisfaction and comfort.

Theoretical Implications

The Marriage of Occupational Therapy and Human Ecology

As an occupational therapist using a human ecology perspective I enjoyed both depth and breadth in the framework for conducting this research on the impact of MS on couples' sexual relations. As an occupational therapist, I was interested in gaining a deeper understanding of the impact of MS from a client-centred perspective. The human ecology framework provided the larger context for understanding the impact of MS from more of a systems perspective on the ordinary business of life of the participants and their interaction with their environment.

The following illustrates the marriage of occupational therapy and human ecology concepts as I came to understand and experience it over the course of this research, including the environmental, holistic, spiritual components.

Environment

Viewing the couple as an ecosystem provides valuable insight into how MS has impacted the couple's reactions and interactions. Every ecosystem contains niches (Klein & White, 1996); interdependences in an ecosystem are not between specific individuals but between specific niches occupied by individuals. The introduction of MS into the family-as-ecosystem precipitates a disruption in the niches occupied by individuals and the interdependencies among those niches, including those interdependencies affecting the couple's sexual life.

A new niche taken on by the husbands was one of “caretaker". This did not appear to cause much distress to the husbands however the wives were quite concerned about sharing the "caretaker" niche with their partner, whereas pre-onset it was a niche in which the women were well established and comfortable. Many of the women in this study were intent upon maintaining their established niches even if it meant pushing themselves to the point of exacerbating their symptoms.

From an occupational therapy point of view, the women in this study were intent upon maintaining their household and sexual roles even though they knew that it may not be possible due to their MS. This attitude may actually have a beneficial impact on the overall sexual relationship as Miller (1994) reported that the longer a non-disabled partner performs the caretaker role, the more difficult it becomes for the couples to return to the pre-injury level of intimacy.

The family-as-ecosystem does not live in isolation from the environment in which it is situated and the family is the environment within which members' needs are met (Badir, 1993). Having a disability like MS can alter how the environment influences a couple as well as how the couple interacts with the environment. From a family ecology perspective, sexuality is a fundamental aspect of family life (Sussman, 1983). A couple's sexual relationship is an essential element of the couple bond on which a family unit is based. The family helps establish gender roles identity and is the structure for acceptable role behaviours (Maddock et al., 1983). Viewing the couple as an ecosystem promotes understanding of the influence a disability may have on how the couple changes and evolves through interaction within itself and within the environment. In this regard, one issue of concern to the couples in the present study was the change in their ability to do things as a couple. The necessity to plan ahead and to reduce or limit their social activities as a result of MS resulted in less spontaneity and a decreased sense of "couplehood" within the social environment which had previously affirmed their sexual bond.

Partner as Environment

As a practising clinician I had noted the lack of research on the impact of disability as a couples issue or the impact of the disability on the non-disabled partner. The women in this study taught me that it is only in the context of having a partner in their life (near environment) that sexuality becomes an area of concern; otherwise, if not partnered other barriers presented by MS would take precedence. Thus, the presence of a partner in their near environment changed the entire dynamic of their experience of the impact of MS on their lives.

Holistic Approach

This "lived experience" of the participants in this study confirms that intervening in problems involving sexuality requires a holistic approach (Dailey, 1984; Rathus et al., 2002; Sipski & Alexander, 1997). Typically, rehabilitation professionals are taught to identify and label specific functional problems and then to intervene as indicated by the problem. The findings of this study suggest it may be an error to do this. Rather, it may be more productive to view problems in the sexuality of those with MS as a syndrome, that is, as a group of things or events that form a recognizable pattern, especially of something undesirable (MSN Encarta Dictionary, 2004). The participants in the study consistently framed their problems in the area of sexuality in the larger context of their relationship, roles and daily activities. Sexual problems caused by the MS were quite varied ranging from physical, cognitive, emotional and interpersonal. Sexual dysfunction was present on all three levels: primary, secondary and tertiary. Therefore, although all the women with MS reported altered sensation and a decrease in sexual response, it was clear that even if this problem was eliminated by focused intervention their sexual issues would not be resolved. Reframing sexual dysfunction in a more holistic manner is consistent with both the human ecology and occupational therapy approaches which consider human beings as a complex composite of physical, social, intellectual, emotional and spiritual components (Canadian Association of Occupational Therapists, 1997; Westney et al., 1988).

Spirituality

Human ecology and occupational therapy both embrace spirituality as central to the human experience (Egan & Delaat, 1997; Westney, et al., 1988). Spirituality is understood as that which provides a sense of meaning (Egan & Delaat , 1997) and as such, it shapes the way people interact and function in everyday life (Young, 1991). In this study, the women with MS seemed to derive a great deal of meaning in their sexual marital relationship from meeting their partner's needs and keeping them happy. Their own sexual satisfaction and needs were considered secondary or not important. This was a valuable insight into the motivation and priorities of these individuals.

Implications of Methods

In approaching the research, more than one paradigm was used. My worldview was as an occupational therapist using a human ecology framework to generate knowledge that is of value to couples whose sexual relationship may be impacted by disability and to front line therapists assisting such couples.

The method used for this study was a hermeneutic phenomenological approach. The role I took for data collection was one of a traveler. It was interesting that with every interview and each day of immersion into the data I became a more savvy traveler. This reminds me of a backpacking trip I took through Europe. At first I remember being a tentative traveler, focused on the logistics as opposed to enjoying the journey. As I began to understand the backpacking culture and resources available I became more relaxed and could take in more of the rich experience. Near the end of the trip I met some people who were just beginning their back packing travels and saw myself in them when I first set out. Now I was considered the expert, providing information and suggestions. I had truly changed during the journey. In the same way this study gradually changed me and helped me to become more empathic to the lived experience of the participants. Even now when I listen to the transcripts of the tapes, I realize that I changed with each subsequent interview. With successive interviews, the number of my questions and probes lessens and the data I gathered was more participant and less me. I became less directive, less process-oriented and more focused on the participant and their story, allowing me to gather richer information. Each participant was like a new destination in a journey that I became increasingly more confident in navigating to and benefiting from the journey.

In the end I feel the method and approach I selected were appropriate for the purpose of gaining insight into the lived experience of couples sexual relationship after the onset of MS. If I were to change anything in my methods I would have done a few more pilot interviews because this would have allowed me to be more comfortable and confident in listening to the participants' stories – not asking questions.

The constant comparison method used in the data analysis allowed for themes and ideas to emerge that may not have been evident when looking at each interview in isolation. Annotating the data with my own values, feelings, thoughts, interpretations and added richness to my experience of the participant's stories.

After completing this study I understand Deploy and Gitlin's (1998) statement that phenomenology differs from other forms of naturalistic inquiry in that phenomenologists believe meaning can be understood only by those who experience it. They added phenomenologists do not impose an interpretive framework on data but look for one to emerge from the information they obtain from the informants. That is exactly how the themes emerged form this study. My role was more as a medium that recorded the data and in that process the patterns and themes emerged on their own. The hermeneutic component was the way I worked with the data and helped clarify the participants' inner voices and understand their experiences in the world that surrounds them (Iannone, 1997).

Implications for Clinical Practice and Service Delivery

The PLISSIT model described earlier is used to structure the following discussion of how the rehabilitation professional can determine the optimum level of intervening in the couples' sexual dysfunction in which the woman has MS.

Permission

The first level ***permission*** involves giving and receiving permission to address sexuality. The findings of this study suggest that women with MS might tend to minimize the effect of the disease on their sexuality as a means of preserving the status quo out of fear or shame. As a result, clinicians may need to probe gently for the truth, rather than taking the women's report or behaviour at face value. Although it is important to treat sexuality as a couple's issue, meeting with the woman separately may allow an opportunity for her to discuss their fears without having to reveal all to her male partner at the same time. She would then benefit from permission to begin to open discussions with her partner, within her comfort zone.

The participants in this study all stated that the critical first step in adjusting to the reality of life with MS was acceptance of the diagnosis and its functional implications. Therefore, in their interactions with the client a crucial role for the clinician is to demonstrate and exemplify acceptance of the sexual impact of MS as a means of facilitating the client's acceptance. For example, because of the unpredictability of MS symptoms, it would be important for clinicians to accept contradictions and ambiguities in the feelings, concerns and issues presented by women with MS regarding their sexual relationship. Clinician needs to refrain from making generalizations or assumptions, even the assumption that a given individual feels the same today as she expressed a week ago.

The key aspect in this stage is for the clinician to bring up the topic of sexuality and thereby give permission for the client to mention any concerns she may have.

Limited Information

The second level, ***limited information,*** involves providing both partners with general information regarding the etiology, pathology and complications associated with the disability (Esmail, et al., 2001), and in this case, how MS may affect their sexual function and experience.

In the present study, the men in particular were hungry for information in order to better understand their partner's experience. Many of the couples held misinformation or where unaware of some of the complications MS was having on their sexual relationship.

The results of the study clearly brought to light the need for better understanding of the impact MS has on sexuality. The women appeared to have a better understanding as they were directly experiencing it. They felt that a huge barrier for them was their husband's lack of understanding about what was happening to them. In the same way the husbands all did not have a good appreciation of how the MS had affected their partner sexually and many felt it hadn't. They also stated they would like to have a better understanding of issues faced by their wives. As Williams (1993) found, with increased information imparted to the spouse, the less negative the impact of the disability on marital satisfaction. Specific areas that came up in this study that should be covered are helping the couple understand the MS itself, the prognosis, any complications, sexual anatomy, physiology and function.

This level is useful to begin to educate the couple. By simply providing information, the clinician may be facilitating attitudinal and behavioural changes (Dicker-Friedman, 1997; Esmail et al., 2001; Thorn-Gray & Kern, 1983).

Specific Suggestions

The third level, ***specific suggestions,*** may be seen as actual treatment and intervention. The types of intervention suitable for the average clinician in a rehabilitation setting are presented below.

Mutual responsibility: The literature shows that optimal couple functioning depends largely on the willingness of both partners to take responsibility for the relationship and the disability cannot be defined as exclusively the domain of the disabled partner (Kreuter et al., 1994a; 1994b; Rolland, 1994; Williams, 1993). Mutual responsibility can be facilitated by involving the partner in all aspects of the care and education of the client (Anderson, 1992; Urey et al., 1987). It is important to introduce sexuality as a couple's issue, not the sole responsibility of the person with MS. In the present study, the women with MS spoke about dealing with sexual issues associated with MS, rarely mentioning their partner. From the men's point of view for the most part sexuality for them as a couple had not been affected. Clearly these couples had not been introduced to the concept of mutual responsibility for the relationship.

Lifestyle issues: Many of the couples in this study indicated that they limit their social interaction outside their relationship, typically due to fatigue. Consistent with Urey et al., (1987), couples in the present study who reported MS as having the most negative impact on their sexual relationship were also found to participate in fewer outside activities alone or as a couple. In this context, clinicians can assist the couple to evaluate their activity patterns and discuss energy conservation strategies that will allow them to have a social life. It may also be necessary to gently point out that acting as if nothing has changed only sabotages adjustment.

***Roles and expectations*:** One area that came up in every interview was how the MS impacted the traditionally held roles. The wives with MS especially were quite distressed regarding how the MS has interfered with their ability to meet the role they held in the relationship. The husbands had for the majority taken on many of their wives' responsibilities as well as caretaking role when the MS symptoms worsened, and did not report being to be bothered by it – it was just something that needed to be done. This may actually have a negative impact on the sexual relationship. Miller (1994) reported that the longer a non-disabled partner continues the caretaker role the more difficult it becomes to return to the pre-injury level of intimacy. The clinician can take an active role in assisting the couple to look at additional resources to assist them in the caretaking responsibilities. As Milligan and Neufeldt (1998) found an attitude aimed at fostering their partner's independence and resiliency tends to have an overall positive impact. The clinician can also assist the couples to establish healthy roles and boundaries. Couples may have to accept the disability and establish new boundaries, which may be different from societal norms or their personal expectations (Rolland, 1994; Samelson & Hannan, 1999).

Specific resources: If and when asked by an individuals or a couple, the clinician should be prepared to suggest specific resources, eg. a book on communication or on sexual pleasuring. Mentioning that such resources exist is appropriate, but they should not be offered unless or until the client initiates the request. Care must be taken by the clinician that the specific resources are not religiously or culturally offensive to the client. Couples should be provide with resources that they consider acceptable to learn about their new sexuality (Dicker-Friedman, 1997; Miller, 1994; Schuler, 1982; Thorn-Gray & Kern, 1983).

Intensive Therapy

The final level, ***Intensive therapy,*** is where the clinician may need to assess their own skills and limitations and how they relate to the couple needs.

Facilitating communication between partners: Because communication is such a critical element of a relationship, and words that are said cannot be taken back, rehabilitation professionals require specialized training and a specific mandate to take on the responsibility of facilitating communication between the couple. This is particularly the case in the context of the findings of this study, in which most of the women with MS had been strategic in what they revealed to their partners and what they kept to themselves. Extreme caution and respect must be exercised by any clinician intervening in the intimate communication between life partners. Forcing the "truth" to come out needs then to be followed through with sufficient processing to restore the balance and safety within the relationship, a task for a qualified marital therapist.

As reported in the literature couples where one partner has a disability, have a higher rate of divorce, therefore, these couples may require more intensive intervention. Also many individuals with primary sexual dysfunction may need to be referred to a specialist.

Limitations of the Study

Sexuality is a value-laden topic that is considered private and sensitive and may cause increased apprehension when discussed (Rathus et al, 2004, Thorn-Gray & Kern, 1983). This factor may have influenced this study in several ways. The first could be in terms of who was willing to participate in the study. Not everyone is comfortable discussing their sexual relationship especially if there may be problems with it. For example one couple chose not to participate in the study after they were given a more detailed outline of the nature of the investigation. Their primary concern was not being comfortable discussing sexuality. Also participants who volunteer may have an agenda to meet or a story to tell. On the positive side, in qualitative research it is sometimes beneficial to have study participants who have more to say then the average population (Moules et al., 2004). In addition the discussions may also have been helpful to the participants in clarifying and increasing their own awareness regarding how they are dealing with the impact of MS on their sexual lives.

The second limitation is the content that is reported. There was quite a difference among participants in terms of level of detail they included when discussing their sexual relationship. Some were almost graphic in their detail, while most tended to describe sexual issues in a general language. There could be a concern that participants edited their information or told me what they thought I wanted to hear, however, because of the methods used I was not concerned on this account. Consistent with a phenomelogical approach, I allowed the participants to set the priorities in the interview (conversation). They told me their story; probes were used only to facilitate more description.

My being an occupational therapist with experience in the sexual health area may have influenced the study findings. At times it felt like the participants perceived me as a therapist rather than as a researcher. During the debriefing, after the tape recorder was shut off, some participants described the session as almost cathartic. They stated it was very therapeutic to be able to talk about these hidden issues with "someone who understands" This may have influenced the direction and type of data gathered during the interview, but because the purpose of the study was to understand their lived experience, their perception of my role might have facilitated their candor.

One might ask how healthy the couple's sexual relationship was before the onset of MS, in terms of sexual satisfaction, behaviors, frequency etc. This would be consistent with a quantitative approach to the study. I specifically chose not to assess the state of the participants' premorbid sexual relationship, as the focus of the study was to describe the lived experience of how MS interfered with their sexual relationship of the couple. For the same reason I also did not attempt to quantify the level of impairment caused by the MS, nor to relate this to impact on sexual relationship. Quantitative level of impairment is quite different from perceived level of impairment (Fifield & Esmail, 2000). Someone with MS functionally may not be severely disabled however emotionally and psychologically they maybe severely impaired. These issues would bring up many methodological inconsistencies and are beyond the scope of this study.

Another limitation of the study may arise from my choice of using a hermeneutic phenomenological approach as opposed to a pure phenomenological approach. Both approaches are appropriate for the purpose of the study: to describe the lived experience of couples impacted by MS. Some would argue that a descriptive phenomenological approach is more appropriate and a better method to explore this subject and minimizes the researcher influence by eliminating the hermeneutic (interpretive) component. My choice of hermeneutic phenomenology acknowledges that my experience and training will influence how I see the data. The process of analysis in which themes are identified and categorized into a textual format is interpretive in itself (Van Manen, 2001). The question remains to what extent did my interpretations influence or alter the true description of the participants' lived experience. To ensure the trustworthiness and credibility of the study and minimize my influence, the following strategies were used: a form of triangulation, partial saturation, member checks, peer debriefing, personal reflexivity and audit trail.

This study was specifically limited to women with MS and their partners. The question arises to what extent the findings can be applied to other groups and situations. For the most part, the findings and major themes that emerged were similar to what has been previously reported in the literature on disability and couples' sexual relationships. The findings are significant in that they illustrate that MS and sexuality is a couples issue and both partners are affected by MS in this regard. These findings set the stage for future research and possibly theory development.

The Next Step – Implications for Future Research

There was considerable evolution from the initial conception of this study to its present form. Initially, the goal was to conduct one study looking at both men and women with MS, however preliminary analysis of the first couple interviews revealed some significant gender-related phenomena. It was decided to complete two separate studies. The first (this study) would focus on women with MS and their partner. A future study has already received funding by Pfizer Canada to focus on men with MS and their partners. Later, the data from both studies can be combined and a grounded theory approach can be applied to develop a more comprehensive understanding and theory formation on the impact MS has on couples' sexual relationships.

In a study of this type it is typical for questions of causality to arise regarding the etiology of the issues and themes described. Again, the point of view and aim of the study determines how the matter of causality is addressed. In this study, using a human ecology perspective had the effect of focusing on the environmental factors that affect the couple.

Future studies will be designed to ensure the environment in relation to the couple will receive closure attention. As a researcher, I have gone through quite a lot of growth and understanding by completing this study.

Outcomes

Completion of this study has provided a greater understanding of the impact MS has on the sexual relationship of couples. It has allowed couples to voice their difficulties, triumphs and concerns in this area. The study has identified some aspects of sexual relationships that are most meaningful to partners and couples and how these have been impacted by MS. The study has provided a much needed voice for the lived experience and perceptions of partners who are in a sexual relationship with an individual with a disability. Finally, the study has identified some coping strategies that couples have found to be effective.

Application

The following are some of the ways study results will be applied to the clinical and academic setting:

- Identification of resources couples can access when dealing with the impact of disability on their sexual relationship.
- Increase understanding and empathy among healthcare professionals as they deal with the needs and concerns of their clients.
- Development of specific strategies for frontline service providers to allow for better assessment and evaluation of how disability impacts a couple's sexual relationship.

- Development of intervention programs designed to assist couples cope with their disability and its impact on their sexual relationship.
- Inclusion of relevant material on couples issues in educational curriculum.

The findings of this study may also be helpful for couples who have been affected by MS. For these couples, the findings may be useful in that:

- Couples may realize that they are not alone and that their fears and insecurities are similar to what other couples are experiencing.
- If they recognize some of the problems at an earlier stage, it may allow them to address them before things progress.
- Couples will be exposed to a number of strategies that others have used in resolving similar concerns. They can model themselves after successful couples in the study by adapting and using some of their strategies.
- The study results will allow both the individual with MS and the partner to develop a better understanding and empathy, as they gain some insight into each others experiences and difficulties.
- The findings can act as catalysis by providing a basis through which couples can redefine what is important to them in their relationship and not feel like they have to follow societal stereotypes when it comes to sexuality and roles in they play. For instance, they can learn to focus more on intimacy and closeness and not feel the pressure to view sex as mere intercourse.

- It can also provide hope for couples where the study results may allow them to view MS as something that could strengthen their relationship despite the problems it presents.

Dissemination of Results

Results will be disseminated in various ways under the categories of service, research and education.

Service:

- An abbreviated version of the research and findings will be published in the Alberta Society for the Promotion of Sexual Health and MS society news letters
- Presentation in a seminar for MS support group or a free workshop on sexuality will be offered and advertised through the MS society; attendees will be given information on the study

Academic research:

- Publication in a peer reviewed journal such as Sexuality and Disability
- A book looking at the lived experience of couples where one partner has MS.
- Appropriate conference presentation.

Academic clinical education:

- Findings will be integrated in the curriculum for both medical students and occupational therapy students' sexuality modules.

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Appendix A

Dailey Definition of Sexuality

Dailey (1984) described sexuality as having five components: sensuality, intimacy, sexual identity, reproduction, and sexualization.

Sensuality relates to our need to be aware of and accepting of our own body through all of our five senses. Knowledge of sexual anatomy and physiology is important in embracing and owning our body and developing a positive body image. Part of being sensual is our attraction to others. Dailey suggested that we each have an 'attraction template', a cluster of certain attributes that get our immediate attention and attract us to others. This template starts early in life and 'kick starts' our sexuality often through fantasy. It could be stated that the mind is perhaps our most important sexual organ as it governs how we feel about ourselves, and others, and guides our behaviours. Our thoughts or opinions about our sexuality and our relationships with others can lead to feelings of guilt, shame, pride and joy. It is suggested that most sexual counselling involves treatment of the mind rather than the body. Another important factor in sensuality is what Dailey describes as 'skin hunger', that is, our need for touch. Although many consider North America to be a rather touch phobic society, we all need physical contact with others. It has been shown that both psychological and physical well being are enhanced by positive touch. Conversely those deprived of positive touch may be more likely to have low self-esteem and general health concerns (Montagu 1978).

Intimacy is described as our need and ability to experience emotional closeness to another human and to have that emotional closeness predictably returned in kind. This usually involves physical intimacy as well, but not necessarily. True intimacy involves being vulnerable through genuine caring, open communication, and appropriate emotional risk taking. Intimacy in sexual relationships requires an ability to communicate openly by giving feedback and instructions to each other knowing and trusting that you will be heard.

Identity is another part of being a sexual person and is a continual process of discovering who we are in terms of our sexuality. We become aware of our gender at about three years of age, however it is through our socialization, education and life experiences that we develop our full sexual identity. Part of our sexual identity is our orientation, that is, which gender(s) we are attracted to sexually. In addition, the roles that we play as men and women are affected by our perceptions of masculinity and femininity.

Reproductive aspects of sexuality are often the most readily discussed issues as they conform to the 'reproductive bias' referred to earlier. However, as lifestyles in our society change and more alternatives regarding conception and child rearing are sought - such as single parenthood, adoptions by gay individuals, and in vitro fertilization - differences in beliefs and values produce conflict among us. Society sets moral standards of behaviour through religious, legal, and cultural systems. However, individuals have the right to make their own choices based on their particular values. In order for individuals to make informed choices there is a need for greater public education regarding medical reproductive technology and the effects of sexually transmitted diseases on both general and reproductive health.

Sexualization is the term used by Dailey to describe our use our sexuality to influence, control and manipulate others. It is important to stress that although much of this component of sexuality may be viewed as negative, there are positive aspects also.

Our style of dress, general appearance, and body language can be used to show respect for others and to enhance our personal and business relationships. However, those same elements can be used to coerce and harass others. Sexual messages, both positive and negative, are prominent in advertising, movies, talk shows, and print media and often lead to misconceptions about healthy sexuality. It is important that sexual health education includes a balance of positive aspects of sexuality as well as negative ones, such as assault and abuse.

These five components - sensuality, intimacy, identity, reproduction, and sexualization are affected by an environment in which sociocultural influences such as family, ethnicity and religion influence the quality of their development. It is important to look at the five components as an integrated whole. Each component influences and is influenced by all other components. The greater the integration of the five aspects in an individual, the more positive his or her 'sexual beingness' (Dailey 1984).

(Fifield & Esmail, 2000 p.179 -180)

Appendix B

Recruitment Notice

Title of Research Project:
Impact of Disability on Couples' Sexual Relationships - Focus on Multiple Sclerosis

Are you interesting in participating in a research project?

Who: Couples in which one partner has been diagnosed with multiple sclerosis for at least 1 year and not more than 10 years, and are between 18 and 50 years old.

Why: There is general consensus that MS significantly impacts an individual's life. What is often forgotten is that MS will also greatly affect the lives of those around the disabled person, particularly the spouse or partner. The impact on the sexual relationship of couples and how to address the various issues is a neglected subject in research. Not enough is known about the couples' personal experiences. Their voice is not recorded in the literature. Knowledge and understanding of the couple's perspective is essential in order for the health professional to provide relevant and timely support and intervention

What: The purpose of the proposed research is to understand the impact of MS on couples' sexual relationship. Specifically, the research aims to understand the following:

1. Each partners' perceptions of the impact of disability on their sexual relationship.
2. What gives each partner meaning in their sexual relationship.
3. What partners consider to be important MS-related factors impacting their sexual relationship.
4. The coping strategies each partner is using and how these have changed since the onset of MS.

Where: The interview will take place in a location convenient to you.

When: The interview can be scheduled at a time most convenient for you.

How: If you choose to volunteer for the study you be required to spend ~one hour being interviewed separately by the investigator of this project. After the interview a short debriefing will be held with you to clarify any issues or answer any questions etc. Length of time for the debriefing will depend on you and what you wish to discuss as a couple, however it is not expected to take more than 1/2 hour.

If you are interested in telling your story about how MS has impacted your sexual relationship please contact me at the following:

Shaniff Esmail, Associate Professor Dept of Occupational Therapy, Faculty of Rehab. Medicine

Appendix C

Letter of Support MS Society

MS
Multiple Sclerosis Society of Canada
Edmonton Chapter
MS Victory Centre, 11203 - 70 Street
Edmonton, Alberta T5B 1T1
Telephone: (780) 471-3034 Facsimile: (780) 479-2256

April 30, 2003

Shaniff Esmail, MSc, OT(C)
Associate Professor
Department of Occupational Therapy
Faculty of Rehabilitation Medicine
University of Alberta
Rm 3-04 Corbett Hall
Edmonton, Alberta T6G 2G4

Dear Shaniff,

I am writing to thank you for meeting with me earlier this month and it is exciting to hear about your proposed research project for people with MS and their partners. We would be very pleased to be involved by informing our members about your project and look very much forward to hearing a presentation of your results upon its completion.

Please contact me when you are ready for the next step and we will assist in letting people know about your research. If you have any questions or concerns please do not hesitate to call me at 471-3034.

Sincerely,

Barbara J. Foxall
Manager, Client Services

Appendix D

List of Resources

AGENCIES

Glenrose Sexual Health Service
Glenrose RehabilitationHospital,
10230-111 Ave,
Edmonton, AB
T5J 3L5

Phone: (780) 471-2262 ext 2284
Fax: (780) 471-7969
Email: sexhealth@cha.ab.ca

- ❖ Provides sexual health services to inpatient and outpatient – referral required.

EDUCATORS/CLINICIANS/THERAPISTS

Larry Brockman, BSc, Bed,
9423 108A Ave,

Edmonton, AB
T5H 1B9

Phone: (780) 429-5405
email:
brockman@freenet.edmonton.ab.ca

- ❖ Specialization in secondary science and French language instruction, theology and ecumenism, group facilitation.
- ❖ Areas of interest: sexuality education, collaborative planning and implementation of community prevention/service projects.

Penny Cuddy, RN, BScN
Cuddy Consulting Services

Phone: (780) 467-7519

- ❖ AASECT certified sexuality educator with over 15 years experience in sexual health.
- ❖ Services include program planning and evaluation, facilitation of workshops for professionals and presentations to groups on sexuality through the lifespan.
- ❖ Speciality services include assessment and counselling for teens and adults with issues related to sexuality for people with disabilities.

Deborah Foster, BScN, MSc

Phone: (780) 469-4684
email: debbief@athabascau.ca

- ❖ Sexuality educator and family therapist.
- ❖ Provides consultation and community presentations in the area of sexuality.
- ❖ Focuses on sexual orientation and sexual health issues.

Thomas Lipinski, PhD
218, 10509 81 Ave.
Edmonton, AB

Phone: (780) 436-2736

- ❖ Chartered Psychologist since 1980.
- ❖ Treats men with sexual dysfunctions, anxiety disorders, trauma, and chronic pain.
- ❖ Facilitates men's groups for men who need to address issues of male sexuality.

Linda McClure, RN, BScN, MSc(cand)
Certified in Clinical Sexology and Sex Education
Annexa Health Consultants
17724 102 Ave,
Edmonton, AB
T5S 1H5

Phone: (780) 448-9852
Fax: (780) 487-4893
email: annexa@home.com

- Therapy for individuals & couples with issues related to physical illness, anxiety, sexuality and disability, and relationships.
- Provides sexuality education to individuals, couples, and professional agencies.
- Workshops for parents, teens, health professionals, support groups.

Edward Sandberg, MSW, RSW(AB)
210 10008 109 Street,
Edmonton, AB
T5J 1M4

Phone: (780) 707-2115
Fax: (780) 707-1404
email: esandberg@home.com

- Individual, couple, & group counselling, primarily for adults and sometimes adolescents.
- Offers a wide range of sexuality and lifestyle counselling in a safe, supportive, non-judgemental environment.
- Areas of interest: sexual orientation, sex roles, gender identity, sadomasochism, fetishism, other paraphilia, sexual addiction, fantasy issues, masturbation, relationship issues, HIV/AIDS, and talking about sexual issues.

PHYSICIANS

Randy Abele, MD
Urologist

Phone: (780) 428-9405
Fax: (780) 424-3198
email: rabele@mail.v-wave.com

- Special interest in medical and surgical treatment and clinical research of male erectile dysfunction.
- Referral from family physician required.
- Member of the Canadian Male Sexual Health Council.

Carmen Tuchak, MD, FRCPC
Specialist in Physical Medicine and Rehabilitation

Phone: (780) 471-8218
Fax: (780) 491-6018

- Interested in neurological disorders affecting sexuality and reproduction.
- Physician referral required by fax.

Appendix E

Informed Consent Form

Title of Research: Impact of Disability on Couples Sexual Relationship - Focus on Multiple Sclerosis

Principal Investigator:	**Co -Investigator**	**Co -Investigator**
Shaniff Esmail Associate Professor Dept of Occupational Therapy, Faculty of Rehab. Medicine Phone: Email: :	Dr. Nancy Gibson Chair Department of Human Ecology, Faculty of Agriculture and Forestry Phone: Email: Nancy.	Dr. Brenda Munro Department of Human Ecology, Faculty of Agriculture and Forestry Phone: Email: Brenda

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Do you agree to be audio taped during the interview? Yes No

Do you understand and agree that the data from this project will be in several ways; Yes No

1) part of the requirements for the completion of a dissertation,
2) various publications in professional as general newsletters e.g. MS society news letter
3) finding will also be presented at various conferences and seminars
4) data will be used in the sexuality courses for both medical students and occupational therapy students.

Do you agree to allow the data collected from you to be used for future analysis? If you agree the same standards of confidentiality will be maintained. Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You can also stop your information from being used. You do not have to give a reason and it will not affect you in any way. To withdraw, ask the interviewer to stop the interview and the tape-recorder. Then, if you wish, tell the interviewer that you do not want your information to be used as described above. Yes No

Has the issue of confidentiality been explained to you? Yes No

Do you understand who will have access to your records and what will the data be used for? Yes No

This study was explained to me by: ______________________

I agree to take part in this study.

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee	Date

See attached information sheet for specific information regarding the research.

Appendix F

Information Sheet for Prospective Participants

Title of Research: Impact of Disability on Couples' Sexual Relationships
Focus on Multiple Sclerosis

Principal Investigator:	Co –Investigator	Co -Investigator
Shaniff Esmail	Dr. Nancy Gibson	Dr. Brenda Munro
Associate Professor Dept of Occupational Therapy, Faculty of Rehab. Medicine	Chair Department of Human Ecology, Faculty of Agriculture and Forestry	Department of Human Ecology, Faculty of Agriculture and Forestry
Phone:	Phone:	Phone:
Email:	Email: Nancy.:	Email: Brenda

Dear Potential Participant:

We are conducting a research study to understand the impact of disability on couples' sexual relationships. The aim would be to get a true description of what you are experiencing. We will be looking to understand:

1) Your perceptions of the impact of disability on their sexual relationship.
2) What gives you meaning in your sexual relationship.
3) What you consider to be important factors related to MS impacting your sexual relationship.
4) Coping strategies you are presently using and what you have used in the past.

In the study we will be interviewing couples where one partner has had a diagnosis of multiple sclerosis for more than one year and less than ten years after the relationship was established. Individuals must also be between the ages of 18- 50. You and your partner will be interviewed separately and we will then have a meeting with all present.

The interview will be conducted in a location you are comfortable with. It is expected to last for approximately one hour. The interview will be tape recorded to allow for the interview to be transcribed for data analysis. Later a second shorter interview will take place to verify the data to ensure accuracy of the information gathered.

You should know that all information collected will be kept confidential and your name will be replaced with a number to protect your identity. Not even your partner will have access to information you provide. All attempts will be made to maintain your anonymity. We cannot guarantee complete confidentiality as some quotes from your interview may be published; these however will be nameless.

While you may not benefit directly from the study, your participation may allow for the improvement of services provided by healthcare professionals. Although, there may be no direct risk to participating in the study you may become aware of issues or be reminded of unpleasant memories relating to MS and sexuality. If any questions or issues come up for you, I may be able to answer some basic questions. I can also provide you with a list of resources where you may seek further support.

Results of the study will be shared in several ways:

1) An abbreviated version of the research and findings will be published in the Alberta Society for the Promotion of Sexual Health and MS society newsletter.
2) Presentation in a seminar for MS support group
3) Published in a research journal
4) Presentation at appropriate conference.
5) The findings will be used in the sexuality courses for both medical students and occupational therapy students.

If you have any questions or concerns please feel free to contact me or any of the co-investigators listed at the top of this letter.

Thank-you for your interest in our study.

Sincerely,

Shaniff Esmail, MScOT
Occupational Therapist
Associate Professor, Department of Occupational Therapy

Appendix G

Letter re: Ethics Approval

UNIVERSITY OF ALBERTA

7 July 2003

Dr. Shaniff Esmail
Department of Occupational Therapy
2-64 Corbett Hall

Dear Dr. Esmail:

03-26 Impact of Disability on Couples' Sexual Relationships - Focus on Multiple Sclerosis (MS)

The Human Research Ethics Board has reviewed your revisions to this application, and it has been approved.

Sincerely,

Debra Davidson, Acting Chair
Human Research Ethics Board

cc N. Gibson
B. Munro

Faculty of Agriculture, Forestry, and Home Economics

2-14 Agriculture-Forestry Centre • University of Alberta • Edmonton • Alberta, Canada • T6G 2P5
Telephone: (780) 492-4931 • Fax. (780) 492-0097
www.afhe.ualberta.ca • e-mail: dean.agforhe@ualberta.ca

Appendix H

Interview Guide

In-depth semi-structured interview.

1. Small Talk – rapport building

2. Some basic introduction questions to enhance comfort and get basic demographic information.
    - age
    - education
    - interests
    - relationship status – years together
    - date of onset of disability
    - basic impairments caused by the disability
    - anything else they would like to add before getting into the interview

3. Define sexuality using the SIECCUS definition (Sexual Information and Education Council of the US)

    "Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values and behaviours of individuals. It deals with anatomy, physiology and biochemistry of the sexual response system, with roles, identity and personality, with individual thoughts, feelings, behaviours, and relationships. It addresses ethical, spiritual, and moral concerns and group and cultural variations".

    Sexuality is a broad area but basically covers basically all aspects of being male and female. Sexuality is part of who we are.

    Open-ended introductory statement/question:

    As you know, the focus of this research is to understand the impact of MS on the sexual relationship of couples – basically what I would like to understand is what we call your "lived experience". You decide what is important – what would you like me to know about this topic.

    Example of prompts/questions used if / as necessary:

    a) Tell me a little about your present relationship.

    b) How have things changed since the onset of the disability?
    - Your thoughts on these changes?

    c) How has your sexual relationship been impacted by your (your partner's) disability?

    d) What gives you meaning in terms of your sexual relationship?

    e) Has the disability had any positive effects on your relationship?

    f) What aspect of your disability tends to cause the most problems?

    g) Have you or your partner had to adjust the role you play – in your relationship?

    h) What have you found to be most helpful in dealing with this whole area?

    i) What are some methods you have used to cope with some of the issues you have identified?
    - Has your coping strategies changed since you (your partner) were first diagnosed?