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Perceptions about the sexuality of women with fibromyalgia syndrome: a phenomenological study

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Abstract

Aims. The aim of this study was to explore and understand the perceptions and experiences of women with fibromyalgia syndrome regarding their sexuality.

Background. Fibromyalgia syndrome is a chronic pathology, which compromises a woman's physical, mental and emotional health. Although concerns related to sexuality are commonly reported, research has tended to focus on the physical symptoms.

Design. An interpretive qualitative research methodology using Gadamer's philosophical hermeneutics was carried out.

Methods. This qualitative study explores the sexuality of women with fibromyalgia syndrome. A focus group and semi-structured interviews were conducted with 13 women with fibromyalgia syndrome. Data were collected between April - June 2014. Participants were recruited until findings reached saturation.

Findings. Three themes define the perception of sexuality for these women: (i) Physical impact: don't touch, don't look; (ii) Sexuality and identity: fighting against their loss; (iii) Impact on the relationship: sexuality as a way of connecting the couple.

Conclusion. Despite limitations, sexuality is important for the identity and quality of life of women with fibromyalgia syndrome. Together with the physical symptomology, guilt, fear and a lack of understanding compromise the coping process. Women need the support of their partner, their socio-family environment and health professionals. Nurses can aid the successful adjustment to sexual problems related to fibromyalgia syndrome.

Keywords: female sexual dysfunction, fibromyalgia syndrome, musculoskeletal diseases, nursing, qualitative methods

Why is this research or review needed?

- In addition to affecting physical and psychological health, fibromyalgia syndrome also compromises a woman's sexual health.
- According to the World Health Organization, negative perceptions of sexuality can influence the individual's coping and adaptation processes.
- The impact of fibromyalgia syndrome on female sexuality needs to incorporate the experiences of the women affected.

What are the key findings?

- Dealing with the problems related to female sexuality in fibromyalgia syndrome implies a comprehensive response from the woman to move forward with her life and sexuality.
- Sexuality and couple/marital life are viewed as elements of female identity which women are afraid of losing.
- Women require sexual information to cope and adapt.

How should the findings be used to influence policy/practice/research/education?

- Chronic treatments and illnesses alter the perception of sexuality, complicating adaptation and coping.
- Health professionals such as nurses should incorporate care and support for female sexual dysfunction experienced in fibromyalgia syndrome into their practice.
- Further research into the perception of female sexuality when dealing with fibromyalgia syndrome is needed.

Introduction

Chronic musculoskeletal pain is a significant problem, which affects between 10–15% of the population (Branco *et al.* 2010). Fibromyalgia syndrome (FMS) is a chronic pain condition with a prevalence rate of 2·7% in the global population (Queiroz 2013), clearly prevailing among women (Thiagarajah *et al.* 2014). Although its aetiology is not clear, genetic, immunological and hormonal factors may be involved. FMS affects the physical, psychological and emotional functioning of the woman, showing symptoms such as fatigue (Olson *et al.* 2015), pain (Bazzichi *et al.* 2012) or depression (Orellana *et al.* 2009). However, it also affects sexual health (Zielinski 2013) and is associated with female sexual dysfunction (FSD) (Kalichman 2008, Rico-Villademoros *et al.* 2012) and changes in libido, pleasure (Prins *et al.* 2006) and sexual relations (Tristano 2009). Research into FMS has focused on physical problems, pathogenesis, treatment and therapy (Lisboa *et al.* 2015, Chinn *et al.* 2016), but there exists a lack of research into the understanding of female sexuality through the experiences of women themselves.

Background

FMS is a chronic pathology, which compromises a woman's physical, mental and emotional health (Zielinski 2013). With a prevalence rate of approximately 2·4% in the Spanish population, it is more common among women than men (MHSPE 2011). FMS is accompanied by hyperalgesia, widespread musculoskeletal pain (Burri *et al.* 2014), paraesthesias and joint stiffness (MHSPE (Ministry of Health, Social Policy and Equality) 2011). It is also associated with sleep disturbances and morning stiffness (Amasyali *et al.* 2016), stress (Thiagarajah *et al.* 2014), fatigue (Olson *et al.* 2015) and climacteric syndrome (Blümel *et al.* 2012). Although its physiopathology is unknown, a history of surgical procedures, emotional trauma or sexual abuse has been described (Bazzichi *et al.* 2013), with the diagnosis being fundamentally clinical (Lempp *et al.* 2009). The American College of Rheumatology (ACR) established diagnostic criteria of musculoskeletal pain for more than 3 months and at least 11 of 18 tender points being painful to the touch. It later added an intensity index for symptoms such as pain, sleepiness and fatigue (Wolfe *et al.* 2010).

FMS interferes with a woman's sexual functioning, as it is associated with fatigue (Blazquez *et al.* 2015), pain (Kalichman 2008, Bazzichi *et al.* 2012), decreased lubrication (Burri *et al.* 2014), affectation of the pelvic floor muscles (Lisboa *et al.* 2015) and medication side effects (Bazzichi *et al.* 2012). Together with the physical symptomology, FMS also affects self-image and relationships (Tristano 2009) and has been associated with depression (Orellana *et al.* 2009, Bazzichi *et al.* 2013), stress (Thiagarajah *et al.* 2014) and hypoactive sexual desire (Yilmaz *et al.* 2012). This situation may lead to avoidance behaviours (Bazzichi *et al.* 2013), a lack of receptiveness (Kengen Traska *et al.* 2012), an absence of sexual relations (De Castro *et al.* 2013) and/or an increased risk of a breakdown of the relationship (Poh *et al.* 2016). When dealing with FMS, a multidisciplinary approach based on holistic models which combine biological, psychological and social factors (Zielinski 2013) can improve the quality of life for the women affected and their partners. Corporality, stigma (Armentor 2015), self-management (Schulman-Green *et al.* 2016), coping strategies and social support (Granero-Molina *et al.* 2016) are also key elements in adjusting to FSD related to FMS.

Qualitative methodologies have proved to be useful in the comprehensive research of FMS (Masi & Vincent 2015, Triviño *et al.* 2016). The sexuality adaptation model (SAM), derived from Roy's Adaptation Model (RAM), constitutes the framework of this study (Roy & Andrews 1999, Roy 2009, Fawcett & Desanto-Madeya 2013). Roy identified the person as a complex and living adaptation system composed of internal processes (regulator and cognitive), which acts to maintain adaptive capacity in the four modes of adaptation (physiological, self-esteem, role function and interdependence). Faced with stimuli from the environment, the person produces answers that can be adaptive or not. In the environment there are focal stimuli, defined as the external or internal situations that the person has to face; contextual stimuli, such as age, that contribute to the effect of focal stimuli and residual stimuli, with unclear role on behaviours (Roy & Andrews 1999, Roy 2009).

The SAM has been used as a theoretical framework in research on sexual experiences (Stewart 2013). The FMS would operate as a focal stimulus that triggers the 'sexuality coping process,' involving the regulator subsystems, responsible for the physiological response and cognator subsystems, reflecting the influences of emotions, experiences and judgements on human interaction and response to stimulus (Stewart 2013). The sexuality adaptive modes of the SAM were identified as: physical sexuality adaptive mode (physical sexual characteristics), personal sexuality identity mode (reflects individual identity with regards to sexual well-being), family–social role mode (reflects the social roles as family woman and labour role) and the intimate/personal relationships mode (regarding close and intimate relationships). Either of these modes, alone or combined, can influence or be influenced by sexual changes or problems (Stewart 2013).

The study

Aim

The aim of this study was to explore and understand the perceptions and experiences of women with FMS regarding their sexuality.

Design

A qualitative descriptive and interpretative design, using Gadamer's philosophical hermeneutics was carried out (Gadamer 2005). The understanding of a phenomenon is influenced by the present, tradition and history (Gadamer 2005), consequently forming preconceptions in individuals, which then help them to understand themselves in their own context. Interpreting a narration or the story of a lived experience involves a fusion of horizons. In this regard, the interpreter's horizon is fused with and incorporates the participants' horizons, thus expanding the interpretation of the latter.

Participants

A convenience sample, obtained in a Fibromyalgia Patients Association was used in this study. A total of 13 women between the ages of 22-56 years old participated in the study, with an average age of 44·8 (SD 9·18) and an average time of 14·3 years diagnosed with FM (Table 1). The inclusion criteria taken into account were: to be a woman, to be over 18 years old, to have been diagnosed with FMS for at least 1 year and to agree to participate in the study. Although 16 women initially agreed to take part, three withdrew from data collection due to a flare-up of FM, sciatic pain and a medical appointment.

Data collection

The study took place in an association of patients with FMS, where a nurse, a psychologist, a social worker and a physiotherapist treat the patients. Data were collected from April–June, 2014. We used a focus group (FG) and in-depth interviews (DI) carried out by a nurse and a psychologist with 3 years' experience in the care and treatment of women with FMS. The FG was conducted prior to the DI, to facilitate the emergence of themes relevant to the

Table 1 Socio-demographic data of the participants (N = 13).

Participant	Sex	Age	FM (years)	Profession/area of work	Employed/ in work
FGW1	Female	35	12	Teacher (Primary school)	No
FGW2	Female	47	16	Teacher	Yes
FGW3	Female	56	17	Cleaner	Yes
FGW4	Female	32	9	Farmer	Yes
FGW5	Female	54	18	Administration	Yes
WFM1	Female	30	16	Teacher	No
WFM2	Female	52	20	Cleaner	No
WFM3	Female	46	10	Cleaner	Yes
WFM4	Female	49	15	Cleaner	Yes
WFM5	Female	53	5	Administration	Yes
WFM6	Female	49	22	Administration	Yes
WFM7	Female	50	25	Administration	No
WFM8	Female	30	2	Daycare center	No

interaction among the participants and was comprised of a total of five women and lasted 40 minutes. It started with the question, 'Tell me about the importance of maintaining an active sexual life with FMS and why?' Eight DIs were also carried out in a quiet, private room. They lasted an average of 35 minutes, allowing us to explore intimate sexual topics. After an introductory question, similar to that of the FG, new questions emerged while the interview was being conducted, such as, how do FM symptoms affect their sexual relationships? and, What other situations or conditions in your life could you relate it to? The DIs would end with the question: Is there anything else, which should be said about these topics? All of the participant responses from the FG and DIs were audio-recorded and transcribed. When finished, the socio-demographic data of the participants was collected. Sample size was determined by theme saturation. All of the data comprised a hermeneutic unit analysed with the program Atlas-ti 7·0.

Ethical considerations

Ethics approval was obtained from the Research Ethics Committee of a university and from the Fibromyalgia Patients Association. Prior to obtaining participant consent, the research team informed the participants of the nature of the study that the conversation needed to be recorded and that it would only be used for research purposes. The women answered the questions freely, being able to leave the study if they deemed it convenient. To ensure anonymity and confidentiality, participants cannot be identified by descriptions or citations and a code replaces their name in the final publication. Only the researchers were able to access the data, guaranteeing their custody and subsequent destruction.

Data analysis

A qualitative approach based on Gadamer's hermeneutic phenomenology was employed in the processes of data interpretation and analysis. A modified form of the stages developed by Valerie Fleming was used (Fleming *et al.* 2003). In the first step, the relevance of the research question was assessed and all researchers decided that it was indeed relevant. The second step was for the researchers to undergo a period of reflection, establishing preconceptions related to female sexuality in relation to FMS. Pre-understanding stemmed from previous research and experience in therapy and care for these women. The third step aimed to achieve an in-depth understanding of the phenomenon through dialogue between the researcher and the participants. New questions emerged such as, 'What role does the partner play in dealing with FSD in FMS?' The fourth step aimed to understand the phenomenon through dialogue with the text. After reading the transcriptions, the participants' experiences were re-examined together with the researchers' horizons and new questions such as 'What influence does the attitude of health professionals have when tackling FSD in FMS?' Examining each sentence meant that themes, sub-themes and units of meaning could be identified (Table 2). The fifth step looked to establish the reliability of the qualitative data, as described in the following section.

Validity and reliability/Rigour

After the interviews, we asked the participants to confirm the transcript and analysis. Credibility was established by engaging participants in sharing their experiences and adding to the richness of the data descriptions by using their own words. To maximize reliability, a clear description of the context, the data collection and analysis was given (Green & Thorogood 2014). In line with philosophical hermeneutics (Gadamer 2005), the rigour is focused on through the selection of participants with experience in the subject and genuine conversations evolved in the interviews. The researchers were open to new ideas from the participants, such as the most intimate experiences regarding their sexuality. The authors incorporated their personal prejudices, a fusion of horizons through the hermeneutic circle that improved the understanding and interpretation of the phenomenon. (Fleming *et al.* 2003).

Findings

Three themes describing the perception of sexuality in relation to women with FMS emerged from data analysis (Table 2).

Physical impact: don't touch, don't look

FMS compromises a woman's physical, mental and social health. For Roy, a person is a system comprised of internal processes, which acts to maintain the ability to adapt. Pain, stiffness and somatic complaints are symptoms, which lower libido, complicate relationships and negatively affect female sexuality. The regulating subsystem implies a significant coping process, mainly related to physiological factors.

Pain, the axis of FSD in FMS

The women agreed that generalized and genital pain is present in the sexual relationship before, during and/or after coitus, lasting hours or days. She referred to pain when

Table 2 Themes, sub-themes and units of meaning.

Category	Subcategory	Units of meaning
1. Physical impact: don't touch, don't look	1·1 Pain, the axis of FSD in FMS	Pain before, during and after sexual intercourse Medicines which aid sexual activity Menopause, fostering FSD
	1·2. Sexual stiffness	Postcoital stiffness Vulvar and abdominal stiffness Nervous towards sex How to explain it to your partner
	1·3. Body image disorders	Feeling fat Inflammation due to corticosteroids Changes to menstruation
2. Sexuality and identity: fighting against their loss	2·1 Wanting an active sexuality	Ambivalent character Continuing with a normal life Sexuality and life in a relationship Sexuality as part of female identity
	2·2 Overcoming the crisis.	Decrease in desire Decrease in quality and frequency Need for foreplay Difficult to achieve orgasm Limitations, looking for alternatives
3. Impact on the relationship: sexuality as a way of connecting the couple.	3·1 Doing it for the other	Loss of libido Satisfying the other (partner) Guilt/frustration in the relationship
	3·2 Uncomfortable sexuality	Feeling desired/wanted Wanting to and not being able to Lack of information

kissing or touching and during foreplay, sometimes affecting them so much that it can play a part in creating an aversion to sex:

> Sometimes you have to say, 'Stop, stop, …you're hurting me, I can't do it'. Or he holds you and … 'Ow, you're hurting me!' (WFM7)

Desire and libido are severely affected, causing stress and 'short-circuits' in relationships which then have negative consequences for both the individual's and the couple's sexuality. According to the women, the partner cannot comprehend this situation, not accepting a response, which they see as 'disproportionate' to minimal stimuli, thus blocking the relationship:

> I tell him and he says, … but 'I haven't done anything to you, anything, I've barely touched you' (partner). (FG)

Along with pain, stiffness and spasticity, the inflammation implies a severe impairment for the women, both in terms of sexual pleasure and their own image:

> I swell up, I swell up loads,… even days after having sex… (WFM1)

Taking medicine to alleviate these symptoms can affect the couple's sex life. Hypnotics, anxiolytics, antidepressants and muscle relaxants contribute to vaginal dryness and a lack of libido and/or satisfaction. Aware of this, the women build up a wary attitude towards to taking medicines; even if they do not reject them, they complement them by increasing foreplay with their partner:

> You have to take your pills when you're told and also you have to 'warm up'. If you don't take time to do that… it doesn't work. (FG)

For women over 45 years old, the physical symptomology is associated with climacteric. They tend to start having pre-menopausal symptomology before healthy women, thus increasing sexual problems:

> I have also started the menopause. You notice more vaginal dryness, less desire. You're dry, it's painful. And after (coitus) sometimes you say 'Ow! Stop' and then you think, 'Is it because of FM or the menopause?' (WFM6)

Sexual stiffness

Although generalized body stiffness has been widely described as a factor in FMS, the women also notice a postcoital stiffness and that their whole body felt rigid or tense. This stiffness was mainly focused on anatomical areas such as the abdomen, with muscular pain and functional consequences affecting urination:

> And I only experience stiffness in that moment, after sex… It hurts! I'm so stiff that I go to urinate and I can't. I want to but I can't. (WFM5)

This stiffness generally passes after a few hours. However, thinking about it before sexual relations means they cannot relax and enjoy their sexuality, even making it difficult to reach orgasm. This situation also causes psychological tension, as they do not know how to explain it to their partner:

> I had a lot of discomfort doing it (coitus), some pain here (vulva) and I didn't have one (an orgasm). I was very nervous, I couldn't relax, I wasn't enjoying it. How can you always explain that? It's like…it's a bit ridiculous. (FG)

Body image disorders

The women explained how their body has changed with FM; they have experienced weight gain, generalized inflammation/swelling and changes to their skin, which they generally attributed to the medication. Also, they displayed a negative body image, blaming both inflammation and weight gain on the corticosteroids:

> I see myself as really fat, swollen. I swelled up with the medication, all of a sudden. When you go to emergency department, the first thing they inject you with is corticosteroids, then you take pills. (WFM4)

Some women mentioned changes in their menstruation. These mainly related to alterations in the quantity, duration and intensity of menstrual pain, which can even start the week before. All of these changes also affect their sexuality:

> It's changed – I never used to get pain but now I do. I start to have horrible pains a week before, very little quantity, it comes that day and then nothing else. (WFM2)

There are also changes to their body, which they attribute solely to FMS. After sexual activity, small lesions to the skin and/or subcutaneous tissue, small haematomas or cutaneous ecchymosis may be found, even appearing days after the sexual encounter. For the women, buried in incomprehension, these lesions are physical facts, which prove the veracity of their pain and their negative body image. They also use it as an excuse to justify the lack of sexual activity to both themselves and their partners:

> I get bruises with a kiss, with a touch, on my stomach, on my thighs… That makes you feel like it (sexual intercourse) even less. (FG)

Sexuality and identity: fighting against their loss

Although the effects of FMS in terms of female sexual functioning are not well known, the connection between the physical and psycho-emotional effects are key to coping, adapting and maintaining quality of life. In Roy's model, the relational subsystem is an important coping process, which acts to preserve adaptive capacities in one's life with regard to self-esteem and role.

Wanting an active sexuality

The women with FMS in our study showed ambivalence towards sexuality – it is either seen as an important aspect of their life or as something, which is overlooked and not shown any interest. For some women, sexuality gradually gets lost until it becomes irrelevant to their life:

> No, for me it's not important and I think that has to be because of FM,… because if not… I don't care, I don't think about it anymore (sex). (WFM5)

However, for other women, it continues to be a key element in their quality of life. The majority included sexuality in a general coping attitude towards life. After being diagnosed with FMS, it is a question of making an effort to move forward, to lead a life, which is as normal as possible, including on a sexual level:

> For me, yes, obviously, it's like before, just as important. I throw myself into it, because I have to do things, I have to have a life, sex too. (WFM1)

Our participants referred to sex as an individual need, which identifies them as human beings and as women. This feeling of identity underlies the problem and characterizes their sexuality. In the words of women with FMS, sexuality is a way of feeling attractive, desired and visible:

> I think that it's important for women to feel attractive, to her partner or to other men. For me, looking good and feeling desired, that's important. (WFM8)

Overcoming the crisis

FMS can change the dimensions of sexuality. Although physical factors such as pain, stiffness or fatigue alter arousal or sexual pleasure, for the women, it also coincides with a subjective lack of interest. This 'crisis of desire' leads to a decrease in the frequency and quality of sexual activity:

> But now, I never feel like it, I don't even remember, I just don't care (laughs). (WFM5)

Women highlighted foreplay as being helpful to create a more satisfying sexual relationship. Touching, caressing and foreplay help to arouse the woman, but as it can be painful, collaboration and communication with the partner is vital:

> Foreplay is what's complicated because it hurts,... but I need it and he has to understand that. (FG)

FMS makes it difficult – but not impossible – to achieve orgasm. However, the women have learnt to avoid making it a goal, accepting that they will not always have an orgasm, regardless of the effort that they make. This can be a sign for them to be more assertive, to take charge of their sexuality by playing a more active role, she herself has to initiate sexual activity:

> You don't feel like it until you actually start... then you get into it and you feel like it more. Yes, I finish (orgasm), but sometimes you're there for an hour and you don't manage it. (WFM7)

The women recognized that they have to deal with 'crisis' periods related to hypoactive desire where they experience more pain and they feel more depressed and disheartened. During these phases, they want to be left alone and do not want their partners to make sexual advances towards them, trying to seduce them, touch them or look at them. They need their partner to be capable of detecting this and respecting it:

> You're more depressed, demotivated, tired – it's more painful. There are crisis periods when I don't want him to touch me... or look at me. He has to understand that! (WFM1)

Despite this, the women look for alternatives to mitigate their problems. In their opinion, the solution is to adopt more comfortable sexual positions or to change posture until finding the best one. They try to be creative to have sexual relations without pain, when they are not tired, to find other means, other habits or other ways:

> There were positions that I couldn't do and I had to change constantly. (FG)

The women also noted that physical exercise was an activity, which improved both their physical and psychological symptoms, thus having a direct, positive effect on their sex life in terms of arousal, frequency and quality:

> With physical exercise, yes, because you're more active, you feel better (laughs). It helps you to get into the mood more. (WFM8)

Impact on the relationship: sexuality as way of connecting the couple

The adaptive process of interdependence is centred on close relationships between people, in terms of purpose, structure and evolution. Dependent relationships themselves affect desire and the ability to give and receive with others.

Doing it for the other

The partner constitutes one of the basic support pillars for women with FMS. Sexuality in a couple involves two people who experience significant changes associated with the illness. From the woman's point of view, the progressive decrease in arousal or desire can ultimately cause a rejection of sexual relations, focusing their sexuality almost exclusively on fulfilling their partner's needs:

> I do it for my husband. Yes, it's for him because I don't feel like having sex at all. (WFM5)

However, this effort is not recognized, the lack of libido in the woman is accompanied by a lack of understanding from her partner. The partner also senses that the woman agrees to sexual relations just to please him. As such, moral dilemmas and feelings of fear, guilt and frustration emerge putting the relationship in serious danger:

> He (the partner) knows I don't do it because I feel like it,... but to satisfy him, obviously. There are times when he finishes (orgasm) and you ummm,... you don't and he also feels guilty and frustrated. (WFM6)

Uncomfortable sexuality

Sexuality is shared – FMS involves the joint adaptation of the couple to deal with changes on a most intimate level. Women need their partners to be involved, to understand the attitudes towards sexuality and to understand them. The women observed that their husbands still find them attractive and do not attribute physical or body image issues to them; they feel desired but also uncomfortable with them:

> He (husband) thinks I'm fine and he shows me that. He gives me encouragement – you're not fat, you look great! Even so, I can't help but feel embarrassed about my flaws...He doesn't care – it's me. (WFM7)

Although the women have painful symptoms and a negative body image, they view sexuality as the 'glue' holding the relationship together. Sex is a constant worry, as they feel responsible for putting their marital life at risk. Keeping their relationship alive is what makes them endeavour not to lose their sex life:

> Sex isn't everything in a relationship but it does bring you together a lot. Because of what I'm going through, I don't do everything I know how to do, I don't respond as much as is needed. (WFM4)

The women know that FMS is affecting their sex life, but in general they lack information. The participants require such information and alternatives from professionals to improve their sexual relations and ease their feeling of not fulfilling their marital duties:

> The psychologist, she told me, 'One day I'm going to give you a talk – having sexual relations is not only penetration, it's also foreplay…' (FG)

Discussion

The aim of this study was to explore and understand the perceptions and experiences of women with FMS regarding their sexuality. The SAM, derived from Roy's Adaptation Model (Roy 2009), has allowed us to understand FMS as a focal stimulus which causes FSD, interpreting the woman's response as part of the processes related to coping and adaptive behaviours. As in other chronic illnesses (Schulman-Green *et al.* 2016), understanding the factors involved in the woman's adaptation process can give information about barriers and facilitators in the self-management of FSD. FMS affects all stages of female sexuality (Rico-Villademoros *et al.* 2012), having a significant impact on physical and emotional functions and quality of life (Roshan *et al.* 2009). According to our results, women experience on-going pain, inflammation, fatigue and stiffness (Burri *et al.* 2014, Olson *et al.* 2015, Amasyali *et al.* 2016), increasing in periods of crisis (Vincent *et al.* 2015) or due to pharmacological therapies (Bazzichi *et al.* 2012). This symptomatology before, during and after intercourse can explain the nervousness of women, their rejection of contact and sexual intercourse. As in other rheumatic illnesses (Poh *et al.* 2016), FSD interrelates physical, psychological and couple factors (Zielinski 2013). The increase in tender points (Ablin *et al.* 2011), body image disorders or processes such as climacteric (Blümel *et al.* 2012) increase the uncertainty and lack of understanding in the couple (Triviño *et al.* 2016).

The nurse can help the woman with FMS to develop strategies that minimize the impact of pain by planning activities which improve the sexual relationship, such as 'warming up' and incorporating massages or hot baths in foreplay (Ryan *et al.* 2008). Advising women on postures (Rosenbaum 2010), relaxation techniques or exercise programmes (Beltrán-Carrillo *et al.* 2013) can alleviate the physical symptoms. The woman has to strive to improve her diet, exercise and relaxation (Grape *et al.* 2015), collaborate in analgesic or sleeping disorder treatments (Durif-Bruckert *et al.* 2015), can help the adaptation and coping process. This effort should be extended to the partner, by explaining what is happening and engaging him or her in a shared sexuality.

Similar to other osteoarticular pathologies, depression and anxiety (Kayhan *et al.* 2016) are associated with hypoactive sexual desire (Yilmaz *et al.* 2012) and less sexual activity (De Castro *et al.* 2013). Difficulties related to arousal, pleasure or orgasm compromise the sexual well-being of women with FMS (Zielinski 2013). Although the women feel desired, they are dominated by fear and the worry of 'not meeting expectations'. This in turn is related to self-image disorders, as experiencing one's body – the vehicle of the self – is vital to female identity (Lempp *et al.* 2009). Sexuality helps define women as human beings, therefore, trivializing them with regard to their FMS can contribute to their invisibility. If women are determined to not give up, healthcare professionals must help them overcome crises and reorient their goals. For the women, feeling understood and visible can improve their adaptation (Kengen Traska *et al.* 2012), dispelling the fear of their relationship breaking down (Kool *et al.* 2006).

The complex and multifaceted nature of FMS has implications for work, social and family relationships (Yilmaz *et al.* 2012), triggering a coping and adaptation process (Schulman-Green *et al.* 2016). The intimate/personal relationships mode encourages the sharing of experiences with others for a smooth adaptation. When facing a lack of social understanding (Armentor 2015), the family and the partner constitute the basic support for this process (Granero-Molina *et al.* 2016). However, they do not speak about their sexual problems, preserving their privacy and the fear of losing their partner, the lack of credibility and not wanting to burden their family with their concerns may explain their silence. Understanding from friends and the workplace may improve their credibility (Armentor 2015) but, as women our participants said, in terms of sexuality, only other women with FMS can understand them and support them (Juuso *et al.* 2014). Isolated from their daily life environments and facing the breakdown of relationships or stigma (Armentor 2015), they find reciprocity and support in patient associations (Kengen Traska *et al.* 2012). Only with women in their situation do they feel understood, not judged and able to share their experiences without concealing themselves (Granero-Molina *et al.* 2016).

Similar to other chronic illnesses (Basson 2010), the majority of women with FMS care about their sexuality and choose not to give up. Consistent with our findings, an active attitude towards sexuality and life (Grape *et al.* 2015), the involvement of the partner (Bazzichi *et al.* 2013) and empathy and understanding from health professionals (Lempp *et al.* 2009, Eide *et al.* 2011) are all factors, which can improve the coping process. However, the sexual problems of women with FMS are not on the agenda of healthcare professionals (Granero-Molina *et al.* 2016). Our participants did not find company, interest, understanding and support in professionals (Escudero-Carretero *et al.* 2010). Nurses, who understand that it is their responsibility to talk to patients about their sexual concerns, can help women with FMS to adapt (Saunamäki *et al.* 2010). Providing clear information about FSD can reduce anxiety and uncertainty in FMS. Making decisions focused on the person (Masi & Vincent 2015), together with an attitude of listening, can reduce fear, guilt and frustration, improving the adaptation and sexual health of women with FMS.

Limitations

This study helps to understand the sexual experiences of women with FMS, but has several limitations. The results are not generalizable to other scenarios since it was conducted in a single Fibromyalgia Patients Association. The implementation of Catholic morality in Spain makes sexuality a subject that is scarcely addressed in healthcare services. The prejudices of the researchers may have influenced the results, but they contribute to reach a new horizon of understanding. The inclusion of participants of other ethnicities or sexual tendencies in the study, could have cast different results. Future research about FSD in FMS could include partners or healthcare professionals.

Conclusion

This qualitative research highlights the complex nature of female sexuality in relation to FMS, contributing to its conceptualization. The SAM has proved its efficacy in studying the experiences of the women affected. Our findings indicated the presence of FSD in FMS, influenced by physical, psycho-emotional and relational disorders, which compromise coping and adaptation processes. Guilt and fear have an impact on female sexuality, which becomes focused on pleasing the partner who, while desiring the woman, does not understand her. The women told us that despite the limitations caused by FMS, sexuality is important for their identity and quality of life. Although some women give it up, for the majority it constitutes a physical, psycho-emotional and relational need. In their battle to preserve their sexual health, women require support and understanding from their partner, their socio-family environment and from health professionals. Nurses, as part of multidisciplinary teams, can explore and recognize female sexuality taking the individual's specific symptoms and experiences into account, aiding a positive adaptation in the context of FMS. Further training and research is essential to develop tools to assess/evaluate female sexuality, coping and adaptation processes in relation to FMS.

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Author contributions

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- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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