University of Alberta

The “lived experiences” of couples’ sexual relationships in men with multiple sclerosis

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Science

Department of Occupational Therapy

Edmonton, Alberta
Fall 2007

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Your file Votre référence
ISBN: 978-0-494-33261-0
Our file Notre référence
ISBN: 978-0-494-33261-0

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ABSTRACT

Multiple sclerosis (MS) significantly impacts sexual lives of individuals with MS and their partners. However, health professionals often feel ill-prepared to treat clients with sexual issues. Understanding a couple's perspective is essential for health professionals to provide relevant support and intervention.

This study aimed to understand the impact of MS on couples' sexual relationships when the male partner was diagnosed with MS during the relationship. Using a phenomenological approach, a description of four couples' "lived experiences" was gathered by semi-structured interview with each partner separately.

Communication was identified as a key element in coping with the impacts of MS. Men with MS was more likely to comply with changes while women tended to take on the martyr roles to protect their partners. Findings suggest clinicians should facilitate open communication, recognizing each partner's intimacy needs and help both partners establish meaningful roles.

Acknowledgements

First, I would like to thank and acknowledge my academic supervisor, Dr. Shaniff Esmail. I would not have this chance in exploring the sexuality domain in occupational therapy without your ample knowledge and encouragement. Thank you for being patient with me and guiding me through the thesis process.

I would also like to thank my co-supervisor, Dr. Lili Liu, for your hard work and valuable feedback. I will never forget the care and attention you showed to me in my research and your support both in and out of my academic life. Thanks to Dr. Brenda Munro for spending time with my thesis and being on my committee.

Special thanks to Jeannine Christopherson. Thanks for all of your help in this research project. I really appreciate your friendship and kindness in leading me in exploring the world of multiple sclerosis.

Thanks to my husband, Luc Shih, for being my backup when I lost my confidence and felt frustrated in this process. Without you, I am sure this journey would not have started and finished. Thanks for living with my stress when you were also struggling with your new life in Canada. Your belief in me and patience kept me moving on.

I would like to thank all of the participants in my study. These individuals allowed me to investigate and describe the intimate details of their experiences. This research would not have been possible without them.

Finally, thanks to the Alberta Council of Professionals for Sexual Health for funding this study.

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Chapter One – Introduction

Multiple sclerosis (MS) is a degenerative disease affecting the spinal cord and/or brain and can strike at any age between 10 and 59. Usually the onset is during the third or fourth decade of life (Speziale, 1997). This is the time during which individuals develop relationships and having a physical disability could seriously limit their opportunities to form intimate relationships (Taleporos & McCabe 2001, 2003). Literature showed that people with disabilities are less likely to marry or have higher divorce rates compared with the general population (DeVivio, LaVerne, Hawkins, Richards, & Go, 1995; DeVivio & Richards, 1996)

Sexuality is a fundamental aspect of a relationship (Sussman, 1983; Zorzon et al., 1999). People with MS indicated that sexuality is a major part of their identities as human beings (Garliardi, 2003; Zorzon et al., 1999). Yim et al. (1998)reported that sex was the most serious problem among 10 problem areas of a marriage when one of the partners has a disability. However, discussions of sex and sexuality are frequently neglected in the health care delivery system (McAlonan, 1996; Miller, 1994).

To have a better understanding of sexuality in individuals with MS, their partners need to be included because the experience is shared by both (Cohen, Wallston, & Wallston, 1979; Esmail, Esmail, & Munroe, 2002; Foley & Sanders, 1997; Kreuter, Sullivan, & Siosteen, 1996; Sadoughi, Leshner, & Fine, 1971; Spica, 1989). The attitude and personality of the partner has a strong influence on an individual's sexuality (Ide, 2004). However, there is very little research focusing on the experience of the partner who does not have the disability in a sexual relationship (Garliardi, 2003; M. Kreuter, M. Sullivan, & A. Siosteen, 1994; Rolland, 1994).

Sexual and marital satisfaction can be improved in individuals with MS and their sexual partners. Individuals with MS stated that having discussions with the medical team about their sexuality improves the relationships with their partners (Foley, LaRocca, Sanders, & Zemon, 2001; Zorzon et al., 1999). However, most health professionals were hesitant in discussing sexuality with clients because they did not think that they were competent to provide sexual health assessments or treatments. Due to insufficient knowledge and preparation, often health professionals chose to neglect the issues related to sexuality with their clients (Ide, 2004). Haboubi and Lincoln (2003) reported that 86% of health professionals had little or no training in sexual issues, and 64% of them stated that they need training in sexuality and sexual issues.

Sexuality and disability are both intensely personal experiences and highly variable among individuals (Hamann & Canli, 2004; Keefe et al., 2004; McNeff, 1997; Rohrbaugh et al., 2002). However, to date research exploring the impact of disability on couples' sexual relationships has been impersonal and tends to be quantitative in nature, describing the rate of separation and divorce, or establishing casual links for the "observed reality". For example, a more severe disability produces a more severe impact on life. As such, the literature does not reflect the personal experiences of people with disabilities and their partners. Their voice are absent in the literature.

To get a more comprehensive understanding of sexuality in individuals with MS, several researchers have emphasized that qualitative interviews are necessary (Isaksson, Ahlstrom, & Gunnarsson, 2005; McCabe, 2004). It is also necessary to understand how the coping strategies adopted by individuals with MS to deal with their illness impact their sexuality and relationships. Therefore, a preceding study (Esmail, 2005) was conducted to understand the essence of what women with MS and their partners are experiencing with respect to their sexual relationships, where "essence" is understood to be a true description of the phenomenon. This second phase of the study then focused on couples in which the male partner was diagnosed with MS. This study collected information from couples in which the male partner was diagnosed with MS after the relationship was established, which was consistent with the preceding study. This study also focused on the impact of MS on couples' lived experiences with respect to their sexual relationships and the coping strategies they used or developed to manage the impact. A couple in this study was defined as two people in a committed relationship, including but not exclusive to heterosexual married and cohabitating couples (Esmail et al., 2002).

Chapter Two – Literature Review

Sexuality

> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors (World Health Organization, 2005).

Sexuality is a major element in our lives as human beings. It is not only how we behave or interact with others sexually, but also who we are and how we develop our sexual roles (Esmail et al., 2002). Each individual develops his or her own definition of sexuality as it is influenced by various factors such as personal experience, cultural background, social expectation, and so on. As a result, how people define sexuality might also change during the different stages of their life processes.

Snell and Papini (1989) proposed three concepts of human sexuality:

sexual-esteem, sexual-depression and sexual-preoccupation. Sexual-esteem was defined as "a generalized tendency to engage in non-specific internal reinforcement toward oneself, as a result of one's capacity to relate sexually to another person" (p. 257). Within this definition, sexual-esteem is a concept which interacts with interpersonal rather than personal settings. In contrast, sexual-depression was defined as "a tendency to feel saddened and discouraged about one's capacity to relate sexually to another individual" (p. 257). The third concept, sexual-preoccupation, was defined as "the persistent tendency to become so absorbed in, obsessed with, and engrossed in sexual cognitions and behaviours, that one virtually excludes thoughts of other matters" (p. 257).

Couples with a Disability

Being married or having a relationship means having a potential supportive partner, which is associated with better health for people with disabilities. A spouse or partner can most provide emotional and caregiving support (Feigin, 1998; Harrison, Stuifbergen, Adachi, & Becker, 2004). Unfortunately, the divorce rate in people with disabilities is almost twice as high than the general population due to the impact of the disease (DeVivio et al., 1995).

In a relationship, disability affects both the individual with the disability and his or her partner. Individuals with disabilities tend to lose their independence in daily activities and sometimes their careers when their physical function is being affected by the disease (Foley, 1992). These changes affect their self identification, personal value, as well as their established roles. These major changes has a profound impact on the overall quality of life and well being (Kreuter, Sullivan, Dahllof, & Siosteen, 1998).

Generally, pre-injury expectations and role definitions in a relationship may be difficult to meet after the presence of a disability (Rolland, 1994). According to Miller (1994), the longer the caregiver role is necessary in a relationship, the more difficult it becomes to return to the pre-injury level of intimacy. In addition, research indicated that a decline in the frequency of sexual activities and sexual satisfaction are commonly reported by individuals with disabilities (Sadoughi et al., 1971). Other problems that affect relationships include perceived constraints on attraction, societal barriers, changes or hesitation in initiating communication, and various other aspects of sexual activities (Foley & Sanders, 1997).

Sexual Dysfunction in Men with Multiple Sclerosis

Disability could decrease the frequency of sexual activity and result in lower sexual satisfaction, which were strong predictors of overall self-esteem in individuals with disabilities (McCabe & Taleporos, 2003; Sadoughi et al., 1971). Compared with other chronic diseases, individuals with MS have a higher rate of sexual dysfunction.

Zorzon et al. (1999) found that 92.1% of men with MS reported sexual dysfunction, compared with 21.9% of men with other chronic diseases. In another study, 24% of men with MS reported total erectile dysfunction (Ghezzi, Malvestiti, Baldini, Zaffaroni, & Zibetti, 1995).

Foley (1992) stated that sexual problems in people with MS can stem from primary, secondary, or tertiary sources. *Primary sexual dysfunction* stems from physiological impairments directly due to demyelinating lesions in the spinal cord and/or brain in people with MS. In men, symptoms include impaired genital sensations, inability to achieve or maintain erections, and decrease or loss of ejaculatory functions. In general, erectile dysfunction is the most significant sexual dysfunction in men with MS (McCabe, McDonald, Deeks, Vowels, & Cobain, 1996; Stenager, Stenager, & Jensen, 1996; Valleroy & Kraft, 1984; Zorzon et al., 1999).

Secondary sexual dysfunction refers to non-sexual physical changes, such as fatigue, spasticity, bladder and bowel dysfunction, and pain. These may affect a person's ability to enjoy sexual activities. Research showed that fatigue and bladder dysfunction are the most common non-physical symptoms among men with MS (Valleroy & Kraft, 1984). Fatigue interferes with sexual interest, and the ability to initiate or continue sexual activities. Therefore, compared to muscular weakness and loss of sensation, fatigue could impede sexual relationships more in individuals with MS (Zorzon et al., 1999).

Tertiary sexual dysfunction refers to psychosocial and culture issues that interfere with sexual satisfaction or performance. Role changes due to disease, low self-esteem, and depression could all result in sexual dysfunction.

Among those factors which affect sexual dysfunction, in the views of partners, the intimacy and willingness to engage in sexual activities are more important than the physiological aspects of sexuality (Miller, 1994). Research on the sexuality of individuals with MS has mostly focused on the physical aspects of sexuality, such as performance and coitus (Garliardi, 2003; McCabe et al., 1996; Valleroy & Kraft, 1984). However, coitus is not always the most important source of sexual satisfaction (M. Kreuter et al., 1994).

Frequency of sexual intercourse did not predict sexual satisfaction (McCabe & Taleporos, 2003). A good relationship is not dependent solely on sexual activity; the depth and stability of the relationship are more important (M Kreuter, M Sullivan, & A Siosteen, 1994). As several researchers have demonstrated, physical dysfunction is not a major barrier to establish close partner relationships, and having a close partner relationship plays a more important role for a person's satisfaction with life (Kreuter et al., 1998; Kreuter et al., 1996; Yoshida, 1994). Therefore, psychosocial factors that affect sexuality, such as feeling intimate or being important to each other, should be focused on more in the relationship.

Partner Relationships and Caregiving

Disability increases stress and affects the roles and personal boundaries experienced by couples (Esmail et al., 2002). Adjustment to a disease is a process undergone not only by the person who has a disability but also the partner. The process of caring for the partner who has a disability leaves the partner who does not have a disability feeling less satisfaction with quality of life and more psychosocial stress (Feigin, 1998; Pozzilli et al., 2004). For men with MS who are in a relationship, their female partners usually become the caregivers after the onset of the disease (Foley, 1992). As caregivers, the partners can experience increased stress from the added and confined caregiver role, increased financial burden, and reduced prospects for their career or employment (O'Brian, 1993). Without appropriate support, the increased dependence on the spouse for basic personal care can place a huge strain on the relationship and further increase stress on the partner (O'Brian, 1993). Furthermore, when the female partner has the role of a caregiver, she might have difficulty feeling like a sexual partner in the relationship and interacting as intimately as the pre-injury level (Miller, 1994). In general, loss of intimacy in a relationship can ultimately threaten the stability of the relationship.

Individual & Gender Differences

Sexuality and disability are both intensely personal experiences; each one is highly variable among individuals and genders (Hamann & Canli, 2004; Keefe et al., 2004; McNeff, 1997; Rohrbaugh et al., 2002). Compared with women, sexual adjustment related to a disability appears to be more difficult for men. Men with disabilities face more barriers in forming relationships than women with disabilities (Taleporos & McCabe, 2003). Men have significantly higher levels of sexual depression, lower levels of sexual satisfaction, and feel they are less attractive to others (McCabe & Taleporos, 2003). Also, men with disabilities tend to experience decreased sexual interest more than women with disabilities (Sadoughi et al., 1971). Zorzon et al. (1999) discovered 57.9% of men with MS are less active sexually compared to 25.7% of women with MS. In regard to sexual satisfaction, men and women have different expectation. When comparing sexual satisfaction between men and women with disabilities, men are more sexually satisfied by the frequency of oral sex while women are more sexually satisfied with deep kisses when looking at activities other then sexual intercourse . (McCabe & Taleporos, 2003).

MaCabe and McKern (2003) found that sexual dysfunction among women with MS is strongly associated with other aspects of their sexual and relationship functioning.

However, it did not appear the same among men with MS. Their research showed men with MS who have sexual dysfunction separate their sexual functioning and relationship. Thus, even if men with MS experience sexual dysfunction, it is less likely to impact their relationship. This applies even though men with MS are unlikely to engage in any form of sexual activity and have low levels of sexual satisfaction (McCabe, 2004).

In addition, Rohrbaugh et al. (2002) showed that the distress level for spouses of people with chronic heart failure (CHF) was varied by gender. Female spouses reported more distress than male spouses and marital quality was significantly lower in male-CHF couples than female-CHF couples. The researchers suggested that the perceptions of marital quality might have correlated with household income which in turn explained the high distress levels for female spouses whose male partners have disabilities.

Clinical Practice in Sexuality for People with Disabilities

Research has demonstrated that when couples face high demands of illness, they are rarely given advice or information regarding their relationships (Parker, 1993). Clinicians tended to centre on the disease rather than providing holistic information and additional attention to the partners of their clients. Some clinicians might have the unfounded idea that too much information would overwhelm their clients, but the opposite is true. For example, participants with MS in Thorne's study (2004) reported that sometimes clinicians made assumptions about needed information or treatment based on how their clients looked and functioned. From their point of view, dealing with this aggressive and unpredictable disease, too much information was always better than not enough.

Occupational Therapist is usually one of the members in the interdisciplinary team. Occupational Therapists focus on improving people's quality of life and helps individuals with disabilities re-establish productive and meaningful roles after disease. Most people with disabilities are not capable of identifying their functions and their contributions in life. When they use incorrect methods to perform daily activities, unexpected failures and unrealistic expectations may create frustrations. These unnecessary frustrations could discourage their attempts to carry on daily activities and become dependent on others. Occupational Therapists help individuals with disabilities recognize and maximize their abilities in order to accomplish their daily activities, which increases their independence (Kennedy, 1987). With a focus on holistic care, Occupational Therapists enable individuals with disabilities to achieve satisfactory performance in occupations of their choices (Law, Polatajko, Baptiste, & Townsend, 2002; McAlonan, 1996). With the purpose of providing relevant client-centred interventions, it is essential that Occupational Therapists have a thorough knowledge and understanding of each partner's perspective (Zorzon et al., 1999).

Summary

MS is a degenerative neurological disease which has a negative impact on sexual activity in terms of frequency, sexual satisfaction, and overall quality of couples' relationships. The literature in the area of disability and sexuality as it affects couples provides some key points. First, sexual dysfunctions can stem from different sources including physical, non-physical and psychosocial changes after the onset of the disease. In addition to the physical aspects of the sexual relationship, disability impacts the expression of affection and intimacy. Loss of intimacy in a relationship can ultimately threaten the stability of the relationship. For men with MS and their partners, the disease often affects their roles in the relationship. The caregiving and financial burden on the female partners could create obstacles and strain on couples' sexual interactions and relationships. The literature also reported gender differences in sexual adjustment, sexual expression, social barriers, and distress levels of people with disabilities and their partners. As Occupational Therapists focus on holistic care, it is essential for Occupational Therapists to have thorough knowledge and understanding of both partners' perspectives of MS in order to provide better interventions.

Focus and Research Questions

The purpose of this study was to develop a comprehensive understanding of men with MS and their partners' experiences in the following areas:

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

Chapter Three – Research Methods

Methods

Qualitative research specifically studies individuals in their natural settings, and gets detailed information (Creswell, 1998). A phenomenological approach was used to achieve the goal of this study because it focuses on a phenomenon of "lived experiences" and seeks to understand the meaning as experienced by several individuals. In a phenomenological study, data analysis proceeds through the method of reduction, the analysis of specific statements and themes, and searches for all possible meanings. The researchers need to set aside all prejudices to obtain a whole picture of how people experience a phenomenon (Creswell, 1998). The proposed goal of this study was to understand the impact of MS on men and their partners especially on their sexual relationships from each of the partner's perspective as accurately as possible.

Participants

For a phenomenological study, it is essential that all participants experience the phenomenon being studied. For the present study which focused on couples' perceptions, both partners were required to participate because they experienced the same phenomenon from unique perspectives. 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 10 individuals (Creswell, 1998). The initial plan of this study was to recruit approximately four to eight couples with the goal to continue until the desired fullness and depth was achieved. The study was set to recruit couples in which the male partners have been diagnosed with MS for at least one year and not more than ten years, and is between the ages of 18 and 60. This age range was chosen because of the significant changes associated with sexual function that occur normally in individuals from ages 18 to 60 (Monga & Kerrigan, 1997). The timeline was chosen since it usually takes a period from one to ten years of adjustment before most individuals come to terms with their diagnosis (McNeff, 1997).

The primary method of recruitment was to contact agencies that commonly have clients with MS. Recruitment information was given to the Multiple Sclerosis Society of Canada – Edmonton Chapter, the Multiple Sclerosis clinic at the University of Alberta Hospital, homecare offices, as well as various rehabilitation offices across Alberta. In total, four couples inquired about the study. One couple did not meet the original inclusion criteria because of the age and the length of time after diagnosis. Due to the difficulties in recruiting participants and the time limit in the recruiting process, it was decided to widen the age range and length of time since diagnosis to include this couple. Another couple established their relationship after the male partner's diagnosis of MS, and the male partner had a divorced with a different woman after his diagnosis. Considering the story from the unsuccessful marriage and the success in the following relationship, it was decided to include this couple in the study.

Thus, all four couples participated in the study. All participants are from northern Alberta and in heterosexual relationships. Three of them are married and one is in a committed relationship. The level of impairment was not formally assessed to ensure the level of impairment would not interfere with the true goal of the study which was to understand the lived experiences of these individuals and not to quantify their stories by attempting to quantify their level of impairment. Table 3-1 describes demographic information of the participants. The description is necessarily broad to protect the anonymity of the participants.

Table 3-1 - Participants Description

Description	Range		Average
	Minimum	Maximum	
1) Age – male – with MS	40	68	55
2) Age – female partners	42	67	51.75
3) # of years married or in relationship	1	34	20.5
4) # years since diagnosis	12	34	23
5) # of years in relationship pre-diagnosis	0	17	5.75

Data Collection

The process of collecting data in a phenomenological study primarily is in-depth interviews (Creswell, 1998). The study used in-depth semi-structured interviews consisting of demographic data and open-ended questions to collect data (modified from a preceding study, see appendix C). The in-depth interviews were utilized to capture informants' perspectives on topics or issues of relevance in their lives. Taylor and Bogdan's study (as cited in Laliberte-Rudman & Moll, 2001) stated that an important character of an in-depth interview is to learn about "what is important in the mind of informants: their meanings, perspectives, and definitions; how they view, categorize, and experience the world" (p. 24).

Interviews were conducted by researcher with eight participants (four couples) separately to get their individual perspectives in order to avoid forcing them to discuss issues which they may not want their partners to be aware of. Participants chose the time and place most comfortable for them. Three couples chose to have the interviews in their homes and one in the office of the Multiple Sclerosis Society of Canada – Edmonton Chapter. The length of the interviews ranged from 30 to 60 minutes. Before beginning the interview, the purpose of the research was explained to each participant again to ensure their understanding of the research and to answer any questions or doubts they had.

Informed consent was obtained for their agreement to participate in the study and for permission to tape-record the interview. Written notes were taken by the researcher to record the observed the behaviour of the participant during the interview. Immediately after the interview, a short debriefing was held to clarify any issues or answer any questions. Later, each participant was called to verify the accuracy of the themes the researcher obtained from the first interview. Participants had the opportunity to add to and refine their story to ensure it accurately described their lived experiences. None of the participants withdrew from the study at any point.

Semi-structured interviews were conducted with a fairly open framework which allowed for focused, conversational, two-way interaction. The semi-structured interviews began with open-ended general questions. The relevant topics were initially identified to address the research questions and to remind the researcher to get comprehensive information. However, not all of the questions were designed ahead of time. Some questions were created during the interview, allowing both the researcher and the participants the flexibility to probe for details or discuss issues.

The interviews were audio taped to allow the researcher to be more attentive to the participants. Immediately after the interview, the tape-recorded data was played by researcher to make additional notes and document emerging themes. The participants' names on all documents were replaced with an identification number to ensure confidentiality. The tape was transcribed by an appropriate service provider and then transcriptions were reviewed by the researcher immediately to ensure accuracy.

Trustworthiness and Credibility

The primary focus in this study was to gather a comprehensive and truthful representation of the phenomena. Debriefing and phone calls after the interviews were used to ensure trustworthiness and credibility, which allowed participants to confirm the information they provided and correct any errors. To ensure the research results "truth value", the data was reviewed by another member of the research team as well as a content expert (a nurse who works clinically with individuals with MS and has conducted studies on sexuality and MS). This process of member checking (peer debriefing) ensured consistency and objectivity of analysis. In addition, tape-recorded procedures and written memos were used to provide accurate data and helped the researcher document a clear path of the research process. This audit trial would to allow for future analysis and replication.

Pilot Interview

A pilot interview was completed with one couple, where the female partner has MS, to assess the quality of the interview. The couple was known to the researcher. Data from this couple was not included in the study.

Data Analysis

In a phenomenological research, data analysis proceeds through a search for all possible meanings, and obtains a picture of how people experience a phenomenon. In the first step of data analysis, notes were written during the interview and immediately post-interview, and memos were written about ways of categorizing data. These written notes acted as the initial sorting-out process. Then, each transcription was reviewed to gain a better understanding of the stories the participants told. The researcher looked closely at the words used by participants, such as the metaphors, or the researcher translated participants' ideas into metaphors. In the second step, the researcher started to reduce the data by developing codes or categories and then grouped the words into meaningful units to put in categories. Following Creswell's (1998) suggestion, researcher began with six categories with shorthand labels or codes, and then expanded the categories as researcher continued to review and re-review the transcripts and notes. Eventually, 30 categories of information were developed.

In the final phase of data analysis, comparisons were made between interviews, and a short narrative was written, briefly describing the primary points under each category. By referring back and forth between interviews, general ideas as to the meaning of the data were identified. The goal of the methods used was to produce constructions that were as informed as possible. In the final stage, the narrative under each category were linked up to compare with what had already been described in the literature about the impact disability has on men with MS and their partners' sexual relations and how it relates to the research questions.

Ethical Considerations

Recruitment

The research project was approved by the Health Research Ethics Board, Panel B, at the University of Alberta. The recruitment procedure allowed the participants to initiate the first contact with investigators. Information about the research project was provided in oral and written format to potential participants once they had contacted the investigators, at which time the information sheet (modified from the preceding study; see appendix D) was mailed out to the potential participants. Inclusion/exclusion criteria were provided to allow participants to withdraw without sharing their personal information. Participants were not directly contacted until they understood the research project and had contacted the researcher or her supervisor with an indication that they agreed to participate in the study.

Before the interview, the process of the study was explained to participants again by the researcher so participants were aware that they were free to withdraw from the study at any point. The researcher then clarified any questions the participants had after the explanation. After participants consented to participate, the informed consent forms were signed. The Standard Consent Template suggested by the Health Research Ethics Board of the University of Alberta was adapted for use in the study (see Appendix F).

Benefits of Participating in the Study

From the literature review, individuals with MS stated that having discussions about sexuality improved their relationships with their partners (Foley et al., 2001; Zorzon et al., 1999). Participation in this study may have allowed participants to become aware of what was important to them in their relationships. Many participants in this study felt good about having the opportunity to help others. Some participants stated that they arrived at a new level of understanding and gained better insight by putting words to their experiences and reviewing their past.

Risks of Participating in the Study

Discussion of the impact of MS on their intimate lives may have forced participants to confront or recall losses and changes since the onset of the disease. In case any negative recalling occurred, a list of resources (see appendix E) was prepared, but none of the participants requested it.

Privacy and Confidentiality

Steps were taken to ensure participants' anonymity and confidentiality of information. Each participant was interviewed separately so the information was not shared with their partners. Immediately after each interview, the participant's name on all documents and recorded tapes was replaced with a coded number to ensure confidentiality. All data was pooled to ensure anonymity. Data was kept in a locked file cabinet and only the researcher and her supervisor have access to it. This information will be destroyed after five years.

Chapter Four – Research Findings

Men with MS

Four major themes emerged from the data collected during the interviews of men with MS:

1. Communication salvaged the relationship.
2. The sexual relationship was re-examined after the diagnosis. Intimacy and closeness were essential.
3. The traditional roles changed after the diagnosis of MS.
4. Their partner's acceptance was a major source of support in the relationship.

Theme 1: Communication Salvaged the Relationship.

All of the men who participated in the study identified open and effective communication as the most important element in their relationships. It was important for their partners to understand how having MS affected them and the men also wanted to know how the disease affected their partners. The men considered it vital to be able to express their thoughts, feelings and needs. They wanted open discussions with their partners regarding any issues or concerns that might surface so these could be resolved together. The following are quotes from the interviews of the male participants:

> ***"... I think that communication is the most important aspect in a sexual relationship. Not only in the sexual aspect but in your whole relationship, the key is communication... communication to me is the number one and most important thing in our relationship..."***

> ***"...The open relationship we have - the willingness of both of us to talk through any issues or concerns that we have - I think that's the biggest thing - to talk, talk, talk about everything, in order to work through things..."***

> ***"...You gotta understand each other. You gotta explain to your wife what you're going through..."***

Honesty and openness are two key elements of communication. To promote understanding both partners need to speak clearly and candidly when conversing. When there is a safe open environment for communication both partners can address issues as they arise and are able to address any issue that is brought to the table. Communication is an interactive process which requires participation by both partners. One participant reported his previous marriage ended in divorce because of communication breakdown. Ambiguity is an obstacle to communication and failure to communicate openly may endanger the relationship.

The following are statements made by some of the male participants:

> ***"…She could not understand that and she could not cope with that… so it eventually led to a divorce…"***
>
> ***"…I think communicating with one another … telling each other what each one would like from each other… If they don't like something, well then we need to express that to one another, because everyone likes something different. …we have to communicate … You HAVE to talk."***
>
> ***"… and to be so honest and open and so that you can feel close and you're not afraid to ask or to say what you need and what you don't need…"***

Several of the participants reported that they felt they were becoming better communicators after the diagnosis and started to employ effective communication skills, such as listening, patience, and tolerance. For some, improved communication enhanced their relationships after the diagnosis. The onset of MS brought lifestyle changes; men with MS reported that they were able to adapt to those changes because of frank communication. They felt open communication conveyed both partners' thoughts and created paths toward solutions. The following quotes illustrate how the male participants were able to enhance their communication with their partners:

> ***"...And that we have to learn to deal with it and with our relationship ...is patience... it's helped me to sit back and actually think about other people in my relationship..."***
>
> ***"...Positive things – I've become maybe a little more patient in dealing with things with my present partners and maybe more understanding in what they are asking for or what they are saying... I clarify what they are saying... I find it easier or better to say or to ask them to clarify what they are asking..."***
>
> ***"...with MS, xxx (partner's name) and I have grown closer together..."***

Theme 2: The Sexual Relationship was Re-Examined After the Diagnosis. Intimacy and Closeness were Essential.

Men have long been stereotyped as only wanting to satisfy their sexual desires with little regard for their partners' needs. The male participants in this study held different views as one man reported "...making love to your wife is more than just intercourse... men have had the stereotype for so long and have been trained to think that's all it was...".

While they stated that intimacy and closeness were more important than intercourse, physical contact was essential for demonstrating feelings and expressing their love which benefited their partners. A strong bond with their partners was perceived as more important than sexual activity itself; however, this perception differed from their beliefs prior to having MS. The following quotes illustrate some of their thoughts:

> ***"...And there's other ways that you show your sexuality... one of MY ways ... is that I am a flirt. I know that, and my wife knows that and she is too, and we get along quite well..."***

> ***"...Sexuality is the whole thing, how you deal and how you act and how you caress and how you touch and how you feel and how you touch people and how they touch you..." Researcher's question: "what do you think is important you in your sexual relationship?"... "Just the physical contact – even if it is only cuddling and kissing, hugging..."***

> ***"... if you talk to women, you'll realize that, to women, sex is probably 10% of it - 90% of it is showing them that they're loved, they're wanted and needed... to them that is really more important than the actual sexual act itself. My wife tells me that over and over***

> ***again anyway [laughs]. So, it kind of reinforces that after a while."***

All of the male participants reported that their sexual function was adversely affected by MS. Fatigue and decreased sensation were the most common symptoms resulting in lack of energy for sexual activity. Their libidos were reduced and they experienced difficulties with having erections and ejaculating. Ultimately, the frequency of sexual activity decreased after the diagnosis of MS:

> ***"...the frequency is different... I'm just too tired..."***
>
> ***"...your sexual activity will decrease ..."***
>
> ***"...one of the things I noticed, with sexual function especially, is the numbness and of course you've got lack of sensation... sensation is a big factor when it comes to intercourse..."***

Some of the men have tried various methods to facilitate sexual activities, such as medication, injections, different sexual positions, or sexual toys. They used oral medication or injections to stimulate erections. Experimentation with different positions helped compensate for fatigue. Sexual toys helped compensate for decreased sensation by providing increased stimuli. The following comments illustrate:

> ***"…we practiced all sorts of things…… all sorts of different things were done and different methods of accomplishing the sex act, but it was just a matter of positioning. Yeah … so we changed…."***
>
> ***"…I'm not able to do a lot of things in bed but I try to do what I can to satisfy her … I use different pills or injections to help with erections and that, which don't always work, but they do work partially sometimes, and we do use marital aids sometimes for her and just to satisfy her, and so – it's been good…"***

Theme 3: The Traditional Roles Changed After the Diagnosis of MS

The majority of male participants indicated that physical changes due to MS altered their traditional roles in their families. They could not perform physical activities like they used to and their status changed from being seen as strong capable men to people who required nursing care. Some male participants had to quit working as they could not perform the duties the job required. The combination of changes often resulted in depression.

One male participant stated that his wife became the breadwinner of the family and he felt frustrated that he could not carry the "man's role" for his family. The men felt they became burden to their partners, who became caregivers, which affected their relationships as couples. Most of the men did not want their partners to be their caregivers. They preferred assistance from homecare, but due to the healthcare system this was not always an option.

The following quotes express their thoughts:

> ***"...the wife and I have changed roles. I don't go to work anymore. I don't do all the physical work around here. I don't do all the yard work and stuff... I'd like to go back to work, but I just physically can't anymore. Now SHE is the breadwinner..."***

> ***"...She helps me to get into bed and to get out of bed sometimes, but, well, I do have home care come in to help me with a lot of things, and we are working on getting more help for me, because I would like to have home care do more for me. I don't want xxx (partner's name) to do things for me. I want to have our relationship just for us. I don't want her to be my caregiver. I want us to have a relationship, not to be, you know, caregiver...."***

The traditional roles in the sexual relationships also changed. Their female partners became more active and began initiating sexual activities. This change was positive for the men because it made them feel accepted as sexual partners, especially after MS impaired their sexual function:

> ***"…the man always seems to,.. maybe just me, but instigate the role or takes the lead role when it comes to having sex with his partner, and I think my wife has come to the point where she's starting to do that…"***

Theme 4: Their Partner's Acceptance was a Major Source of Support in the Relationship

The majority of the men expressed appreciation for their partners' acceptance and understanding of MS, and saw this as their major source of support in their relationships. They felt their partners realized how MS affected their abilities and understood their limits. Being accepted as sexual partners helped them establish confidence and strengthened their sexual relationships:

> ***"…I think a lot has to do with the attitude of the wife or the woman in the relationship, especially with sexual function…our relationship is great. My wife has never said, 'well gee what's wrong with you?' …She's never blamed me for it, which is a big help."***

> ***" I think what happens is that when your partner, especially you know like my wife, will put in more effort… it helps me not only***

> ***psychologically but physically... I know that she's in the position where she wants to make love, that I know that it helps me...."***

Some men asked their partners to leave the relationship when they were diagnosed or at least when the disease worsened. They did this because they did not want to become a burden to their partners. These men faced the dilemma of living alone but would prefer that to becoming a burden to their partners. Other male participants reported feeling fortunate that their partners were willing to maintain their relationships after they had been diagnosed with MS. The following are quotes by the male participants:

> ***"...I know I've brought that up with xxx (partner's name) several times, that if I got too disabled that I would not want to be a burden on her, but she does not think like that. She says that she would not ever put me into extended care or anything. She would keep me here, but if I got to a point where I was too disabled, I would not want to be a burden on her either, though..."***

> ***"...I told my wife, 'well, you didn't marry me with MS so if you want to leave you can leave.' She says, 'I'm in for the long run...'"***

Female Partners of Men with MS

The following themes arose from the female participants, whose male partners have MS:

1. Communication is the most important aspect of the relationship.
2. The sexual relationship changed. Intimacy is the priority.
3. Dealing with loss/sacrifice.
4. Women took on the protective caregiver roles. (Embraced the disorder to protect their husbands/partners).

Theme 1: Communication is the Most Important Aspect of the Relationship

Like the men in this study, all of the women indicated that good communication was the foundation for maintaining their relationships. They talked and expressed their feelings, and usually took the lead in initiating communication. They brought forward issues and asked for their partners' help in resolving them. They wanted interactive communication with their partners and wanted their complete involvement when solving problems. These women indicated that their partners used better communication skills and were more willing to openly express their needs after the diagnosis of MS. This was viewed as a positive outcome. Communication enabled them to discuss and deal with the difficulties they faced. Interaction also facilitated a greater understanding of one another, and enhanced the relationships:

> ***"...The communication is very important...to find out what's working, what's not working...basically just the communication I think that's the most important..."***
>
> ***"...Lots of times we talk...we are brutally honest with each other...we're very expressive emotionally to each other..."***
>
> ***"...I always express my feelings..."***
>
> ***"...I was the one that would bring it to his attention and say: 'look, we're not getting along well now'...I'd say, 'okay, tonight you're gonna come home from work, and we're gonna sit down and talk about it...'"***
>
> ***"...It taught us how to be very honest with each other...a positive thing for him—to learn how to ask for and to accept help..."***
>
> ***"...He was a man who didn't really express his feelings...after he was diagnosed...it came out for awhile...then he realizes some things and then can kind of verbalize them a little bit..."***

The female participants used communication to maintain and enhance their relationships. They were proactive from the time of diagnosis in order to express their feelings about the diagnosis and also learn how their partners felt about the diagnosis. Overall, they felt communication improved after the diagnosis and realized that honesty was the key element, but they still filtered communication. Although all female participants stated that they expressed their feelings honestly with their partners, these women were still cautious. They were able to manipulate the conversation because they took the lead in the conversation in order to protect their partners. They chose the topics and avoided issues that could cause severe conflict or hurt. They hid some of their feelings from their partners and when conversing they decided to withhold the truth. They felt their partners also hid things from them as indicated by the following quotes:

> ***"...It (sex) is more important to him than it is to me...but I cannot let him know..."***

> ***"...We also talk...but we fight over piddly things instead of the big issues because those ones we can discuss..."***

> ***"...maybe I don't see everything that goes on with xxx (partner's name) emotionally because I think he hides a lot from me, that he doesn't tell me but there are things that you just sort of by instinct pick up when you live with someone for so long, that you just know it..."***

> ***"…I complain [laughs]. I go – 'oh, I gotta wash the dishes, and then I have to do this, and then I have to take the dogs out, and then I have to do this, and then I have to go to the store, and then I have to do this'… I want someone to baby me –don't know.***
>
> ***Researcher's Question: "do you tell him what you need?"… "no, I don't tell him what I need…"***

Theme 2: The Sexual Relationship Changed. Intimacy is the Priority

All of the women in the study indicated that MS had a negative impact on their sexual relationships. Most of the participants still had sexual activities with their male partners. However, the frequency decreased after the diagnosis due to sexual dysfunction, such as numbness in the genital region, which affected their partners' erectile functions, and due to their partners' decreased libidos. This decreased frequency and interest in sexual activities made the female participants feel frustrated and discouraged because it seemed like their partners were not attracted to them as expressed below:

> ***"…With him, if it takes too long he'll lose his erection…"***
>
> ***"…It slowed down after because I think he started (losing) quite a bit of sensation…"***

> ***"...I don't think he has much of a sex drive... So, sometimes I feel like he's not attracted to me or ...I don't know if he's almost turned his own mind off because things don't function, so it's almost like he's blocked that out as an interest in his life now..."***

To combat sexual dysfunction issues, such as erectile dysfunction, many of the couples tried to modify their sexual activities in order to "catch the moment". The female participants reported their male partners used assistive devices, such as vibrators and sex videos, to increase sensation and compensate for the numbness in the genital region. The sexual toys provided extra stimuli and excitement in order to stimulate an erection. Some female participants enjoyed the addition of sexual toys; while others found the sexual toys impersonal:

> ***"...He likes the little sex toys so we're into it..."***

> ***"With him if it takes too long he'll also lose his erections so we have to be a little bit quicker so...so we – get – vibrator, and that seems to excite him as well ..."***

> ***"...He went out and bought me a little vibrator... So I would use, but I really – I didn't like it and I didn't use it for the simple fact it was very – cold, impersonal, it's nothing."***

The women stated that having sex in the relationship is important; however, some felt that sex is still more important for their male partners. They participated in sexual activities in order to satisfy their partners' needs and to boost the men's confidence, especially after sexual function became impaired. Some of their comments illustrate this:

> ***"...it's important to relationships to have a sexual relationship...for xxx (partner's name)...it's more important to him than it is to me... because with him it's 95% mental rather than physical. As long as you seem like you're really into it, then he's quite confident...to him that was his manhood, you know, like I can still do this..."***
>
> ***"...I think xxx (partner's name) felt the sexual act meant a lot...What is important? Um, well to me it's important that xxx (partner's name) be satisfied, and to him it's for me to be satisfied, so it's a giving relationship rather than a selfish one..."***

Displays of affection, such as emotional and physical closeness, were hampered by the disease and these were considered more important than sexual activity. After the diagnosis, physical contact with their partners decreased because of unsteady gaits or confinement to wheelchairs deprived and affected their partners' abilities to express affection, such as giving hugs. Those hugs and cuddles provide the physical closeness for intimacy, where was the most valuable part of the relationship:

> ***"...when he started losing more function in his arms, I used to go to a lot of gentlemen and ask for hugs...because I need it...."***

> ***"...now if we're to hug standing up, I have to be careful so we're not falling over. It's just that kind of thing. Yeah, just his physicalness... yeah, it's just – I guess that's what I really, really miss..."***

> ***"...the relationship with a person is more important than the rest of it...I crawl in bed, we watch TV every night and snuggle and so..."***

> ***Researcher's Question: "what do you think is important in a sexual or couple relationship? "...just the feeling, the want of just knowing that I look forward to coming home...when I know he's going to be home...I like to give him a kiss goodbye in the morning...and...just that, just knowing that he wants my kiss and that I want to give him a kiss..."***

A sexual relationship is part of a couple's relationship. All female participants reported their partners' sexual functions were affected and the frequency of sexual activities decreased after the diagnosis. However, for the female participants, a sexual relationship was established by physical intimacy and feeling needed. Losing intimacy frustrated them more than the decrease in sexual activity. Their goal for participating in sexual activity was to satisfy their male partners' needs instead of theirs.

Theme 3: Dealing With Loss/Sacrifice

Most of the women stated they lost their friends, lives, and freedom as their partners' MS progressed. When it came to a point that their male partners started to use a walker or wheelchair, it became very difficult to go out together. Most restaurants, movie theatres, and public buildings were not wheelchair or walker accessible. When going out with their partners who have MS they became apprehensive because they worried they would find themselves in a predicament that they could not manage. These environmental barriers restricted their freedom as couples outside their homes and they stopped going out together. Families and friends did not understand the disease and were fearful. Because their friends were uncomfortable they were forced to give up their old friends and previous social lives:

> ***"...His social network is different...he has totally abandoned them (the old friends)—or they have abandoned us...you lose a lot of friends..."***
>
> ***"...We used to go out, we used to go dancing and...now we don't..."***
>
> ***"...a lot that we shared in our married life, such as traveling and dancing and, uh, playing cards and visiting in other people's homes – can't do it with a wheelchair. Everybody's got stairs. How do you get in and out?..."***
>
> ***"...with his disability I realize physically it's difficult to get around, but on the other hand, I just find that when we are challenged with a lot of obstacles out there in the world, whether we're going shopping or we want to go to see something or whatever, all of those obstacles make it difficult..."***

The women felt they needed to sacrifice their own lives and freedom. They became the breadwinners of their families as well as maintained the households. They became their partners' caregivers and continued their roles as mothers. They had no time for themselves and the stress of endless work greatly affected their lives:

> ***"...Not having time for myself..."***

> ***"...I never had any day off, and that was very, very difficult...the cooking and the cleaning and the yard work...everything was always kind of falling on my shoulders..."***
>
> ***"[Question: what's the impact in your life?] The physical work for me, not having time to myself to do what I want to do...I want to sit down and just do nothing; I don't want to work all the time...too much caregiving on my part..."***

To relieve stress, some of these women chose to get away from their environment temporarily so they could release tension between them and their male partners. Some reported that taking a short bus trip with friends helped them to maintain social lives. One female participant reported that the physical environment, such as stairs and narrow washrooms, was one of the major barriers to their social lives. Therefore, taking a vacation in a barrier-free environment enabled them to retrieve their outside lives as couples. Escaping the stressful environment and temporarily leaving day to day difficulties recharged their energy and made it easier to carry on.

> ***"...I take off – I take a holiday about twice a year... you just HAVE to get away, every so often and you also – I do it because it also helps me to get my bearings back again..."***

> ***"...I find if I go out for a little while, even if I get to go shop a little bit, even just go walk around a second hand store, even if it's just for an hour it feels like I'm like free of it... so it's a break for me. Then I come back and – I still got the mess to deal with [laughs]..."***

> ***"...things were so frustrating and everything and I said this is too disappointing. That's it. We're gonna look forward to a vacation.... And it worked, it was very good ... we'll have a relationship, sexual, because I was relaxed, I didn't have the worries..."***

Losing their personal and social lives after their male partners' illness was commonly reported by the female participants. The physical barriers of the outside environments, financial burden, and caregiving duties forced women to sacrifice their freedom inside and/or outside their homes. In order to keep and refresh their energy to deal with these difficulties, these female partners took breaks from their stressful environment.

Theme 4: Women Took on the Protective Caregiver Roles. (Embraced the Disorder to Protect their Husband/Partner)

In order to maintain their relationships, the female participants realized they must accept the disease, either willingly or unwillingly. They sought as much knowledge as possible in order to prepare themselves and help their partners endure the disease. They learned about the progression of MS and were cognizant of their partners' limitations. They saw MS as a part of their male partners and embraced it as their disease. Instead of the women only being partners they also became mothers, teachers, and caregivers. They carried out both theirs duties as well as and their male partners' duties both inside and outside their homes:

> ***"..I educated myself so that I knew what could happen. I educated myself in understanding, trying to understand the disease, just even the mechanisms of the disease, the trying to – how can I say this? – to learn different methods to alleviate some of the symptoms but yet I never thought that I could take it away. I knew it was a reality, so maybe that's part of it is understanding the reality of it through education…"***

> ***"…xxx (partner's name) almost made the MS our disease instead of his disease…"***
>
> ***"…It's still good. It's just – different…"***
>
> ***"…It was his diagnosis but it was our disease…"***
>
> ***"..The role changed a bit…now with MS I'm more of a caregiver…"***

While their partners still can perform sexual activities, women reported feeling guilty if they refused. They felt that having sex helped their male partners prove their manhood. Therefore, they would participate in sex as a consolation, giving their partners' needs precedence over their own:

> ***"…I feel bad but I'm just not really interested…I wish I could find something that would make me feel more interested…if he can still perform, why aren't I utilizing that…"***
>
> ***"…even if I'm not in the mood then still…I will provide him with it because it satisfies him and it makes him feel good…"***

As the disease progressed and their own physical condition declined with age, some female participants became frustrated and felt guilty that they were no longer able to provide all the necessary care. All of the women hesitated to ask for help because they felt their partners were their responsibilities. They felt guilty about asking for help to lighten their load, either from their families, hired housekeepers or homecare. They also felt guilty about taking time for themselves or having a few interests of their own.

> ***"...It seems the more disabled xxx (partner's name) becomes the more frustrated I become. As I am getting older it is harder because I cannot do all the things I used to do for xxx (partner's name)... and I felt very guilty because I really felt it's my responsibility to look after him..."***

> ***"...and I'm putting over-stress on the other kids. You know, xxx (child's name) help, help xxx (partner's name) with this ... do this xxx (child's name), I'm trying to help xxx (partner's name) get to the bathroom. xxx (child's name), I'm trying to get help xxx (partner's name) into bed; can you do this? So I feel like I'm – I feel guilty because I'm always putting too much on my kids."***

All Participants

The themes that emerged from the interviews of both the men with MS and their female partners were similar. However, in some themes there were differences in how men and women looked at the issues. The common themes were as follows:

1. Communication is the most important part of a relationship.
2. MS affected sexual activity, sexual needs and intimacy.
3. The established roles changed after the diagnosis of MS.
4. The acceptance of MS supported the relationship.

Theme 1: Communication is the Most Important Part of a Relationship

All participants emphasized that communication was the key to ensuring their relationships survived after the diagnosis. Both men and women used communication to acquire or give information regarding the effects of MS on their lives. They wanted to be understood by their partners so their partners recognized their limits and difficulties in dealing with the changes after MS. It helped them to negotiate their needs and expectations in a manner that satisfied both partners. On the other hand, there was some discrepancy in how the partners used communication. For men, communication was an information exchange process which was used to verbalize their needs and solve conflicts that arose in life. Conversely, women used communication more spontaneously and proactively in order to help one another deal with the disease. They tended to initiate the communication and encouraged their male partners to verbalize what they were experiencing. In addition to delivering information, women used communication to fulfill their affective needs and emotional expressions helped them release their tension. Some quotes from the interviews demonstrated the differences in the usage of communication:

> ***Male participant: "But we can't read each other's minds and we don't always send the right signals to one ... You have to communicate and if you don't communicate, I believe things will just get worse ..."***
>
> ***Female participant: "...xxx (partner's name) and I are brutally honest with each other. We have learned to do this if we were going to survive living with MS, we had to learn to be brutally honest with each other, and there are times that say when he gets very demanding that I will – I'll have to tell him back off, leave me alone, I don't want to do this no more, and he also he gets mad, he'll tell me I don't want to be talked to like that. We're very expressive emotionally to each other..."***

Both men and women stressed the need to talk and identified openness and honesty as two essential elements in communication. However, female partners reported discrepancy in what they thought and what they did. Women tended to guard their conversation and sensed their partners' hidden emotions. This contradiction did not appear in the male participants.

In contrast, there was consistency between partners. While one of the partners reported that they openly discussed how MS impacted their relationship, the other partner confirmed the statement and both partners described that their relationship was improved after the diagnosis. One couple illustrated it with the following:

> ***"...she is able to come in and tell me and not feel that she's challenged... That's really what it amounted to... talk about it and, and work it out..."***
>
> ***"What is very positive to us is the strength of our relationship. It has strengthened us instead of weakened us. It's taught us how to be very honest with each other which I think very few married couples have ever learned in ALL of their years of marriage..."***

Theme 2: MS Affected Sexual Activity, Sexual Needs and Intimacy

Both men and women identified that MS did affect their sexual activity and decreased the frequency. However, men and women had different perspectives on why MS affected their sexual needs and relationships. For men with MS, the decrease in sexual activity was a process of the disease. All of the men reported that MS symptoms, such as fatigue and physical disability, were the main reasons for changes in their sexual lives. None of them verbalized symptoms of tertiary sexual dysfunction, such as stress, changed traditional roles, decreased libidos, or fear of incompetence in performing sexual activity. Conversely, women first noticed that intimacy decreased prior to the declining of sexual activity. They reported changes in both themselves and their male partners. The women agreed that fatigue and physical disability due to MS impacted their sexual lives. However, the effects of the emotional aspects, such as stress, as well as the effects of the caregiver/care receiver roles might be the main reason that decreased sexual desire for both partners. The differences were illustrated with the following statements:

> ***Male participant: "... the frequency is different. ... I'm just too tired... And it's my one leg, my right leg is, might as well say it's a piece of meat. It doesn't work very well, so it's hard moving around and stuff"***

> ***Male participant: "Things change…. we went to some classes and xxx (his wife's name) and I in the beginning and they talked about all sorts of things and you can do it, you can do it orally …and we just basically got to the point that xxx (partner's name) didn't want… and I couldn't do anything about it so we just decided that okay we're not going to.."***
>
> ***Female participant: "I for some reason am not interested anymore… I don't feel that sort of closeness… maybe part of the caregiving, part of the more and more responsibility does come on me…***

Both men and women mentioned that intimacy is more important than sexual activity. While none of the men reported that intimacy or sexual contact had changed after being diagnosed with MS, the female participants reported that their male partners' physical disabilities decreased intimacy in their relationships. For example, women described how men stopped hugging them because their arms were weak and how they avoided sexual contact. These physical contacts were very precious to women. None of the female participants mourned the loss of or the decrease in sexual activity, but some of the women did mourn the loss of physical contact.

Theme 3: The Established Roles Changed after the Diagnosis of MS

Both men and women reported that MS affected their established roles not only in home management and maintaining daily routines, but also affected the interaction of the sexual relationships. No matter how severe the MS was, it appeared that all female partners played the protector roles and carried on many responsibilities which traditionally belonged to men. Women became the mothers, teachers and caregivers for their male partners while men became children, students and care-receivers. These changes diminished the equality in the couples' relationships and created high-low imbalanced relationships. Some of the following quotes may explain the sense of an unequal relationship:

> ***Male participant: "You gotta explain to your wife what you're going through, and try to be as nice to her as possible and forget – well like I used to argue with my wife once in a while when I was before MS. I don't argue anymore. What's the sense in arguing?"***
>
> ***Female participant: "I was the one that would bring it to his attention…the first thing I would always say to him is okay there was a reason we got together. And because of that reason, we're going to make this work…. someone had to be sort of the***

> ***instigator of it or whatever and like I say maybe it's because I'm a caregiver, I don't know, but you know it was kind of like okay there's a problem. It needs to be looked at or dealt with or you know, we need to do something about it."***

Both partners reported that these changes frustrated them. Male participants were frustrated that they were incapable of maintaining their traditional, pre-diagnosis roles while female participants were frustrated with the endless workload from their added roles. On the other hand, men reported appreciating their female partners' efforts while women reported the gratification of being needed and the accomplishment of taking care of their male partners.

Theme 4: The Acceptance of MS Supported the Relationship

The acceptance of the disease was a crucial component in the couples' relationships. While all female participants expressed their acceptance of the disease, not all of the men accepted to the same extent. For example, one man expressed his frustration of staying at home instead of being the financial provider for the family that he used to be. Men stated that the acceptance by their female partners was a great support for them. It strengthened their relationships and encouraged them to communicate their needs. Women reported acceptance because it was the practical way of maintaining the relationships as it included willingness to explore and understand the disease. In other words, when one of the partners did not accept the disease, frustration and barriers were exaggerated and, in turn, blocked communication and caused failure of a marriage. Some of these quotes illustrate the benefit of acceptance and damage from resistance to acceptance of the disease:

> ***Male participant: "…She has been understanding that I am tired most of the time, and that I can't do things that I might like to do… she understands that I just can't do it …I can see that I am lucky to have got her…"***
>
> ***Female participant: "…I educated myself so that I knew what could happen. I educated myself in understanding, trying to understand the disease, just even the mechanisms of the disease, the trying to – how can I say this? – to learn different methods to alleviate some of the symptoms"***
>
> ***Female participant: "…he's not totally not accepting it but he's not embracing it, you know? Put it that way. And I see that frustration and that hurts too…"***

Chapter Five – Discussion and Conclusion

The Lived Experiences

The purpose of this study was to understand the lived experiences of couples in which the male partners were diagnosed with MS. This study explored how MS affected sexual relationships in couples. This comprehensive knowledge can assist clinicians in their work with couples affected by MS and provide insight for the couples themselves. Furthermore, learning from others' lived experiences can help couples avoid frustration from ignorance of the disease process (Thorne et al., 2004).

The research findings indicated MS significantly impacted the male participants' physical functions. Fatigue was the most common symptom reported, which severely decreased their ability for physical activity, including sexual activity. Because of fatigue, some male participants were forced to rely on their female partners for personal care, such as transfer and dressing. Fatigue also affected the men's motivation in sexual activity. Although male participants did not disclose having a lack of confidence, becoming care-receivers and feeling like incompetent sexual partners created doubts of their own masculinity.

Consequently, men began to avoid all forms of sexual contact believing intimate contact would lead to sexual intercourse. Their doubts regarding their own performance caused them withdraw from their sexual relationships. Sexual activity then decreased or ceased. The men's sexual-esteem decreased after these changes. As a result, they allowed their female partners to take more active roles in maintaining and enhancing their sexual relationships.

The research findings indicated MS also significantly impacted the men in their traditional roles. The MS symptoms adversely affected their roles as lovers, husbands, and financial providers for their families. The male participants then became depressed and frustrated about lacking competence in these traditional roles. Relationships were ultimately impacted when the men became withdrawn and inactive in the relationships.

On the other hand, the female participants lived in a world of sacrifice. Although the interview questions focused exclusively on their sexual relationships, most of the women framed their responses in the context of their other roles within their relationships, in particular the added and changed traditional roles after the onset of MS. They felt it was their responsibility and commitment to maintain and ensure survival of the relationships. Thus, they sacrificed their lives and freedom to help and protect their male partners who were dealing with the disease. They gave priority to their male partners' needs and forced themselves to take ownership of their relationships.

Whereas female participants reported the impact and the dissatisfaction in their sexual relationships, they admitted they filtered conversations to hide feelings regarding their dissatisfaction of life, which included sexual interaction with their partners. Although communication was reported as essential in the relationships, in which openness and honesty were two key elements, women used "white lies" to protect their partners as the truth they felt could hurt their male partners' confidence. They were deeply frustrated by the loss of intimacy, but they still tried to maintain positive attitudes to encourage their male partners by hiding their negative emotions. They took on their male partners' roles and responsibilities not only around their homes but also when it came to sexual intimacy. These women understood their male partners' limitations and frustrations in things they were no longer capable of doing. Women became more active in initiating sexual contact in order to maintain intimacy in their relationships and to help raise their partners' sexual-esteem as it related to sexual activity. They forced themselves to have intercourse with their partners despite the fact that stress from work reduced their passion for sex. Thus, the outward actions and words of women in this study did not necessarily reflect their inner thoughts.

The results of the present study were consistent with a previous study conducted by Taleporos and McCabe (2001) whose findings demonstrated that individuals with disabilities had strong interests in and a desire for sexual expression. All participants in this study identified sexuality as a critical component of their relationships. Intimacy was recognized in their definition of sexuality and was confirmed by all participants as the most essential part of a relationship while they valued sexual intercourse differently.

Communication in the Relationship

Rolland (1994) stated that open communication is essential to living well with chronic disease. Effective communication helps couples identify and normalize difficult feelings and re-establish their relationships. All participants in the current study identified communication as the key element to maintain and strengthen their relationships and help them deal with the impact of MS. This is consistent with results of previous research done by Rolland (1994). The research findings demonstrated that all participants agreed on the importance of communication as both men and women reported increased and improved communication helped them to clarify and solve conflicts. All of them emphasized the need to communicate with openness and honesty in order to maintain their relationships. Through communication, men became more sensitive toward their relationships, thus fulfilling women's needs to be understood. The understanding from female partners encouraged the men's acceptance of their illness and ultimately enhanced their relationships.

Couples conveyed their desires and thoughts through the interactive process of communication. The research findings showed that communication can be significantly impacted when one of the partners fails to participate. Ultimately, inadequate communication would affect the relationship. Male participants reported that having MS helped them realize the importance of communication and this was a positive change. In the process of dealing with life and MS, they were forced to verbalize their thoughts and participate in communication. Comprehensive communication improved their relationships because it helped their female partners understand what they were experiencing and vice versa.

On the other hand, women used communication more proactively and took the lead in communication after the diagnosis. Communication was their tool to fulfill the desire to understand their partners and, in turn, to be understood. They were pleased with their improved relationships because their male partners became better communicators after the diagnosis.

Honesty and openness were identified by all participants as the most important components of communication. However, female participants lived with the dilemma that honesty and openness could endanger the benefits of communication and be hurtful to their partners. Because women tended to initiate communication, it allowed them to manipulate and filter the topics of conversation. They protected their partners by avoiding or concealing issues that they considered destructive. For example, one female participant reported that they only fought over minor issues instead of the big issues because she knew they could discuss small things without causing irreparable damage to the relationship.

In addition, they felt that their male partners also concealed thoughts from them. Interestingly, none of the male participants reported they disguised conversation or that their female partners hid things from them. This ignorance may have existed because the men with MS still struggled to deal with disease and the women protected their partners and elevated the men's needs above their own.

Sexual Dysfunction after MS

All of the men in the present study reported having sexual dysfunction as a result of MS. This is consistent with previous research which indicated that 92.1% of men with MS reported sexual dysfunction after the onset of symptoms (Zorzon et al., 1999). The experiences shared by the male participants encompassed 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); and tertiary (psychosocial and cultural issues that may interfere with sexual satisfaction or performance).

In men with MS, the most common symptoms of primary sexual dysfunction reported were decreased sensation, decreased libido, and difficulties with erectile function. Secondary sexual dysfunction included fatigue, decreased mobility, and in-coordination. When the researcher asked what affected their sexual activity, male participants did not directly verbalize having symptoms of tertiary sexual dysfunction due to the abstract nature of psychosocial and cultural issues. The reported changes that might relate to tertiary sexual dysfunction were lower sexual/self-esteem, depression, feelings of reduced masculinity, feeling less attractive, change in gender roles within the family, feelings of dependency, and previous or fear of unsatisfied performance after the onset of MS symptoms (Sanders, Foley, LaRocca, & Zemon, 2000).

All men reported frustration with their primary sexual dysfunction because it directly affected their abilities to have sexual intercourse. They started to compensate by changing sexual positions or adding sexual toys. However, with the progression of the disease, many of them stopped or dramatically decreased the frequency of sexual activity while secondary sexual dysfunction further affected them. Secondary dysfunction, such as the increased difficulties in moving body parts, significantly reduced their sexual drive. All of these changes after the onset of MS, then, led to tertiary sexual dysfunction and ultimately decreased their motivation for sexual contact or interaction with their female partners.

In addition, tertiary sexual dysfunction was reported by the female participants. Changes in traditional gender roles, fatigue, and stress of endless work decreased their interests in sexual activity. This decreased sexual interest and generated guilt in women because they felt their refusal would harm their male partners' masculinity.

Impact of Disability on Sexuality and Couple/Sexual Relationships

Consistent with Gagliardi's (2003) findings, all participants in the present study identified sexuality as "friendship, sharing, and understanding". Not all participants perceived that MS caused deterioration in their sexual relationships, which was reported in McCabe's findings (1996). This different perception may be due to the exclusion of sexual intercourse in some participants' definition of sexuality. Some participants reported their relationships were "changed" and others experienced an improvement in the quality of their sexuality and relationships. Similar to other research findings, men with MS indicated the illness had a positive influence on their relationships and their partners also claimed that their marital relationships had improved since the diagnosis of MS (Hakim et al., 2000; Mohr et al., 1999).

Taleporos and McCabe (2001) found that some individuals felt their disabilities decreased their value as sexual partners. Garliardi (2003) stated all of her research participants reported that they were sexually active prior to having MS, but became sexually inactive after the diagnosis. This was confirmed by the participants who had MS in this study. Sexual dysfunction affected men's manhood as they believed a man should be sexually competent and satisfy their female partners' needs. This reduced sexual-esteem contributed to the tertiary sexual dysfunction found in men with MS and discouraged men from participating in sexual activity.

Male participants highlighted the importance of intimacy and closeness in their relationships, which confirmed Miller's (1994) and Perrone's (2004) findings that intimacy provided the foundation for meaningful expression and enhanced a relationship. These results were also similar to what male participants reported from the preceding study (Esmail, 2005). However, in this study, it appeared that men over-emphasized intimacy and devalued intercourse in their sexual relationships. Some men devalued intercourse because their female partners said it was not important. Some said intercourse was not important and intimacy was enough for their relationships when MS reduced the ability to have erections.

Although men did not admit to lacking confidence during sexual intercourse, the avoidance of sexual contact and redefinition of sex demonstrated it. These men were forced to focus on intimacy and closeness in order to compensate for their inability to perform sexually. To illustrate, despite decreased confidence in their sexuality, men were comforted because their partners initiated sexual activity, thus providing reassurance that men were valued as lovers in their relationships (McCabe & McKern, 2003). Being accepted as sexual partners became a significant issue for men with MS.

Research findings indicated that male participants tended to allow their partners to take the lead in their relationships, and reported appreciating their partners' efforts. However, instead of fighting for their relationships, these men reassigned the power to their partners, which allowed women to dominate and preserve their relationships. Contrary to the men's attitudes in the relationships, women stated that their lives focused totally on maintaining the relationships. This difference in attitude may be due to unequal power in the relationships because men were in the care-receiver roles and women were the caregivers. Some men felt they were a burden and suggested their partners leave the relationship so their female partners would not have to endure their disease and the men would not be the weaker partners in the relationships.

Female participants reported sexual activities, physical contact, and intimacy declined or stopped entirely after the diagnosis. While they accepted decreased sexual activity, they were more frustrated by reduced physical contact and loss of intimacy. Only one female participant directly stated that sex was not important in the sexual relationship and all of them identified intimacy as a priority in their sexual relationships. Women tended to devalue sex perhaps to compensate for their partners' sexual dysfunction. Some women also reported decreased libidos, which may have resulted from tertiary sexual dysfunction that included worrying, fatigue and stress from work.

On the other hand, women noticed the avoidance of sexual contact by their male partners due to their erectile dysfunction and decreased mobility which affected one's ability to have intercourse. To maintain intimacy in their relationships, women were forced to take lead roles in sexual activity, which encouraged men's participation. They found their initiation increased their partners' sexual-esteem because being capable of having intercourse and the continued role as a sex partner confirmed their manhood. This response motivated women to continue their initiation. Not surprisingly, the women reported feeling guilty if they refused or were uninterested in sex while their partners were still capable of having intercourse. As a result, they forced themselves to have intercourse with their partners even when they had no desire for sex. In addition, while men constantly shunned sexual contact, women's sexual-esteem decreased and they started to doubt their own sexual attractiveness. Ultimately, it impacted their passion for sex and their sexual relationships.

Some women stated their relationships became loving platonic relationships after the diagnosis of MS. They maintained very good friendly relationships and looked after one another. Although MS strengthened their friendship which was positive, they felt they were forced to give up intimacy or the sexual part of the relationships. Because these new relationships resulted from men's inability to have sexual intercourse, the women were obligated to accept the change. They felt the effort of continuing sexual activity and the continuing incompetent performance of men in sexual activity could hurt their partners' manhood and create conflict, which they had no energy to deal with.

Consistent with other studies, the present study illustrated that for partners who do not have a disability, feelings of emotional closeness, mutual concern and willingness to participate in a variety of sexual activities are more important for sexual fulfillment than intercourse (M. Kreuter et al., 1994; Kreuter et al., 1996; Miller, 1994). Women in this study still acknowledged the value of sexual activity, but its absence was acceptable to them when intimacy existed. Unfortunately, all female participants reported that MS not only affected their sexual activity but also decreased intimacy. The caregiver role might be the major reason intimacy was affected. This was supported by Miller (1994) who reported that the longer a partner who does not have a disability continues to perform the caregiver role, the more difficult it becomes to return to the level of intimacy there was before the onset of MS.

Caregiver Stress and Role Shift

Disability has been shown to increase stress and affect the roles experienced by couples (Feigin, 1998; Rolland, 1994). Consistent with the literature, all women in this study had increased caregiver roles and took over many of the traditional male roles during an exacerbation or when the MS worsened (Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000; Foley, 1992). They became leaders in intimacy and became protectors of their male partners. As a female partner, they felt caregiving and added roles were their responsibilities. As a result, they sacrificed their own activities in order to provide care and reported decreased social contact due to time limitations. Consistent with the literature reported by O'Brian (1993), these women felt confined by their caregiving tasks and suffered from the stress of being 24-hour caregivers. Although they endeavoured to provide all of the care, these women still experienced guilt when they became less competent in their caregiver roles due to aging or time limitations.

In addition to the caregiver roles and household tasks, the female partners also took over financial responsibilities after their male partners were unable to work due to MS. Consistent with the research findings of Parker (1993), women eventually sacrifice freedom to handle new responsibilities. However, this sacrifice might create an unequal balance in a relationship. The changes in the dynamics and power balance within the couple's relationship could further impact the relationship (Perrone, 2004)

On the other hand, consistent with a previous finding (Newsome & Schultz, 1998), men in this study did not want their partners to be their caregivers. They wanted to have "couple" instead of "caregiver-care recipient" relationships. They were upset by being perceived as weak or incompetent men. Although they appreciated their female partners' efforts in maintaining the relationships, they felt frustrated and depressed about the changed relationships.

Coping with MS as a Couple

Coping abilities were addressed in the literature with regard to how it influences people's adjustment to life with a disease. Parker (1993) reported that couples who face the illness together may actually become closer to one another. This was also demonstrated in this study. For some couples, when one of the partners reported that they fought the illness "together", it was confirmed by the other and both partners claimed that the disease improved their closeness. Conversely, one male participant's previous unsuccessful marriage demonstrated that the absence of communication or care by either partner would have an effect on the relationship.

The male participants in this study were not very articulate when asked directly about the strategies they used to cope with issues that arose in their sexual relationships.

Nevertheless, they all stated that interactive communication was a very important and an unbeaten tool for dealing with their altered lives post-diagnosis, which was consistent with previous literature (Esmail, 2005; Perrone, 2004). A positive change was that the men became more perceptive about their relationships and the needs of their partners'. This was a welcomed change confirmed by their female partners.

None of the men reported that they felt stressful or sensed their female partners' stress, disguised communication, and dissatisfaction in their sexual relationships. This insensitivity toward changes after having MS may have been one of their coping strategies. McCabe (2002) reported that when men with MS focused on the positive it was a significant predictor of sexual satisfaction. Other reasons included the guarded communication their female partners used in order to protect them. Men may have been too focused on their disease and then became insensitive to their surroundings. Consistent with findings from a study conducted by Chan (2000) whose participants had spinal card injuries, life satisfaction might result from accepting a lower standard of life style, thus decreasing stress for people living with disabilities.

Although their relationships were filled with stress and sacrifice, some female participants reported advantages in providing care for their partners. Previous research (Pozzilli et al., 2004) showed that improvement in the health or emotional status of the individuals with MS has positive end results for the caregiver. In some respects, the caregiver roles satisfied their motherhood needs and they were content with being needed by their partners. This was demonstrated in Perrone's report (2004), which concluded that awareness of a caregiver's contribution and accomplishment in the caregiving role can motivate the caregiver and provide positive feedback to their relationship.

The most common coping strategy reported by women was to escape from the stressful environment, which was consistent with other findings (Chan, Lee, & Lieh-Mak, 2000). They took breaks away from their homes, either alone or with friends. While they sacrificed their freedom to maintain their relationships, these breaks renewed their energy to cope with the endless workload they carried after the onset of their partners' MS. While environmental barriers to wheelchairs or walkers became obstacles in their social lives, travelling with their partners to barrier-free environments helped couples re-establish and enjoy entertainment outside their homes.

All female participants identified acceptance of the illness as a positive attitude toward the disease. This acceptance led to the desire for a thorough knowledge of the disease. They did a great deal of research, seeking information from variable resources so they would be fully competent to fight the disease. When dealing with chronic illness, using a positive attitude toward problem-solving was one of the efficient coping strategies reported by Perrone (2004) . Armed with an abundance of knowledge, women took the protector and tutorial roles to lead their partners through the disease. On the other hand, acceptance from their partners helped men adjust to the disability. Moreover, it helped women re-evaluate and decrease expectations from their male partners. Changing expectations successfully helped the partners re-establish their relationships, which is consistent with studies that found changed expectations characterized the process of crafting a meaningful life after illness (Chan et al., 2000; Thorne et al., 2004). When primary sexual dysfunction influenced sexual activity, alternate ways for achieving intercourse were reported by most of the participants. This study demonstrated that oral medication, injections, change in sexual positions, sex videos, and sex toys were used by the couples to facilitate and enhance sexual activity. Satisfaction with these modifications and assistive devices varied in different participants. Some male and female participants reported enjoyment with the modifications and assistive devices, while one female participant described sex toys as impersonal and cold.

Speziale (1997) reported that couples who relied solely on one another for emotional support could place an extra burden on the relationship and could distance themselves from the resources that might be beneficial. Surprisingly, only some of the participants in this study reported that they acquired support from other resources. The reluctance might be a result from women's guilt from seeking others' help, limited time due to heavy workloads and men's reluctance due to feeling they are perceived as weak by other people. The absence of outside supports may have created tension in the relationships and stress levels for the female participants.

Couple Characteristics that Predict Successful Adjustment

Other researchers (Brown & Giesy, 1986; Milligan & Neufeldt, 1998; Perrone, 2004) have found that individuals with disabilities who have more positive attitudes and acceptance of their disabilities are more likely to continue in strong positive couple relationships. In the present study, this was demonstrated by the women with partners who had MS. These women had positive attitudes and accepted their partners' MS, as one woman stated "it was his diagnosis, but our disease". They kept their commitment to their relationships. This positive attitude was also demonstrated by some female participants who stated that they enjoyed being needed and saw their roles as valuable.

While most of the male participants perceived their adjusted life positively, some still held negative attitudes toward their illness and were depressed due to losses after the diagnosis. Those who reported positive emotions and better adjustments were still productive in their families, communities, and societies. This finding emphasized the importance of remaining productive despite having a physical disability. It also supported the argument that a man who has expectations of fulfilling former roles would be dissatisfied with his performance. As a result, he would fail in re-establishing a meaningful role after the disease or ignore his contribution in the new role if there was one. The disease would become more difficult to accept.

McCabe et al. (1996) found that most of the couples express strong negative emotions in relationship to their illness and although MS has a negative impact on sexual function, they still consider their relationships to be strong sources of support. This was confirmed in this study. Although all participants described negative effects in their relationships due to MS, through increased communication and understanding, all couples were able to move their relationships to a point where they achieved a level of satisfaction.

Gender differences

When comparing the results of this study with the preceding study (Esmail, 2005), gender in general appeared to be the key factor in how individuals responded to MS as it related to their sexual relationship. Women tended to use similar approaches in dealing with disability whether they had MS or their partners had MS. The women hid their emotions and avoided some issues that might endanger their relationship. All the women took on the "burden" and felt that they were obligated to satisfy their male partners' needs. This in turn tended to influence the males perceptions and responses to having MS or having a partner who has MS.

Male participants in both studies were shielded from the true impact of MS in regards to their sexual relationship. These differences appeared to be a direct result of how each gender communicated with each other and coped with changes after the onset of MS. This was also due to the fact that women were not always fully honest with men. For men whose female partners have MS, they did not feel their sexual relationship changed. Women with MS forced themselves to participate in sexual activity because they were afraid of being abandoned or not meeting their male partner's needs. While the men who had MS, were not aware of the changes that their female partners reported. Their female partners again were not fully honest with them stating that sex was not important. Their motivation for being dishonest was to protect men with MS and not feel pressured into participating in sexual activity that may result in unsuccessful sexual performance and further frustration.

In this study, both men with MS and their female partners reported sexual dysfunction and decreased frequency in sexual activity. Men with MS experienced decreased sensation, difficulties with erectile function, and fatigue, while female partners reported the added physical workload, stress of limited time, and caregiver roles decreased their sexual desires and resulted in decreased sexual activity. However, in the preceding study (Esmail, 2005), only women with MS reported major changes in sexual activity. The possible reason for the difference is men with MS have more obvious sexual dysfunction which directly affects their sexual performance. For women with MS, the primary sexual dysfunction, decreased sensation in genital area, might not directly impact their participation in sexual activity and can be more easily hidden.

Limitations of the Study

Sexuality is a private and sensitive topic. Most people are not comfortable with discussing their sexual relationships, especially when there may be problems with them. This may have explained the difficulties the researcher had in recruiting participants. Even with the couples that volunteered, the willingness of disclosing difficulties regarding sexual dysfunction may have been limited or filtered, especially with the depth of content. For example, not many of the participants initiated telling their stories or details regarding sexual dysfunction until the researcher directly asked. In addition, quite often the researcher needed to ask questions to facilitate more description as the participants tended to answer the questions quickly and were reluctant to tell the stories that they thought the researcher might not need to know.

In general, these participants voluntarily participated in this study, they are more likely to have an agenda of where they want to share their success. Also, couples who are still struggled in their relationships, may not be comfortable, confident or ready to share their experiences. As demonstrated in the interviews, most of the participants were enthusiastic in telling their stories as they felt their stories could help other individuals who have MS. After the tape recorder was turned off, many participants told the researcher that they hoped their stories were helpful. This may have influenced the direction and type of data gathered during the interviews as they might have tended to tell the successful sections of their lives.

Implications for Clinical Practice and Service Delivery

Many clinicians report feeling incompetent to address issues in couples' relationships due to having limited knowledge (Ide, 2004). While couples seek consultation regarding their sexual relationships, clinicians often find themselves with insufficient information to provide effective solutions (Ide, 2004). This study provided lived experiences that would benefit clinicians with first hand information. Although the results cannot be generalized, they may allow clinicians to better understand how MS impacts couples' relationships and the issues that might be faced by people with MS and their partners.

This study demonstrated some general issues that may impact a relationship, but each couple has its own unique challenges. After getting permission from couples, clinicians should initiate topics related to sexuality to give couples to discuss their sexual relationships (Esmail et al., 2002).A sexual history, including changes before and after the onset of MS from each partner, can help clinicians better understand individual preferences in a sexual relationship. By using interactive communication, clinicians can help couples to recognize changes or issues that happened after the onset of MS and identify the positive aspects of their relationships. Emphasizing positive aspects in a relationship encourages a more positive attitude toward impacts that result from MS and supports couples in continuing their relationships (Rolland, 1994).

Although the importance of communication was reported by all participants, it was filtered. This disguised communication could ultimately affect a relationship. While participants in this study were relatively adjusted to their disease and reported improved communication after the onset of MS, there could be couples who avoid communication. Clinicians should identify those couples and help facilitate and increase more open communication. Clinicians can provide communication programs to help couples identify their needs. Fears in the dilemma of "white lies" and destructive topics should also be discussed between couples. Being a third person in the communication program, clinicians are able to act more objectively and facilitate effective communication to help couples find language to describe their issues after the onset of MS. Clinicians could be more proactive in addressing sexual and relationship issues that may cause problems to the marriage or relationship (Hakim et al., 2000). A problem focused approach, instead of emotional expression and conflicts, should be encouraged to solve the issues. This, in turn, assists in marital adjustment after the disease (Yalcin & Karahan, 2007).

Research results suggested that a sexual relationship is important in a relationship, although the definition of sexuality and a sexual relationship differed between participants. In particular, intimacy was reported as an essential element in a relationship. Clinicians should help couples define their intimacy needs and help each partner acknowledge his or her partner's needs.

Caregiver burden was demonstrated as the most significant source of stress for the female partners of men with MS in this study. Some caregiving tasks can be provided by a community healthcare agency to ease their burden and help relieve their stress. However, not all participants reported that they were provided with adequate information regarding available resources and some female participants reported feeling guilty about bringing in help. Clinicians could help couples find available outside resources and provide support for caregivers in using outside help. Education regarding stress relief and methods in building supportive networks should be emphasized and provided to couples, especially female partners. While caregiving tasks are unavoidable to the female partners, clinicians can help them recognize their contributions to their relationships, which would motivate them to provide better care (Perrone, 2004). Supportive programs that focus on improving health for men with MS, instead of focusing on the loss and sacrifice of caregivers, would help female partners re-establish their meaningful roles in life (Perrone, 2004) .

Harrison et al. (2004) reported that higher levels of acceptance of illness in people with disabilities were associated with lower levels of marital concerns. Research also shows that a productive and meaningful role in life increases the acceptance of having a disability (Perrone, 2004) . As a result, it is important for men with MS to enhance their contribution and productivity in their relationships. However, most medical interventions are focused on lost functions and seeing people with MS as "patients" who need to be cared for. Clinicians, especially occupational therapists, can use activity analysing skills to help men with MS identify and utilize their remaining abilities in activities of their choice. occupational therapists can help couples learn how to modify activities to match the function of men with MS in order to maximize their independence and productivity in life (Kennedy, 1987). Occupational therapists can also help men with MS choose appropriate adaptive devices to compensate for their lost function, which would enhance performance and achievement of desired activities. For example, using sexual toys can provide extra stimulus during intercourse, which might help with an erection. Maximizing success rate in performing activities help men with MS raise their confidence after losing their competence in the activities that they used to do independently.

In particular, men with MS can lose all of their traditional established roles, such as lovers, husbands, financial providers and fathers. Female partners tend to have increased roles, which partially belonged to their male partners before the onset of MS. Including men and their partners' expectations, clinicians can assist couples to prioritize their needs, recognize the changes in their lives, adjust to the new roles, and establish realistic roles corresponding to their capabilities (Hakim et al., 2000). This process helps both partners accept their adjusted roles. Ultimately, it can increase the productivity of men with MS, lower the caregiver's stress, and facilitate the process of acceptance.

Fatigue was reported as the main physical dysfunction in this study, which significantly impacted couples' sexual relationships. Clinicians, especially occupational therapists, can help men with MS use their energy more efficiently such as identifying their workload, knowing the amount of energy needed for certain activities, prioritizing activities of their choice, and modifying activities. These techniques can help men with

MS successfully perform selected activities. For example, couples can schedule sexual activity on particular days and save energy for it. During sexual activity or intercourse, couples can explore different positions that require less energy. For men with MS, understanding how to schedule their time helps them use their limited energy more effectively.

Implications for Future Study

The present research has met its goal of exploring the impacts of MS on couples' sexual relationships where the male partners were diagnosed with MS. Although the result might not be generalized, the date can be used by clinicians when dealing people with MS and his or her partner. It is critical that individuals with MS understand the changes that could occur in their sexual relationships due to MS. If clinicians can effectively help these couples handle the impacts of MS has on their sexual function, these couples may find be better able to cope with all the issues identified in this study.

The impact of MS on each individual sexual relationship may vary for different age, gender, length and type of relationship, the financial situation, and a range of other factors. The strategies clinicians uses should be client centered based on the unique situation the couple are in. Future research is necessary to determine what types of strategies would effective in preventing the deterioration in sexual relationship This information can be included in education programs for people with MS and their partners. In addition, there is still limited information about how couples can adjust or modify their sexual activities and the benefit of sexual assistive devices such as medication, or toys. Further research is needed for to develop a more comprehensive picture of the consequences of MS on couples' sexual interaction.

Conclusion

The results of the present study demonstrated that MS has a negative impact on many aspects of a couple's relationship. For people with this illness, the diagnosis not only affects their physical function but also the sexual interaction with their partners. The physical impacts eventually lead to psychosocial changes which impact a couple's relationship even more than the diagnosis itself.

In order to maintain their relationships, MS has forced men to become better communicators. They were more understanding and sensitive toward their relationships, which was confirmed and recognized as positive change by their female partners. Both men and women reported increased and improved communication and identified openness and honesty as two essential elements in communication. However, while women tended to initiate the conversation to encourage men's participation, the communication was filtered. Women avoided the destructive topics to protect their male partners, but none of the men sensed this disguised communication.

In terms of their sexual relationships, both men and women emphasized the importance of intimacy which was also reported in the preceding study (Esmail, 2005). Some of the men devalued sexual intercourse after MS impacted their performance in sexual activity, while some of the women identified sex as a valued component in their sexual relationships. Although men identified sex as a way to express love and to fulfill their partners' needs, they still tended to avoid all forms of physical contact. Men felt intimate contact should lead to sexual intercourse, which they could not completely fulfill. The avoidance and decreased intimate contact from men discouraged women from participating in sexual activity and ultimately impacted their sexual relationships.

Men tended to comply with changes after the diagnosis and hesitated in seeking help or in continuing their relationships. They felt their female partners were more instrumental in maintaining and enhancing their relationships. On the other hand, women tended to sacrifice and focused their daily lives on meeting the needs of their partners with MS. This reaction is very similar to the women with MS in the preceding study (Esmail, 2005). Women with MS felt they needed to be the "superwoman" and took their male partners' needs over theirs. Both women took on the protector roles and the burden either their own disease or their male partners' illness. These women also forced themselves to have sex to satisfy their male partners' needs.

Women also demonstrated more positive attitudes toward their partners' MS. Yet, women still experienced guilt when they failed to meet their partners' expectations or when they felt they were not competent in their caregiver roles.

For each partner, remaining in meaningful roles and recognizing each of their contribution to the relationship increases the acceptance of disability and encourage positive adjustment after illness. Clinicians should help couples understand how MS could impact their relationships. Clinicians can provide programs to facilitate open communication, use a problem focused approach to identify each partner's needs, and provide education on available resources to ease caregiver burden and stress.

In conclusion, among four heterosexual couples where men have MS, communication was identified as very important for all of the participants, but it was filtered. Women with partners who have MS tend to take on the burden of the disease, the martyr roles, and the protector roles. Men with MS were more likely to be shielded from the true impact of the disease as it relates to their sexual relationship. Intervention focused on both partners would help them adjust the imbalance of their relationship and improve their sexual relationship.

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Appendix A – Recruitment Posting

Title of Research: The "lived experiences" of couples' sexual relationships in males with multiple sclerosis

Are you interesting in participating in a research project?

Who: Couples in which *male partner* has been diagnosed with multiple sclerosis (MS) after the relationship was established. The male partner has MS for at least 1 year and not more than 20 years, and is between 18 and 60 years old. Both partners are needed.

Why: There is a 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 partner. The impact on the sexual relationship of couples and how to address the various issues are neglected subjects 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.

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

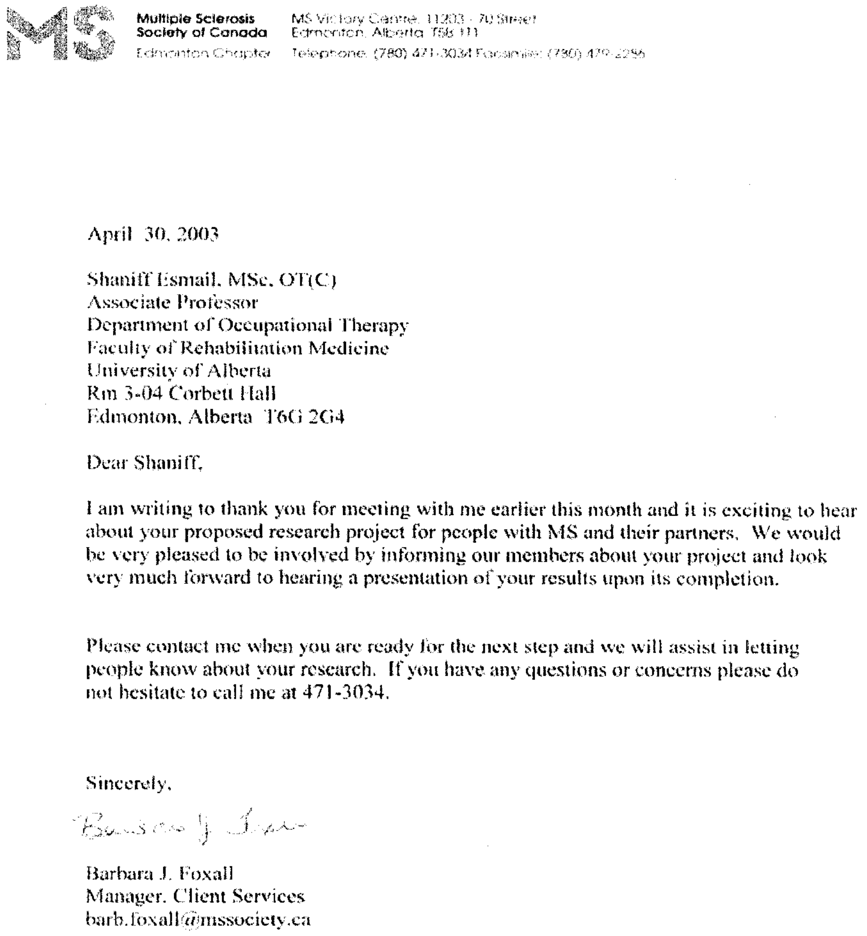
When: The interview can be scheduled at a time most convenient for you.

How: If you choose to volunteer for the study you will be required to spend one hour being interviewed separately by the investigator of this project. Immediately after the interview, a short debriefing will be held with you to clarify any issues or answer any questions. Later, a second shorter interview including the ideas researcher get from the first interview will take place by phone to verify the data and ensure accuracy of the information gathered.

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

Hueichen Jane Huang, MSc Student
Phone: 435-5469 Email: hueichen@ualberta.ca
Dept of Occupational Therapy, Faculty of Rehab. Medicine

Appendix B - Letter of support from M.S. Society of Canada-Edmonton Chapter



Multiple Sclerosis
Society of Canada
Edmonton Chapter

MS Victory Centre, 11203 - 70 Street
Edmonton, Alberta T5B 1T1
Telephone (780) 471-3034 Facsimile: (780) 479-2296

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
barb.foxall@mssociety.ca

Appendix C - Interview guide

<u>In-depth semi-structured interview</u>

1. Small Talk – rapport building

2. Some basic introduction questions to enhance comfort and get basic demographic information.

- age
- educations
- 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 covers basically all aspects of being male and females. Sexuality is part of who we are.

4. Open-ended introductory statement/question

As you know, the focus of this research is to understand the "lived experiences" of couples' sexual relationships in males with multiple sclerosis – basically what I would like to understand is what we call your "lived experiences". You decide what is important – what would you like me to know about this topic.

5. Questions will be asked when the participant has nothing more to add or the topic goes significantly away from the focus of the research.

Example of prompts/questions used if / as necessary:

- Tell me a little about your present relationship
- How has things changed since the onset of the disability?

-Your thoughts on these changes?

- How has your sexual relationship been impacted by your (your partner's) disability?
- What give you meaning in terms of your sexual relationship?
- Has the disability had any positive effects on your relationship?
- What aspect of your disability tends to cause the most problems?
- Have you or your partner had to adjust the role you play – in your relationship?
- What have you found to be most helpful in dealing with this whole area?
- 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?

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Appendix D – Information Sheet for Prospective Participants

Principal Investigator:
Shaniff Esmail, Associate Professor
Dept of Occupational Therapy, Faculty of Rehab. Medicine
Phone: 492-0397, Email: shaniff.esmail@ualberta.ca

Co-Investigator:
Hueichen Huang, MSc student
Dept of Occupational Therapy, Faculty of Rehab. Medicine
Phone: 435-5469, Email: hueichen@ualberta.ca

Background and purpose:

We are conducting a research study to understand the "lived experiences" of couples' sexual relationships. The aim would be to get to the essence of what the partner(s)/couples is/are experiencing, where the "essence" may be understood as a true description of the experience.

Specifically, the research aims to understand:

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.

Before going further it maybe helpful for you to understand the context in which sexuality will be viewed and defined. Sexuality is a broad concept that incorporates both behaviours and emotions and their interplay with other elements of a relationship. Sexuality is a major component of who we are as individuals and not simply what we do sexually. 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 also includes our ability to develop warm caring intimate relationships. 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, 2002).

Procedures:

In the study we will be interviewing couples in which male partner has been diagnosed with multiple sclerosis. We will interview you and your partner separately. You will be asked about your perception of how your (your partner's) illness has impacted your sexual relationship. The interview will be tape recorded to allow the interview to be transcribed for data analysis however it may be shut of at anytime at your request.

Confidentiality:

You should know that all information collected will be kept confidential and your name will be replaced with an identification number to protect your identity. Not even your partner will have access to information you provide. All material and content from the interviews will be stored in a secure location in University of Alberta for 5 years. All data are accessible only to the primary investigator. Although some quotes from your interview may be published, these will be kept anonymous. In addition, while direct quotes will not be attributed to any individual, one's spouse may be able to identify them based on what was said

Possible Benefits and Risks:

While you may not benefit directly from the study, your participation may allow for the improvement of services provided by healthcare professionals. If any questions or issues come up, I may be able to answer some basic questions and I can provide you with a list of resources and the contact information with M.S. Society where you may seek further support.

Results of the study will be shared in several ways: 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, presentation in a seminar for MS support group, published in a research journal, and presentation at appropriate conference. The findings may be used in the sexuality curriculum for both medical students and occupational therapy students.

Contact Names and Telephone Numbers:

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. You can also contact Paul Hagler, Associate Dean of Faculty of Rehabilitation Medicine, at 492-9674 who is independent from this study.

Thank-you for your interest in our study

Sincerely,

Shaniff Esmail, Associate Professor, 492-0397
Hueichen Huang, MSc student, 435-5469

Appendix E – List of Resources

The Alberta Council of Professionals for sexual Health (2004). A directory of professionals with an interest in sexual health.

See attached booklet

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Appendix F – Informed Consent Form

Title of Research: The "lived experiences" of couples' sexual relationships in males with multiple sclerosis

Principal Investigator:
Shaniff Esmail, Associate Professor
Dept of Occupational Therapy, Faculty of Rehab. Medicine
Phone: 492-0397, Email: shaniff.esmail@ualberta.ca

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
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 in the writing of the research paper.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	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.