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# ILLNESS INTRUSIVENESS AND SEXUAL SATISFACTION AMONG WOMEN WITH MULTIPLE SCLEROSIS

by
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B. A., University of New Brunswick, 2008

A Thesis

Presented to Ryerson University

in partial fulfillment of the requirements for the degree of

Master of Arts

in the Program of

Psychology

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#### Illness Intrusiveness and Sexual Satisfaction among Women with Multiple Sclerosis

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Master of Arts

Psychology

Ryerson University

2010

#### **Abstract**

Multiple sclerosis (MS) is a disorder of the central nervous system that occurs in 55,000 - 75,000 Canadians. MS causes symptoms such as muscle weakness, poor balance, pain, fatigue, bladder and bowel dysfunction, and sexual dysfunction. Although high rates of sexual dysfunction are well documented among MS patients, predictors of sexual satisfaction among this population have been understudied. Illness intrusiveness (how intrusive one finds his or her illness) has been found to mediate the link between illness symptoms and quality of life. Therefore, the mediational role of illness intrusiveness between sexual dysfunction and sexual satisfaction was examined in this cross-sectional study. Eighty-two women with MS completed self-report measures to investigate how illness intrusiveness mediated, and age moderated the relationship between sexual dysfunction and sexual satisfaction. Higher illness intrusiveness into intimacy mediated sexual dysfunction and sexual satisfaction. The impact of illness intrusiveness and other relationship variables on sexual satisfaction are discussed.

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Illness Intrusiveness and Sexual Satisfaction among Women with Multiple Sclerosis

Currently there are 55,000 to 75,000 Canadians diagnosed with Multiple Sclerosis (MS);
a prevalence rate that ranks fifth highest worldwide (Multiple Sclerosis Society of Canada [MS Society], 2010). Those afflicted with MS face significant challenges as they are frequently diagnosed in young adulthood (25 to 32 years of age), when people are typically beginning careers and starting families (World Health Organization [WHO], 2008). The diagnosis of MS is more common among certain segments of the population, with an uneven gender distribution of 3:1 for women to men (MS Society of Canada, 2009). Caucasian individuals are also more commonly diagnosed with MS; however, this may be more reflective of available medical resources than the true distribution of the disease (WHO, 2008).

MS affects the central nervous system (CNS) whereby the body's immune system incorrectly targets the myelin sheath (involved in transporting messages to the spinal cord and brain) (MS Society, 2010). This error causes an array of devastating symptoms, including spasticity and weakness of the muscles, poor balance, pain, fatigue, trouble with vision (i.e., blurry vision or blindness), bladder and bowel dysfunction, changes in cognitive functioning, and sexual dysfunction (WHO, 2008).

#### **Types of MS**

MS presents in a variety of forms, with symptoms that frequently change over the course of the illness. Progressive Relapsing MS is uncommon (found in about 5% of cases) and those with this type of MS face a continuous increase in symptoms along with 'flare-ups' (periods with more MS symptoms) (MS Society, 2010). Relapsing remitting MS occurs in 75 to 90% of newly diagnosed patients, causes more disability, and has a pattern of flare-ups with partial or full symptom resolution. Relapsing remitting MS commonly develops into secondary progressive

MS, where each attack leads to a slow and steady increase in symptoms with only partial recovery (MS Society, 2010). The final type, primary progressive MS, afflicts 10-15% of patients (MS Society, 2010) and causes an unrelenting progression of MS symptoms (MS Society, 2010). In rare cases, patients with primary progressive MS later develop periods of remission, but these individuals still follow a trajectory of increased symptom severity (MS Society, 2010).

#### **Quality of Life and Mental Health**

Research shows that those diagnosed with MS often face compromised overall quality of life (QOL) and psychological health due to the unpredictable variety of symptoms, as well as the daily struggles of living with MS (e.g. McCabe & McKern, 2002; Turpin, Carroll, Cassidy, & Hader, 2007). For example, when those diagnosed with MS were compared to a sample of healthy individuals in a study by McCabe and McKern (2002), those with MS faced significantly poorer QOL in subjective mental health, physical health, social relationships, and their environment (e.g., their home life, and financial situation). In addition, women with MS have lower QOL in all these areas compared to men with MS (McCabe & McKern, 2002). Such findings have been upheld in other research where people diagnosed with MS had lower overall QOL in both physical and mental health domains compared with a healthy sample of participants (Turpin et al., 2007).

In addition to lower QOL, depression is widespread among those with MS. Recent point prevalence estimates based on a current episode of clinical depression among MS patients range from 45 to51% (Bamer, Cetin, Johnson, Gibbons, & Ehde, 2008). In a meta-analysis of 33 studies that compared rates of depression among individuals with MS, individuals with other chronic illness, and those in good health, MS patients faced the highest risk of depression (with

the exception of those with chronic fatigue syndrome) (Dalton & Heinrichs, 2005). Clearly, MS patients face a high risk for depression.

#### Prevalence of Sexual Dysfunction in MS

Along with other negative outcomes, those with MS suffer from elevated rates of sexual dysfunction, such as erectile problems in men, and difficulties with orgasm, loss of genital sensation, and lack of lubrication in women (Miller, Bourdette, Ritvo, & Stuart, 1994; Zorzon et al., 1999). Compared with the general population, individuals living with MS report less frequent sexual intercourse and increased sexual dysfunction (McCabe, McKern, McDonald, & Vowels, 2003). Sexual dysfunction rates are elevated compared to other groups, with 73.1% with MS, 39.2% with other chronic medical illness and 12.7% of healthy controls reporting these troubles (Zorzon et al., 1999). There is also some preliminary evidence that sexual dysfunction may occur at differing rates depending on the form of MS. For example, sexual dysfunction was reported in 77.1% of relapsing remitting cases, 77.8% of secondary progressive cases, and in 100% of primary progressive cases (Demirkiran, Sarica, Uguz, Yerdelen, & Aslan, 2006).

#### **Causes of Sexual Dysfunction in MS**

Foley posits that sexual dysfunction in MS is caused by three factors: 1) neurological damage, 2) MS-related symptoms, and 3) psychological and social challenges (Foley & Werner, 2004). Neurological damage can cause direct problems with sexual functioning such as genital numbness in women or loss of erection in men (Zivadinov et al., 1999); this has been labeled primary sexual dysfunction (Foley & Werner, 2004). Secondary sexual dysfunction refers to MS-related physical symptoms, (e.g., fatigue, muscle spasms, and bladder or bowel control issues) that indirectly lead to sexual dysfunction (Foley & Werner, 2004). Tertiary sexual dysfunction results from psychological or social factors (e.g., increased strain on intimate relationships due to

MS), and can cause or exacerbate existing sexual dysfunction (Schmidt, Hofmann, Niederwieser, Kapfhammer, & Bonelli, 2005; Foley & Werner, 2004).

Several studies have documented these three general influences. Increased numbers of MS brain lesions are associated with greater sexual dysfunction (Barak, Achiron, Elizur, & Gabbay, 1996). Moreover, one study found that 47% of participants recruited from a MS clinic reported their neurological symptoms negatively affected sexual activity through decreased arousal, orgasm, and enjoyment of sexual intercourse (Borello-Franceet al., 2004). In addition, men with MS experience more difficulties with achieving an erection and experience delayed ejaculation more frequently than men in the general population. Women with MS are more likely than those from the general population to experience genital numbness (McCabe et al., 2003).

Support for secondary sexual dysfunction has also been found. For example, MS-related bladder and bowel dysfunction can lead to secondary sexual dysfunction. Hennessey, Robertson, Swingler, and Compston (1999) found that 82% of participants with MS either used a catheter or had bladder dysfunction; an additional 29% had lost bowel control at some point and while 54% suffered from constipation. Given these high rates of bladder and bowel dysfunction, Bezkor and Canedo (1987) suggested planning for sexual activity must become an essential a part of sexual intercourse for these couples. The authors noted that the extra concern over bowel and bladder control difficulties and the associated planning needed for sexual activity may worsen sexual function (Bezkor & Canedo, 1987). Moreover, sphincter dysfunction is associated with physical problems that can *cause* sexual dysfunction. A significant relationship of bladder function with sexual dysfunction has been found in MS patients, where 75% of patients reported sphincteric dysfunction and 73.1% reported sexual dysfunction (Zorzon et al., 2001). Other physical

symptoms such as fatigue, pain, muscle spasms, and weakness also significantly correlate with greater sexual dysfunction (Zivadinov et al., 1999).

Evidence also exists for the presence of tertiary sexual dysfunction among MS patients. Research has found strong correlations between depression and sexual dysfunction among those with MS (Barak et al., 1996). Likewise, Zivadinov and colleagues (1999) reported that elevated depression scores were significantly associated with greater severity of sexual dysfunction. Relationship troubles may also lead to worse sexual functioning. It is well accepted that MS can lead to various social challenges such as role changes in an intimate relationship (e.g., Esmail, Munro, & Gibson, 2007), and those with MS report lower relationship satisfaction when compared with the general population (McCabe, 2002). Further, there is a significant association between relationship satisfaction and sexual functioning for women with MS, with greater relationship dissatisfaction associated with poorer sexual functioning (McCabe, 2002).

#### **Gender and Sexual Dysfunction**

The prevalence of sexual dysfunction among individuals with MS ranges from 50 to 73% in men, and 45 to 70% in women (Fletcher et al., 2009). Other estimates of female sexual dysfunction are higher, with 79.6% of women with MS reporting at least one symptom of sexual dysfunction (McCabe, McDonald, Deeks, Vowels, & Cobain, 1996). Some propose that estimates of sexual dysfunction for women may be underestimated, given that men suffering from erectile dysfunction are often unable to have intercourse, while sexual dysfunction in women may compromise the quality and frequency of sexual intercourse (Dupont, 1996). However, the extant data clearly indicate that sexual dysfunction is a frequent issue for both men and women with MS.

The causes of sexual dysfunction appear to differ between genders. Compared with men, women with sexual dysfunction report more problems with sphincter and bladder dysfunction (Zivadinov et al., 1999), worries over incontinence, muscle spasms, weakness during sexual intercourse (Koch, Kralik, & Eastwood, 2002), and fatigue (found in 90.9% of women with sexual dysfunction) (Demirkiran et al., 2006). Therefore, since sexual dysfunction presents quite differently across genders, it is important to examine sexual dysfunction in MS in women separately from that of men.

#### Sexual Satisfaction and MS

Extensive research on the prevalence of sexual dysfunction among MS patients has been conducted; yet, research on sexual satisfaction in this population is extremely limited.

Preliminary data suggest that those with MS experience significantly lower sexual satisfaction compared to the general population (McCabe et al., 2003). There is also initial support for a strong connection between greater sexual dysfunction and lower sexual satisfaction among MS patients (McCabe, & McDonald, 2007). However, there is not always a direct relationship between increased sexual dysfunction and sexual satisfaction. Instead, other psychological variables may mediate this relationship (McCabe & McDonald, 2007). Although there are no published data on this topic for populations with MS, research conducted with healthy samples of adults found that greater perceived sexual dysfunction was associated with decreased sexual satisfaction (Dunn, Croft, & Hackett, 2000). Therefore, it may be hypothesized that appraisals surrounding sexual dysfunction or illness symptoms within a population with MS may negatively impact sexual satisfaction.

Although those living with MS face a variety of challenges, the importance of sexual satisfaction to an individual's QOL cannot be overlooked. In the general population, sexual

satisfaction is associated with relationship satisfaction, love for one's partner, and the overall commitment to the relationship (Sprecher, 2002). Support from one's partner is a major source of social support for individuals with MS (Gulick, 1994); and positive partner support is associated with lower disability among those with MS (O'Brien, 1993). Understanding the psychological factors associated with sexual satisfaction may result in insight into how to improve this important area of QOL.

#### **Illness Intrusiveness Theory and Research Support**

Although there is an extensive body of literature that has examined appraisals of illness symptoms in general, and their overall impact on QOL, this literature has yet to examine how appraisals specific to sexual dysfunction impact sexual satisfaction. Therefore, it may be useful to investigate how appraisals of sexual dysfunction are associated with sexual satisfaction though the use of an existing model of general illness appraisals. One such construct is that of "illness intrusiveness" (Devins et al., 1983), which provides a useful framework for understanding the relationship between illness symptoms, (e.g., MS-related sexual dysfunction) and their negative impact on one's life (e.g., poor sexual satisfaction).

Devins and colleagues (1983) defined the concept of illness intrusiveness as "the extent to which the illness and/or its treatment interferes with important facets of a patient's life." Using this definition, they created the Illness Intrusiveness Ratings Scale (IIRS). The IIRS is a seven-point scale that assesses 13 life domains affected by chronic illness: "work, financial security, marital need satisfaction, recreation, family and marital relations, other social relations, sex, self-expression, religious expression, community and civic activities, health, and diet."

Moreover, they suggested physical symptoms lead to appraisals about the extent that an illness intrudes into one's life. When one makes more negative illness appraisals, this is

theorized to lead to worsened psychological adjustment, above and beyond that of illness severity. Lastly, this model suggests that demographic and psychosocial variables, such as age, income, and stressful life events, can moderate the effect of disease factors on illness intrusiveness (Devins et al., 1983).

Indeed, research demonstrates support for this model. Specifically, several studies have found illness intrusiveness to significantly mediate the relationship between greater illness symptoms and worse psychological adjustment in chronically-ill populations, such as those with irritable bowel syndrome (IBS) and breast cancer (Bloom, Stewart, Johnston, & Banks, 1998; Dancey, Hutton-Young, Moye, & Devins, 2002). In addition, a study that examined illness intrusiveness among a sample of individuals with arthritis, renal disease, and MS found that the relationship between sleep quality and depression was mediated by illness intrusiveness, with increased illness intrusiveness worsening the effect of poor sleep quality on depression (Devins et al., 1993a). Illness intrusiveness appears to have a substantial role in explaining outcomes for various illnesses through worsening the effect of illness symptoms on psychological outcome.

#### **Illness Intrusiveness in MS Populations**

Illness intrusiveness experienced by MS patients is elevated compared to those with renal disease and arthritis (Devins et al., 1993b). Among those with MS, illness intrusiveness is a robust predictor of physical and psychological QOL (Mullins et al., 2001; Shawaryn, Schiaffino, LaRocca, & Johnston, 2002). Illness severity, disability, and fatigue have been found to significantly predict greater illness intrusiveness in MS. Furthermore, greater illness intrusiveness is an important predictor of poorer psychosocial well-being among patients with MS (Devins, Seland, Klein, Edworthy, & Saary, 1993). Illness intrusiveness also mediates the

relationship between physical symptoms and psychological adjustment in MS patients (Devins et al., 1993a; Shawaryn et al., 2002).

Overall, the Illness Intrusiveness Model predicts—and is supported by—studies of chronically ill populations (including MS). However, to date, studies have only examined general illness symptoms and QOL. No research has examined the extent to which illness intrusiveness ratings mediate the relationship between specific symptoms of MS-related sexual dysfunction and sexual satisfaction, which is the aim of the current study.

#### Illness Intrusiveness and Age

Within this model, it is also proposed that various psychological, social, and contextual factors moderate the effects of illness intrusiveness on adjustment (Devins et al., 2009). Many variables play important roles in moderating the impact of illness intrusiveness on psychological outcomes such as well-being and quality of life. For example, male gender is associated with poorer outcome (Dancey et al., 2002) and lower income and more recent stressful life events moderate the relationship between illness and increased illness intrusiveness (Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006). Age is another important contextual variable that has generally been found to moderate the effect of illness intrusiveness on adjustment (e.g., Devins et al., 1996). In one study of patients with rheumatoid arthritis there was a moderation effect of age on illness intrusiveness for emotional distress, such that younger people faced greater illness intrusiveness, and therefore greater distress than older individuals (Devins, Edworthy, Guthrie, & Martin, 1992). The moderating effect of age has also been observed among MS populations where illness intrusiveness had a more negative effect on the mental health of younger patients than older patients (Devins et al., 1996).

Although many variables can moderate the effects of illness intrusiveness on chronic illness, age may play a key role in moderating illness intrusiveness among those with MS. As noted earlier, the onset of MS often occurs during young adulthood, generally between 25 to 32 years of age (WHO, 2008). Younger age appears to be a crucial moderating factor for illness intrusiveness, as chronic illness is "off track" from one's expected life course (Devins et al., 1992). MS offers a unique and important opportunity to examine age differences in the relationship between illness intrusiveness and sexual satisfaction. Specifically, the current study aims to examine the extent to which younger age increases the negative impact of illness intrusiveness on sexual satisfaction.

#### **Summary of the Current Research**

Although the prevalence of sexual dysfunction among those with MS is well documented, there has been a scarcity of research on the degree to which sexual dysfunction impacts sexual satisfaction as noted by McCabe and colleagues, (2003). In addition, no research to date has examined the degree to which appraisals of illness intrusiveness might mediate sexual dysfunction and sexual satisfaction, or whether age may moderate the impact of illness intrusiveness. Up until quite recently, much of the research on sexual dysfunction in populations with MS has neglected to use measures designed for the unique symptoms of sexual dysfunction experienced by this population. However, there has been a recent shift in focus to examining sexual dysfunction where MS-specific symptoms are classified as primary, secondary, and tertiary sexual dysfunction (e.g., Fletcher, 2009). Sexual satisfaction among the general population is important for maintaining a strong partnership (Sprecher, 2002). Given that partner support is one of the most important forms of social support for those with MS, and, in turn

predicts QOL, further research on sexual satisfaction among MS populations is needed (Gulick, 1994; O'Brien, 1993).

#### **Purpose and Hypotheses**

The primary aim of this study was to examine the mediational role of illness intrusiveness between sexual dysfunction and sexual satisfaction among those with MS. In addition, the moderating influence of age on illness intrusiveness was examined. Finally, exploratory analyses examined whether total and life domain specific illness intrusiveness (intimacy, instrumental, and relationships and personal development) mediated the relationship between sexual dysfunction (total, primary, secondary, and tertiary) and sexual satisfaction.

<u>Hypothesis 1:</u> Illness intrusiveness was hypothesized to mediate the relationship between sexual dysfunction and sexual satisfaction; with greater illness intrusiveness leading to lower sexual satisfaction (see Figure 1).

**Hypothesis 2:** It was hypothesized that there would be a significant interaction (moderation effect) of age by illness intrusiveness. Specifically, greater illness intrusiveness was hypothesized to be more strongly associated with poor sexual satisfaction in younger adults compared with older adults with MS (see Figure 1).

**Exploratory Hypotheses:** Total and life domain specific illness intrusiveness (intimacy, instrumental, and relationships and personal development) were examined as potential mediators between sexual dysfunction (total, primary, secondary, and tertiary) and sexual satisfaction (see Table 1).

Figure 1. Hypothesized Model of the Mediational Effect of Illness Intrusiveness and the Moderation Effect of Age.

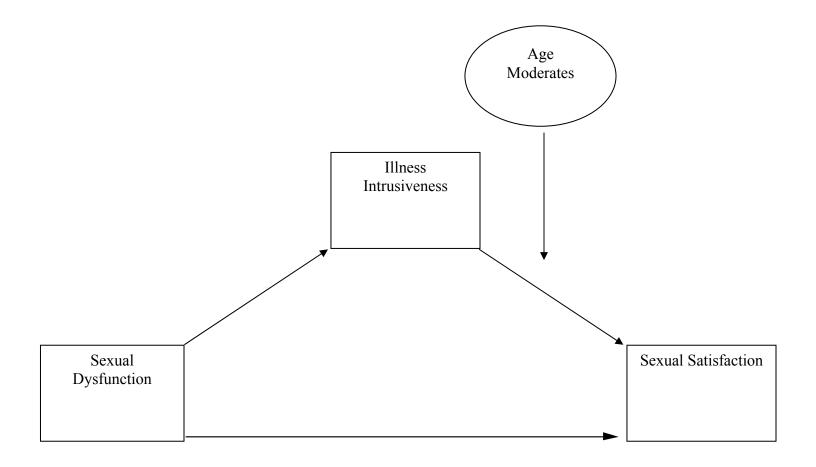


Table 1

Exploratory Hypotheses with IIRS and MSISQ-19 Subscales

Number	Predictor	Mediator	Outcome
1	MSISQ-19 Primary	IIRS Relationships and Personal Development	SSS
2		IIRS Instrumental	
3		IIRS Intimacy	
4		IIRS Total	
5	MSISQ-19 Secondary	IIRS Relationships and Personal Development	SSS
6		IIRS Instrumental	
7		IIRS Intimacy	
8		IIRS Total	
9	MSISQ-19 Tertiary	IIRS Relationships and Personal Development	SSS
10		IIRS Instrumental	
11		IIRS Intimacy	
12		IIRS Total	
13	MSISQ-19 Total	IIRS Relationships and Personal Development	SSS
14		IIRS Instrumental	
15		IIRS Intimacy	

*Note.* Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19), the Sexual Satisfaction Survey (SSS), and Illness Intrusiveness Ratings Scale (IIRS).

#### Method

#### **Participants**

Participants were recruited to take part in a larger study examining the effect of MS-related symptoms, stresses and relationship dynamics of 120 couples living with MS. Prior to conducting this research, permission from both the Ryerson University and St. Michael's Hospital (SMH) Research Ethics Board was obtained. Couples were recruited from both the general community and from a large Toronto MS clinic. Participants from the general community were recruited through study advertisements posted through chapters of the Multiple Sclerosis Society of Canada in Atlantic Canada, Ontario, and Alberta. In addition, recruitment was also conducted through St. Michael's Hospital Multiple Sclerosis Clinic (MSC), one of the largest MS clinics in North America.

To maximize power, the current analyses used only female patient data, as women have a much higher prevalence rate of MS than men (MS Society, 2009). In addition to these conditions for inclusion in the present analyses, there were also several specific criteria for study recruitment as this sample was primarily recruited for a larger study on the impact of MS on couples. A total of 82 female patients with MS were included in the current study.

*Inclusion Criteria:* Participants were eligible to participate when they: 1) had a confirmed diagnosis of MS by a physician, 2) were 18 years of age or older, 3) were able to give informed consent, 4) were able to read and speak English fluently, 5) identified as being in a partnership for at least six months.

Exclusion Criteria: Participants not eligible to participate in the study met criteria for one or more of the following: 1) no confirmed diagnosis of MS by a physician, 2) were less than 18

years of age, 3) were unable to give informed consent, 4) were not able to read and speak English fluently, and 5) were not in a coupled relationship for six or more months.

#### **Measures**

**Demographics.** Demographic information was collected through a self-report measure that included questions on age, gender, relationship status and duration, employment, income, education level, duration and type of self-reported MS diagnosis, and ethnicity.

The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19). The MSISQ-19 is a 19-item self-report measure designed to assess sexual dysfunction among people with MS. It assesses the three types of sexual dysfunction found among people with MS: primary, secondary, and tertiary sexual dysfunction through questions such as, how problematic are your "bladder and urinary symptoms" for sexual activity. Scores range from 1 (never) to 5 (always), and greater scores indicate more severe symptoms of sexual dysfunction. The MSISQ-19 has been found to have good convergent validity by its correlation with the Marital Satisfaction Inventory (MSI) Sexual Dissatisfaction Scale r = 0.40, p < .01 (Sanders, Foley, LaRocca, & Zemon, 2000). Moreover, the scale has demonstrated divergent validity through its weaker correlation with the MSI Problem Solving Skills and Affective Communication subscales respectively r = .30, p < .01 and r = .31, p < .01. The scale also has excellent reliability ( $\alpha = .91$ ) (Sanders et al., 2000). The MSISQ-19 and its subscales also displayed strong reliability in the current study ( $\alpha = .85 - .92$ ) (see Table 2).

The Sexual Satisfaction Survey (SSS). Sexual satisfaction was assessed using the SSS self-report measure. The SSS is one of ten scales found on the Multiple Sclerosis Quality of Life Inventory (MSQLI), a self-report measure designed to examine quality of life specifically among people with MS with questions such as "how satisfied are you with the amount of physical

affection expressed in your relationship". This scale assesses sexual activity within the last six months and contains five items assessing satisfaction with one's sexlife and perceptions of one's partner's sex life satisfaction. The sexual satisfaction scale is scored by summing the four individual items, (scores range from 1= extremely satisfied, to 6 = extremely dissatisfied). The SSS has been found to have a strong reliability of  $\alpha$  = .91 as well as good construct validity through consultation with experts in MS (Ritvo et al., 1997). The SSS in the current study was also found to have good reliability ( $\alpha$  = .94) (see Table 2).

**Illness Intrusiveness Ratings Scale (IIRS).** Illness Intrusiveness was measured using the IIRS. The IIRS is a self-report measure designed to assess how intrusive people living with a chronic illness find their condition. The concept of intrusiveness has to do with how much a person thinks their illness interrupts their daily life with questions like "how much does your illness and/or treatment interfere with you sex life". This self-report scale contains 13-items and each item is measured on a seven-point scale that ranges from "not very much" to "very much". The IIRS was examined as a total score, as well as three subscales assessing intimacy, instrumental (e.g., intrusiveness in work and finances), and relationships and personal development (Devins, 2010). The IIRS appears to demonstrate strong construct validity in that patients with a kidney transplant reported significantly less illness intrusiveness than those on dialysis. Past research found support for its discriminant validity, as defensive response styles were not significantly correlated with illness intrusiveness (Devins et al., 1990; Devins, 1994). Past research that used the IIRS has found it to have high reliability in MS populations ( $\alpha = .79$ ) (Devins et al., 1993). The reliability of the IIRS and its subscales in the in the current research were also high ( $\alpha = .80 - .91$ ) (see Table 2).

Table 2

Internal Consistencies for the MSISQ-19, IIRS, and SSS

Variable	Internal Consistency (Cronbach's α)		
MSISQ-19			
Total	.92		
Primary	.85		
Secondary	.86		
Tertiary	.88		
IIRS			
Total	.91		
Relationships and Personal Development	.85		
Intimacy	.80		
Instrumental	.83		
SSS Total	.94		

#### **Procedure**

Interested participants recruited through the community were asked to call or e-mail the study office to take part in a brief phone-screening interview and provide informed consent.

Community participants who were eligible to take part in the study then provided informed verbal consent to a trained researcher. Individuals from the MS clinic who were interested in participating provided verbal consent at clinic, or, were also given the option of providing consent at a later time over the telephone. The consent process took approximately 15 minutes for participants from both the community and clinic.

Participants were given the choice of completing a paper or online survey. To maintain confidentiality of participants using the online survey, secure-socket layer technology (the most secure method of encrypting data used on banking and e-commerce sites) was used and no personally identifying information was requested within the surveys. The survey took one 1 - 1.5 hours to complete and participants were given a \$40 gift card as compensation for their time. To be inclusive of participants who had vision or mobility challenges due to the progression of their illness, the option of an enlarged print-version of the survey or other appropriate accommodations were made. Given MS-related fatigue is a major symptom for many patients (Janardhan & Bakshi, 2002) the online survey allowed for participants to take breaks and continue at a later time for their comfort.

#### **Data Analysis**

Hypothesis one posited that illness intrusiveness would mediate the relationship between sexual dysfunction and sexual dissatisfaction (see Figure 1). To determine mediation, four conditions must be satisfied: 1) There must be a significant relationship between the independent variable (i.e., sexual dysfunction) and the mediator (i.e., illness intrusiveness), 2) There must be

a significant relationship between the mediator (i.e., illness intrusiveness) and the dependent variable (i.e., sexual dissatisfaction), 3) There must be a significant relationship between the independent variable (i.e., sexual dysfunction) and the dependent variable (i.e., sexual dissatisfaction), 4) When the independent variable (i.e., sexual dysfunction) and the mediator (i.e., illness intrusiveness) are entered as simultaneous predictors, the relationship between the independent variable (i.e., sexual dysfunction) and the dependent variable (i.e., sexual dissatisfaction) must be greatly reduced (Baron & Kenny, 1986; Fairchild & MacKinnon, 2009).

In addition, a bootstrapping procedure was used to test the indirect effect of illness intrusiveness on the relationship between sexual dysfunction and sexual dissatisfaction. A macro application developed by Preacher and Hayes (2004) was used to create a series of bootstrapped non-parametric mediation tests. For each analysis, 10,000 re-samples from the dataset was created using random sampling with replacement, thus creating a much larger and more reliable dataset. The point estimate is the mean indirect effect computed over 10,000 samples and the estimated standard error is the standard deviation of the 10,000 estimates. A 95% confidence interval (CI) was calculated for the point estimate.

Recent advances in statistics have led to the increased use of the bootstrapping technique, which enjoys a number of advantages. Bootstrapping does not assume the data are normally distributed. Moreover, the approach provides increased power compared to the Baron and Kenny method, which has increased rates of type II error (accepting the null hypothesis when it is, in fact, false), with each step in this method leading to an increased potential for type II error (Hayes, 2009). In addition, mediation is calculated from the *product* of 'a' (the path of the IV to the mediator) and 'b' (the path of the mediator to the DV), however, this a X b path, which is an interaction effect, is not normally distributed (see Figure 2). Therefore, the assumption that the

data are normal, especially in light that the interaction effect is not normally distributed, is invalid when examining mediation effects. Therefore, bootstrapping, a non-parametric approach, has been recommended by a number of researchers (i.e. Preacher & Hayes, 2004; Preacher, Rucker, & Hayes, 2007; Hayes, 2009).

Bootstrapping 're-samples' the data multiple times (in this case, creating 10,000 more samples), thus rendering a more accurate estimate of the actual values of the population based on the sampled data (Hayes, 2009). Each time re-sampling is conducted, the analysis provides an approximation of the indirect effect (i.e., the intervening role of the potential mediator between the IV and DV). Based on distribution of each indirect effect over the 10,000 samples, a confidence interval is created (which was set to the 95<sup>th</sup> percentile for the current analyses). The generated indirect effect estimates are then listed in order from lowest to highest, resulting in a new output confidence interval named the 'percentile - based bootstrap'. This percentile-based bootstrap confidence interval is interpreted by examining whether 0 is crossed, and if it is not crossed, one can be sure within the limits of the confidence interval that an indirect effect exists (Hayes, 2009).

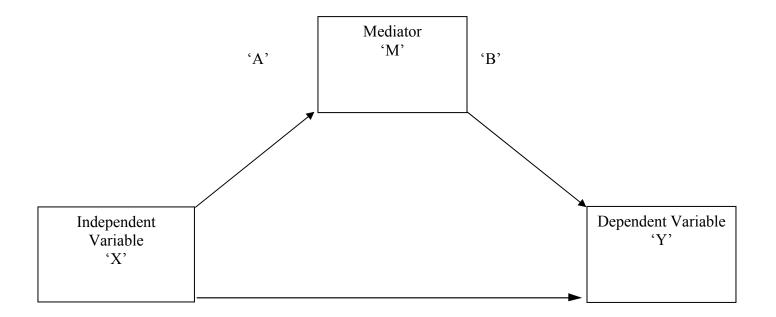
However, just because there is an indirect effect does not indicate that the third variable is indeed a "mediator." Rather, an indirect effect signifies that there is a relationship between the IV, DV, and hypothesized mediator when they are tested at once (the IV does influence the proposed mediator, and this in turn influences the DV). There is only an indirect effect when no statistically significant relationship is initially found between the IV and DV; therefore, there is nothing to "mediate" per se. On the other hand, when there is a significant direct relationship between the IV and the DV, a significant percentile-based bootstrap estimate can be correctly termed a mediator (Hayes, 2009; Mathieu & Taylor, 2006).

Hypothesis two posited that there would be a significant interaction (moderation effect) of age by illness intrusiveness, such that higher illness intrusiveness would bear a stronger relationship to greater sexual dissatisfaction in younger adults with MS compared to older adults with MS (see Figure 1). To examine age as a moderator, a multiple regression analysis was performed with sexual satisfaction as the outcome variable. Three blocks of variables were entered into the equation: 1) Main effect of illness intrusiveness, 2) main effect of age, measured continuously in years, 3) the interaction of illness intrusiveness X age. Post-hoc analyses were planned to decompose any significant interaction effect. Specifically, in the event of a significant interaction, a median split on age was to be performed (low vs. high), and the relationship between illness intrusiveness and sexual dissatisfaction was to be examined separately for each group (Baron & Kenny, 1986; Fairchild & MacKinnon, 2009). In addition, a bootstrapping analysis for moderation (a conditional indirect effect) was conducted (Preacher, Rucker, & Hayes, 2007).

#### **Exploratory Analyses**

Additional analyses were also performed with the total and each of the three types of sexual dysfunction found on the MSISQ-19, with the SSS total score as the outcome and the IIRS total score and three subscale scores (intimacy, instrumental, and relationships and personal development) examined as mediators. These exploratory analyses were conducted using the same bootstrapping procedure discussed previously (Preacher & Hayes, 2004). Given that these exploratory analyses involved an additional 15 tests (see Table 1), the alpha level was set to  $\alpha = .003$  using a Bonferroni correction.

Figure 2. Figure of the a X b Path in Mediation Based on Hayes (2009).



#### **Results**

#### **Participant Demographics**

A total of 82 women diagnosed with MS were included in the analysis (all demographic information is listed in detail in Table 3). The majority of the women in this study identified as Caucasian (86.6%), with 8.5% reporting another ethnicity (Arab/West Asian, Black, Aboriginal, South Asian, and South-East Asian). Because these data were obtained from a larger study of couples, all women were partnered with an average relationship duration of approximately 17 years (SD = 10.7 years). Over half of the participants (56.1%) reported a college or university education and 41.5% reported no college/university education. Much of the sample was not employed (54.9%) with another 43.9% reporting current employment. Based on categories available from self-report data, over half the (53.7%) participants reported an annual income of 0 - 40,000, 24.4% reported between 40,000 – 75,000 and the remainder reported over 75,000. Most of the participants had been diagnosed with relapsing remitting MS (72%), 9.8% had secondary progressive MS, 3.7% had primary progressive MS, 1.2% had progressive relapsing MS, and 1.2% met diagnostic criteria for relapsing remitting and primary progressive MS. The average duration of MS diagnosis was 9 years (SD = 8.3 years).

Table 3  $Sample\ Demographics\ (N=82)$ 

Variable	Percent	M	SD
Age (Years)		42.5	10.4
Ethnicity			
Caucasian	86.6		
Other	8.5		
Recruitment Site			
Clinic	40.2		
Community	59.8		
MS Type			
Relapsing Remitting	72.0		
Secondary Progressive	9.8		
Primary Progressive	3.7		
Progressive Relapsing	1.2		
Relapsing Remitting and	1.2		
Primary Progressive			
MS Duration (Years)		9 years	8.3 years
Employment Status			
Employed	43.9		
Not Employed	54.9		

Variable	Percent	M	SD
Education			
High School	18.3		
Some College/University	23.2		
College/University	50.0		
Graduate School	6.1		
Annual Income			
0-40,000	53.7		
40,000 – 75, 000	24.4		
More than 75, 000	13.4		
Relationship Status			
Married/Partnered	100		
Relationship Duration (years)		17 years	10.7 years

#### **Demographics and Recruitment Sites**

Prior to examining differences between recruitment sites, data were checked for outliers, and test assumptions (i.e., normality and linearity) were examined. No outliers or violations of assumptions for any of the statistical tests described earlier were present (Tabachnick & Fidell, 2007; Field, 2009). Regarding recruitment source, 33 women (40.2%) were recruited for this study from the SMH clinic and 49 (59.8%) were recruited from the community. Nearly all the women from the community and clinic had a diagnosis of relapsing remitting MS. No significant differences emerged between participants recruited from clinic versus community on age, MS duration, relationship duration, scores on illness intrusiveness, sexual dysfunction, sexual satisfaction, education, or employment. Differences between clinic versus community on annual income, MS type, ethnicity, and sexual activity could not be assessed as the chi-square analysis had an expected count of less than 5 (Field, 2009). Please see Table 4 for a detailed breakdown on diagnosis type, relationship status, ethnicity, employment, and education for women recruited from the clinic versus community sources.

Table 4

Demographics: Community versus Clinic (N = 82)

Variable	Number from Clinic	Number from Community	Chi Square Value	Significance of Chi Square
Relationship Status				
Married/Partnered	33	49		
Ethnicity				
Caucasian	25	46		
Other	5	2		
Employment Status			.01	p = .92
Employed	14	22		
Not Employed	18	27		
Education			.03	p = .85
No College/University	14	20		
College/University	18	28		
MS Type				
Relapsing Remitting	26	33		
Secondary Progressive	0	8		
Primary Progressive	2	1		
Progressive Relapsing	0	1		
Relapsing Remitting and	0	1		
Primary Progressive				

*Note*. Only chi square values for education and employment could be reported as the other cell counts were less than 5.

# Differences between Sexually Active and Non-Sexually Active Groups

Analyses examined whether there were significant differences between those who reported sexual activity versus those who did not report sexual activity over the last six months. Table 5 displays the results of the chi-square analyses for demographic differences for participants in the sexually active versus not sexually active groups. More participants reported sexual activity in the last six months (n = 72) compared to those who reported no activity in the last six months (n = 10). Those who reported no sexual activity in the last six months were older (M = 50, SD = 10.5) than those who reported sexual activity in the last six months (M = 41, SD =10), t(80) = -2.68, p < .01. Those reporting sexual activity in the last six months had been in a relationship for fewer years (M = 16.6, SD = 10.2) than those who were not sexually active (M =24.7, SD = 11.3), t(80) = -2.44, p < .05. Participants who were sexually active in the last six months reported less symptoms of primary sexual dysfunction (M = 2.76, SD = 0.98), than those who were not active (M = 3.49, SD = 0.91), t(78) = -2.12, p < .05. Moreover, those who had engaged in sexual activity in the last six months reported lower illness intrusiveness on the intimacy subscale (M = 3.51, SD = 1.85) than those who did not (M = 4.80, SD = 2.04), t(80) = -2.04, p < .05. No other significant differences between the groups were found. Please see Table 5 for demographic information grouped by sexually active versus non-active participants.

Table 5

Demographics: Sexually Active versus Non- Sexually Active (N=82)

Variable	Number Sexually Active	Number Non- Sexually Active		
Recruitment Site				
Clinic	30	3		
Community	42	7		
Relationship Status				
Married/Partnered	72	10		
Ethnicity				
Caucasian	61	10		
Other	7	0		
Employment Status				
Employed	35	1		
Not Employed	36	9		
Education				
No College/University	28	6		
College/University	42	4		
Annual Income				
0-40,000	38	6		
40,000 – 75, 000	18	2		
More than 75, 000	11	0		

Variable	Number Sexually Active	Number Not Sexually Active	
MS Type			
Relapsing Remitting	55	4	
Secondary Progressive	5	3	
Primary Progressive	3	0	
Progressive Relapsing	0	1	
Relapsing Remitting and Primary Progressive	1	0	

*Note*. Chi square values could not be obtained as the cell counts were less than 5.

## **Sexual Dysfunction**

Given that the MSISQ-19 is a relatively new measure (Sanders, et al., 2000), scores have not yet been standardized. Therefore, a mean score was calculated for the total score and each subscale (primary, tertiary, and secondary sexual dysfunction) of the MSISQ-19. Women in this study reported occasional primary (M = 2.84, SD = 1.0), secondary (M = 2.19, SD = 0.83), tertiary (M = 2.56, SD = 1.08), and total (M = 2.46, SD = 0.81) sexual dysfunction (see Table 6). Although several studies have used the MSISQ-19, currently there are no published means available to be compared to the current sample.

### **Sexual Satisfaction**

The sexual satisfaction scale ranged from 4 to 24, with greater scores indicating lower sexual satisfaction (Ritvo et al., 1997). The 72 women who reported sexual activity within the last 6 months reported slight sexual dissatisfaction (M = 11.50, SD = 6.03) (see Table 6). Upon comparing the mean of the current sample to that of a sample of MS patients undergoing treatment of depression (M = 15.70, SD = 6.63), sexual satisfaction was significantly better in the current sample (t = 4.16, df = 159, p < .05) (Culp, Hart, Belanger, & Mohr, 2010, in progress).

#### **Illness Intrusiveness**

A total IIRS score was created by summing all 13 items, resulting in a score ranging from 13-91. Higher scores indicated higher illness intrusiveness (Devins, 2010). Among this sample, the mean illness intrusiveness total score was M = 44.74, SD = 17.76 which is comparable to another study of multiple sclerosis patients (M = 45.4, SD = 15.66), with no significant differences between the studies (t = .30, df = 254, p = .76) (Devins et al., 1996). Although no cutoffs have been identified for severity of illness intrusiveness, these scores are approximately in the middle of the scale, reflecting a moderate degree of severity. On the IIRS

Table 6
Scores on the MSISQ-19, IIRS, and SSS

Variable	M	SD	Actual Range
MSISQ-19			
Total	2.46	0.81	1.05 - 4.11
Primary	2.84	1.00	1.00 - 4.60
Secondary	2.19	0.83	1.00 - 4.11
Tertiary	2.56	1.08	1.00 - 5.00
IIRS			
Total	44.74	17.76	13.00 - 78.00
Relationships and Personal Development	2.84	1.36	1.00 - 5.50
Intimacy	3.66	1.91	1.00 - 7.00
Instrumental	4.38	1.81	1.00 - 7.00
SSS Total	11.50	6.03	4.00 - 24.00

subscales, low to moderate scores on the relationship and personal development (M = 2.83, SD = 1.36), intimacy (M = 3.66, SD = 1.91) and instrumental subscales (M = 4.38, SD = 1.81) were found, where 1= "not very much" and 7= "very much" interference in one's life (see Table 6).

# **Tests of Hypotheses**

## **Hypothesis One: Causal Steps Test and Bootstrapping**

Prior to running regression analyses, the data were examined for multivariate outliers, multicollinearity, herteroscedasticity, linearity, and normality. No influential outliers were found and no violations of the assumptions of linear regression were present (Tabachnick & Fidell, 2007; Field, 2009). Next, hypothesis one (that there would be mediation between sexual dysfunction and sexual satisfaction by illness intrusiveness) was tested. As planned, an analysis of mediation based on the guidelines of Baron and & Kenny (1986) was carried out. To test mediation using the approach by Baron and Kenny, four regression equations were conducted.

First, a regression analysis tested the effect of sexual dysfunction (MSISQ total) on illness intrusiveness (IIRS total) and was significant,  $R^2$ adj = 0.33, F (1, 67) = 33.96, p = .001 with a greater MSISQ-19 total score associated with higher IIRS total score ( $\beta$  = 0.58, SE = 2.30, p = .000). The second regression analysis examined the impact of illness intrusiveness (total IIRS score) on sexual satisfaction and the overall model was significant,  $R^2$ adj = 0.11, F (1, 67) = 9.70, p = .003, with a higher IIRS total score significantly associated with poorer SSS score ( $\beta$  = 0.36, SE = 0.04, p = .003). The third regression analysis tested the relationship between sexual dysfunction and sexual satisfaction. Greater sexual dysfunction (total MSISQ-19 score) was associated with worse sexual satisfaction (the SSS score) ( $\beta$  = 0.34, SE = 0.88, p = .004) and the model was significant,  $R^2$ adj = 0.10, F (1, 68) = 8.94, p = .004. Finally, sexual dysfunction and illness intrusiveness were entered in Step 1 and Step 2 of the regression respectively. Neither

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sexual dysfunction ( $\beta$  = 0.18, SE = 1.10, p = .21) nor illness intrusiveness ( $\beta$  = 0.24, SE = 0.05, p = .09) were unique predictors of sexual satisfaction, although the overall model was s significant,  $R^2$ adj = 0.11, F (2, 65) = 5.24, p = .008. Given that illness intrusiveness was no longer predictive of sexual satisfaction once it was added as the second step in the model, it was not a significant mediator of the relationship between sexual dysfunction and sexual satisfaction (Baron & Kenny, 1986; Fairchild & MacKinnon, 2009) (See Table 7).

For the current analyses, bootstrapping was conducted to determine whether illness intrusiveness (IIRS total score) was either a mediator or an indirect effect between sexual dysfunction (MSISQ-19 total) and sexual satisfaction (SSS). The mediation macro for SPSS created by Preacher and Hayes (2004) was used conduct the bootstrap analysis. This analysis resulted in a 95% confidence interval that crossed 0 (-.17 – 2.54), bootstrap estimate = 1.10, SE = 0.69. Based on these results, neither a mediation effect nor an indirect effect was detected.

Table 7

Regression for Mediation of Sexual Dysfunction and Sexual Satisfaction by Illness Intrusiveness

Regression Number	В	SE B	β	$R^2$ adj	F	Significance
1. Regression of total sexual dysfunction on illness intrusiveness						
Step 1	13.38	2.30	0.58	0.33	33.96	p = .001
2. Regression of total illness intrusiveness on sexual satisfaction						
Step 1	0.12	0.04	0.36	0.11	9.70	p = .003
3. Regression of total sexual dysfunction on sexual satisfaction						
Step 1	2.63	0.88	0.34	0.10	8.94	p = .004
4. Regression of overall model on sexual satisfaction						
Step 1 (sexual dysfunction)	2.47	0.91	0.32	0.09	7.37	p = .008
Step 2 (sexual dysfunction)	1.38	1.10	0.18	0.11	5.24	p = .21
Step 2 (illness intrusiveness)	0.08	0.05	0.24	0.11	5.24	p = .09

# **Hypothesis Two: Moderation by Age**

The hypothesis that there would be a significant interaction (moderation effect) of age by illness intrusiveness was also examined. As planned, a multiple regression was first conducted to determine whether there was a significant interaction. Illness intrusiveness, age, and the interaction of illness intrusiveness X age were entered as predictors of sexual satisfaction after having centered the terms (Tabachnick & Fidell, 2007). Age ( $\beta$  = 0.09, p = .45) and age X illness intrusiveness ( $\beta$  = 0.08, p = .48) were not significantly associated with sexual satisfaction, however, illness intrusiveness was significantly associated with sexual satisfaction ( $\beta$  = 0.36, p = .00), with the overall regression found to be significant,  $R^2$ adj = 0.10, F (3, 65) = 3.51, p = .02. Given that the interaction of age X illness intrusiveness was not statistically significant, no post-hoc tests were conducted to decompose the interaction term.

To follow up on the previous test of moderation, an additional bootstrapping analysis for moderation (known as a conditional indirect effect) using a macro for SPSS was run, given the benefits of bootstrapping analyses discussed previously (Preacher, Rucker, & Hayes, 2007). This analysis produced a 95% confidence interval that crossed 0 (-.18 – 2.63), bootstrap estimate = 1.17, SE = 0.71. Therefore, consistent with the regression analyses, the result of the bootstrapping analysis showed no moderation effect by age.

### **Exploratory Hypotheses**

Bootstrapping analyses were used to test the mediating or indirect effect of the IIRS subscales and total score between the MSISQ-19 subscales and total score (predictors) and the SSS (outcome). As a total of 15 exploratory analyses were conducted (see Table 1), thus increasing the likelihood of Type I error, a Bonferroni correction (Tabachnick & Fidell,

2007) was used to modify the significance of the overall model to  $\alpha = .003$ . Of the 15 analyses performed, four were statistically significant.

First, illness intrusiveness in intimate relationships (bootstrap estimate = 1.73, CI = .68 - 3.09) was found to have a significant indirect effect between secondary sexual dysfunction and sexual satisfaction and the overall model remained significant after applying the Bonferroni correction ( $p \le .001$ ). However, as no significant relationship was found between secondary sexual dysfunction and sexual satisfaction (p = .19), this finding was classified as an indirect effect. Three mediational effects were found for the impact of illness intrusiveness on intimate relationships between tertiary sexual dysfunction and sexual satisfaction (bootstrap estimate = 1.67, CI = .74 - 2.80), sexual dysfunction total score and sexual satisfaction (bootstrap estimate = 2.01, CI = .72 - 3.61), and primary sexual dysfunction and sexual satisfaction (bootstrap estimate = 0.96, CI = .20 - 1.83). A significant relationship between the predictor and outcome variables was found for each analysis (p =.02, p = .004, and p = .001), with the overall models reaching significance even after applying the Bonferroni correction in all analyses (p = .001). Other analyses did not show significant mediation or indirect effects (see Table 8 for details and for all other nonsignificant results).

## **Summary of Results**

There was no mediation, indirect effect, or moderation by total illness intrusiveness scores between total sexual dysfunction and sexual satisfaction. Indirect and mediational effects were found, however, upon examining the subscale score of illness intrusiveness in intimate relationships. Specifically, there was an indirect effect of illness intrusiveness in intimate relationships between secondary sexual dysfunction and sexual satisfaction. In

addition, there was a mediation effect, in that illness intrusiveness for intimate relationships mediated the relationships between primary, tertiary, and overall sexual dysfunction scores and sexual satisfaction (see Figure 3).

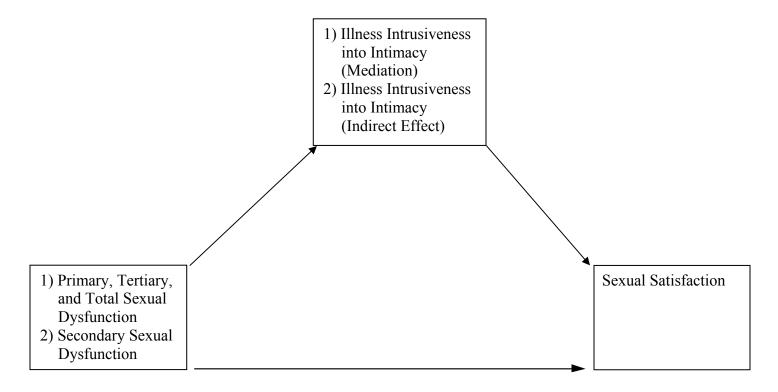
Table 8

Results of Exploratory Analysis with IIRS and MSISQ-19 Subscales

Predictor	Mediator	Outcome	DV on IV (c path)	Indirect Effect a x b (99% CI)	
MSISQ-19 Primary	IIRS Relationships and Personal Development	SSS	2.98***	0.30	(-0.19-0.94)
	IIRS Instrumental		2.90***	0.16	(-0.11-0.56)
	IIRS Intimacy		2.97***	0.96	(0.20-1.83)
	IIRS Total		2.91***	0.43	(-0.07-1.18)
MSISQ-19 Secondary	IIRS Relationships and Personal Development	SSS	1.20	1.26	(0.18-2.64)
	IIRS Instrumental		1.04	0.69	(-0.09-1.69)
	IIRS Intimacy		1.19	1.73	(0.68-3.09)
	IIRS Total		1.04	1.55	(0.44-2.89)
MSISQ-19 Tertiary	IIRS Relationships and Personal Development	SSS	1.51*	0.84	(-0.06-1.89)
	IIRS Instrumental		1.44*	0.33	(-0.19-0.89)
	IIRS Intimacy		1.54*	1.67	(0.74-2.80)
	IIRS Total		1.42*	1.04	(0.19-2.00)
MSISQ-19 Total	IIRS Relationships and Personal Development	SSS	2.60**	0.69	(-0.53-2.08)
	IIRS Instrumental		2.50**	0.38	(-0.47-1.21)
	IIRS Intimacy		2.63**	2.01	(0.72-3.61)

Note. \*p < .05, \*\*p < .01, \*\*\*p < .001. The bolded estimates and the 95% CI represent statistically significant findings after a Bonferroni correction was applied.

Figure 3. Figure of Significant Results.



#### Discussion

# **Summary of Purpose and Findings**

Strong evidence has been found for increased sexual dysfunction among individuals with MS (McCabe et al., 2003). Despite this, few researchers have focused their investigations on sexual satisfaction among those with MS (an important correlate of sexual dysfunction), or on the predictors of sexual satisfaction. The current study contributes to the small literature on sexual satisfaction within MS populations by examining: 1) the extent to which illness intrusiveness mediated the relationship between sexual dysfunction and sexual satisfaction and 2) the extent to which age moderated the relationship between illness intrusiveness and sexual satisfaction. Moreover, the unique association of primary, secondary, and tertiary sexual dysfunction and with illness intrusiveness appraisals in various life domains (e.g., intimate relationships) was investigated.

Findings showed that overall illness intrusiveness did not mediate sexual dysfunction total scores and sexual satisfaction, and that age did not moderate the impact of overall illness intrusiveness on sexual satisfaction. However, the intimacy subscale of illness intrusiveness did influence the relationship between sexual dysfunction and sexual satisfaction. Specifically, an indirect effect for illness intrusiveness in intimacy was found between secondary sexual dysfunction and sexual satisfaction such that greater illness intrusiveness was associated with lower sexual satisfaction. As well, illness intrusiveness in intimacy mediated the relationship between total, primary, and tertiary sexual dysfunction and sexual satisfaction, with higher illness intrusiveness associated with worse sexual satisfaction.

#### The Role of Illness Intrusiveness on Sexual Satisfaction

The mean scores within the current study were compared to those of other MS samples to examine whether the current participants differed from those of previous research. The current sample mean for illness intrusiveness (M = 44.74, SD = 17.76), was comparable with that of a study by Devins and colleagues (1996) (M = 45.40, SD = 15.66). This finding suggests that illness intrusiveness among those in the current sample was similar to that found in other samples with MS. It was not possible however to compare the means of the MSISQ-19 for the sample as the two previously published studies that used the MSISQ-19 did not report means (i.e., Sanders et al., 2000; Demarkiran et al., 2006). Given this, it is currently unknown whether the current participants differ significantly from other MS patient samples on self-reported sexual dysfunction. Finally, although no other studies with published means for sexual satisfaction that used the SSS could be found, a manuscript in progress by Culp and colleagues (2010) on MS patients from a psychotherapy trial found higher sexual dissatisfaction (M = 15.70, SD = 6.63) compared to the current sample (M = 11.50, SD = 6.03). As that sample used by Culp and colleagues (in progress) was from a trial of psychotherapy for depression among MS patients (Mohr et al., 2005), it is possible that having a diagnosis of major depression was associated with higher sexual dissatisfaction.

The primary hypothesis that overall illness intrusiveness would mediate sexual dysfunction and sexual satisfaction was not supported. This finding differs from the general literature where extensive support for the mediational role of illness intrusiveness between disease symptoms and general outcomes (e.g. QOL, fatigue and depression) (Devins et al., 1993a; Dancey et al., 2002; Shawaryn et al., 2002) has been found. In one such study, overall illness intrusiveness among a population with irritable bowel syndrome (IBS) mediated the

relationship between both IBS-related stigma and IBS symptoms and QOL (which included various aspects of daily life such as physical impairment, mental health, and social responsibilities). The authors concluded that greater illness intrusiveness heightened the negative effect of IBS symptoms on QOL (Dancey et al., 2002). Another study found that among those diagnosed with chronic medical illnesses - including arthritis, renal disease, and MS - the link between poor sleep quality and increased symptoms of depression was mediated by greater illness intrusiveness (Devins et al., 1993a). In addition, another study found greater illness intrusiveness mediated the relationship between more severe neurological symptoms and higher levels of fatigue (Shawaryn et al., 2002). Despite the findings of the current study, there is strong published evidence for the mediational role of illness intrusiveness between illness symptoms and physical and psychological outcomes.

There are several possible reasons that total illness intrusiveness did not mediate sexual dysfunction and sexual satisfaction in the current study. Mean scores for sexual dysfunction, illness intrusiveness and the associated subscales, and sexual satisfaction were all within the midrange (see Table 6). Upon further examination of these scores, although there was a wide range of overall reported sexual dysfunction (1.05 - 4.11), the standard deviation from the mean (2.46) was minimal (.81) indicating most scores were not evenly distributed across the ranges. Sexual dissatisfaction scores ranged from 4 to 24 and the standard deviation from the mean score of 11.50 was 6.03 and illness intrusiveness scores ranged from 13-78 with a standard deviation from the mean of 44.74 of 17.76. While symptoms of sexual dysfunction were present, these may not have been severe enough to be appraised as highly intrusive in one's life. However, upon reviewing previous studies that found support for mediation by illness intrusiveness, mean scores of illness intrusiveness from the present study were found to be comparable to other

published data (i.e., Dancey et. al. 2002). Therefore, it is unlikely that mediation was not found due to decreased severity of illness intrusiveness in this sample.

A second possibility is that the construct of illness intrusiveness may not be the most relevant for understanding the relationship between sexual dysfunction and sexual satisfaction. Specifically, illness intrusiveness may be too broad to impact the direct link between sexual dysfunction and sexual satisfaction, and a more specific measure of the appraisal of sexual dysfunction symptoms on sexual satisfaction may better explain this relationship. Currently there are no MS-specific measures that have been designed to examine appraisals of MS-related sexual dysfunction (Foley & Werner, 2004). Given that the two-item intimacy subscale of the IIRS mediated sexual dysfunction and satisfaction, a more detailed measure examining specific appraisals of illness related sexual dysfunction might be better able to assess how negative appraisals about MS-related sexual dysfunction impacts sexuality among these patients.

In support of the need to measure highly specific appraisals of sexuality, there was significant mediation as well as an indirect effect found for the intimacy subscale of illness intrusiveness (i.e., "How much does your illness and/or its treatments interfere with your relationship with your spouse? / your sex life") (Devins, 2010). Illness intrusiveness in intimacy was found to mediate the link between overall, tertiary, and primary sexual dysfunction and sexual satisfaction. Here, higher sexual dysfunction was associated with increased illness intrusiveness in intimacy, and greater illness intrusiveness in intimacy was associated with poorer sexual satisfaction. Illness intrusiveness in intimate relationships also influenced the relationship between secondary sexual dysfunction and sexual satisfaction, with higher secondary sexual dysfunction and greater illness intrusiveness resulting in poorer sexual satisfaction. Although the current study does not allow the causal direction of the relationship to

be determined, one possibility is that participants in this sample appraised the presence of sexual dysfunction (overall as well as primary, secondary, and tertiary) as negatively interfering in their lives resulting in increased illness intrusiveness in intimacy, which then was associated with lower sexual satisfaction.

Although illness intrusiveness in intimacy was found to explain at least part of the relationship between sexual dysfunction and sexual satisfaction, there are likely other psychological variables that play a more influential role. Specifically, other relationship variables might better explain the link between greater sexual dysfunction and lower sexual satisfaction. Research conducted in healthy, non-chronically ill populations found better perceived social support and positive interactions within a partnership was strongly associated with sexual satisfaction (Haning et al., 2007; Ojanlatva, et. al. 2005). One large study conducted with 21,101 healthy participants found that individuals who reported greater social support from their spouse were significantly more comfortable discussing sex and also reported greater sexual satisfaction (Ojanlatva et. al. 2005). In line with such findings, another study found that among healthy couples, discord between partners was associated with poorer sexual satisfaction (Haning et al., 2007). There has also been evidence found for the importance of positive relationship dynamics among couples in which the male partner experienced chronic pelvic pain. Here, poorer sexual function and more negative relationship dynamics predicted decreased sexual satisfaction for the couple (Smith, Tripp, Pukall, & Nickel, 2007). Clearly, the dynamics of a relationship play an important role in the sexual satisfaction of couples from the general population.

Moreover, while the literature is quite limited thus far, preliminary results do suggest that relationship variables such as relationship satisfaction also impact sexual satisfaction among individuals with MS. In fact, relationship variables may take on an increased importance due to

MS-related challenges placed on these couples, and an increased need to work through these problems (such as changes to sexual functioning or household responsibilities) (Koch et al., 2002; Esmail et al., 2007). Those with MS have been found to have lower relationship satisfaction and sexual satisfaction compared to the general population (McCabe 2002; McCabe et al., 2003). When patients with MS were asked to evaluate the impact of MS on their sexual relationship, those who were more content in their current relationship also believed MS had improved their sexual relationships (McCabe et al., 1996). This suggests that that relationship satisfaction likely influences the extent to which MS symptoms negatively impact appraisals of sexual function and satisfaction.

There is also evidence for the importance of communication for sexual satisfaction among those with MS. One study of factors associated with sexual satisfaction among women with MS led to the conclusion that more active coping and less cognitive impairment among women with MS predicted higher sexual satisfaction. The authors posited that perhaps these factors are associated with increased communication and engagement in the relationship, resulting in improved sexual satisfaction. In addition, there were significant correlations between sexual dysfunction, sexual satisfaction, and relationship satisfaction, demonstrating that these constructs were all likely interrelated for women with MS (McCabe, 2002). Another study compared sexual satisfaction, sexual dysfunction, and relationship components (e.g., relationship satisfaction and communication) between healthy participants and those with MS, and found that only sexual dysfunction differed between groups, with those with MS having greater dysfunction. Although this study should be interpreted carefully given that the sample sizes of the MS (n = 42) and general healthy population (n = 32) were low, it is interesting that only sexual dysfunction differed between the samples. It may be that because both groups in McCabe (2002) reported

relatively high relationship satisfaction, this buffered the deleterious effect of sexual dysfunction for the MS group. In line with this possibility, a qualitative study of MS and sexual intimacy between couples found that those who were successfully able to discuss changes in their relationship due to MS (including changes to sexual functioning) were better able to find ways to adapt to such challenges, and reported improved sexual relationships (Esmail et al., 2007). These data suggest that having more positive relationship factors such as better communication may serve to decrease the negative impact of sexual dysfunction on sexual satisfaction.

## **Moderation of Illness Intrusiveness by Age**

In the current study age was hypothesized to moderate the negative impact of illness intrusiveness on outcome, with those with a younger age reporting worse outcomes from increased illness intrusiveness compared to older individuals. Younger age has been theorized to lead to a more detrimental influence of illness intrusiveness on psychological outcomes, as chronic illness among these individuals may be seen as a violation of the usual ageing progression (Devins et al., 1992). However, no significant moderation effect of age on illness intrusiveness was revealed among this sample in the current study. This finding stands in contrast with past research that has consistently found the negative impact of illness intrusiveness declines over time (e.g., Devins et al., 1996). It is important to consider that overall illness intrusiveness did not seem to mediate sexual dysfunction and sexual satisfaction among this sample, and subsequently, it is not surprising that further moderation of this relationship by age was not found. Along with lack of mediation, the age distribution of the sample may have contributed to the lack of a moderation effect for age. The sample had a mean age of 42.5 (SD = 10.37) with the oldest participant being 68 years of age. Moreover, only 25.5% of our total sample was 50 years or older. Given that the overall sample size of this study was 82, the

analyses may not have contained enough older adults to properly assess the moderational effect of age, and therefore was statistically underpowered.

Other research that found support for moderation by age displayed larger age ranges (e.g., 24-81 years) and within sample sizes over 100 (e.g. Devins et al., 1996; Devins et al., 2009). One study found a moderation effect of age between illness intrusiveness and mental health after controlling for MS symptoms and perceived life stressors (Devins et al., 1996). Among younger age groups, illness intrusiveness greatly increased the risk of depression and poor emotional well-being (i.e., 30 years). However, participants at age 50 displayed a significant decrease in the negative effect of illness intrusiveness on depression and emotional well-being, while by age 70, illness intrusiveness no longer altered depression or emotional well-being. While the average age of this sample was also middle-aged, there was a significantly larger sample (N = 174) of individuals in this study, more variance in older age, and therefore greater power to detect significant moderation effects (Devins et al., 1996).

Other research has also found support for the moderating effect of age on illness intrusiveness among rheumatoid arthritis patients. However, once again, these studies had a larger sample size (105 and 110 respectively) and higher mean age (57.2 and 53.0 respectively) (Devins et al., 1992; Devins et al., 2009). In summary, compared to other published samples, the younger average age of participants and smaller sample size of the current study may have contributed significantly to the lack of moderation effect of age, as these were significantly lower compared to previous research that found such differences.

#### Limitations

There are several limitations to the current study. Although this study examined the mediation and moderation of sexual dysfunction and sexual satisfaction by illness intrusiveness

and age, based on well-researched and empirically-supported models, this was a single time point study. Given this, the causal sequence between sexual dysfunction, sexual satisfaction, and its proposed moderators and mediators cannot be determined. A longitudinal or multiple time point study might have allowed for greater opportunity to examine causal sequencing (Mathieu & Taylor, 2006). In addition, the study relied upon self-report measures that may be vulnerable to threats to validity such as self-report bias, inaccurate reporting of actual behaviors due to misremembering past events, or an individual's interpretation of their relationship (Butzer & Campbell, 2008; Redelman, 2009). In addition, participants who were comfortable enough to volunteer to take part in a study on about how MS impacts their relationship as a couple may have higher relationship and sexual satisfaction than general population with MS (Butzer & Campbell, 2008).

While the current study used the illness intrusiveness model to conceptualize the impact of illness symptoms (sexual dysfunction) on the outcome (sexual satisfaction) other models could have been used to examine this relationship as well. The illness intrusiveness model posits that illness intrusiveness mediates the relationship between a stressor (the illness) and its outcome (QOL) (i.e. Devins et. al., 1983), alternatively, the stress and coping model could have been used to examine the other mediators between sexual dysfunction on sexual satisfaction. Briefly, the stress and coping model puts forth that when an event occurs (in this case illness symptoms), the level of stress associated with this event is appraised by an individual. A person then decides how to cope with this event based on this appraisal. Therefore, this model proposes that appraisals and coping mediate the relationship between the event and the outcome (Lazarus & Folkman, 1984). However, while it may be interesting in the future to examine how the appraisals and the resulting coping mediate sexual dysfunction and satisfaction, the construct of

illness intrusiveness arguably better addressed important appraisals about the effect of the illness on one's personal life and sexual relationship that are not addressed in the stress and coping model (Lazarus, 1993; Devins 2010).

It should also be noted that there were some significant limitations to the psychometric properties of the MSISQ-19. Specifically, the MSISQ-19 reported a convergent validity r = 0.40, and divergent validity r = 0.31 that were quite close (Sanders et al., 2000). However, while the psychometric properties of this scale are not as strong as those reported by other popular measures of sexual dysfunction such as the Female Sexual Function Index (FSFI) (Rosen et al., 2000), unlike the FSFI, the MSISQ-19 is the only scale that specifically measures the unique symptoms of sexual dysfunction that are problematic in MS such as genital numbness (Zivadinov et al., 1999). In addition, the scale offers subscales that report levels of primary, secondary, and tertiary sexual dysfunction. It should be noted, however, that while these are useful theoretical categories of sexual dysfunction in MS, the reliability of this classification method has not been formally tested to date.

Additionally, given that these data were collected for the purpose of a larger study on couples living with MS, there may have been a selection bias wherein less distressed individuals chose to take part in the study (Butzer & Campbell, 2008). Only including coupled individuals likely led to a sample of participants with less physical disability and greater sexual satisfaction being included in the current study. For example, among individuals with physical disabilities, those with more physical disability were less likely to be in a relationship and also reported lower sexual satisfaction (Taleporos & McCabe, 2003). These authors theorized that having greater physical impairments might decrease one's chances of forming a romantic relationship. This may be especially relevant in our sample, as MS is often diagnosed in young adulthood

when such relationships may not yet be formed (WHO, 2008). Therefore, the findings of the current study are likely more applicable to MS patients who face fewer challenges with sexual dysfunction and disability. In addition, those within the current sample were likely less distressed than the general population of MS patients as they had a high level of education and volunteered for the study, and therefore may have been better able to access resources than a random sample of patients with MS.

This study also did not control for depression. Given the high point-prevalence rate of depression among those with MS (45 to 51%) (Bamer et al., 2008) it would be important in future research to examine the possible effect of depression on outcome. Specifically, given that this study used self-report measures, and depression is known to create a negative bias in thinking (Teasdale, 1983), participants who were depressed may have been more likely to appraise their symptoms as more intrusive and may have been more likely to reported lower sexual satisfaction. A preliminary regression was run in order to control for the effect of depression and it did not impact sexual satisfaction, however, this should be replicated in future studies with larger power.

Finally, while there were no significant differences between recruitment sites, there were significant dissimilarities found between the women who were sexually active and those who were not. Sexually active women (versus non-active women) were younger, had been in a relationship for fewer years, and reported less primary sexual dysfunction and less illness intrusiveness on the intimacy subscale. Given that the analyses could only be conducted with sexually active women (n = 72) the study findings apply better to younger, sexually active women with MS, with a shorter relationship duration, and less primary sexual dysfunction.

# **Strengths**

Despite its limitations, this was the first known study to examine the mediational effect of illness intrusiveness on sexual dysfunction and sexual satisfaction in an MS population. This study also adds to the limited literature on sexual satisfaction among individuals with MS (McCabe, 2004) and unlike several previous studies (e.g., Sanders et al., 2000), the current research used validated measures that have been created for individuals with MS. In addition, there was a high response rate and good internal reliabilities for the questionnaires. Finally, the current findings point the possible importance of illness intrusiveness into intimacy and appraisals of sexual dysfunction on sexual satisfaction for individuals with MS.

# **Future Directions and Clinical Implications**

Future research would benefit from examining dyadic data to investigate the impact of MS on the relationship of the couple as a whole (McCabe et al., 1996). Longitudinal research should also be used to assess the impact of sexual functioning, appraisals, and relationship variables on satisfaction overtime among those with MS in order to be better able to determine predictors of sexual satisfaction among those with MS. This study examined the role of illness intrusiveness on the relationship between sexual dysfunction and satisfaction among women with MS; however, it would be important to examine this relationship among men in the future given the presence of sexual dysfunction, and illness intrusiveness in both genders (Fletcher et al., 2009; Mullins et al., 2001).

The majority of this sample was Caucasian and no information on immigration status was collected. To date, there has been no research on the role of ethnicity and immigration status on sexual satisfaction among those with MS. Research with healthy populations has shown that individuals of certain ethnicities hold more liberal sexual attitudes (Benuto & Meana, 2010).

Therefore, it cannot be assumed that sexuality is the same across groups. Further research with MS patients of different ethnicities, as well as with recent immigrants should be conducted to examine whether the current findings are applicable to these populations. Also, no research exists on sexual satisfaction among patients with MS in same-sex relationships. While research from the general literature is limited, it is clear that while most factors involved in sexual satisfaction do not vary greatly between same-sex and heterosexual relationships, some differences do exist, and therefore, it is necessary to examine sexual satisfaction among both heterosexual and same-sex relationships (Holmberg & Blair, 2009). While the present study included individuals of various sexual orientations, the majority were in heterosexual relationships and it will be important in future studies to investigate the relationship between these variables for individuals in same-sex relationships.

Given the sample size of the current study, it was not possible to control for all potential contributing factors to sexual satisfaction. Important variables to examine in the future would be illness duration and severity, relationship variables such as communication and relationship satisfaction, as well as depression and fatigue, given their high prevalence rates among those with MS (e.g., Janardhan & Bakshi, 2002; Bamer et al., 2008). While the sample size did not allow for further investigation into the impact of illness intrusiveness for women who were sexually inactive, it would be helpful in future research to interview women with MS who are sexually inactive.

The results suggest that appraisals of sexuality appear to mediate the relationship between sexual dysfunction and sexual satisfaction. This study underscores the importance of examining intimacy-specific appraisals among MS patients who report symptoms of sexual dysfunction.

Currently, there does not seem to be a detailed assessment of such appraisals validated for

individuals with MS. It might be important for future research to develop methods to better assess these appraisals of sexual functioning among MS patients, to determine whether such appraisals should be targeted in effort to improve sexual satisfaction. Such methods might involve the creation and validation of a more comprehensive measurement of intrusiveness of sexual dysfunction into intimacy created for specific symptoms of MS-related sexual dysfunction. Longitudinal research could be used along with such a measure to examine what impact these appraisals have on sexual satisfaction overtime.

While symptoms of sexual dysfunction and decreased sexual satisfaction were present in the current sample, there appeared to be significant variability in such challenges among participants. In addition, level of sexual satisfaction was not solely determined by the level of sexual dysfunction. Therefore, while it appears important to assess both sexual dysfunction and satisfaction among patients with MS, there is significant variation in the presentation of such challenges. While this was the first study to examine the role of illness intrusiveness on sexual satisfaction among a sample with MS, it seems that appraisals about intimacy are associated with sexual satisfaction among this sample. Longitudinal studies should further investigate the potential role of appraisals about sexual dysfunction on sexual satisfaction. However, while appraisals about illness intrusiveness into intimacy are likely an important issue to examine in the future, other relationship variables such as couple's communication and relationship satisfaction would likely make greater contributions to sexual satisfaction (McCabe et al., 1996).

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