

# A Mindfulness Psychoeducational Group Intervention Targeting Sexual Adjustment for Women with Multiple Sclerosis and Spinal Cord Injury: A Pilot Study

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**Abstract** The high prevalence of sexual difficulties experienced by women with a neurological disability, such as multiple sclerosis (MS) or spinal cord injury (SCI), is well documented in the literature. The link has also been established between sexual problems of this population and decreased quality of life. Despite the frequency of sexual difficulties and the importance of sexual health for persons with MS or SCI, sexual dysfunction is an area largely un-addressed in practice settings and there are surprisingly few intervention studies in this area. This study aimed to evaluate the usefulness of an existing, previously tested, group psychoeducational intervention in the population of women with neurological disabilities. Six women were recruited to participate in the psychoeducational sessions, which involved education, mindfulness, and cognitive behavioural therapy. Despite a very small sample size, this study suggests that this intervention may be beneficial for women with MS or SCI in improving sexual functioning (especially in the domains of sexual desire and arousal) and in being less judgmental of their inner experiences. Findings suggest a psychoeducational approach (including mindfulness) has the potential to positively influence sexual adjustment for women with MS and SCI.

**Keywords** Sexual adjustment · Sexual dysfunction · Spinal cord injury · Multiple sclerosis · Psychoeducational · Mindfulness · Canada

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## Introduction

The development of an individual's sexual identity and sexual expression is a complex biopsychosocial phenomenon with influences ranging from genetics to sociocultural factors. It is well established that chronic illness and disability can have significant deleterious effects upon sexuality and quality of life (QOL) in women [1–3]. Multiple sclerosis (MS) and spinal cord injury (SCI) are two such disabling conditions [4, 5]. In Canada, MS prevalence is known to be high, with recent estimates ranging between 55 and 240 per 100,000 [6]. The prevalence ratio of women to men with MS, as reported by a Scandinavian study is 2.35:1 [7]. SCI prevalence (traumatic and non-traumatic injuries) in Canada is estimated at 2525 per million population and with a minimum male-to-female ratio of 2:1 [8].

These neurological disabilities can profoundly affect one's sexuality in many ways and at many levels. In the literature on MS and sexuality, the sexual sequelae have been categorized as having three levels of responsible factors: primary, secondary and tertiary [9]. Primary effects refer to any sexual difficulties resulting directly from the impact of the disease or injury on neurophysiology (e.g. altered genital sensation, anorgasmia, and decreased biological desire). Secondary effects include any disruption in sexual health from indirect factors associated with the condition (e.g. fatigue, pain, spasticity, bladder and bowel issues, or side effects of medications). Tertiary effects refer to body image changes and altered perception of "sexual self" due to negative societal stereotypes and myths existing around sexuality and disability. One study did examine the frequency, distribution and interrelation of these primary, secondary and tertiary factors [10]. In a cross-sectional design of 271 women with MS, 172 or 63.5 % of women had sexual dysfunction (SD). Of these 172 women, 52.4 % had SD related to primary factors, 37.5 % had secondary SD, and 41 % had tertiary SD.

The sexual consequences for women with SCI could also be organized in terms of primary, secondary and tertiary factors. Although, perhaps more important to note is the fact the responsible factors are interrelated and the sexual outcomes and possible interventions are complex [11]. In a large-scale survey of both women and men with SCI [12], 83 % agreed that their SCI had altered their sexual sense of self. In the same survey, 83 % said that improving sexual function was important in improving their quality of life. Research on female sexual response and SCI has reported about half of the women experienced vaginal lubrication and only a third experienced orgasm after SCI [13]. More current research revealed that orgasmic experience and genital sexual arousal, although possible even for women with complete injuries, required increased intensity and duration of stimulation [14]. In addition, bladder and bowel issues and autonomic dysreflexia are known to negatively impact sexual activity and intercourse [12]. Furthermore, the length of time required to adjust to sexual health challenges post-SCI may take upwards of one to two decades, and is often reliant on the presence and involvement of a long-term partner and remaining open-minded to sexual pursuits [15].

In order to address the sexual concerns of this population of women (and men) with neurological disabilities, the Sexual Health Rehabilitation Service has offered an interdisciplinary, comprehensive, client-centred approach to health care delivery for over 40 years [16, 17]. The model of service delivery involves the application of restorative and rehabilitation principles and is based on a specialized body of knowledge generated through research and clinical practice evidence. Practitioners of sexual health rehabilitation<sup>1</sup> offer education, medical and nursing interventions, and emotional support to best address their clients' sexual

<sup>1</sup> Sexual health clinicians (registered nurses with background in neurological rehabilitation and specialty training and education in sexual medicine and sexual health); a consultant sexual medicine physician, and

concerns. One overarching goal of sexual rehabilitation is facilitating an individual's (or couple's) sexual adjustment following a change in health status. In earlier studies on populations of persons with disability, the term "sexual adjustment" was linked to sexual self-concept and adapting to sexual limitations, as well as to partner satisfaction and frequency of sexual activity [18–20]. In this study, the term "sexual adjustment" refers to the changes one might make to move towards a positive sense of sexual well-being. Sexual well-being is defined by Laumann et al. [21] as "the cognitive and emotional evaluation of an individual's sexuality". Sexual self-view/self-esteem, are terms also used in sexual rehabilitation, and refer to how a person is able to define themselves as a sexual being in light of their disability [22]. Stevenson and Elliott [23] further elaborate upon this definition adding that: "Illness and the related issues (e.g. continence, hygiene, independence) can adversely affect one's sense of sex appeal, masculinity or femininity. Previous social roles may be upset or reversed, further undermining sexual confidence". Furthermore, former personal beliefs about sex and disability may influence how they view themselves post injury or illness and their sexual confidence may be affected as a result [22, 23].

Having an effective intervention to accelerate the sexual adjustment for women with disabilities would greatly enhance their quality of life, however, there have been no such intervention-based studies to date. While existing qualitative research has been explorative in nature, it has offered direction for intervention studies. One example is a study by Ekland and Lawrie [24], who surveyed ten women with SCI and identified common themes around what factors support sexual adjustment. These factors included: access to peer support or mentors, participation in a women's group, and availability of health care professionals. Forsythe and Horsewell [25] also affirmed that women with SCI wanted to discuss issues with other women who had experienced similar problems.

## Purpose of Study

This study was designed to offer an existing intervention tool to women with MS and SCI. The treatment combined cognitive behavioural therapy, mindfulness based skills, and education, and was originally developed and found to be effective for female cancer survivors as well as a more general population of women experiencing sexual difficulties [26]. The purpose of this study was to adapt treatment to a specific population of women with disabilities. We predicted that, compared to pre-treatment, this adapted intervention would result in a significant improvement in the primary endpoint of sex-related distress. We also predicted improvements in secondary endpoints of sexual functioning, relationship functioning, mindfulness skills, and body image satisfaction.

## Materials and Methods

### Participants

Participants for this study were recruited through advertisements. A research coordinator, trained by a sexual medicine psychologist, conducted the telephone screening interviews to

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Footnote 1 continued

other members of the client care team on an ad hoc basis (including: psychologists, urologists, physiatrists, physiotherapists and occupational therapists).

determine participant eligibility. Inclusion criteria were women between the ages of 19 and 65 who had been living with MS or SCI for at least 1 year, were fluent in English, and who met the criteria for Female Sexual Arousal Disorder (FSAD) or Hypoactive Sexual Desire Disorder (HSDD) according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition [27]. Participants were screened for depression using the Beck Depression Inventory (BDI), a validated measure for depression [28]. Participants were excluded if they had a score >19, given that severe depressive symptoms would have interfered with participants' ability to complete the homework assignments. Ethical permission to conduct the study was obtained through the university and associated medical center where this research took place. All participants gave their informed consent prior to participating.

## Procedure

The study intervention consisted of five 90-min sessions, spaced 2 weeks apart, completed within a 10 week time frame. Questionnaires were administered at three junctures of the study: immediately prior to, immediately following, and 6 months after completing treatment. The groups were co-facilitated by a sexual health clinician (registered nurse specializing in sexual health rehabilitation) and a registered clinical counsellor (M.Ed., R.C.C.). Homework exercises were assigned at the end of every session and discussed at the start of the following group session. Following treatment, a research coordinator conducted a focus group with three study participants and one clinician to obtain qualitative feedback about participating in these groups and on next steps for program development. This research is a triangulation of both qualitative and quantitative measures.

## Measures

### *Primary Endpoint: Sex-Related Distress*

Sex-related distress was measured with the 12-item Female Sexual Distress Scale (FSDS), a valid, reliable measure of sexually related distress in women [29].

### *Secondary Endpoints*

Our secondary endpoints focused on sexual functioning and arousal, relationship functioning, mindfulness skills, and body esteem related to having a physical disability. Different domains of sexual functioning were assessed with the Female Sexual Function Index (FSFI), a 19-item validated measure of sexual response in women [30], and the 32-item Detailed Assessment of real-life Sexual Arousal (DASA), an unpublished questionnaire used in the clinical setting to assess self-reported mental sexual arousal, genital tingling, genital wetness, and self-reported pleasure in response to a variety of different types of sexual stimulation [31]. Relationship satisfaction was assessed with the 32-item Dyadic Adjustment Scale (DAS), a reliable, valid and long-utilized measure of relationship adjustment [32], and mindfulness was measured with the Five Facet Mindfulness Questionnaire (FFMQ), a 39-item valid and reliable instrument [33]. Of note, this measure has been used previously with patients with fibromyalgia and was found to be a reliable and valid measure with which to assess mindfulness in that population [34]. We also assessed body esteem with the 10-item Physical Disability Sexual and Body Esteem Scale (PDSBE), a scale with strong psychometric properties, used to measure the capacity to feel positive about one's sexual self and body esteem while living with a disability [35].

**Table 1** Description of PED exercises (d-PED additions are highlighted)

	Title of exercise	Description of exercise
Education	Prevalence	A review of the prevalence of sexual difficulties in general population Prevalence rates in MS and SCI Summary of research for sexuality and MS/SCI
	The 4 P's (4 P's = predisposing, precipitating, perpetuating and protective factors)	A framework for understanding the development of sexual difficulties
	Anatomy and physiology of physical response	To provide women with basic information about A&P of the female genital structures (clitoris, vagina, labia, hymen) Internal anatomy pictures
	Sexual desire	To review the Basson Sexual response cycle and have the women think about their own motivations for being sexual and their own experience of this cycle
	Relationship evaluation	To provide a framework for discussing the role of relationship factors in women's current experience of sexuality
	Relationship enhancement/communication exercise	Review of John Gottman's principles of a relationship. Women are asked to have a structured conversation with their partner
	Kegels	Women are asked to practice Kegel exercises 10 times, twice a day for 2 weeks
	Sexual aids	Introduction on how to use fantasy, erotica and vibrators PleasureAble manual provided <a href="http://sci-bc-database.ca/wp-content/uploads/PleasureABLE-Sexual-Device-Manual-for-PWD.pdf">http://sci-bc-database.ca/wp-content/uploads/PleasureABLE-Sexual-Device-Manual-for-PWD.pdf</a>
Mindfulness-based	Introduction to mindfulness	Participants to practice mindfulness for 5 min per day × 2 weeks and record process. Daily mindfulness practice is encouraged to continue throughout the 10 weeks of the intervention
	Focusing	Have the woman take 15–30 min to focus on her external body (in the bath or shower) clearing mind of distracting thoughts and focus on aspects of her body she appreciates
	Self observation	Using the Anatomy diagram, women are asked to notice their genital parts and describe them in a non-judgmental way
	Self observation and touch	This exercises expands on the focusing and self-observation as it incorporates genital touch paying attention to sensations
	Mindfulness of thoughts in life	Women are to continue the daily mindfulness practice and begin to pay attention to the content of their distracting thoughts
	Self sensate focus	Women are encouraged to use the mindfulness skills learned in the previous weeks to attend to their whole body and be aware of their sensations. The goal is to have women re-connect to pleasure

**Table 1** continued

Title of exercise	Description of exercise
Body mapping	Using the instructions for self-sensate focus, women are asked to document the areas of sensation using a diagram and a numbering system
Partnered sensate focus	Based on the exercise developed by Masters & Johnson; It is aimed at teaching the woman to remain present while receiving intimate touch, decrease anxiety and to notice pleasurable sensations without the pressure of having to achieve arousal or orgasm
Mindfulness, observing judgments	Women are asked to continue with the 5 min of mindfulness daily and pay attention to the content of their distracting thought. Are these thoughts judgments? Are they positive or negative? What triggered them?
CBT Common sexual beliefs	Exploration of sexual beliefs and myths
Body image	Conversation with self or other woman about how body image and sexuality are related
CBT model	To introduce the link between one's thoughts, feelings and behaviours in a sexual situation
Thought record	Explanation on how to use this tool to replace her current automatic, irrational thoughts with more balanced ones

## Group Intervention

The group intervention was modeled after a similar intervention that has been developed and found effective for cancer survivors with sexual dysfunction, and more generally for women seeking treatment for low sexual desire [36, 37]. In brief, the intervention combined elements of: education, Cognitive Behavioural Therapy, and Mindfulness Based Therapy. A modified version of this effective treatment was developed for the current population of women who experience a physical disability.

Adaptations to the treatment intervention for this population included: (1) adding information regarding the prevalence of sexual difficulties in MS and SCI populations; (2) incorporating “body-mapping” exercises into the set of existing sensate focus or body exploration exercises (see Table 1). “Body-mapping” involves the creation of a visual diagram of the entire body, followed by application of a sensory rating scale (−5 = very uncomfortable; 0 = no sensation, and +5 = pleasurable). The third addition was to include a description of the female internal reproductive anatomy, in response to previous research findings [38]. The addition of the mindfulness practice of “observing judgements” was the fourth and final adjustment to the existing treatment. The rationale behind this focus on “observing judgements” stemmed from literature which points to more women with disabilities having a negative body image and sexual self-view [39]. The process involved being “mindful” about their subjective judgements when exposed to different objects (ones that typically evoke positive or negative responses). This exercise was meant to give women an opportunity to recognize the impact of negative self-talk on their own sexual self-view. In addition to the aforementioned changes to the treatment, disability specific research and information was also provided to the participants. Throughout this manuscript, we refer to the intervention as d-PED (psychoeducational treatment adapted for women with disability).

## Data Analysis

Given the small sample size, this study was primarily interested in effect sizes, for which we used Cohen's *d*. In addition, we calculated a within-subjects repeated measures analysis of variance (ANOVA) comparing participant scores across the three time points. We predicted significant changes from pre- to post-treatment, as indicated by at least moderate effect sizes, and we predicted no significant change (i.e. no loss in improvement) from post-treatment to follow-up, for the primary endpoint of sex-related distress.

## Results

### Subject Recruitment and Attrition

From 2009 to 2011, a total of twelve women who met the inclusion criteria consented to participate in this study. One woman withdrew before providing any baseline data due to extenuating circumstances that made travelling to group sessions too burdensome. Eleven women provided baseline data (mean age 47.9, SD 11.2, range 25–61 years). Of the remaining eleven subjects, one woman withdrew for unknown reasons before starting the d-PED. Another woman requested to withdraw before she started the d-PED because she was no longer able to make the time commitment. Two women did not receive the d-PED intervention due to insufficient enrolment for a third group offering. These women were referred back to individual counselling with a sexual health clinician. The seven remaining subjects completed all five sessions of the d-PED and the pre- and post-intervention questionnaires. Six out of seven participants completed the final 6-month questionnaire. The seventh participant was unable to complete the final questionnaire due to a severe relapse in her MS that required hospitalization. At the 6-month post d-PED time point, one subject's information was missing from the FSFI data set due to not being sexually active within the 4 weeks time period stipulated by that particular questionnaire.

During the study period, two separate d-PED group interventions were held. The first group included three participants and the second group included four participants. A third group was cancelled due to low participant recruitment.

### Participant Characteristics

Of the seven participants who participated in the d-PED, five women reported being in a long-term, monogamous, heterosexual relationship; one woman was in a new heterosexual relationship (about 3 months), and the seventh participant identified as heterosexual, divorced and currently single. Two of the six women in a relationship reported being satisfied with the level of closeness in their relationship at study entry. All women identified as being Caucasian. Six women had been diagnosed with multiple sclerosis (onset ranged from approximately 2.5 to 42 years) and one woman with spinal cord injury had incomplete paraplegia (almost 3 years post-injury). In terms of severity of disability, one participant rated her disability as mild, three participants rated their disability as moderate and three participants rated their disability as severe. Two subjects with MS were ambulatory and the other five women used some form of mobility aid (electric or manual wheelchairs), one being dependent for transfers. All but one participant had completed a post-secondary education program.

## Effects of Treatment on the Primary Endpoint: Sex-Related Distress

An examination of effect sizes on sex-related distress between each of the time points showed a strong effect of treatment from pre- to post-intervention, Cohen's  $d = 1.19$  (Table 2). However, this effect did not reach statistical significance,  $F(2,10) = 2.11, p > .05$ .

## Effects of Treatment on Secondary Endpoints

### *Sexual Functioning and Arousal*

There was a significant effect of treatment on FSFI desire scores,  $F(2,10) = 4.64, p = .038$ . Among women who reported having participated in “sexual activity” during the previous 4 weeks, a similar significant effect was also found for FSFI arousal,  $F(2,10) = (2,8) = 10.38, p = .006$ . The increase in orgasm scores was not significant,  $F(2,8) = 3.09, p > .05$ , though there was a very strong effect size from pre- to post-treatment. Reports of genital pain similarly did not significantly change with treatment,  $F(2,8) = 0.55, p > .05$ . Sexual satisfaction did not significantly change with treatment,  $F(2,8) = 1.46, p > .05$ , though there was a very strong effect size from pre to post-treatment. Overall sexual functioning did significantly increase with treatment,  $F(2,8) = 6.08, p = .025$ , and the effect size was very large. Given the established clinical-cutoff for scores on the FSFI total score (26.55), it is evident that women in our sample had a significant improvement with treatment that fell into the non-clinical range, but then some of those gains were lost at the 6-month post-treatment evaluation point. Self-reported disability severity is not correlated with any of the FSFI subscales. Years post disability is negatively associated with sexual desire, but the  $p$  value is just short of significant ( $p = .091$ ). Years post disability is also associated with higher sexual arousal ( $p = .006$ ). On the measure of sexual arousal, there was no significant increase in DASA mentally excited subscale scores,  $F(2,10) = 0.80$ , Genital Tingling,  $F(2,10) = 1.34$ , or pleasant genital sensation,  $F(2,10) = 0.08, p$ 's  $> .05$ ; however, the increase in genital wetness was significant,  $F(2,10) = 5.04, p = .03$ . For the genital tingling and wetness domains, the effect size corresponded to a very strong effect with treatment. Effect sizes associated with each of the changes between pre and immediately post treatment, and from post-treatment to follow-up, are presented in Table 2.

### *Relationship Satisfaction*

None of the subscales of the DAS reached statistical significance following treatment: consensus subscale,  $F(2,10) = 3.29, p > .05$ ; satisfaction subscale,  $F(2,10) = 1.52, p > .05$ ; cohesion subscale,  $F(2,10) = 0.94, p > .05$ ; affectional expression,  $F(2,10) = 3.07, p > .05$ . Consensus and Satisfaction score increases saw strong effect sizes associated with these non-significant changes (Table 3).

### *Mindfulness*

Scores on the FFMQ observing subscale improved (though not-significantly) with treatment,  $F(2,10) = 2.14, p > .05$ . Similar non-significant effects were found with FFMQ awareness,  $F(2,10) = 1.48, p > .05$ , non-reactivity,  $F(2,10) = 0.85, p > .05$ , and describing,  $F(2,10) = 0.82, p > .05$  subscales. Non-judgment significantly decreased with treatment,  $F(2,10) = 6.08, p = .019$  (Table 3).

**Table 2** Female sexual function index (FSFI), detailed assessment of real-life sexual arousal (DASA) and female sexual distress scale (FSDS) subscales score comparison between baseline, 2 weeks post-intervention and at 6 months post-intervention

Sub-scale	Time point	n	Mean	SD	Effect size <sup>a</sup>
FSFI					
Desire*	Baseline	11	2.13	0.73	
	2 weeks post-PED	7	3.09	1.17	1.83
	6 month post-PED	6	2.80	0.82	-0.85
Arousal*	Baseline	10	3.03	0.64	
	2 weeks post-PED	5	4.86	0.72	4.49
	6 month post-PED	5	3.60	1.34	-3.69
Lubrication	Baseline	10	3.78	1.63	
	2 weeks post-PED	5	4.50	1.87	-0.15
	6 month post-PED	5	4.74	1.15	0.31
Orgasm	Baseline	9	1.91	1.11	
	2 weeks post-PED	5	3.20	1.52	3.61
	6 month post-PED	5	3.36	1.51	0.20
Satisfaction	Baseline	9	3.02	0.72	
	2 weeks post-PED	5	4.24	1.34	1.68
	6 month post-PED	5	3.04	1.82	-0.77
Pain	Baseline	8	4.70	1.69	
	2 weeks post-PED	5	5.76	0.54	0.27
	6 month post-PED	5	6.00	0.00	0.80
Total*	Baseline	8	18.88	3.47	
	2 weeks post-PED	5	26.28	4.39	6.78
	6 month post-PED	5	23.74	5.63	-0.85
DASA					
Mentally excited	Baseline	10	3.73	0.95	
	2 weeks post-PED	6	3.96	1.36	0.39
	6 month post-PED	6	4.28	1.34	0.60
Genital tingling	Baseline	10	3.36	1.51	
	2 weeks post-PED	6	4.02	1.54	0.63
	6 month post-PED	6	4.52	0.97	0.48
Genital wetness	Baseline	10	3.08	1.06	
	2 weeks post-PED	6	3.87	1.98	1.76
	6 month post-PED	6	4.02	1.95	0.42
Pleasant genital sensation	Baseline	10	3.90	1.66	
	2 weeks post-PED	6	4.43	2.17	0.20
	6 month post-PED	6	4.37	1.95	-0.21
FSDS					
Sexual distress	Baseline	11	27.91	5.86	
	2 weeks post-PED	7	21.29	8.46	-1.19
	6 month post-PED	6	26.00	10.33	1.38

\* Significant repeated measures ANOVA  $p < .05$ . FSFI subscale ranges are 1.2–6. DASA subscale ranges are 1–7. FSDS range is 0–48

<sup>a</sup> Effect sizes were calculated with Cohen's D

**Table 3** Dyadic adjustment scale (DAS), five facet mindfulness questionnaire (FFMQ), and physical disability sexual and body esteem scale (PDSBE) subscales score comparison between baseline, 2 weeks post-intervention and at 6 months post-intervention

Sub-scale	Time point	n	Mean	SD	Effect size <sup>a</sup>
<b>DAS</b>					
Dyadic consensus	Baseline	9	46.56	8.65	
	2 weeks post-PED	6	48.67	6.62	1.32
	6 month post-PED	6	45.33	8.76	-1.77
Dyadic satisfaction	Baseline	9	35.00	6.20	
	2 weeks post-PED	6	38.50	5.96	1.93
	6 month post-PED	6	32.67	12.18	-1.01
Dyadic cohesion	Baseline	9	14.78	4.79	
	2 weeks post-PED	6	13.00	3.79	0.30
	6 month post-PED	6	13.67	3.27	1.49
Affectional expression	Baseline	9	6.89	2.32	
	2 weeks post-PED	6	8.83	0.41	0.13
	6 month post-PED	6	7.33	2.50	-0.84
<b>FFMQ</b>					
Observing	Baseline	11	27.27	4.41	
	2 weeks post-PED	7	25.86	3.58	-1.15
	6 month post-PED	6	28.83	3.87	1.73
Describing	Baseline	11	28.73	6.13	
	2 weeks post-PED	7	29.71	6.23	0.99
	6 month post-PED	6	28.17	5.78	-0.30
Acting with awareness	Baseline	11	23.00	4.94	
	2 weeks post-PED	7	27.00	5.74	0.93
	6 month post-PED	6	26.67	4.32	0.06
Non-judging of inner experience*	Baseline	11	26.45	6.06	
	2 weeks post-PED	7	28.14	5.05	0.59
	6 month post-PED	6	29.33	3.33	0.76
Non-reactivity to inner experience	Baseline	11	23.18	2.18	
	2 weeks post-PED	7	25.57	2.82	0.80
	6 month post-PED	6	23.50	3.27	-0.44
<b>PDSBE</b>					
Sexual esteem	Baseline	11	2.00	0.63	
	2 weeks post-PED	7	3.71	4.06	0.78
	6 month post-PED	6	2.50	0.69	-0.65
Attractiveness	Baseline	11	2.42	1.12	
	2 weeks post-PED	7	2.38	1.18	0.07
	6 month post-PED	6	2.50	1.09	-0.46
Body esteem	Baseline	11	1.88	0.73	
	2 weeks post-PED	7	2.24	0.92	0.46
	6 month post-PED	6	2.44	1.29	0.57

**Table 3** continued

Sub-scale	Time point	n	Mean	SD	Effect size <sup>a</sup>
Total	Baseline	11	2.09	0.52	
	2 weeks post-PED	7	2.87	1.92	0.64
	6 month post-PED	6	2.48	0.58	-0.72

DAS subscale ranges: DAS consensus is 0–65; DAS affectional expression is 0–12; DAS dyadic satisfaction is 0–50; DAS cohesion is 0–24

FFMQ subscale ranges: observe, describe, act with awareness, and non-judgment is 8–40; non-reactivity range is 7–35

PDSBE subscale ranges: Sexual Esteem is 4–20; Attractiveness to Others is 3–15; Body Esteem is 3–15

\* Significant repeated measures ANOVA,  $p < .05$

<sup>a</sup> Effect sizes were calculated with Cohen's D

### *Body Esteem*

On the physical disability sexual and body esteem scale, there were no significant effects of treatment on the sexual esteem subscale,  $F(2,10) = 1.45$ ,  $p > .05$ ; Attractiveness,  $F(2,10) = 1.27$ ,  $p > .05$ ; Body Esteem,  $F(2,10) = 1.62$ ,  $p > .05$ ; or Total score,  $F(2,10) = 1.62$ ,  $p > .05$ . All effect sizes were small to moderate (Table 3).

### **Qualitative Data Analysis**

Participant feedback forms and transcripts from the focus group were read separately by the research coordinator and sexual health clinician and after grouping similar subject matters, themes were identified. A consensus was then reached in identification of major occurring themes. The themes were: (1) The value of mindfulness practice; (2) How exploring sexuality and sexual self-view has a positive effect on self-acceptance; (3) Benefit of peer interaction. The following quotes from the participants were taken from the feedback form and elucidate the key themes.

#### *Value of Mindfulness Practice*

... [Mindfulness] was the most difficult thing to remember but probably the most valuable tool.

Mindfulness...finally some ability to let go of the “must do”.

#### *The Effect of Exploring Sexual Self-View*

It raised my awareness that even though I am 60 and very disabled, it is not unreasonable to reconsider allowing my sexual being a chance to re-emerge.

Session reinforced a broad, liberal view of sexuality: I may not be perfect, but I am Okay.

... talk yourself into the fact that you are worth it... it is worth taking 2 h out of your life every 2 weeks, just for you.

### *Benefit of Peer Interaction*

discussions with other women in the same situation was helpful.

communication: I feel a lot better equipped to tackle difficult topics.

In addition to the themes, the study participants made comments on the effectiveness of the d-PED format as well as suggestions for improvement to any future group processes. General comments on the d-PED process included:

In the act of doing this [group], it opened a door. It was kinda neat  
When I first started this I didn't really know what to expect... I guess, you know, I was kind of hoping maybe it would like kick start something. And it didn't really do that, in you know, in my mind, but it helped. It was a beginning.  
I wish I would have known this stuff 25 years ago

Study participant suggestions for improving future groups included: more time for discussion; less content in each session; provide audio for mindfulness practice once group ends; more in-session mindfulness exercises (including body image and pain relief); more body image content/discussion as it relates to CBT and Mindfulness; incorporating a partner component (i.e. handouts/guides for partners). One participant suggested that 2–5 years post diagnosis would be the best time to do the exercises in the group.

## **Discussion**

### **Recruitment Challenges**

In terms of recruitment, one significant limiting factor was the DSM-IV criteria for HSDD and FSAD in that subjects needed to report “significant distress either to you personally or in your relationship”. The element of “distress” did not really reflect the women’s subjective experience with desire or sexual arousal. This had implications for the number of participants that were eligible for the study. Some potential subjects did not pass the pre-screening for this study because, although they’d experienced changes in desire and arousal since the diagnosis, they did not perceive these as cause for “distress” per se. In fact, in response to this recruitment challenge, the researchers changed the screening question to read: “does this difficulty bother you or cause strain in your relationship.” Perhaps women with disabilities tend to not fit the “distress” criteria for FSAD and HSDD because they have already experienced losses in many other aspects of their life in the form of secondary and tertiary effects of MS or SCI (body image, mobility, bowel and bladder function). In comparison with the distress caused by these losses, the sexual function changes may be viewed as less significant, or even as an expected consequence of the disease/disability [40, 41]. Despite the fact some of the participants did not fit the strict criteria for FSAD and HSDD, they were indeed interested in working on the sexual part of their lives.

Another issue related to recruitment was the difficulty enrolling women with spinal cord injury in the study. Despite a relatively even number of inquiries from both women with SCI

and MS, only two women out of the twelve who consented to participate had a spinal cord injury. Possible barriers to study participation for these women were inability to take time off work, transportation issues, and/or living out of town. The development of an on-line based d-PED intervention may address some of these accessibility issues for this population.

### **Limitations of Study**

We acknowledge that the small sample size is a major limitation of this pilot study. It is, therefore, difficult to attribute study findings to the d-PED intervention directly. While effect sizes suggest that the treatment was effective, or at least trending towards such, caution must be taken in drawing any conclusions given the small sample size. Future studies including an adequately powered sample size are needed in order to verify these findings. The fact there is only one subject with SCI who completed the d-PED, also limits our ability to draw conclusions based on this sample. We opted to use this subject's data, however, as our clinical experience is that many of the psychological adjustment issues are similar for women with MS and with SCI.

Another limitation of this pilot study is the possible biases created by subject attrition, despite the fact that most women withdrew due to extenuating circumstances unrelated to the treatment. Subject selection bias may also have been a factor given most women were in long-term monogamous relationships. Furthermore, as this is a pilot study, results lack generalizability to the larger population of women with spinal cord injuries and other disabilities who also experience sexual difficulties.

### **Relevance of Findings**

Despite a very small sample size, our quantitative findings suggest that this d-PED intervention may be beneficial for women with MS and SCI in improving their sexual functioning. Self-reported severity and years since disability were not associated with pre-treatment levels of sexual functioning. The only exception was that women with more years since diagnosis tended to have lower desire, but this could simply be a function of age. Interestingly, more years post disability was associated with higher sexual arousal. Perhaps women, despite losing their desire, become more in tune with their bodies and sexual arousal responses.

On the FSFI domains of sexual desire and arousal, although the gains were most significant, they did not sustain into the 6-month post-treatment evaluation point. In contrast, the application of a similar intervention to women with sexual dysfunction secondary to gynaecologic cancer found that significant gains were retained at the 6-month follow-up period [42]. The reasons why these two populations had different long-term responses to a similar treatment are not known; however, it may be that baseline differences in the rates of sexual difficulties may have contributed to this. There is also evidence that women with more depressive symptoms benefit more from this type of intervention than women with low depressive symptoms [43]. Again, it may be that co-occurring mood symptoms may have contributed to the lack of long-term efficacy. Finding a way to maintain these gains over time will be key to the success of future d-PED interventions. In this study it may be that the regular discussion and increased thoughts of sexuality contributed to the positive outcomes in the 2 weeks post scores. Sustaining this discussion and sexual thoughts into the future could be accomplished through periodic electronic connection (with clinicians and/or peers). An on-line version of this intervention with a group

chat or peer mentoring portion may be something to consider in future offerings of this intervention. This could also mitigate the issues around accessibility of the groups.

The mindfulness-based skills within the treatment also lead to a significant decrease in judgement of their inner experiences (i.e. they were less likely to place judgment upon their thoughts and feelings). The results from the qualitative data further substantiate the concept of mindfulness as an important part of a woman's experience of her sexuality. The d-PED allowed women to be less judgmental of their individual experiences as evidenced by this quote from one of the participants: "I may not be perfect, but I am Okay". As sexual adjustment for women with disabilities can often be delayed up to two decades, [16, 39] this intervention has the potential to be very beneficial to this process. One participant stated: "It raised my awareness that even though I am 60 and very disabled, it is not unreasonable to reconsider allowing my sexual being a chance to re-emerge" and another "wished she had known this stuff 25 years ago".

The d-PED permitted women to share their experiences with other women who were of similar circumstances. This intervention satisfies the recommendations from previous studies in this area [25, 26, 44] which include: peer support, group format, and access to health care professionals.

Sexual Self-view is an area in sex and disability research that has been given some attention, yet little is known about therapeutic interventions. Tepper [16] describes the journey towards sexual self-acceptance experienced by women after a SCI, which includes the concepts of "cognitive-genital dissociation," followed by "sexual disenfranchisement," then "sexual rediscovery." It is possible that this d-PED intervention might expedite the process of adjusting to a disability/illness and establishing a more positive sexual self-view. This theory informs future practice and interventions geared towards women with SCI and MS. Ultimately the value of the d-PED for women with disabilities/chronic illness may lie in its potential to *enhance* sexual self-view and quality of life rather than as a treatment for sexual dysfunction.

## Conclusion

More research is required to determine the clinical relevance of utilizing the d-PED in the population of women with disabilities. However, this preliminary trial was a first attempt at an intervention-based study in this field and the results were encouraging. In fact, findings suggest this d-PED intervention, specifically the mindfulness-based practices and peer involvement, is beneficial for women with MS and SCI. Given the challenges with recruitment and retention, the authors would consider the following for a future project: removing the DSM-IV criteria for FSAD and HSDD as an inclusion criterion for participation; and the development of an on-line version of the intervention to address the accessibility issues in this population. The authors recommend using these findings to inform the development of future research and clinical endeavors.

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## Compliance with Ethical Standards

**Conflict of interest** The authors declare that there is no conflict of interest associated with the research/clinical work outlined in this paper submission.

**Ethical Standards** This study was approved by the appropriate research ethics board (the Behavioural Research Ethics Board at the University of British Columbia) and therefore was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the study subjects were omitted from this manuscript.

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