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ORIGINAL PAPER

Sexual Dysfunction in Multiple Sclerosis

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Abstract To describe sexual dysfunction (SD) in persons with MS, its impact on quality of life and relationship with bladder function. Persons with definite MS ($n = 73$) from a tertiary hospital database, interviewed using standardized measures. For *disability*: Neurological Disability Scale (NDS), American Urological Association Index, Urogenital Distress Inventory (UDI6), Incontinence Impact Questionnaire (IIQ7) and Personal Experiences Questionnaire (PEQ); *participation*: Multiple Sclerosis Impact Scale (MSIS). Mean age 50 years, 73% female, 52% progressive MS and 60% with detrusor overactivity. Fifty-one (72%) had PEQ scores indicating SD. Women reported greater SD than men ($p = .013$). SD included: lack of enjoyment of sexual activity (32%), failure of arousal (30%) and anorgasmia (47%). Patients who reported MS impacted 'a great deal 'on their sex lives, compared with those who did not, showed significant differences on PEQ Sexual Frequency ($p = .01$), IIQ7 ($p = .03$), UDI6 ($p = .04$) and both MSIS subscales (Physical $p = .04$; Psychological $p = .03$). The PEQ Sexual Frequency scale significantly correlated with NDS (rho $= -.30$), QoL Bladder score (rho $= -.35$) and MSIS Physical subscale (rho $= -.30$). No association was found between SD and age, years since diagnosis, stage or severity of MS. SD is complex and often overlooked in clinical care. Improved management options for SD may improve QoL in these persons.

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Introduction

Persons with Multiple Sclerosis (pwMS) have a high prevalence of sexual dysfunction (SD), ranging from 40 to 80% in women and up to 90% in men [1]. Many primary, secondary and tertiary factors in MS can contribute to SD [2] (See Box 1). Neurological impairments that affect sexual function in pwMS include: diminished genital sensation [3], pain, spasms, pelvic floor weakness, and fatigue [4, 5]. Other factors such as greater disability and neuropsychological sequelae of MS (e.g. depression) can also impact SD [5, 6]. The most common issues reported by pwMS include decreased genital sensations and lubrication, decreased desire or libido and orgasmic capacity [4, 7]. Gruenwald et al. [8] suggest that cerebellar involvement in MS leads to impaired orgasmic ability due to lack of timing and coordination involving the autonomic system (genital engorgement, tachycardia, sweating) and the somatic system (pelvic floor, associated limb muscle contractions).

SD occurs across the MS disease spectrum including persons with mild disease. Although often underestimated it can negatively impact quality of life (QoL) and intimate relationships [6, 9, 10]. More SD has been reported in older pwMS and those more disabled with longer disease duration. SD is associated with depression, anxiety and low educational levels [7]. A previous study of pwMS at 2–5 years after diagnosis (EDSS scores <6.5, 80% relapsing remitting MS type) and presence of bladder issues and SD, reported a poorer QoL compared with those with lesser symptoms [11].

The neurological control of sexual response (and bladder function) involves both the parasympathetic and sympathetic nervous systems. One study ($N = 133$) which explored the association between bladder and SD found that although SD in MS was common, those with urge incontinence were less likely to have orgasmic dysfunction [9]. The influence of specific neurological impairments, physical disability and bladder problems on SD need further investigation. The aim of this study was to quantify SD in pwMS with a longer disease duration (mean 9 years) living in the community; and its relationship to bladder symptoms and QoL in these persons.

Methods

Participants and Setting

This study was part of a larger prospective trial of rehabilitation in pwMS, conducted at the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia. The

Box 1 Conceptual model of sexual dysfunction in MS[2]

Primary factors (demyelinating changes within the central nervous system that alter the sexual response) such as decreased genital sensation and libido causing decreased frequency and/or intensity of orgasm.

Secondary factors are MS related physical issues that alter sexual response indirectly, such as pain, spasticity, bladder dysfunction, fatigue, muscle weakness, decreased memory and attention.

Tertiary changes refer to psychosocial matters that negatively impact sexual function such as decreased self confidence, poor body image, altered family role, dependency; and internal beliefs regarding 'sexuality' and disability.

participant selection criteria and methodology have been described previously [12, 13]. Participants with 'definite' MS [14], and stage and severity category using Expanded Disability Status Scale (EDSS) [15] levels were recruited from the RMH MS database (sourced from membership of the MS Society or hospital clinics). The participants' were divided into three groups: mild (EDSS 0–3), moderate (3.5–6.0) and severe (EDSS 6.5–8). These persons were active and mobile in the community (EDSS scores for mobility 2–8), and had adequate cognition (KFS score range 0–2) for reliable report. Participants with cognition scores KFS $\geq$2 and those with relapse in the 3 months prior to recruitment were excluded.

As previously reported [12, 13], 204 patients listed on the RMH MS Database were identified as being eligible for this study. All were contacted by mail and invited to participate in the project. The 101 who replied affirmatively and returned approved consent forms were telephoned by the primary researcher to explain the study further and organize the interview appointment.

All participants were interviewed at their homes by independent trained researcher (LO) using a structured format. Interviews took approximately 1.5 h. Appropriate rest breaks were provided during the interview. The research assistant did not prompt participants, but provided assistance for those who had difficulty with completing the questionnaires. A total of 71 (of 101) participants completed the interview. Two patients were unable to complete the entire interview, one patient died and 1 withdrew consent, 2 relocated to another state, 2 responded after analysis was complete and 14 were away and/or unavailable. Eight patients declined interviews as they had 'no problems' with their bladder or sexual function.

Measurement

A face-to-face structured interview technique was used to allow clarification of patient responses, inquiry into sexual symptoms and issues, and their impact on everyday life and social role performance using a number of standardized measures (see below). Demographic information, MS stage and EDSS scores were obtained from the RMH Database; and urodynamic studies (within previous 18 months) from the medical record.

Participants were asked to indicate the extent their neurological problems affected their sex life. Responses were rated on a four point Likert scale (1 = not at all, 2 = a little, 3 = somewhat, 4 = a great deal). The intensity and consequence of symptoms was focused on those experienced by the participant in the previous 3 months.

Impairment and Disability

Bladder

UK Neurological Disability Scale (NDS) [16] (bladder subscale only) measured bladder symptom severity and level of disability. Previous research suggests this scale is reliable, responsive and a valid measure of disability [16]. The severity score for each item ranged from 0 = normal bladder to 5 = daily urinary incontinence. The severity grade for level of disability ranges from grade 0 = normal status to grade 5 = total loss of function- maximal help required.

American Urological Association (AUA) Symptom Index has seven questions concerning urinary symptoms and one question concerning QoL [17]. Respondents are asked to rate the severity of each symptom using a 6 point scale (0–5). The total score ranges

from 0 to 35 (asymptomatic to very symptomatic) with scores categorized as mild (symptom score <7), moderate (score range 8–19) and severe (score range 20–35).

Urogenital Distress Inventory-Short Form (UDI6) [18] and the *Incontinence Impact Questionnaire (IIQ7)* (17) [19] (abbreviated versions) were used to assess impact of UI symptoms upon QoL. UDI6 is a symptom tool and IIQ7 measures the impact of symptoms. The response scale to each item ranges from: Not at all, Slightly, Moderately and Greatly. The Cronbach alpha for IIQ6 and UDI7 range from .74 to .95 [20]; and test retest reliability using intraclass correlation coefficient was .59.

Sexuality

Personal Experiences Questionnaire (PEQ)-Short Form [21] measured SD [9] and includes 11 items derived from McCoy Female Sexuality Questionnaire [22]. The sexual domains assessed include sexual frequency and responsivity, libido, feelings for partner, dyspareunia and vaginal dryness. It is a concise instrument, easy to administer and practical in busy clinical settings.

Participation

The Multiple Sclerosis Impact Scale-29 (MSIS29) [23] measures the physical and psychological impact of MS from the patients' perspective. It shows good variability, small floor and ceiling effects, high internal consistency and high test–retest reliability. The summary scores of the two MSIS scales are generated by summing the individual items (scored 1–5), with high scores indicating greater impact.

Statistical Analyses

Descriptive statistics were generated for each of the PEQ items, subscales and the Total PEQ. The internal consistency of the Total PEQ in this sample was assessed using Cronbach Alpha coefficient with a value over .70 considered acceptable [24]. A cut point of 7 on the Total PEQ suggested by Dennerstein [21] was used to identify patients with SD. Chi square tests were conducted to compare demographic and disease characteristics of those patients with, versus without, SD according to the PEQ. Spearman correlation coefficients were calculated between scores on the PEQ subscales and Total PEQ with other measures assessing bladder problems (AUA, NDS, IIQ7, UDI6).

Descriptive statistics were also generated for the single item assessing patient perceptions of the impact of their neurological condition on their sex life. Responses to this item were collapsed into two groups (not at all, a little, somewhat versus a great deal). Mann–Whitney U tests were used to compare these two groups on the PEQ subscales, Total PEQ and other measures of bladder problems.

Results

Sample Characteristics

The 71 pwMS (73% female), age range 29–65 years (Mean = 50 years), represented all stages of MS disease spectrum and severity (EDSS 2–8), and the majority (60%) had

Table 1 Sample characteristics ($N = 71$)

Sample characteristic	
Age	Range 29 to 65 years
	Mean = 50 years
	SD = 9.1 years
Gender	
Male	19 (26.8%)
Female	52 (73.2%)
EDSS	
0 to 3.0	12 (16.9%)
3.5 to 6.0	40 (56.3%)
6.5 plus	9 (12.7)
Stage of disease	
Relapsing remitting (RR)	19 (26.8%)
Secondary progressive (SP)	43 (60.6%)
Primary progressive (PP)	9 (12.7%)
Years since diagnosis	Range 0–23 years
	Mean = 9.48 years
	SD = 6.3 years
Urodynamic bladder dysfunction	
Neurogenic detrusor overactivity	43 (60%)
Detrusor -sphincter dyssynergia	13 (18%)
Neurogenic detrusor overactivity & concurrent detrusor sphincter dyssynergia	11 (16%)
Poor bladder compliance	4 (6%)

neurogenic detrusor overactivity (see Table 1). A total of 58 respondents (83%) had a current sexual partner, and 70 reported a heterosexual orientation.

Responses to the Short Form of the Personal Experiences Questionnaire (PEQ)

Descriptive statistics for each of the PEQ items and subscales and the Total PEQ are presented in Table 2. The internal consistency of the PEQ in this sample was good with a Cronbach alpha value of .85.

A substantial proportion of sample indicated that they did not find sexual activities enjoyable (32%), with many failing to feel aroused (29.6%) and 47.9% reporting they never experience orgasm during sexual activity (Table 3).

A total of 51 patients (72%) fell below the cut point of 7 on the PEQ suggested by Dennerstein [21] indicating SD. A higher proportion of females (81%) recorded scores indicating SD when compared with males (47%: Chi-square = 6.11, $df = 1$, $p = .013$). There was no association between SD according to the PEQ and age, EDSS group, stage of disease or years since diagnosis.

Association Between PEQ and Other Measures

The PEQ *Sexual Frequency* scale showed low, but statistically significant Spearman correlations with the NDS (rho = −.30), the QoL Bladder score (rho = −.35), and the

Table 2 Descriptive statistics for Personal Experiences Questionnaire (PEQ) subscales and total scores ($N = 71$)

	Mean	SD	Median	Possible range	Actual range
Sexual responsivity	2.85	1.61	2.67	1–6	1–6
Sexual frequency	.86	.95	1.0	0–5	0–3
Libido	1.58	1.52	1.0	0–5	0–5
Dyspareunia	1.54	1.08	1.0	1–6	1–6
Feelings for partner	3.66	1.85	3.5	1–6	1–6
Total PEQ	5.29	3.27	5.0	1–16	1–12

Sexual responsivity = sum of items 1, 2 and 3, divided by 3

Sexual frequency = item 9

Libido = item 8

Dyspareunia = item 6

Feelings for partner = sum of items 4 and 5, divided by 2

Total PEQ = sum of sexual responsivity, frequency and libido subscale scores

MSIS Physical subscale (rho = −.30). The PEQ *Sexual Responsivity* subscale showed a significant correlation with the NDS (rho = −.32) while the PEQ *Dyspareunia subscale* correlated with the MSIS Psychological subscale (see Table 4). The Total PEQ recorded no significant correlations with any other scale, with all correlation coefficient values below .27.

Patient Perceptions of Impact of Neurological Condition on Sex Life

Patients were asked to what extent their neurological condition impacted on their sex life, with 13 (18%) responding 'not at all', 11 (15.5%) 'a little', 16 (22.5%) 'somewhat', and 31 (43.7%) 'a great deal'.

Mann–Whitney U tests, comparing individuals who responded 'a great deal' against all other respondents, revealed significant differences on the PEQ *Sexual Frequency subscale* ($p = .01$), IIQ7 ($p = .03$), UDI6 ($p = .04$) and both MSIS subscales (Physical $p = .04$; Psychological $p = .03$). No significant difference however was found for the Total PEQ ($p = .09$). Chi square tests indicated no association between those patients identified with SD on the PEQ and those patients who indicated that their neurological condition impacted 'a great deal' on their sex life (chi square = .43, $df = 1$, $p = .51$). Of the 51 patients identified with SD on the PEQ 27 (53%) reported 'not at all', or 'a little', or 'somewhat' impact of their neurological condition on their sex lives. On the other hand, 35% (7/20) of the patients identified as having no SD on the PEQ reported a 'great deal' of impact.

Discussion

Various physical and psychosocial difficulties can cause SD in pwMS. This study confirmed SD in pwMS in the community; and its association with bladder function and participation restriction. Approximately two-thirds (72%) had SD based on the PEQ scores (cut-point of 7). One-third reported lack of enjoyment of sexual activities and failure to feel aroused, while 47% were anorgasmic. This is in contrast with a previous report [9] of women with MS ($N = 133$) where 73% were sexually active and majority indicated ability

Table 3 Responses to individual Personal Experiences Questionnaire (PEQ)

Items	Not at all					A great deal
	1	2	3	4	5	6
1. How enjoyable are sexual activities currently for you	23 (32.4%)	3 (4.2%)	13 (18.3%)	15 (21.1%)	6 (8.5%)	11 (15.5%)
2. How often during sex activities do you feel aroused or excited	21 (29.6%)	14 (19.7%)	8 (11.3%)	9 (12.7%)	11 (15.5%)	8 (11.3%)
3. Do you currently experience orgasm (climax) during sexual activity	34 (47.9%)	10 (14.1%)	7 (9.9%	7 (9.9%)	9 (12.7%)	4 (5.6%)
4. How much passionate love do you feel for your partner	14 (20.9%)	9 (13.4%)	7 (10.4%)	10 (14.9%)	7 (10.4%)	20 (29.9%)
5. Are you satisfied with your partner as a lover	18 (26.9%)	5 (7.5%)	10 (14.9%)	7 (10.4%)	5 (7.5%)	22 (32.8%)
6. Do you currently experience pain during intercourse	52 (73.2%)	9 (12.7%)	4 (5.6%)	4 (5.6%)	1 (1.4%)	1 (1.4%)
7. Does your partner experience difficulty in sexual performance	37 (55.2%)	5 (7.5%)	8 (11.9%)	9 (13.4%)	5 (7.5%)	3 (4.5%)

	Never	Less than once a week	Once or twice a week	Several times per week	Once a day, sometimes twice	Several times a day
	0	1	2	3	4	5
8. Give an approximate estimate of how many times you have had sexual thoughts or fantasies (daydreams) during the last month	23 (32.4%)	16 (22.5%)	13 (18.3%)	10 (14.1%)	5 (7%)	4 (5.6%)
9. Give an approximate estimate of how many times during the past month you have had any sexual activities	33 (46.5%)	19 (26.8%)	15 (21.1%)	4 (5.6%)	0	0

Table 4 Spearman correlation coefficients between Total Personal Experiences Questionnaire (PEQ) and other measures

	Total PEQ	Sexual responsivity	Sexual frequency	Libido	Dyspareunia	Feelings for partner
AUA	−.08	−.19	−.09	.06	.02	−.19
NDS	−.26	−.32*	−.30*	−.09	−.01	−.19
UDI6	−.12	−.15	−.19	−.01	.16	−.08
IIQ7	−.01	−.09	−.14	.09	.13	−.12
QoL Bladder	−.09	−.14	−.35*	−.09	.16	−.07
MSIS psych	−.11	−.19	−.25*	.08	.32*	−.09
MSIS physical	−.18	−.24*	−.30*	.01	.07	−.22

Sample sizes vary between 68 and 71 due to missing data

NDS Neurological Disability Scale, *AUA* American Urological Association Incontinence Score, *UDI6* Urogenital Distress Inventory Scale, *IIQ7* Incontinence Impact Questionnaire, *QoL* Quality of life item from AUA, *MSIS Psych* Multiple Sclerosis Impact Scale Psychological, *MSIS Physical* Multiple Sclerosis Impact Scale Physical

*$p < .05$

to be aroused, enjoy sexual activities and experience orgasm. This report however did not specify the severity or stage of MS, the time since MS diagnosis nor cognitive status of persons in the study cohort. Findings in our study are consistent with other reports [25] where 33% of women reported anorgasmia; and 45% women reported general SD [26]. Correlations between MRI findings and report of SD suggest demyelinating lesions may cause anorgasmia [27]. In our study there was no association between the patient reported SD and age, years since diagnosis, stage or severity of MS. These findings demonstrate the complexity of human sexual response. Further research is needed to determine impact and relationships between SD and neurological disabilities.

Bladder difficulties in MS can contribute to SD [6, 9]. In this study a majority ($N = 51$, 72%) indicated SD and 60% of these had detrusor overactivity (urodynamics within previous 18 months). This is in contrast with reports [9] that pwMS with urge incontinence were less likely to have orgasmic dysfunction. In our previous study of pwMS ($N = 73$) [13] urinary symptoms (incontinence, urgency, frequency) negatively impacted emotional health, ability to perform household chores and recreation and had a detrimental impact on QoL. The present study found significant negative correlations between the PEQ *Sexual Frequency* scale and NDS (rho = −.30), the QoL AUA Bladder score (rho = −.35), and the MSIS Physical subscale (rho = -.30). This is consistent with reports [28] that demyelinating MS lesions that affect physical function and bladder impairments also cause SD. The type of bladder dysfunction (urodynamic pattern) and its relationship with SD however needs further investigation.

This study found the PEQ *Dyspareunia* subscale correlated with the MSIS Psychological subscale. The report of dyspareunia (diminished lubrication) was lower (4.5%) compared with other reports [4, 9]. Many psychological factors associated with chronic debility and MS related issues (depression, low self esteem, changed role in family) have been implicated in SD in pwMS [7, 10, 28]. Although a detailed investigation of all these factors was beyond the scope of this study, future studies are needed to explore SD and psychological issues. Rehabilitation intervention should focus on the education of MS participant (and partner) and the management of physical and psychological issues that may impact on SD.

In a previous study of women with MS [9] 45% of participants indicated sexually bothersome neurological symptoms assessed using the question: *'to what extent do their neurological problems affected their sex life"?* (1 = not at all, to 4 = a great deal). In our sample 65% reported sexually bothersome symptoms on the same question. As expected those who responded 'a great deal' (compared with all other pwMS) had significant differences on the PEQ *Sexual frequency subscale*, both bladder impairment and impact scales (UDI6, IIQ7) and MSIS subscales (physical and psychological). Interestingly, about 35% (7/20) of pwMS identified as having no SD on PEQ also reported that MS impacted '*a great deal'* on their sex lives. This needs further evaluation in pwMS.

Health related QoL is difficult to define in MS patient populations. The limitation in activity alone accounts for only minor variation in overall QoL, as many factors influence QoL. It is difficult to analyse and compare clinical reports of SD in pwMS due to lack of appropriate outcome measures that do not fully capture its complex constructs. Commonly used tools such as the PEQ, and the Multiple Sclerosis Intimacy and Sexuality Questionnaire [29] may not be sensitive enough for use and this may contribute to the wide variation in the reported SD in pwMS. The PEQ needs more detailed psychometric assessment in neurological patient populations.

A number of factors strengthened the methodological rigour of this study in comparison with other SD studies focusing on pwMS. A homogeneous community cohort with 'definite' MS and quantified physical and cognitive deficits (EDSS 2–8 and KFS 0–2) provided reliable information in face to face interviews. The study sample methods and response rate was adequate. In addition, a range of validated measures captured the range of activity limitation and participation restriction in these persons in the 3 months prior.

Limitations of this study include issues of generalizability of results due to relatively small number of participants ($N = 71$), and cross sectional nature limited to a metropolitan geographical region in Victoria, Australia. The pwMS however were a representative sample, referred from public and private facilities across Victoria. The findings require replication in other larger MS samples. Interviews for persons with EDSS scores >6.5 were challenging due to fatigue levels and the need for frequent rest breaks. Whenever possible, interviews were conducted in the morning. Persons with EDSS scores >8, or those who were institutionalized, were not included. The analyses in this cross sectional study are correlational in nature and causations for associations observed cannot be established. This study does not capture the full impact of SD on pwMS and their families. Impact of psychological factors on SD in this cohort was beyond the scope of this study.

SD in MS is not associated with age, time since diagnosis, stage or severity of MS. The demyelinating lesions causing physical impairments and bladder dysfunction in MS also affects SD. As SD is complex, its impact on participation and QoL for pwMS is often underestimated. The existing deficiencies in services for SD require a collaborative practice model with integrated care (neurology and rehabilitation teams) to address many related disabilities. These include improved awareness of SD in MS by treating clinicians. More research using larger cohorts is needed to develop specific interventions for SD. Greater attention to psychological issues impacting SD is required, as well as those affecting participation such as family and social reintegration, and QoL. This involves education and support for pwMS (their partners), as well as the treating clinicians.

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Conflict of Interest None.

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