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ORIGINAL PAPER

The Sexual Lives of Women Living with Fibromyalgia: A Qualitative Study

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Abstract
This study examined women's perceptions of the impact of FM on a broad range of aspects of their sexual well-being as well as on their romantic and sexual relationship. Participants were 16 women diagnosed with FM currently in a romantic relationship living in North America who participated in a semi-structured interview. Inductive thematic analysis identified four themes: (1) Do I want to have sex? That's a complicated question; (2) The impact of FM on women's sexual well-being is not uniform; (3) It's about more than sex and more than just me; (4) Elements that ameliorate or exacerbate the effect of FM's on SWB. Together, these results point to the variability and complexity of the effects of FM on women's sexual well-being. The results are discussed in terms of the importance of assessing and addressing a wide range of aspects of the SWB of women with FM.

Keywords Fibromyalgia · Sexual well-being · Women · Chronic pain · Coping

The sexual lives of women living with Fibromyalgia: a qualitative study

Fibromyalgia (FM) is a chronic pain syndrome characterized by widespread pain, fatigue, nonrestorative sleep, mood disturbances, and memory impairments [1–3], that affects 2–3% of adults and is diagnosed 6 to 9 times more frequently in women than in men [1, 4, 5]. FM has a profound negative impact on diverse aspects of quality of life including overall physical, mental, occupational, and social functioning [6]. For the vast majority of people with FM, the syndrome also negatively impacts romantic relationships, including interfering

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with having an enjoyable and satisfying sex life. Researchers have found 71–97% of people with FM report adverse effects on their sexual functioning [1, 7]. Specifically, women with FM report lower sexual desire and arousal, more difficulties reaching orgasm, more genital pain, and lower sexual satisfaction than matched controls [8–11] although there is considerable variability between individuals [8]. FM also impacts women's male partners who report lower sexual and relationship satisfaction, less frequent sexual activity, and poorer erectile function than matched controls [12–14].

A key criticism of research on the impact of FM on sexuality is that it has narrowly focused on sexual function and dysfunction [8, 15, 16]. The study of sexuality, however, should incorporate the broader concept of sexual well-being (SWB), which encompasses both positive (e.g., subjective sexual satisfaction) and negative (e.g., sexual dysfunction and distress) sexual domains [17–19]. These positive and negative domains, although related, are partially independent [19]. For example, individuals who report a sexual dysfunction can report high sexual satisfaction, and vice versa [20], meaning SWB is more than the absence of distress, disease, or dysfunction [21]. Relevant components of SWB include sexual scripts (i.e., enacted sexual activities), motivations, thoughts, and feelings. Improving our understanding of SWB in women with FM could have important implications for the adjustment of patients and their partners. First, SWB is directly associated with better psychological well-being and quality of life [17, 22, 23]. Second, SWB is associated with better relationship satisfaction and stability [17, 22, 23] and researchers have found that a loving, committed partner can be an integral source of social support to persons struggling with chronic pain [24–26]. From a physical standpoint, having a supportive partner has been linked to reduced pain sensitivity and functional impairment [24, 26].

A second limitation of existing research is that previous studies have mainly used quantitative methods to compare women with FM and matched controls on standardized questionnaires. Although quantitative research has helped identify differences between women with and without FM, little is known about the lived experiences of women with FM with respect to their sexuality. This includes their perceptions of the meaning and impact of FM-related changes on their SWB, how various FM symptoms and treatments contribute to or ameliorate the impact of FM on their sexual lives, and how FM and SWB interact to impact their romantic relationship. Further, little is known about how women perceive the impact of FM on their partner's SWB and relationship satisfaction. To our knowledge, only a few qualitative studies have examined the sexual experiences of women with FM [27–29]. In part one of their two-phase study, Ryan and colleagues [29] interviewed five women with FM and found FM limited women's ability and willingness to engage in sexual intercourse, resulting in greater avoidance of sexual activity and less frequent intercourse. Their participants attributed these unwanted changes to FM symptoms such as pain, fatigue and stiffness as well as medication side-effects. In a second phase of the study [29], 41 women with FM completed self-report questionnaires in which they could write detailed responses to questions about the impact of FM on sexuality. Twenty-six (63%) women indicated pain and fatigue had altered their sexual relationship, including reduced sexual frequency and lack of desire. Twenty-nine (71%) women indicated FM had put a strain on their relationship with their partner. Similarly, Matarín Jiménez et al.'s [27] 13 female participants reported FM had resulted in decreased sexual desire and, further, that post-coital pain and stiffness intefered with their sexual enjoyment. The women also worried the lack of sexual activity threatened the future of their relationship. Despite these difficulties, however, some of the women felt having an active sex life was an important part of their lives and identity. Although these studies provide some initial insights into the sexual lives of women with FM, much remains unknown. Thus, the goal of the current study was to broaden our understanding by examining women's perceptions of the nature and extent of changes to a broad range of aspects of their SWB as a result of FM, the impact of these changes on themselves and their partners, and the elements that have exacerbated or ameliorated the effects of FM on their SWB.

Method

Participants

Sixteen women with FM were recruited from across Canada using print and electronic advertisements on patient listservs, Arthritis Society newsletters, in-person and online support groups, and online classified websites. Snowball sampling was also used wherein participants were encouraged to forward the advertisement to any of their relevant contacts. To be included in the study, individuals had to be English-speaking, 21 years of age or older, in a romantic relationship of at least 6 months, and have FM diagnosed by a physician. Individuals with severe comorbid health conditions (e.g., cancer) were not eligible to participate in this study because such medical conditions can also impact SWB.

Measures

Background questionnaire A questionnaire was developed for this study to gather relevant demographic, relationship, physical and mental health, and FM-related information (types of treatments used and the impact of these treatments on their symptoms).

Fibromyalgia Survey Diagnostic Criteria [30] The FSDC was used to obtain an FM severity score and to confirm that participants who had been diagnosed with FM by a physician met the diagnostic criteria. The FSDC includes two subscales. The Widespread Pain Index assesses 19 different body areas where pain or tenderness was felt during the past 7 days (scores range between 0 and 19). The Symptom Scale assesses the severity of three symptoms (fatigue, cognitive problems, and unrefreshing sleep) during the past week (scores range between 0 and 9) and the presence of abdominal pain or cramps, depression, and headache during the past six months (scores between 0 and 3). Scores are summed to create the FSDC total score ranging between 0 and 31. An FSDC score greater than 13 classifies 93% of patients correctly, with a sensitivity of 96.6% and a specificity of 91.8%, when compared to the ACR 2010 diagnostic criteria [30, 31]. The FSDC has good to excellent test-retest reliability and internal consistency for the total score [32]. In the current study, internal consistency for the total score was excellent ($\alpha = 0.90$).

Fibromyalgia Impact Questionnaire revised (FIQR) [33] The FIQR is a widely used and well-validated disease-specific measure of health status for individuals with FM [33]. In the current study, Domain 3 of the FIQR was used to assess the severity of ten common FM symptoms (pain, energy, stiffness, sleep quality, depression, memory problems, anxiety, tenderness to touch, balance problems, and sensitivity to noise/light/odors/ cold) in order to provide descriptive information about the sample. Each item is rated on an 11-point (0–10) scale anchored with bipolar descriptors (e.g., no pain – unbearable pain). Participants' responses are summed and higher scores represent greater symptom severity. In the current study, internal consistency for the total symptom severity score (i.e., Domain 3 of the FIQR only) was excellent (α = 0.87).

Interview protocol A semi-structured interview guide was created to address the objectives of the study and gaps in the literature. To help establish rapport, participants were first asked to describe their experiences with FM including how the illness had affected their lives and romantic relationship in general. Subsequently, participants were asked to describe their sexual lives before and after the development of FM and follow-up questions/probes were used to elicit information about the impact of FM on various aspects of SWB including desire, arousal, satisfaction, orgasms, genital pain, and the sexual script (e.g., types and length of sexual activities). Participants were also asked about their perceptions of how specific FM symptoms (e.g., pain, fatigue) or treatments (e.g., medication) contributed to any reported changes in their SWB and how these changes impacted their emotional well-being. Finally, participants were asked to reflect on how FM impacted their emotional well-being, sexual and romantic relationship, and their partner's SWB. Specific follow-up questions/ probes were used to gather information pertaining to how the women communicated with their partner about the sexuality-related changes, strategies they had used to ameliorate the sexual changes they experienced, and any factors that may have ameliorated or exacerbated the changes.

Procedure

Participant recruitment began following the receipt of ethical approval from the University Research Ethics Board. Advertisements instructed interested individuals to contact the researchers via email to obtain additional information and set up a mutually beneficial time to conduct the interview. Interviews were conducted by a member of the research team experienced in sexuality research and qualitative interviewing (LC and PSI). Fifteen women were interviewed via telephone, and one woman was interviewed in person. Prior to the interview, participants were emailed a copy of the consent form and questionnaire package to review. To begin the interview, the consent form was reviewed with participants and they were asked to provide verbal consent to participate and audio-record the interview. Participants then responded to the items on the questionnaires verbally. Next, participants participated in a 60 to 90-minute semi-structured interview. Participants received a $50 gift card for their participation.

Data Analysis

The digitally recorded interviews were transcribed verbatim, anonymized (to ensure confidentiality), verified for accuracy, and transferred to NVivo (qualitative analysis software) for analysis. All transcripts were analyzed using an inductive Thematic Analysis [34]. Thematic Analysis is a flexible approach that, when used inductively, permits researchers to categorize or ‘code’ data without a pre-existing, theory-driven coding framework [34]. Put simply, this approach allows the content of the interviews to dictate the codes [34]. The SWB construct was considered a sensitizing concept that provided a frame of reference with which to thematically analyze our raw data [35, 36]. Generally, sensitizing concepts promote a more flexible approach to identifying and defining phenomena in qualitative research by suggesting to researchers a general direction to look at based on their analytic goals whilst omitting exactly which items to look for [35]. Thus, the SWB lens served as a sensitizing lens through which our data was viewed that did not impose definitive instructions on what to see or how to interpret results, consistent with an inductive approach.

Initial coding of the data began during the data collection phase. After the completion of eight interviews, the interviewers (LC and PSI) reviewed the transcripts to generate an initial coding map. While the remaining interviews were ongoing, the research team met regularly to review the transcripts and initial codes, identify and discuss patterns within the data, consider alternative data interpretations, adjust the coding map to better represent participants’ lived experiences, and ensure no noteworthy codes had been missed or misrepresented. The remaining eight interviews were coded by a third member of the research team (JH). Approximately half of these transcripts were also reviewed by other members of the research team to ensure no noteworthy codes had been missed or misrepresented. Initial codes were then examined and grouped into themes based on shared meaning and recurring concepts. These themes were then reviewed and refined by the primary coder (JH) and then reviewed, discussed, and refined by all members of the research team.

Results

Participants

Demographic characteristics Sixteen women (*M* age = 45.3, *SD* = 12.0, Range 28–67 years) with FM participated in this study. All of the participants had engaged in at least some post-secondary education following completion of a high school diploma (31% had completed their post-secondary degree). Eight (50%) participants indicated they left the workforce and two (12.5%) had reduced their work hours as a result of their FM. Four participants (25%) were employed outside of the home. All the women in this study were in a romantic relationship (*M* duration = 14.8 years, *SD* = 16, Range = 8 months to 43 years) and the majority were living with their partner (43.8%) or their partner and children (43.8%). One participant (6.3%) was living with her children and one (6.3%) was living alone at the time of the interview although both were involved in romantic relationships of at least 6 months. Fourteen women (87.5%) reported having a male partner and two (12.5%) reported having a female partner. Four participants (25%) reported being in new romantic relationships following divorce (6.3%) or separation (18.8%) from a long-term partner subsequent to the development of FM.

FM illness characteristics On average, participants had been living with FM symptoms for 10.2 years (*SD* = 13.7, range = 0.3–44 years). All of the women reported having received a diagnosis from a physician. Fifteen (93.8%) of the participants had FSDC scores ≥ 13

confirming they likely meet diagnostic criteria for FM. The final participant's score (12) was just below this clinical cut off score. On average, participants' scores on the FSDC ($M=20.2$, $SD=6.7$, Range 12–31) and FIQR ($M=68.5$, $SD=16.8$, Range 46–99) were similar to, or more severe, than the population samples used to validate these measures.

Current treatment approaches being utilized by the participants included medication (81.3%), physiotherapy (12.5%)/exercise (37.5%), or psychotherapy (18.8%)/support groups (50%). A majority (87.5%) also used complementary medicine (e.g., naturopath, massage, acupuncture, supplements, etc.). Nevertheless, most participants (62.5%) reported these treatment approaches had *very little* or only a *small* impact on improving their symptoms.

Other health characteristics: As would be expected, a majority of our sample reported having comorbid physical (62.5%) or mental health (37.5%) difficulties including arthritis, sleep apnea, irritable bowel syndrome, diabetes, lupus, depression, or anxiety. Given the focus of this study is SWB, participants were also asked about their experiences related to menopause: 6 (37.5%) reported having had a hysterectomy, 3 (18.8%) had not had a menstrual cycle in the last 12 months, 2 (12.5%) had irregular menstrual cycles, and 5 (31.3%) had regular menstrual cycles. Furthermore, 2 (12.5%) were taking oral contraceptives and 2 (12.5%) were taking a hormone replacement.

Impact of FM on sexual well-being

All of the interviews showed that FM had impacted the women's SWB; however, the nature and extent of the impact was complex and varied. The four main themes identified in the transcripts highlight this complexity. At the most fundamental level, there was a great deal of variability in how FM had impacted participants' desire for sex and willingness to engage in sexual activity (Theme 1: Do I want to have sex? That's a complicated question). When the women chose to have sex, there was variability in their descriptions of how FM affected the various components of sexual well-being (Theme 2: The impact of FM on women's sexual well-being is not uniform). In turn, the women expressed how the changes to their sexual well-being also impacted their sexual self-perceptions, mental well-being, and romantic relationship (Theme 3: It's about more than sex and more than just me). In facing these changes to their SWB, the women identified using a number of individual and dyadic factors to manage the impact of FM on their sexual lives (Theme 4: Elements that ameliorate or exacerbate the effect of FM's on SWB).

Theme 1: do I want to have sex? That's a complicated question

There was variability in the women's expressed desire for sex. Some women reported that, as a result of their FM, their sexual desire had decreased substantially or was non-existent. Sample statements made by these women include: *my mind is not there, sex is the last thing I think about*, or *I've lost the desire…I don't feel like having sex anymore*. One woman expressed that, if it was not for her partner, she would not *want to have sex for months.* In contrast, other women reported that, despite their FM symptoms, they still experienced sexual desire and continued to *look forward to* [sex]. For example, one woman stated: *I want it [sex] all the time, [sex was] very painful but I mean…I wanted to do it because you miss that so much.*

Some of these women noted their level of sexual desire fluctuated with the intensity of their pain. For example, one woman indicated that, on a good day her sexual desire was *probably a 9...* [but on a bad day] *maybe like a 3 or a 4*. Nevertheless, many of the women who expressed continued desire for sex were reluctant to engage in sexual activity or avoided doing so due to fears about the physical consequences, most often concerns about pain during or after sexual activity. This is illustrated well by one participant who stated that *the desire - the want - is still there, but by the time I get upstairs…I went from…I want to do this to…how am I going to avoid this?* That is, for many of the women, the pain was so generalized and severe that they did not enjoy being touched despite their desire for physical intimacy:

> *It's not just 'honey I have a headache'…lots of time you don't feel like being touched. You don't feel like being touched, it's just that simple. Especially when you have…a flare-up, you ache way down to your toes. So, sex is the last thing on your mind for sure!*

Many of these women engaged in an active process of balancing their sexual desire and the benefits of engaging in sexual activity against the costs. For example, one woman commented that *usually for me…I could [have sex]… but what do I [have going] on in the next few days because I know I'm going to be in extra pain*, explaining that the benefits of sexual activity now had to be weighed against the negative consequences. Similarly, another described how even when she experienced sexual desire she often *chickens out* because she is already *really sore and [doesn't] want to make it any worse.*

Adding to the complexity of navigating their sexual relationship, the women described how, in addition to pain, other physical symptoms (e.g., headaches, fatigue, etc.), menopause, and comorbid mental health symptoms were reciprocally related to each other and also influenced their level of sexual desire and willingness to engage in sexual activity. For example, one woman stated:

> *Well my mood is directly related to my pain level. My irritability level is directly related to my pain level…so if I'm cranky, irritable and in pain, I'm not going to want to have sex.*

Multiple women also described how medication side effects including (but not limited to) weight gain (*what bothers me more sexually and it affects the fibro is my weight*; [I don't] *want* [my husband] *looking at* [me] *at all)* and nausea (*when you're nauseous you don't really want to have sex…. right?)* negatively affected their sexual desire.

Theme 2: the impact of FM on women's sexual well-being is not uniform

Most of the women who desired and continued to engage in sexual activity, described changes to the frequency, duration, timing, and behaviors they engaged in. However, the specific changes differed from one woman to another. For example, most but not all women reported they engaged in sexual activity less frequently than they did before the diagnosis of FM, although this ranged from somewhat less frequently (*I mean we probably haven't had sex in three weeks)* to dramatically less frequently (*I haven't had sex in a year and a half)*.

Finding a good time to engage in sexual activity was also complicated by FM symptoms as illustrated by one woman who stated:

> *... my normal sexual rhythm is I wanna have sex at night and usually at the end of the day I just want to go to bed* [due to fatigue] *so that impacts how often we have sex.*

Many of the women also described unwanted changes to their sexual script including the duration and nature of the sexual interaction. For example, some women indicated the length of the sexual relations with their partner had decreased. Other participants reported engaging in less foreplay before penile-vaginal intercourse particularly when they are experiencing more FM symptoms. Others noted having to restrict or alter sexual positions to avoid pain:

> *[the] positions or how long they can be held changes* and *more energetic positions or anything that puts pressure like on my knees or anything like that doesn't happen anymore.*

Finally, some women discussed how their partner had stopped initiating sexual activity. For some, this resulted in reduced sexual frequency. For others, this resulted in changes in the couple's initiation sequence:

He doesn't initiate things anymore, he waits for me to initiate…which can be an irritant a little bit but I now realize is because he just assumes I'm in pain. So, he will wait for me to let him know I'm ok and we're good to go.

The women also noted a variety of changes, some positive and some negative, to their sexual response. On the positive end of the spectrum, some women reported that on days when their FM symptoms were low, their sexual arousal was higher and they felt more sensitive than before their diagnosis. For example, one woman stated *everything is just really more heightened;* another stated her ability to become aroused has not decreased at all *if anything, it's increased.* In contrast, many women discussed difficulties related to their sexual response—that is, reduced arousal (*it's completely gone for me…there is no arousal at all)* and lubrication (*I occasionally have light bleeding - like very occasionally….I think I am more dry*). With respect to orgasm, some women described how the time it took to achieve an orgasm was *a great deal longer*, *they just don't happen as quickly*, or *they did not happen at all.* Others indicated orgasms were now *a little less intense* than they were before FM or that difficulties with orgasm only occurred when they were experiencing severe pain (e.g., *you couldn't you know, focus – you know, enjoy yourself and let go cause you're trying to block the pain).* Lastly, some women reported developing genito-pelvic pain following the onset of their FM that made sex *excruciatingly painful* or feel *like a sharp knife [was] going right through the vagina.*

Despite the changes to women's sexual functioning and sexual script, the women varied in their feelings about their sex life. A few of the women felt satisfied with their sex life, *I know I'm pretty satisfied with our sex life.* However, they also tended to contextualize their continued satisfaction by adding a disclaimer such as I'm satisfied *given the situation* or when *I'm able* [to engage in sexual activity]. Most the of the women reported FM negatively impacted their sexual satisfaction and pleasure although there was considerable variability in the extent to which they were less sexually satisfied. For example, one woman indicated her sexual satisfaction, *might be a little bit…maybe 25% less* whereas another woman described her sexual satisfaction as *a big fat zero*. Here too, women linked their reduced sexual satisfaction and enjoyment directly to their pain and pain-related anticipatory anxiety.

> *It's completely affected* [the enjoyment] *because now I can't - I don't feel like I can enjoy it anymore so it's* [kind of] *like the only thing I'm going to get out of this is more pain so let's just get it over with.*

Theme 3: it's about more than sex and more than just me

The women we interviewed indicated the changes to their SWB had adversely impacted them emotionally, including a loss of sexual self-esteem and confidence, which in turn further reduced their SWB. In terms of the effects on their psychological well-being generally, several women conveyed the sense of loss they felt in response to the changes in their sex lives, and their feelings of sexual inadequacy (e.g., *part of me is missing or broken. I feel like I'm in the discount bin at stores*). Many women specifically described feeling undesirable. For example, one woman stated:

> *It's almost as if there's not enough words in the world to make me feel desirable…it's like it doesn't matter what he says [or] what he does, I just don't feel good enough.*
> Another woman expressed similar feelings.
> *I don't feel pretty. So, I… want to hide in the dark you know? Where it would be to turn on the lights take a shower together now it's turn off the lights and hide in the dark.*

Many of the women described concern, worry, and guilt with respect to possible negative effects of changes in their own SWB on their partner's SWB and the relationship. Some of the women were worried that their relationship would suffer or they would *just start resenting each other* if they did not regularly engage in sexual activity. They expressed beliefs that, in a healthy relationship, you *have to have sex*.

Some women indicated that, because of their concerns for their partner's SWB and for the quality and longevity of their romantic relationship, they would push through the FM symptoms and lack of desire and, in a way, force themselves to engage in sexual activity (e.g., *although we seem to be ok with it now*, *I know that I consciously have to make an effort…to have sex with him*). For some though, engaging in sexual activity to meet their partner's needs had a positive effect. One woman reported feeling less *guilty once he's been pleased* while another said

> *I know this has to happen so I'm going to force myself to make it happen kind of thing and I mean once I actually like force myself and get into it then it's like 'ok no this was a good idea.'*

.Theme 4: elements that ameliorate or exacerbate the effects of FM's on SWB

Some women reported using a number of strategies to ameliorate the impact of FM on their sexual lives and maintain their SWB. This included mindful modifications to their sexual script, strategies to manage their FM symptoms, and efforts to enhance their overall self-esteem as means to enhance their SWB. Several women expressed how they made changes to their sexual script in order to work around the FM symptoms that interfered with their sex lives. This included engaging in sexual activity on days when symptoms of FM were less severe and altering how they engaged in sexual activity. For example, one woman commented:

> *Sometimes if I'm having a really bad day I might just have to tell him 'Hey, my knee hurts, we're not, you know gonna have sex in that position, let's do it this way'.*

Several women noted that engaging in strategies to manage the FM symptoms such as psychotherapy, yoga, mindfulness meditation, and exercise helped to keep their sexual relationship alive. This is demonstrated well by one woman who expressed:

> *I put into place psychotherapy to help with the diagnosis and that's had a huge positive beneficial impact on my pain, and I've started exercising extremely regularly which has had a positive impact on pain and fatigue as well, so there would be even fewer limitations maybe than there ever have been.*

Other women resumed behaviors geared towards making them feel better about themselves and more sexually desirable. One woman, for example, noted that wearing nicer clothes and using make-up made her feel more desirable: ... *if I can feel pretty... maybe I can feel better about myself... with the hair and the makeup and the pretty clothes and that sort of a thing... will make me feel more desirable which will hopefully bring back the sex.*

Many of the women reported the overall context of a satisfying relationship helped with their sex lives. They indicated being in a long-term relationship where they felt connected and supported by their partner and comfortable spending time with them were important to their relationship in general and sexual life in particular. Some women attributed this to their partner's attitudes and characteristics such as being supportive, accommodating, and understanding. For example, one participant explained:

If he comes home and I'm laying down or if I'm you know saying [I] had a bad headache today he just won't even [try to be intimate] ...which is very good in some ways cause he's not persistent like a lot of men.

Another woman, quoting her husband, said:

> *I love you and yes you have fibromyalgia but we will work around that, you've got to stop feeling guilty about not being able to do that [sex]. I'm ok...I'm an easy man and a flexible man and when you have energy we'll do things and don't worry so much about it.*

Several women remarked they were pleased because their partners had become more affectionate, gentler, or *much more cuddly* since their diagnosis and this contributed to their relationship satisfaction and their SWB. A positive relationship also helped women to feel they and their partner were working as a team to find solutions to sexual barriers resulting from the woman's FM.

Several women emphasized the importance of good communication with their partner about the changes in their sexual lives to their SWB. They identified the need to be able to communicate about "good" and "bad" days for sexual activity, negotiate aspects of the sexual relationship (e.g., the best times of day to engage in sexual activity and types of sexual activities that resulted in the least pain), and resolve problems when they arise. One woman who felt she and her partner had good sexual communication said:

We talk things out…we try to be close that way. We recognize that our sexual relationship is just one component of our relationship so it needs attention as well given, you know, everything that's going on…we still have to talk it out and troubleshoot.

Another participant remarked that she felt relieved by the communication between her and her husband: *We communicated a lot and that was so important it lessened the pressure and stuff cause I knew it was ok to stop but he would still love me.* The women also identified compromise as important in maintaining a positive sex life:

…acknowledging the pattern of 'Hey, you always wanna do it in the morning, I'm always at night," …identifying 'Okay, well I really don't like to do it in the morning [because] I'm achy and tired.' You're a couple… trying to come to a compromise of 'Alright, well the last two times it was the morning, let's do it the evening or, let's start a little earlier so I can get to bed'. So it's just been a lot of talking.

Conversely, the women who had poor communication with their partners felt this had adversely affected their SWB. Some women noted they were unable to talk to their partner about the sexual changes they had experienced due to FM, either due to a lack of their own comfort talking about sexuality or because of their partner's unwillingness to engage in these conversations.

> *These are things like… women just don't talk about these things with their men… Women talk to other women but not to other men.*
> *He doesn't really talk too much about how all this affects him…well, sexually no. I don't think we've ever had that discussion.*

Discussion

The goal of this study was to enhance our understanding of the effects of FM on the SWB of women in a romantic relationship by examining a broad range of aspects of SWB. In keeping with previous research that has focused on sexual function only [37–39], many (but not all) women reported FM had had a negative impact on various aspects of their SWB, particularly their sexual script. However, we extended this research by showing that the relationship between FM and SWB is complex and the changes and impact FM exerts on women's SWB are not universal.

FM impact on SWB

Several of our findings speak to the complexity of the relationship between FM and SWB for women. First, although some women reported that their sexual desire was reduced or absent, others reported that they still desired sex even though they were not engaging in sexual activity. Many of these women were not willing to engage in sexual activity because they feared the negative consequences afterwards (i.e., pain, soreness, etc.). This suggests that FM does not affect all components of sexual desire equally [40, 41]. Researchers have proposed that sexual desire is made up of three different components [41, 42]: sexual *drive* (a biological impulse), which is influenced by anatomical and neuroendocrine processes; sexual *wish* (a cultural component), which reflects values and rules about sexual expression; and sexual *motivation* (a psychological force), which is influenced by mental, interpersonal and social contexts. Our results show FM affects the different components of sexual desire differently. That is, whereas sexual *drive* may be intact for some women, their sexual *motivation* is not [41]. These results suggest that to fully understand the impact of FM and women's SWB, researchers and clinicians need to do a more nuanced assessment of sexual desire.

Second, in keeping with previous research [8, 10, 37, 43, 44] and meta-analysis [45], many women in our study reported sexual functioning difficulties including diminished lubrication, sexual arousal and orgasm inconsistency, and genital pain. However, not all women reported sexual functioning difficulties, with some women reporting no changes to their sexual functioning or even heightened sexual arousal. Furthermore, few women reported difficulties across all the domains of sexual functioning; the specific domain(s) affected varied from woman to woman. This extends previous research by pointing to a greater variety and a more positive picture of the sexual functioning of women with FM than the one drawn from quantitative research. However, it is possible that women decided to participate in our study because they had more positive sexual experiences and attitudes than is typical of women with FM (i.e., self-selection bias). Alternatively, this discrepancy could be explained because the questionnaire typically used to assess the sexual function of women with FM, the Female Sexual Function Index [46], tends to overestimate the frequency of sexual functioning problems in women who do not engage in sexual activity [47, 48]. To add to this complexity, our results show that despite these negative changes, some women reported being sexually satisfied. Although previous quantitative studies typically report that FM negatively affects sexual satisfaction among women with FM [37–39, 49–51], our results show that this is not always the case and that there is a lot of variety in the extent to which FM affects sexual satisfaction. This could be associated with the amelioration strategies and creativity put in place to minimize the negative effect of FM and to keep an active and satisfying sex life [27, 28].

Third, although past research has focused for the most part on sexual functioning difficulties [10, 43], our results show that FM may have an equal or larger impact on other aspects of SWB, particularly the sexual script. In keeping with previous studies [27, 28], most women reported a reduction in the frequency of sexual activity. However, the women also described how FM negatively affected other aspects of the sexual script such as the duration, timing, and the types of sexual activities they engaged in with their partner. They felt compelled to make these changes because they found sex in certain positions more painful and their fatigue prevented them from engaging in sexual activity at the end of the day [27, 28]. Finally, many women also reported being affected emotionally and that their feelings about themselves as a sexual person (i.e., low sexual self-esteem and poor body image) had changed due to their FM. These feelings were often accompanied by a sense of loss [27, 28]. These results have important implications as psychological and emotional factors are often neglected in the literature. For example, sexual self-esteem has never been examined in quantitative studies and the only evidence of diminished sexual self-esteem come from qualitative research [27]. These results suggest researchers need to assess a range of markers of SWB and health care providers need to address not only the behavioral and physical changes to women's SWB resulting from FM but also consider their affective response to these changes [52].

Maintaining a satisfying sex life in the Face of FM

Many of the women in our study reported engaging in proactive strategies, sometimes in collaboration with their partners, to try to maintain their SWB. That is, they adopted a *flexible* coping style [53, 54]. A flexible coping style refers to the "ability to shift cognitive or behavioral focus in order to manage acute and chronic sexual dysfunction" [53]. Women reported finding ways to control their pain during sexual activity. For example, they frequently cited modifying their sexual script by having sex on days when FM symptoms were less severe, or by changing sexual positions. By redefining and renegotiating their sexual script, some women and couples were able to maintain their sexual relationship, thereby contributing to the women's SWB [55]. Similarly, Mazo and Estrada [28] found that women and couples who modified their sexual script to accommodate their FM symptoms and associated difficulties were more capable of maintaining a sex life and experiencing pleasure. These behaviors are best viewed as assimilative actions or activities to transform "ways of living in accordance with the values, aspirations, or developmental goals that define the individual's normative self" [56].

Women also reported that the strategies they used to manage their FM symptoms, such as their pain and fatigue, helped maintain their SWB. Accepting the diagnosis of FM and its associated difficulties, as well as accepting pain as something that is *controllable*, can lead to seeking experiences that provide joy and pleasure [28, 57]. Additionally, for some women, their FM symptoms brought about changes to their interactions with the partner that the women experienced and described as positive. These interactions involved engaging in *gentler* sex and more affectionate behaviors (e.g., hugging and kissing). Postmenopausal women [58, 59] and cancer survivors [60] report similar experiences. Gilbert et al. [60] found that engaging in affectionate behaviors were strategies used by those who could not engage in coital sex. These activities were not only sexually satisfying, but also created a stronger sense of closeness between partners. These results show that, despite the FM symptoms and the negative impact of FM on SWB, women with an FM diagnosis can have a satisfying sexual life with their partner. However, in order to make this happen they may need to identify and adjust to a "new normal".

The results also indicate that the fate of the sexual relationship depends on more than just FM symptomatology and individual coping efforts and point to the importance of the interpersonal context and the quality of the overall relationship for women's SWB. That is, many women reported that being in a positive romantic relationship and having good communication with their partner were crucial for maintaining their SWB. Ussher et al. [54] called this the *intersubjective nature of sexual renegotiation*, meaning that the renegotiation of sexual activity is an intersubjective experience that takes place between the person with an illness and their partner and, hence, the context of a positive relationship (e.g., effective communication) was the main facilitator of renegotiated sex. Our results are consistent with this concept in that, SWB was better in the overall context of a satisfying relationship, when couples communicated effectively with each other and when women reported having an understanding and supportive partner. In this context of a good relationship, engaging in communication is a way of negotiating a mutually pleasurable sexual script [61–63] that worked for women and their partners. Similarly, an understanding partner who is willing to communicate and renegotiate sex also helped in having a more pleasurable sexual life [64]. In contrast, having a non-supportive partner made coping with the SWB challenges of FM more difficult. These results suggest it is import to involve both partners in any efforts to help women in a relationship enhance their SWB.

Limitations and future directions

As is common in research on FM due to difficulties with recruitment, our sample was small. This made it impossible to explore whether participant characteristics such as age or the length of time since diagnosis affected women's SWB. In addition, the women in our study were quite homogeneous (e.g., highly educated and only two had a female partner). Because of the nature of FM and the topic of the study, this study likely suffers from self-selection bias, in that only women with more positive sexual experiences and attitudes may have decided to participate. Furthermore, although our participants showed great variety on their FM characteristics (e.g., time since diagnosis, pain severity and intensity), it is likely that women with particularly severe FM symptoms did not have the energy to participate in research and thus did not volunteer. Future studies need to address these limitations by examining the experiences of women with different educational levels, sexual orientations and identities, and symptom levels.

Conclusions

Our results suggest the relationship between FM and SWB is complex and varied. They add to the existing literature that has focused on sexual behavior and sexual response by showing that FM affects various aspects of SWB differently across women, but that some women and partners can adapt to their situation and have a satisfying and pleasurable sex life. These results highlight the importance of conceptualizing sexual well-being as a multidimensional construct and assessing a wide range of aspects to get an accurate picture of the sexual lives of individuals with FM. They also point to women's active role in developing strategies to ameliorate the impact of FM on their sexual lives with their partners. Because of this complexity and the importance of individual and interpersonal factors, adopting a universal medical or pharmacological approach might not help all women (and their partners) and could even result in distress and frustration [65, 66]. Rather, health care providers need to be aware of and address the diversity and complexity of effects of FM on women's sexual well-being. More research also is needed to understand the variables that contribute to a positive SWB in order to develop tailored interventions and health promotion programs.

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Declarations

Competing interests The authors have no relevant financial or non-financial interests to disclose.

Research involving human participants The study was designed and performed in line with the ethical standards of the Canadian Psychological Association and was approved by the University of New Brunswick Research Ethics Board.

Informed consent Informed consent was obtained from all individual participants included in the study.

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