

Correlates of Sexual Dysfunction in Men and Women with Multiple Sclerosis

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Abstract: Sexual dysfunction (SD) is an often overlooked disability in multiple sclerosis (MS). The purpose of this study was to investigate the relationship between SD and other disabilities in men and women with MS. The sample included 32 men and 219 women. The men ranged in age from 32 to 65 years with a mean of 47.6 years. The women ranged in age from 22 to 77 years with a mean of 45.4 years. Data were collected using Guy's Neurological Disability Scale and a demographic questionnaire. In men, a significant positive relationship was found between SD and lower-limb and bladder disability. No relationship was found between SD and other MS disabilities. The most common problems for men involved erection and ejaculation. For women, a significant positive relationship was found between SD and all other MS disabilities. The strongest correlation was between SD and fatigue. The most common problems for women involved vaginal lubrication and orgasm. No relationship was found between SD and number of years with MS or age in either men or women. An open dialogue about SD may improve quality of life for people with MS. Interventions may include symptomatic treatment, referral of the couple for sexual counseling, and other approaches that may include sensory body mapping to enhance communication and pleasure for the couple living with MS.

Sexual dysfunction (SD) affects the lives of many men and women with multiple sclerosis (MS). SD is important in MS, but unfortunately it is often overlooked (Demirkiran, Sarica, Uguz, Yerdelen, & Aslan, 2006). The extent of SD is unclear, especially during the early stages of MS, when people are less disabled (Nortvedt et al., 2007).

Foley (2005) stated that 50%–90% of men and 40%–80% of women with MS are thought to have sexual complaints or concerns. Men most frequently report a diminished ability to attain or maintain an erection and difficulty achieving orgasm. Women most often report a decrease in or loss of sexual desire, vaginal dryness, problems with orgasm, and sensory changes in the genitals.

Psychosocial issues are also thought to have an association with SD. Some issues identified include

lowered self-esteem, body image, change in family roles, loss of confidence, and beliefs and expectations about sexuality in the context of living with a disability (Foley, 2005). Factors associated with SD are thought to include changes to the nervous system related to the disease process, bladder and bowel disability, fatigue, spasticity, muscle weakness, problems with concentration, and hand tremor. Although numerous possible factors are thought to be associated with SD, few studies have investigated SD in men and women with MS. The purpose of this study was to investigate the relationship between SD and other MS disabilities in men and women with MS.

Literature Review

Demirkiran and colleagues (2006) investigated the type and frequency of sexual problems in 51 patients with MS. Participants included those with relapsing-remitting MS (68.6%), secondary-progressive MS (17.6%), and primary-progressive MS (13.7%). Those with progressive forms of MS are usually more disabled than those with relapsing-remitting MS. The investigators found that age, duration of disease, education level, Expanded Disability Status Scale (EDSS) score, and ambulation index were similar for men and women. Fatigue was found to be significantly more common in women with SD than in men (90.9% versus 61.6%, respectively; $p = .02$).

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Nortvedt and colleagues (2007) examined bladder, bowel, and sexual problems in 56 people 2 to 5 years after they were diagnosed with MS. The investigators found that the major problem for men was achieving and sustaining an erection. For women, the major problem was sexual interest and achieving orgasm. Men were significantly more dissatisfied with sexual function than women ($p = .01$). No relationship was found between sexual problems and level of disability as measured by the EDSS ($r = .24, p = .12$).

Gruenwald and colleagues (2007) investigated quantitative sensory testing in 41 women with MS. Twenty-five participants were found to have SD. Participants' EDSS scores ranged from 0 to 6 with a median of 2.5, indicating mild disability. The most common complaints were decreased libido (61%) and problems with orgasm (54%). Significant relationships were found between clitoral vibratory sensation and orgasmic dysfunction ($r = .42, p = .006$). Another significant relationship was found between cerebellar deficit and orgasmic dysfunction ($p = .001$).

Zivadinov and colleagues (1999) conducted a study in Italy to investigate SD in 108 patients with MS (38 men and 70 women). In men, no relationship was found between SD and physical disorders, disability and dependency, bladder dysfunction, fatigue, cognitive deterioration, neurological impairment, or bowel dysfunction. In contrast, women had a number of significant relationships between SD and physical disorders ($r = .42, p = .0017$), disability and dependency ($r = .43, p = .0006$), bladder dysfunction ($r = .37, p = .0035$), fatigue ($r = .30, p = .0284$), cognitive deterioration ($r = .30, p = .0280$), and neurological impairment ($r = .28, p = .0306$). There was no relationship between SD and bowel dysfunction in women. In both men and women, no relationship was found between SD and duration of disease, suggesting that the autonomic nervous system may be affected early in the disease process.

McCabe (2002) investigated SD in 381 people (144 men and 237 women) with MS and 291 people (101 men and 190 women) from the general population. The investigator found that both men and women with MS were more likely to experience sexual problems than the general population. The most common problems for men, in descending order, included erectile problems (37.3%), lack of sensation or numbness (35.9%), lack of sexual interest (31.7%), failure to ejaculate (29.6%), too long to ejaculate (23.2%), difficulty masturbating (23.2%), other sexual problems (19.7%), ejaculating too soon (16.2%), and painful intercourse (2.1%). Sixteen percent of men reported no problem with sexual function. The most common problems for women, in descending order, included failure to have an orgasm (45.1%), lack of sexual interest (42.9%), lack of sensation or numbness (36.2%), poor vaginal lubrication

(34.8%), difficulty becoming aroused (32.6%), painful intercourse (17.9%), difficulty masturbating (15.6%), other sexual problems (13.8%), and impossible intercourse (2.2%). Nineteen percent of women reported no problem with sexual function. Women with MS were found to have significantly higher levels of SD than men with MS. The only significant predictor of sexual satisfaction in men with MS, among all coping strategies and health-related variables studied, was the coping strategy of focusing on the positive. In contrast, women who had a less detached style of coping and less cognitive confusion were found to have higher levels of sexual satisfaction.

McCabe, McKern, McDonald, and Vowels (2003) investigated sexual and relationship functioning in people with MS. The sample included 120 men and 201 women with MS. The investigators found that there was not a strong relationship between sexual and relationship functioning in men. They noted that men appeared to separate sexual functioning and relationship functioning, thereby lessening the impact of SD on the relationship. A strong relationship was found between SD and other aspects of relationship functioning in women with MS.

Borello-France and colleagues (2004) sought to identify factors associated with SD in 133 women with MS. The investigators hypothesized that SD would be associated with neurologic impairment and higher levels of distress caused by bladder symptoms. The participants were found to be sexually active (73%), and the majority were able to feel aroused, experience orgasm, and enjoy sexual activity. Women who were more distressed about urge incontinence were more likely to have higher levels of arousal and orgasm function than those who reported less distress over urge incontinence. The investigators noted that a limitation of their study was that they did not directly measure the type and level of neurological impairment and level of physical disability in the participants. They suggested that future studies investigate the impact of physical disability on sexual function in women with MS.

Method

Research Question

Is there a relationship between sexual disability and other MS disabilities in men and women with MS?

Instruments

The Americanized Guy's Neurological Disability Scale

The Guy's Neurological Disability Scale (GNDS) was originally developed in the United Kingdom by Sharrack and Hughes (1999). The GNDS consists of 12 functional domains of disability: cognitive, mood, visual, speech and communication, swallowing, upper limb, lower limb, bladder, bowel, sexual,

fatigue, and other disabilities (e.g., pain, spasms, vertigo). Each of the 12 domains is graded on a 5-point scale according to severity and impact on the individual, as judged by the help needed to perform these functions (0 = *normal status*; 5 = *total loss of function—maximal help required*).

The possible range of total scores on the GNDS is 0 (*no disability*) to 60 (*maximum possible disability*). A mean score of 20 on the GNDS is equivalent to a score of 6.0 on the EDSS (Sharrack & Hughes, 1999). The EDSS is the gold standard for assessment of disability in people with MS. The EDSS score is determined by a neurologist, who assesses the following functions: pyramidal, cerebellar, brain stem, sensory, bowel and bladder, visual, and cerebral (mental). An EDSS score of 6.0 indicates that intermittent or unilateral constant assistance (cane, crutch, or brace) is needed to walk about 100 meters with or without resting (Kurtzke, 1983).

The Americanized version of the GNDS includes some modification in the wording of the questions to reflect the vocabulary and phrases used in the United States as well as some refinement and clarification of the instrument. The Americanized version of the GNDS was found to be a reliable measure. The 2-week test-retest reliability was $r = .91$, $p = .000$, indicating good reliability over time. Cronbach's alpha at time 1 was .79, at time 2 was .78, and at time 3 was .80, indicating good internal consistency (Fraser & McGurl, 2007).

Demographic Data Questionnaire

A demographic data questionnaire was developed by the researcher and was used to collect the following information about the participants: gender, ethnicity, education, marital status, household income, and disease-modifying medications for MS.

Data Analysis

This study is a secondary analysis of data collected by Fraser and McGurl (2007) for conducting the psychometric testing of the Americanized version of the GNDS in people with relapsing-remitting MS.

Results

The sample in the original study (Fraser & McGurl, 2007) included 253 people with MS. Because two participants did not indicate their gender, they were excluded from this secondary analysis. The final sample size for this study was 251. Inclusion criteria were a diagnosis of relapsing-remitting MS, a history of one or more relapses in the past 2 years, minimum age of 18 years or older, willingness and ability to complete all evaluations related to the study, willingness to provide informed consent, and an e-mail address. Exclusion criteria included significant medical illnesses other than MS. Institutional

review board approval was obtained for the original data collection from Monmouth University, West Long Branch, NJ. See Table 1 for a description of the sample.

Because sexual function differs between men and women, the data were split by gender and examined for correlates of SD in each group. A Spearman's rho correlation was run on the data to answer the research question. This nonparametric test was used because the distribution of scores was skewed. Descriptive statistics were also run.

Men ($n = 32$) ranged in age from 32 to 65 with a mean of 47.6 years ($SD = 8.9$). The number of years since the diagnosis of MS ranged from 3 to 16 years with a mean of 6.9 years ($SD = 3.5$). Scores on the GNDS ranged from 2 to 34 with a mean of 14.0 ($SD = 8.3$). Men reported SD in several areas including lack of sexual interest (9.4%); altered genital sensation, pain, or spasms (6.3%); and sexual problems that totally prevented sexual activities (15.6%). More than one-quarter of men (28.1%) reported problems with having an erection or ejaculation. No problems with sexual function were reported by 40.6% of the male participants.

Women ($n = 219$) ranged in age from 22 to 77 years with a mean of 45.4 years ($SD = 9.3$). The number of years since the diagnosis of MS ranged from 1 to 25 years with a mean of 8.7 years ($SD = 5.9$). Scores on the GNDS ranged from 0 to 42 with a mean of 15.3 ($SD = 9.0$). Women reported SD in several areas including lack of sexual interest (6.8%); problems satisfying self or sexual partner (0.9%); altered genital sensation, pain, or spasms (2.3%); and sexual problems that totally prevented sexual activities (9.1%). More than one-quarter of the women (29.2%) reported problems with vaginal lubrication or orgasm. More than half of the women (52%) reported no problems with sexual function. See Table 2 for the comparison of men and women.

In men, a significant positive relationship was found between SD and lower-limb disability ($r = .46$, $p < .01$) and bladder disability ($r = .45$, $p < .01$). No relationship was found between SD and other MS disabilities. In addition, there was no relationship between SD and the number of years since the diagnosis of MS ($r = .26$, $p > .05$) and between SD and age ($r = .14$, $p > .05$).

In women, a significant positive relationship was found between SD and all other MS disabilities measured by the GNDS. The correlations are presented according to the strength of the relationship between the SD and the following MS disabilities: fatigue ($r = .34$, $p < .01$); upper limb ($r = .32$, $p < .01$); cognitive ($r = .28$, $p < .01$); lower limb ($r = .27$, $p < .01$); bowel ($r = .27$, $p < .01$); bladder ($r = .27$, $p < .01$); speech and communication ($r = .27$, $p < .01$); mood ($r = .24$, $p < .01$); swallowing ($r = .24$, $p < .01$); pain, spasms, or dizziness ($r = .19$, $p < .01$); and visual ($r = .16$, $p < .05$).

No relationship was found between SD and the number of years since the diagnosis of MS ($r = .12, p > .05$) and between SD and age ($r = .10, p > .05$). See Table 3 for the comparison between men and women.

Discussion

The findings revealed that a substantial percentage of men who participated in the study experienced difficulties related to erectile and ejaculatory dysfunction. Men also reported SD in several areas including a lack of sexual interest; altered genital sensation, pain, or spasms; and sexual problems that totally prevented sexual activities. A large proportion of women with MS reported problems with vaginal lubrication and difficulty achieving orgasm. Women also reported SD in several other areas including a lack of sexual interest; altered genital sensation, pain, or spasms; problems satisfying self or sexual partner; and sexual problems that totally prevented sexual activities. No problems with sexual function were reported by more than one-third of the men and about half of the women.

The most significant finding of this study was that the relationship of SD and MS disabilities is different for men and women. SD for women encompassed a vast array of disabilities when compared with men. Zivadinov and colleagues (1999) reported similar findings in 70 women with MS living in Italy. The investigators reported a significant relationship between SD and physical disorders, disability and dependence, bladder dysfunction, fatigue, cognitive deterioration, and neurological impairment. In the 38 men who participated in their study, no relationship was found between the variables. Similarly, McCabe (2002) found that women had higher levels of SD than men.

For both men and women, a significant positive relationship emerged between SD and lower-limb disability. This finding confirms a common belief held by MS healthcare professionals about the relationship of these two disabilities. A significant positive relationship was also found between SD and bladder disability; the strength of the relationship was stronger for men than for women. Nortvedt and colleagues (2007) also found that sexual problems were related to bladder problems for both men and women.

Fatigue was found to have the strongest positive relationship with SD in women. Demirkiran and colleagues (2006) reported that fatigue was significantly more common in women with SD than in men. There were no significant findings about the relationship between SD and the number of years since the diagnosis of MS and between SD and age. These findings are similar to those reported by Zivadinov and colleagues (1999), who suggested that the autonomic nervous system was affected early in MS.

Table 1. Sample Characteristics

Characteristic	Men (<i>n</i> = 32)	Women (<i>n</i> = 219)
Ethnicity	%	%
White (Not Hispanic)	96.9	94.5
African American	0	2.7
Other	3.1	2.8
Education		
High school diploma or associate degree	48.4	46.3
College degree	51.6	53.7
Marital Status		
Married	77.4	66.8
Divorced, separated, or single	22.6	33.2
Household Income		
<\$20,000 to \$59,999	25.9	42.7
\$60,000 to >\$100,000	58.1	43.2
Choose not to answer	16.0	14.1
Current Disease-Modifying Medication		
Avonex	46.9	38.1
Betaseron	18.8	7.8
Copaxone	18.8	23.4
Rebif	15.5	11.9
None	0	18.8

Table 2. Sexual Dysfunction Responses on Guy's Neurological Disability Scale

Response	Men (<i>n</i> = 32)	Women (<i>n</i> = 219)
	%	%
No problem with sexual function	40.6	51.6
Lack of sexual interest	9.4	6.8
Problems satisfying self or sexual partner	0	0.9
Altered genital sensation, pain, or spasms	6.3	2.3
Problems with erection or ejaculation (men) or problems with vaginal lubrication or orgasm (women)	28.1	29.2
Sexual problems that totally prevent sexual activities	15.6	9.1

Implications

The GNDS provides an easy way to initiate discussions about sensitive issues related to SD. An open dialogue about SD offers the potential to significantly improve function and quality of life for people with MS by providing practical solutions for SD.

Because symptoms of dysfunction may be distressing for many people, proper identification and treatment are important. For male dysfunction, phosphodiesterase 5 inhibitors have been shown to be very effective in improving erectile function for many men with MS. Additional treatment modalities such as penile implants, intracavernous therapy, and vacuum devices continue to be viable options for some male patients (DasGupta & Fowler, 2003).

Although less is known about SD in women, a number of beneficial therapies exist. For example, estrogen, applied as a topical cream or by vaginal ring, and various over-the-counter lubricants may be

Table 3. Correlates of Sexual Dysfunction

Disability	Spearman's Rho	Spearman's Rho
	Men (<i>n</i> = 32)	Women (<i>n</i> = 219)
Cognitive	.12	.28**
Mood	.28	.24**
Visual	.19	.16*
Speech or communication	.18	.27**
Swallowing	.33	.24**
Upper limb	.03	.32**
Lower limb	.46**	.27**
Bladder	.45**	.27**
Bowel	.12	.27**
Fatigue	.07	.34**
Other (pain, spasms, dizziness)	.32	.19**
Years with multiple sclerosis	.26	.12
Age	.14	.10

p* ≤ .05. *p* ≤ .01.

beneficial in improving vaginal dryness and clitoral sensitivity, consequently reducing pain and discomfort during intercourse (DasGupta & Fowler, 2003).

Because fatigue has the strongest positive relationship with SD in women, people with MS should be helped to identify strategies to manage fatigue. These strategies may include maintaining a cool temperature in the home, planning rest periods, and discussing medications to help reduce fatigue with a healthcare professional. Because lower-limb disability is a correlate for SD in both men and women, patients should be taught strategies to reduce leg tightness and spasticity, such as stretching and strengthening exercises and yoga, and should discuss medications for spasticity with a healthcare professional.

It is important for nurses to accurately assess SD. Both men and women need to be assessed for lower-limb and bladder disability and SD. The findings from this study suggest that assessment for SD in women should include, in priority order, questions about fatigue; upper-limb function; cognitive functioning; bowel disability; speech and communication; mood; swallowing; pain, spasm, or dizziness; and visual disturbances.

For most people with SD related to MS, finding alternative treatments to improve sexuality and intimacy can be encouraging. Body mapping is one such treatment. Communication and pleasure are the objectives of sensory body mapping (Foley, 2005). It can be used to rekindle sexual pleasure. "Developing a sensory body map to explore the exact locations of pleasant, decreased, or altered sensations can improve intimate communication and set the stage for increasing pleasure" (Foley, p. 5). The body mapping exercise takes about 20 minutes to complete. The person should be disrobed in a comfortable, private environment. The person starts by systematically touching his or her body from head to toe, varying the rate, rhythm, and pressure of the

touch while noting areas of pleasure (Foley). The person informs his or her partner of specific pleasure areas. The partner conducts the same exercise, indicating his or her own pleasure areas. Partners take turns providing pleasure to each other without engaging in a sexual act or trying to achieve an orgasm (Foley).

A referral for sexual counseling may also be beneficial. Foley, LaRocca, Sanders, and Zemon (2001) used psychoeducational and counseling interventions in the rehabilitation of SD in MS, marital satisfaction, and marital communication. The investigators found that enhanced communication between the couple about critical problems and emotions resulted in improved sexual satisfaction, marital satisfaction, problem-solving communication, and effective communication. They also found that enhanced communication with healthcare professionals allowed tailored symptom treatment for SD.

Future research is needed to further explore gender differences in SD in MS. A more comprehensive measure of SD is recommended in future studies. For men, SD can be assessed using the International Index of Erectile Function questionnaire, developed by Rosen and colleagues (1997). For women, SD can be assessed using the Female Sexual Function Index, developed by Rosen and colleagues (2000). Additional research is needed to further explore other psychosocial factors that may be related to SD and MS, such as self-efficacy, self-esteem, roles, and relationships.

Limitations

The sample in this study consisted primarily of well-educated Caucasian women, the majority of whom were married. Other ethnic groups were minimally represented in the sample of participants with MS. The sample of men (*n* = 32) was small compared with that of women (*n* = 219). In a larger sample of men, additional correlates may be identified.

Summary

SD is underassessed for people with MS. Research findings suggest that most people with MS have SD. Although in recent years more studies have examined various aspects of SD in people with MS, there is still much to learn. Assessment for SD is essential for proper intervention and treatment.

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