Sexual functioning of women with fibromyalgia

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Abstract

Objective

To examine sexual functioning at the specific phases of the sexual response cycle among women with fibromyalgia.

Methods

The Questionnaire for screening Sexual Dysfunctions - Short Form (QSD-SF) was filled out by 63 premenopausal, heterosexual women with fibromyalgia (age: 21-54 years) who were recruited at meetings of regional patient associations.

Results

The women with fibromyalgia did not differ from healthy women of an age reference group with respect to functioning in the excitement and the orgasm phases, but reported more problems with sexual desire and satisfaction, more pain in their body, and insensitivity (but not pain) in their genitals before, during or after having sex. Mental distress, but not pain, was a significant predictor of virtually all aspects of sexual dysfunction.

Conclusion

Our study generates the hypothesis that the psychological but not the physiological aspect of the sexual response cycle is more disturbed than normal in fibromyalgia. This finding needs confirmation in a more representative population.

Key words

Fibromyalgia, sexual response cycle, sexuality, psychological sexual dysfunctions, libido, quality of life, pain.

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Introduction

Sexuality is an important aspect of life. As sexual functioning is strongly connected with physiological and psychosocial functioning (1), the symptoms of fibromyalgia will likely obstruct sexuality. Psychophysiological phases in the human sexual response cycle have been specified (2): the desire (appetite), excitement, plateau, orgasm, and resolution phases. Once started, this cycle usually works like an automatic positive feedback mechanism. We hypothesize that pain as well as mental distress and physical disability will reduce sexual desire, and will hamper the excitement and orgasm phases, while physical effort during previous phases and pain may result in less satisfaction during the resolution phase.

The prevalence of sexual difficulties in patients with chronic pain is high (3). Interviews reveal a considerable decrease in sexual desire of women with fibromyalgia (4). Questionnaires indicated that fibromyalgia had adversely affected the sex lives of 71% of the patients (5). These studies used global perceptions of sexual functioning, while the clarification of sexual functioning at the phases of the sexual response cycle at which problems occur, will give clues for appropriate educational and therapeutic interventions. The aim of our explorative questionnaire study was to examine sexual functioning at the specific phases of the sexual response cycle among women with fibromyalgia. For that aim, sexual functioning of women with fibromyalgia was compared to control reference values and it was examined whether sexual dysfunction was predicted by pain, mental distress, and physical disability.

Materials and methods

Participants

Inclusion criteria were (a) female gender, (b) 20 to 55 years of age, (c) premenopausal according to self-report, and (d) having a heterosexual relationship of at least one year. Questionnaires were handed out at regional meetings of the Dutch Fibromyalgia Association in Gouda, Maarssenbroek, and Amsterdam. Some of the women took questionnaires to hand these out to patients who were not at the meeting. It is well established that participation in research of sexual functioning is low, especially when highly intimate questions about excitement and orgasm are posed (2). Of the 137 women who fulfilled the inclusion criteria and took questionnaires, 63 actually returned the questionnaire (response rate 46%).

Control reference group

As a control reference group, an existing data file was used with scores on the Questionnaire for screening Sexual Dysfunctions. This healthy (no serious disease or disability) reference group consisted of sisters (in law) or friends of women who were treated for early stage gynecological cancer (6). We selected the 66 female members of the reference group who were similar to our population of patients: 20 to 55 years of age, premenopausal, and having a heterosexual relationship of at least one year.

Instruments

The questionnaire included questions about demographic characteristics, disease history, and medication as well as the Questionnaire for screening Sexual Dysfunctions - Short Form (QSD-SF) (7), and the RAND SF-36 questionnaire to measure mental well-being and physical function (8).

The QSD-SF is a multidimensional self-report questionnaire to assess the frequency of and trouble experienced with sexual problems during the past few months. Seventeen scales assess sexual functioning during four phases of the sexual response cycle (desire, excitement, orgasm, and resolution), while six scales assess genital and bodily pain. Frequencies of sexual activities are rated on 7-point (1 = less than once per month, 7 = several times a day) or 5-point Likert-scales (1 = almost never, 5 = always). Five-point Likert-scales are also used to assess the experienced trouble (1 = no trouble, 5 = very much trouble) and satisfaction (1 = very dissatisfied, 5 = very satisfied). Two scales had poor reliability in our study: ‘frequency of premature

orgasm' (α =.40) and 'frequency of insensitivity in genitals before, during, or after sex' (α =.50). The internal consistency of the other scales varied from low (α =.53) to very high (α =.87).

Using the separate scales of the QSD-SF questionnaire, we computed summary scores for problems in the four phases of the sexual response cycle (desire, excitement, orgasm, resolution) as well as for the two sexual pain scales ('genital pain and insensitivity' and 'body pain'). The Cronbach's alpha reliabilities of these summary scores in our study were moderate (0.70) to high (>.70): .70 for sexual desire, .82 for excitement, .82 for orgasm, .70 for resolution, .78 for genital pain and insensitivity, and .95 for body pain.

Common problems of fibromyalgia such as physical disability, mental distress, and pain are generally measured with questionnaires such as the FIQ (9) or SF-36 (10) that tend to differentiate between fibromyalgia and other rheumatic conditions (11). SF-36 scores of mental well-being and physical function are correlated with scores of the Fibromyalgia Impact Questionnaire (10, 12). We used the RAND (SF-36) Health Survey to assess physical function and mental well-being (8). Two summary component scores were computed by aggregating scores from the eight scales of the SF-36: the physical component summary score assesses physical function and the mental component summary score assesses mental well-being (13). These transformed summary scores have a mean of 50 and a standard deviation of 10 in the normal population.

Statistical analysis

Statistical analyses were performed using SPSS 11.5 for windows. Differences were considered significant when $p < 0.05$. Student's t-tests for continuous data and Chi^2 tests for categorical data were used to compare demographic characteristics of women with fibromyalgia and healthy women. Because the scores at the scales were most often not normally distributed, the sexual functioning of women with fibromyalgia and healthy women was compared using Mann-Whitney U tests.

The summary scores for problems in the four phases of the sexual response cycle and the two sexual pain scales had normal or nearly normal score distributions (maximal skewness 1.3). Parametric statistics were used to analyze these scores. To examine determinants of sexual functioning, in a first step Pearson product moment correlations were calculated between the summary scores of sexual functioning and the potential determinants age, education, pain, mental well-being, physical functioning, and anti-depressant and anxiolytic medication. Then, the five predictor variables that were correlated with at least one aspect of sexual functioning, were entered in multiple regression analysis. These predictor variables were pain, physical functioning, mental well-being, and use of antidepressants or anxiolytics.

Results

Characteristics

All women with fibromyalgia reported to be premenopausal, to have a heterosexual relationship of at least one year, and to be diagnosed as fibromyalgia patient (76.2 % by a rheumatologist, 11.1 % by a general practitioner, 4.8 % by a rehabilitation physician, 1.6 % by an internal medicine physician, and 6.3 % unknown (2 patients did not know who made the diagnosis and 2 patients did not fill out this question). The participants who were diagnosed by a rheumatologist did not differ with respect to pain severity from the other (23.8%) participants: pain on the visual analogue scale was 66 mm versus 63 mm for the two groups (t = .41; p = .687).

Of the 38 patients who used analgesic drugs, 34 used regularly nonsteroidal anti-inflammatory drugs, 9 opioids, and 16 paracetamol. Of the 15 patients who used antidepressants, 7 had tricyclics, 7 selective serotonin reuptake inhibitors, and 1 a serotonin and norepinephrine reuptake inhibitor. The anti-epileptic drug gabapentin might have been prescribed against pain. The disease-modifying anti-rheumatic drug used was sulfasalazine. Single patients used medication against diabetes, asthma, and hypothyroidism (Table I).

The 63 participating women with fibromyalgia were between 21 and 54 years. The women with fibromyalgia and healthy women did not differ with respect to age, but differed with respect to education and relationship variables (Table II). The healthy women were biased towards the tertiary educational level, while the majority of the women

Table I. Characteristics of 63 patients with fibromyalgia.

Duration of fibromyalgia symptoms, mean (range) yrs.	11.6 (9-39)
Time between onset and diagnosis, mean (range) yrs.	6.1 (0.17-34)
Working status, number (%)	
Working	10 (15.9)
Temporary benefit	8 (12.7)
Benefit of Workmen's Compensation Act	29 (46.0)
Unemployed	12 (19.0)
Housewife	4 (6.4)
Medication use, number (%)	
yes	47 (74.6)
no	16 (25.4)
Medication use, number (%) of patients using medication	
Analgesics	38 (60.3)
Antidepressants	15 (23.8)
Antihypertensives	4 (6.3)
Anxiolytics	6 (9.5)
Anti-epileptics	2 (3.4)
DMARD	2 (3.4)
Pain severity (Visual Analogue Scale scores during the past week), mean (range) in millimeters.	64 (12-97)

Table II. Characteristics of the research participants.

	Women with fibromyalgia (n = 63)	Healthy women (n = 66)	t /χ^2
Age in years			t = -1.21 ns
mean (SD)	39.3 (8.2)	41.0 (8.0)	
minimum	21	24	
maximum	54	55	
Educational level (%)			χ^2 = 15.74‡
primary	-	1.5	
secondary	71.0	36.4	
tertiary	29.0	62.1	
Living together (%)			χ^2 = 4.52*
yes	92.1	78.8	
no	7.9	21.2	
Relationship duration in years mean (SD)	13.4 (10.3)	9.9 (7.8)	t = 2.17*

*p < 0.05, ‡ p < 0.001, 2-tailed tests.

with fibromyalgia obtained secondary education (p < .001). The women with fibromyalgia were living together with their partner for a longer period than the healthy women (p < .05), and more patients than participants of the control group actually lived together with their partner (p < .05).

Sexual functioning

Women with fibromyalgia reported more problems with typical desire phase sexual activities, while none of the scales of the sexual excitement phase and the sexual orgasm phase showed a difference between patients and the healthy group (Table III). At the resolution phase, the women with fibromyalgia reported to be sexually less satisfied than the healthy women.

Sexual pain

Women with fibromyalgia reported more problems with genital insensitivity as well as pain in other parts of their body before, during, or after having sexual contact with their partner, but genital pain did not differ between the groups (Table IV).

Post-hoc analyses

To check if education level affected the results of patients with fibromyalgia or the healthy women, for both groups the sexual functioning scores of women with primary or secondary education versus tertiary education were compared. None of the comparisons yielded a significant result.

Table III. Sexual functioning according to the sexual response cycle of women with fibromyalgia and healthy women; median, 25th – 75th percentile and Z values.

	Fibromyalgia (n = 63)		Healthy (n = 66)		Mann-Whitney U
	Median	25th-75th	Median	25th-75th	Z
Desire phase					
Frequency of masturbation & sexual fantasy	1.7	1.1 – 2.4	2.2	1.8 – 3.1	-3.362‡
Frequency of sex with partner	3.0	3.0 – 4.6	4.0	3.0 –5.0	-2.087*
Frequency of sexual aversion	1.0	1.0 – 1.3	1.0	1.0 – 1.0	-2.034*
Experienced trouble with considerable sexual desire	1.0	1.0 – 1.0	1.0	1.0 – 1.0	-1.833
Experienced trouble with little sexual desire	1.0	1.0 – 2.0	1.0	1.0 – 1.3	-2.635*
Experienced trouble with sexual aversion	1.0	1.0 – 1.7	1.0	1.0 – 1.3	-1.999*
Excitement phase					
Frequency of sexual excitement problems	1.5	1.0 – 2.0	1.7	1.3 – 2.0	-.637
Frequency of lubrication problems	1.0	1.0 – 2.0	1.0	1.0 – 1.7	-.736
Experienced trouble with sexual excitement problems	1.5	1.0 – 2.3	1.7	1.3 – 2.0	-.161
Experienced trouble with lubrication problems	1.3	1.0 – 2.3	1.3	1.0 – 1.7	-.635
Orgasm phase					
Frequency of orgasm problems	1.7	1.2 – 2.3	1.8	1.3 – 2.3	-.857
Frequency of premature orgasm	1.0	1.0 – 1.0	1.0	1.0 – 1.0	-.296
Experienced trouble with orgasm problems	1.3	1.0 – 2.2	1.7	1.0 – 2.0	-.408
Experienced trouble with premature orgasm	1.0	1.0 – 1.0	1.0	1.0 – 1.0	-.484
Resolution phase					
Frequency of negative emotions	1.0	1.0 – 1.3	1.0	1.0 – 1.3	-.669
Frequency of sexual satisfaction	3.5	2.5 – 4.0	4.0	3.4 – 4.0	-2.059*
Experienced trouble with negative emotions	1.0	1.0 – 1.8	1.0	1.0 – 1.3	-.785

*p < 0.05, ‡p ≤ 0.001, 2-tailed tests.

Table IV. Pain of women with fibromyalgia and healthy women; median, 25th – 75th percentile, and Z values.

	Fibromyalgia (n = 63)		Healthy (n = 66)		Mann-Whitney U
	Median	25th-75th	Median	25th-75th	Z
Genital pain and insensitivity					
Frequency of pain in genitals during sex	1.5	1.0 – 2.1	1.0	1.0 – 1.5	-1.237
Frequency of insensitivity in genitals before, during, or after sex	1.0	1.0 – 1.5	1.0	1.0 – 1.0	-2.217*
Experienced trouble with pain in genitals during sex	1.5	1.0 – 2.5	1.0	1.0 – 2.0	-1.595
Experienced trouble with insensitivity in genitals before, during, or after sex	1.0	1.0 – 2.0	1.0	1.0 – 1.1	-2.425*
Body pain					
Frequency of pain in other parts of the body before, during, or after sex	3.0	2.0 – 4.0	1.0	1.0 – 1.0	-8.543‡
Experienced trouble with pain in other parts of the body before, during, or after sex	3.0	2.0 – 4.0	1.0	1.0 – 1.0	-8.779‡

*p < 0.05, ‡p ≤ 0.001, 2-tailed test.

Table V. Pearson product-moment correlations (*r*) and regresssion weights (β) of multiple regression analyses predicting sexual functioning from five predictors: pain, physical functioning, mental wellbeing, antidepressants, and anxiolytics.[a]

	Desire		Excitement		Orgasm		Resolution		Genital pain and insensitivity		Body pain	
	r	*β*	*r*	*β*	*r*	*β*	*r*	*β*	*r*	*β*	*r*	*β*
Pain	-.02	-.03	-.21	-.25*	-.25	-.30*	-.12	-.16	-.11	-.16	-.02	-.08
Physical functioning	-.23	-.26	-.21	-.24	-.14	-.21	-.27*	-.39†	-.15	-.22	-.12	-.27
Mental wellbeing	-.36*	-.36†	-.26*	-.28*	-.23	-.26*	-.37†	-.46‡	-.22	-.23	-.35†	-.40†
Antidepressants	.18	.07	.36†	.26*	.23	.14	.13	-.07	.02	-.05	-.20	-.35†
Anxiolytics	.23	.14	-.05	-.05	-.09	-.08	.39†	20	-.04	-.06	.05	-.07
adjusted R^2		.12*		.18†		.11*		.24†		-.01		.16*

Note. [a] A positive *r* and β indicate that the predictor is related to more problems with desire, excitement, orgasm, resolution, genital pain, and body pain; the β-values are of the full model with all the predictors entered; *$p < .05$, †$p < .01$, ‡$p < .001$.

To examine the influence of medication, comparisons were made between women with fibromyalgia who did and did not use medications that might influence sexual functioning. Sexual functioning did not differ for patients who did and did not use antidepressants with the exception of two scales: Mann-Whitney U tests showed that antidepressants went together with excitement (p = .016) and orgasm (p = .035) problems. The group that used anxiolytics reported more sexual dissatisfaction (p = .034). The groups that did and did not use antihypertensives showed no significant differences with respect to sexual functioning.

Predictors of sexual functioning

Pearson product moment correlations were calculated between the summary scores of sexual functioning and the potential determinants age, education, pain, mental well-being, physical functioning, and anti-depressant and anxiolytic medication. Age and education were correlated with none of the sexual functioning summary scores. The variables pain, physical functioning, mental well-being, and use of anti-depressants and anxiolytics were correlated with at least one of the sexual functioning scores (see the values under *r* in Table V). These five variables were entered in multiple regression analysis to examine their relative predictive contribution to individual differences in sexual functioning. In multiple regression analysis, more severe pain was significantly associated with fewer problems in the excitement and orgasm phases (see the values under β in Table V). Better physical functioning went together with less problems in the resolution phase. Mental well-being was associated with better sexual functioning in all four phases of the sexual response cycle and with less pain in the body. The use of antidepressants was associated with less severe body pain and more problems in the excitement phase. The use of anxiolytics went together with more problems in the resolution phase.

Discussion

Women with fibromyalgia who were recruited at meetings of regional patient associations did not differ from healthy women with respect to functioning in the excitement and the orgasm phases, but they reported more problems with sexual desire and satisfaction.

Moreover, they experienced more pain in their body and insensitivity in their genitals before, during or after having sex. Mental distress, but not pain, was a significant predictor of virtually all aspects of sexual dysfunction.

Although widespread pain is the agreed upon characteristic feature, the occurrence of many more physical and psychological symptoms is also typical of fibromyalgia (14). Our observation of problems with sexual desire, aversion, and satisfaction in fibromyalgia agrees with the general observation that sexual dysfunction is more likely among women with poor emotional health and well-being (1). Regression analysis confirmed that within the group of patients with fibromyalgie, mental distress is associated with sexual dysfunction. Like our study, another recent study found that diminished sexual desire is the most common sexual problem in fibromyalgia (15). For several women, the lack of sexual desire is one of many signs of living a restricted life aimed at avoiding pain and distress rather than pursuing pleasant activities. The lack of sexual desire may be a reflection of a more general deficit in identifying feelings (16), especially positive feelings (17). Also known psychological oppressors of sexual desire like depressed mood, negative thoughts, anti-fantasy, stress, anger, and fear as well as physiological oppressors like medications with sexual side-effects will have resulted in more sexual avoidance and less sexual desire (1, 18, 19).

Part of our patients used antidepressant medication against pain or depression, which may have had a possible negative impact on sexual functioning (20-22). Our analysis suggests a positive effect of antidepressants on body pain, possibly reflecting the known positive effect of amitriptyline on widespread pain (23, 24). We observed adverse effects of antidepressants on orgasm problems (in one but not the other analysis) and excitement problems (in all analyses). Our results may reflect adverse effects of common dose antidepressants on physiological aspects of sexual functioning as well as positive effects of low dose antidepressants on pain severity.

Pain in the body before, during and after sex was by far the most prevalent problem of sexual functioning in our patients. This reflects the classifying feature of fibromyalgia: widespread pain. Pain during and after sex may color the memory of the act, let women forget the positive experiences of it, and interpret it more negatively. Although problems with genital insensitivity differed from healthy persons, pain in genitals did not. This suggests a low prevalence of dyspareunia in our group. The diffuse, widespread pain of fibromyalgia perhaps does not generalize to pain in genitals and involves other physiological processes than the local, burning, and sharp pain of dyspareunia (25).

This interpretation is supported by our observation that pain severity was hardly related to sexual function and, surprisingly, more severe pain was even associated with less severe problems in the excitement and orgasm phases. The absence of an association between pain and psychological aspects of sexuality may be explained by our group being rather homogeneous with respect to having pain. Because our study did not include physiological measures, we can only speculate about the mechanisms behind the negative correlation between pain and the physiological aspects of sexuality in our research participants with fibromyalgia. Both pain (26) and the sexual response cycle (27) are under the control of numerous endocrine, and central nervous system influences. Several neuropeptides that are involved in pain are also involved in sexual behavior. Animal studies suggest that, among other neuropeptides, corticotrophin-releasing hormone (CRH) inhibits and substance P facilitates sexual functioning (28). Paradoxically, this could lead to the hypothesis that sexual functioning of fibromyalgia would be even enhanced, because CRH hyposecretion and elevated levels of the pain amplifying neuropeptide substance P are common in fibromyalgia (29). Other findings support the hypothesis that physiological mechanisms involved in pain syndromes such as activity of opioid peptides would inhibit sexual functioning. Our study demonstrated no differences in the excitement and the orgasm phase of the sexual response cycle between women with fibromyalgia and healthy women. This suggests that the sexual response cycle, once started, passes off uncomplicated in fibromyalgia.

A major limitation of our study is that patients were recruited among members of a patient association. This may be a selective sample of the population that functions relatively well and our findings may, therefore, not fully generalize to the female fibromyalgia population. Moreover, we used self reports of fibromyalgia diagnosis. Although in our study verification of the criteria for the classification of fibromyalgia (30) did not take place, 76.2 % of the research participants reported to be diagnosed by a rheumatologist, and only 4 patients did not clearly indicate who made the diagnosis. That the healthy reference group was higher educated did not affect the results of our study, with the exception of trouble with sexual aversion. Our patient selection and classification procedure hampers generalization and makes our study explorative and hypothesis generating.

Our study provided an important clue on sexual functioning of women with fibromyalgia. The psychological but not the physiological aspect of the sexual response cycle appears more disturbed than normal. This would imply that possible excitement and orgasm problems are secondary to desire and satisfaction problems. Our result needs confirmation in a more representative sample of patients. If confirmed, the finding indicates that individual interventions should often focus on the cognitive-affective and relational aspects of sexuality. A main challenge is to improve the quality of life of women with fibromyalgia, with the goal to learn to enjoy life more, including sex.

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