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## **TITLE**

### **SOCIAL SUPPORT TO FEMALE SEXUAL DISFUNCION IN FIBROMYALGIA**

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## **KEYWORDS**

Fibromyalgia, sexual dysfunction, female, phenomenology.

## **ABSTRACT**

The aim of this study is to describe and understand experiences related to social support for women with fibromyalgia who suffer from sexual dysfunction. An interpretive qualitative research methodology based on Gadamer's philosophical hermeneutics was used. Data collection included a focus group and in-depth interviews with 13 women who averaged 44.8 years of age and 14.3 years since being diagnosed with fibromyalgia. Data were analyzed using Fleming's method and two themes were identified: 'searching for understanding in socio-family support' and 'lack of formal support regarding fibromyalgia patient's sexuality'. The partner constitutes the main support for women with fibromyalgia. Although they can find understanding and social support in patient associations, they lack formal support from healthcare professionals. Women demand trusted and expert professionals, like sexologists and nurses, in order to carry out a multidisciplinary approach to tackle sexual dysfunction associated with fibromyalgia.

## **INTRODUCTION**

Fibromyalgia (FM) is a non-articulate rheumatic syndrome characterized by chronic musculoskeletal pain and multiple pain points when pressure is applied to the body. Worldwide, the prevalence of FM is 2.7 % (Queiroz, 2013) and reaches 2.4% in Spain (MHSPE, 2011). It is a syndrome that is difficult to diagnose and mainly affects women, altering their physical and emotional functioning as well as their sexual health (Zielinski, 2013). Studies have associated FM with the following psychiatric comorbidities: major depression, mood, bipolar and panic disorders (Bazzichi et al., 2013), problems with coping, and social stigma (Sin & Madden, 2008; Armentor, 2015). FM has also been related to female sexual dysfunction (FSD) (Kalichman, 2008; Ablin, Gurevitz, Cohen, & Buskila, 2011; Rico-Villademoros et al., 2012; Burri, Greven, Leupin, Spector, & Rahman, 2012), affecting desire, pleasure, pain and intimate relationships (Tristano, 2009). Although the multifactorial character of FSD in FM has been acknowledged (Ablin et al., 2011; Yilmaz, Yilmaz, & Erkin, 2012), research regarding family, work and social support is lacking.

## **BACKGROUND**

FM is a chronic illness with unknown physiopathological mechanisms; related research has mainly focused on its etiology (Häuser, Koss, Üceyler, Klose, & Sommer, 2011), physical problems, treatment and therapy (Lisboa, Sonehara, Oliveira, Andrade, & Azevedo, 2015). While a history of surgical procedures, emotional trauma or sexual abuse is common (Bazzichi et al., 2013), its diagnosis is eminently clinical. Together with musculoskeletal pain, hyperalgesia, allodynia, paresthesia or joint stiffness (MHSPE, 2011), FM is also characterized by generalized chronic pain (Burri, Lachance, & Williams, 2014), sleep disorders (Crooks, 2007; Amasyali et al., 2015), stress (Thiagarajah, Guymer, Leech, & Littlejohn, 2014) and fatigue (Olson, Zimka, & Stein,

2015). The American College of Rheumatology (ACR) established a set of basic diagnostic criteria for FM in 1990. These diagnostic criteria were modified to focus on: widespread pain (number and location of areas in which the patient has had pain over the last week), symptom severity (fatigue, waking up unrefreshed, and cognitive symptoms), symptoms have been present at a similar level for at least 3 months and the patient does not have a disorder that would otherwise explain the pain (Wolfe et al., 2010).

FM compromises women's physical, mental and emotional well-being and can affect their quality of life (Zielinski, 2013; Anyfanti et al., 2015) and sexuality (Tristano 2009; Ablin et al., 2011; Burri et al., 2012; Amasyali et al., 2015). FSD is common in women with FM, being related to neurovegetative symptoms (Blazquez, Ruiz, Aliste, García-Quintana, & Alegre, 2015), pain during sexual intercourse (Kalichman, 2008; Bazzichi et al., 2012), decreased lubrication (Burri et al., 2012) or affected pelvic floor muscles (Lisboa et al., 2015). Together with depression (Orellana, Gratacós, Galisteo, & Larrosa, 2009; Bazzini et al., 2013) and stress (Burri et al., 2012; Thiagarajah et al., 2014), FM is also related to hypoactive sexual desire (Yilmaz et al., 2012) and decreased libido (Ablin et al., 2011), possibly even producing an aversion to sexual relations (De Castro et al., 2013).

Together with the physical symptomology (Bazzichi et al., 2013), the multifactorial character of FSD in FM has highlighted the need to explore subjective experiences. Corporality (Råheim & Håland, 2006), stigma (Armentor, 2015), self-management (Schulman-Green, Jaser, Park, & Whittemore, 2016), coping (Sim & Madden, 2008) and social support (Armentor, 2015; Poh et al., 2016), are all factors that can compromise quality of life for these women and their partners (Tutoglu, Boyaci, Koca, Celen, & Korkmaz, 2014). Several studies have highlighted the importance of the

partner, family (Kengen Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2012), social relationships (Grape, Solbrække Kirkevold, & Mengshoel, 2015), work environment (Juuso, Skär, Olsson, & Söderberg, 2014), and support groups (Arnold et al., 2008) as part of the social support to FM patients. We explored 46 articles regarding FM and FSD worldwide, seven of which were carried out in the authors' country. We did not find any literature specifically focused on social support for women suffering from FSD associated with FM. Consequently, there is a need for more literature to address the effects of social support with regard to sexual dysfunction. Together with treatment or therapy, it is also necessary to further explore understanding in the social support systems for FSD in FM from the point of view of the women themselves. We have employed Callista Roy's model (Roy, 2009) as a theoretical framework for this qualitative research. When faced with a lived experience or focal stimulus, nurses can contribute to improve individuals' and groups' adaptation level with regard to the physiological, self-concept, role function and interdependence modes. FSD in FM is a focal stimulus that affects identity and spousal and social relationships, together with those related to family and work, triggering a coping process in order to find adaptive responses.

### **Aim**

The aim of this study was to explore and understand the experiences and expectations of women with FM regarding social support systems for FSD.

### **METHODS**

#### **Study Design**

A qualitative approach based on Gadamer's hermeneutic phenomenology was employed. The key categories in Gadamer's approach are comprehension, interpretation, fusion of horizons and prejudices. Tradition sets prejudices in the

individual that allow them to understand themselves within their context (Gadamer 2005). Understanding a phenomenon involves not only the present, but also our culture and history (Gadamer 2005, p. 360-377). Interpreting a text 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' horizon, thus expanding the interpretation of the latter. The study took place in the premises of the Local Fibromyalgia Association (LFA). Its 420 members are attended to by a psychologist, a nurse, a social worker and a physiotherapist.

### **Participants**

The participants in this study were women diagnosed with FM. Using a convenience sample, participants who met the following inclusion criteria were selected: to be female, to be over 18 years old, to have been diagnosed with FM at least 1 year before the data collection and to agree to participate in the study. A total of 16 women initially agreed to participate but three dropped out before data collection due to a FM flare, sciatic pain and medical appointment respectively. Of the total number of participants, five women comprised the focus group (FG) while eight women participated in in-depth interviews.

### **Data collection**

Data collection was completed between April and June 2014. A FG and in-depth interviews were performed. The FG started with the question, "What are your experiences related to female sexuality and FM?" After 40 minutes, the final question, "Is there anything else you would like to add on the topic?" was asked. The in-depth interviews allowed for the exploration of emerging themes – themes that are little studied and more inaccessible. All of the interviews were individual, private and lasted an average of 35 minutes. The participants' responses were recorded and transcribed,

together with the field notes. Data collection was stopped after data saturation was reached, recording the information and creating a hermeneutic unit with the aid of the computer program Atlas-ti 7.0.

### **Data analysis**

In line with a Gadamerian-based hermeneutic research method, in the analyses of FGs and interviews, a modified form of the stages developed by Valerie Fleming was used (Fleming, Gaidys, & Robb, 2003). The first step was to decide if the research question was relevant in relation to the methodological assumptions; the researchers decided it was. In the second stage, the researchers reflected upon the topic in order to identify preconceived ideas regarding FM and sexuality in women. Our pre-understanding derived from our research and experiences of therapy and care of women with FM. The third step was to achieve understanding via dialogue with the participants. Conversations between the researcher and the participants aimed to achieve a deep understanding of the phenomenon through a fusion of horizons. New questions arose during this stage, “What needs are related to sexuality for women with FM?” and “What role does desire play?”. The fourth stage aimed to comprehend the phenomenon through dialogue with the text. An open reading of the transcriptions demonstrated that the phenomenon was poorly defined and that female sexuality is often forgotten in FM. The participants’ experiences and the researchers’ horizons were re-examined in light of the complete text, asking new questions, “How do the women channel their demands?” or “What role do the women assign to the partner and the healthcare professionals?” Examining each sentence allowed us to identify units of meaning, sub-themes and themes. In the fifth stage, reliability of the qualitative data was established. In order to increase trustworthiness, triangulation between researchers was performed; three researchers analyzed the data separately, discussing any differences until reaching an

agreement. Interview settings were described so as to improve transferability. In order to guarantee dependability, recordings, data analysis, notes and interview guides have all been kept. To ensure confirmability, the participants verified the results.

### **Ethical considerations**

Ethics approval was obtained from the Research Ethics Committee. Before obtaining consent from the participants, the researchers informed them of the study both verbally and in writing. The anonymity of the women was ensured, together with the possibility of accessing results after the study finished.

## **RESULTS**

The definitive sample was comprised of 13 women with an average age of 44.8 years ( $SD=\pm 9.18$ ; range=22-56) and an average of 14.3 years since being diagnosed with FM. The participants' characteristics are provided in table 1. Two themes emerged from the data related to social support for women with FM and sexual dysfunction, and can be seen together with their subthemes and units of meaning in table 2.

### **1. Searching for understanding in socio-family support.**

According to Callista Roy's model, social and spiritual elements together with those related to role and interdependence with close friends or family constitute methods of adaptation involved in the coping process. The participants stated that women with FM need family and social support, together with understanding from those who surround them, something that they generally find in their partners.

#### **1.1. The partner: the first link of support for FSD in FM.**

The women with FM in our study agreed on the need for support from their partner, whom they considered to be a vital aspect in moving forward with their daily lives. Intimate relations may be affected for women with FM and adapting means sharing with their partner and reaching understanding. In cases of an early diagnosis, the

partner shares in the development of the illness and its repercussions for sexual relations from the beginning, being actively involved in the search for solutions:

*Once I was diagnosed with FM, since we were going out, he has been taking me to have massages and stuff. Because I was in terrible pain - I had contractures and so I had loads of massages...and so on for years and years. (WFM4)*

Living with the illness implies a joint adaptation process for both the women and their partners. The effects of this process are highlighted in aspects of their sex life, where they share intimate and private experiences. On many occasions, it is the men who take the initiative and provide the necessary support for their partners:

*His support is so important. He helps me at home, he takes me everywhere – he takes me places, he picks me up. ... He understood straightaway. (WFM6)*

This initiative and support from the partner also extends to the search for information regarding possible solutions to the sexual problems associated with FM:

*Yes, in fact, it was him who started to look into what it could be, what I could have and we went to hospital. He is my main support. (WFM1)*

The women need their spouses to be involved in their sex lives; to accompany them to informative talks where they learn to understand in more depth what is happening to them, how FM affects sexuality and how to find solutions. However, their ultimate objective is to increase their comprehension of the women and their illness, to understand their behavior and attitudes:

*... it would be good if they explained it to the partners, that when you have a strong chronic pain, you are physically not up to having a sexual relationship and that if you need to rest while having sex, that's quite normal, because physically, your body needs to rest. (WFM8)*

## **1.2. Breakdown of relationships: living with the threat.**

Women with FM experience several changes to their body and relate them to factors such as the menopause or pharmacological treatments used to control symptoms. It is the women themselves who seem to self-impose a negative body image based on gaining weight and feeling bloated or in pain.

*He's fine, he says that it's OK. He knew me before and he knows me now but for me it's not the same because I see myself so differently. (WFM1)*

The patients reported a negative perception of their body image. However, the partners seem to adapt well to FSD associated with FM; they do not reject their wives because of their physical appearance, attitude or evasive sexual behaviors. In fact, they find them to be attractive and sexually desirable, which is described as a source of support by the participants:

*... in his eyes, I'm always beautiful – I'm beautiful to him. It makes me emotional (smiles affectionately) because it's true, because I'm like this (pulls at T-shirt). I walk into the kitchen and say, "Ugh, I'm so fat" and he says, "You're beautiful - you're beautiful and you're really hot!" (laughs). (WFM4)*

Although the women with FM spoke positively of their partners, they are still afraid that they do not understand them – a fear which they live with every day of their lives. They constantly fear that their partners will not fully be able to assimilate what is happening to them. Even if their partners encourage them or try to cheer them up, the women believe that they are trying to help but that they do not truly understand:

*It's like he's waiting for me to be like I was before. How do you explain to someone who is completely healthy that you just can't do it? Just no, just with the slightest touch..., and that's apart from not feeling like it. (FG)*

The fear of the partner's incomprehension results in a lack of desire and the belief that they are not satisfying their partner's sexual needs. Consequently, feelings of

anxiety and fear emerge. They live in constant fear that their partner, faced with an unfulfilling sexual life, will tire of the situation and leave them:

*I think he might get fed up of it. I've spoken to him about it and he told me no, never. He shows his affection towards me... but it's me who puts up the barriers.*

(WFM1)

The problem is that FM creates a new situation, one to which the partner may not adapt or assimilate. In terms of our framework, it is a focal stimulus that requires adaptation, not only from the person affected, but also from those closest to her:

*... that was one of the reasons for breaking up – he didn't manage to take it in, how I am.* (WFM7)

This lack of adaptation in terms of FSD associated with FM causes distancing and a lack of family and spousal support. If the partner is not able to understand the changes in the woman's life and adjust accordingly in everyday life, including sexual relations, it may lead to a breakdown of the relationship:

*So I decided that the best thing for me was to leave him, because someone who doesn't support me, who's not always there for me, isn't worth it.* (WFM7)

### **1. 3. Patient associations as a source of social support for FM.**

Two pillars of the coping process are adapting the group's self-concept, focused on psychosocial and spiritual elements, and adapting roles, focused on the role that the person plays in society. Although the women speak about FM with family members, this does not occur with sexuality. The intimate nature of sexual problems, together with the need for the women to be strong and not overwhelm their close family with their worries, could explain this silence:

*At home I talk about the illness a bit with my daughter, just between ourselves, the changes, ... but no, not about sex.* (WFM3)

The participants in our study recognized the role of their partner as a source of support. Nonetheless, the understanding of sexual disorders associated with FM seemed to be a subject for only the women themselves:

*Yes, he understands me... but I think they understand me better here (at the association). Normally women with FM understand each other better. (WFM7)*

The LFA plays a vital part in providing social support for these women. They feel understood, not judged, and able to share experiences without hiding anything, helping each other to face the illness.

*Since I've been coming to the association, I've come to understand FM. Now, being here with other people and seeing they have the same symptoms as you and everything... it's like you understand the illness better. (WFM2)*

Although the women recognized the active role the partner plays in the search for solutions to FSD in FM, they also said that their partners were reluctant to take part in LFA activities.

*I'm coming to the association because of him. The only thing he needs to do now is come to the association himself – that's something I haven't managed to get him to do yet. (WFM4)*

## **2. Lack of formal support regarding FM patient's sexuality.**

For women with FM, the support they can receive from the health system and professionals is essential. However, in the majority of cases they are met with a lack of understanding and a distant, disinterested attitude. From the participants' testimonies, it can be deduced that healthcare professionals focus on physiological and physical adaption. Social aspects and those related to role and interdependence are ignored, despite being strongly related to FSD.

### **2.1. FM – a stigmatized illness.**

Women with FM need support from healthcare professionals, but our participants feel stigmatized by the system and healthcare workers. They feel they are labeled as mentally-ill patients. Met with this lack of credibility in medical consultations, they are afraid to speak about FM and even more so about the associated sexual problems.

*The rheumatologist, no, he doesn't believe it... So I don't talk to him about FM, not to mention sexuality. (WFM3)*

According to the participants, women with FM do not receive a sense of support from healthcare professionals, who they find to have a lack of interest and belief. Together with evasive behaviors, professionals give responses based on stereotypes, causing feelings of indignation among patients:

*The only thing the traumatologist tells me when I go to see him is, "You have to lose weight". It makes you feel bad, ... you get angry. (WFM5)*

Another response from doctors is the prescription of medicines to combat pain. As such, the women become polymedicated patients, suffering from multiple side effects that do not help them either in carrying out daily activities or with their sexual problems. A clear example is the prescription of opiates:

*I took it, but the muscular weakness was so bad in my legs that I couldn't get up... I told them that I wouldn't take Tramadol® anymore or any other drug. They told me, "Well then, next time you can go to mental health". (WFM7)*

Our participants feel that they are treated as if they were psychiatric patients, being prescribed antidepressants or medicines for mental health. This disbelief propagates the stigma of FM, creating barriers that prevent the tackling of more private problems such as sexuality.

*I left the consultation feeling really down... you feel like they're not listening to you. He told me that he was going to send me to a psychiatrist. There was no sensitivity... so I wasn't exactly going to talk or ask about sex. (WFM8)*

## **2.2 Sexuality trivialized, not on the professional agenda.**

The sexual problems of women with FM seem to be absent from consultations with healthcare professionals – they are simply forgotten. This was a concern for the participants who recognize the fact that they have questions and need information:

*Well even more so when you're younger as you'll be more sexually active. And you get worried because you see your symptoms and you don't know if you're alone, if something's wrong, ugh! (WFM-8)*

Women with FM demand more training and information related to sexuality from healthcare professionals. Factors such as how FM affects sexual relations and how to overcome barriers and cope with symptoms including pain or stiffness need to be explained to women and their partners.

*No, I've never talked to anyone about sex. With the gynecologist, yes, but just the normal stuff... (WFM6)*

Healthcare professionals also need training in how to improve trust and communication with FM patients, how to clarify patients' doubts and how to avoid the "conspiracy of silence". When women diagnosed with FM discuss the physical symptoms (pain, menstrual disorders or menopause) of their illness with healthcare professionals, vague questions related to a lack of sexual desire are also asked.

However, participants have not found the responses to be satisfactory, instead being met with evasive answers that neither put them at ease nor help them:

*They should tell you, "If you notice some discomfort while having sex, it's normal, don't worry". It's like you have to find things out for yourself. (WFM8)*

The inadequacy of these consultations may also apply to psychologists or physiotherapists, as they do not seem to provide the support the women need either.

*With my psychologist yes, that I had a lower libido, that I was disinterested. She just listened, she told me to be patient, ... but no recommendations. (WFM1)*

The lack of trust and information, together with the intimate nature of FSD, may lead women diagnosed with FM to consult professionals with whom they had a closer relationship. Although the study's participants mainly identify their GP as the professional they have known for years and, therefore, the one they would go to for advice, they also point at nurses as a source of help and support. In their opinion, problems related to female sexuality in general and with FM in particular could be addressed in nurse consultations:

*Yes, but it would also be a good idea for our health center to have a nurse dedicated to that, a nurse who was an expert in sexuality. (FG)*

In addition, they also look towards sexology professionals. The LFA itself has organized informative sessions with a sexologist, an experience that our participants regarded as positive:

*I went to a sexologist and I asked lots of questions. She answered me and helped me a lot, you know? Because ummm..., they explain things to you, tactics you couldn't even imagine and they're good to know. (FG)*

## **DISCUSSION**

The aim of our study was to explore, describe and understand the experiences of women with FM in relation to social support for FSD associated with the illness. From the analysis of our results, two main themes emerged: `searching for understanding in

socio-family support' and 'sexuality trivialized, not on the professional agenda'. Callista Roy's adaptation model (Roy, 2009) has allowed us to study FSD as a contextual stimulus that generates a coping process with the need for spousal, social and professional support. FSD is common in women with FM (Tristano, 2009; Rico-Villademoros et al., 2012), having a negative effect on all stages of sexual functioning (Ablin et al., 2011). Pain, fatigue or the difficulty to maintain certain positions leads to significant physical limitations (Burri et al., 2014). However, together with distress and anxiety, a dissatisfying or unfulfilling relationship with their partner is the main predictor of FSD in FM. Similar to other rheumatism, partners detect changes in their sexual relationship (Poh et al., 2016) and a decline in their sex life. Their quality of life is also affected (Tutoglu et al., 2014; Anyfanti et al., 2015) and they soon become involved in the search for solutions, forming the main source of support for FSD in FM. They may even adopt an overprotective role towards their partner, with debatable results for their sexual relationship (Kool et al., 2006).

Well-being, body image and sexuality are all interlinked. Women with FM want to escape their body, which they view as shameful and/or as having betrayed them (Råheim& Håland, 2006). This situation, in turn, affects partner relations and alters the couple's relationship in general (Crooks, 2007). FM has negative effects on the patient's physical, mental and social health, affecting their quality of life and compromising their identity. Disorders related to pain (Kalichman, 2008), tiredness (Crooks, 2007), fatigue or the need to rest (Olson et al., 2015; Amasyali et al., 2015) affect motivation and sexual function. They require a constant effort to adapt, something for which support from the partner is essential (Schulman-Green et al., 2016). During the coping process, women with FM encounter problems associated with emotional (Bazzichi et al., 2013) and depressive (Orellana et al., 2009; Yilmaz, et al., 2012) disorders, together with

those related to desire, arousal and sexual satisfaction. Issues such as avoidance behaviors (Bazzichi et al., 2013), lack of sexual relations (De Castro et al., 2013) and fear of breaking up with their partner (Poh et al., 2016) emerge. Women with FM are not receptive to their partners who they believe do not understand them (Sim & Madden, 2008; Kengen Traska et al., 2012).

As seen with other rheumatisms (Poh et al, 2016), social support is essential in FSD associated with FM. Faced with a lack of social understanding (Armentor, 2015), the family becomes a source of support for the patient's health and well-being (Kengen Traska et al., 2012). Understanding from friends and in the work environment (Juuso et al., 2014; Schulman-Green et al., 2016) may also contribute to credibility and help to reduce stigma (Armentor, 2015). However, in the patient's opinion, only someone with their problem can understand them, valuing the support of other women with FM (Juuso et al., 2014). When the illness removes them from the spaces that comprise their daily lives (Crooks, 2007) and they are faced with the loss of sexual relations (Armentor, 2015), women with FM find in patient organizations the reciprocity and social support they need to cope with and self-manage sexual problems (Kengen Traska et al., 2012; Schulman-Green et al., 2016).

A lack of credibility, legitimacy and visibility (Sim & Madden, 2008; Juuso et al., 2014) are all factors contributing to the lack of formal support for FSD in FM. Healthcare professionals trivialize sexual problems, attributing them to changes in physiological (Blümel et al, 2012) or mental health (Yilmaz, et al., 2012). Focused on physical adaptation, professionals appear distant and disinterested, limiting their support to pharmacological treatments with negative effects for female sexual normofunctioning (Bazzichi et al., 2012). FSD seems to be ignored in consultations; professionals forget this key need for quality of life in cases of FM (Anyfanti et al.,

2015). According to our results, in their constant fight for adaptation everyday life (Uva, Solbrække, Kirkevold, & Mengshoel, 2015), women with FM want to be listened to (Sim & Madden, 2008), to be taken seriously and to participate in decision-making (Juuso et al., 2014). When faced with asymmetric relations, they require understanding, information and support.

An evaluation of FSD needs to be incorporated into the routine care for women with pain, chronic fatigue, surgical treatment or fibromyalgia (Lin, 2014; Burri et al., 2014) and considered in conjunction with aspects related to physical, psychological and social support (Tristano, 2009; Orellana et al., 2009; Blazquez et al., 2015). Women require information and guidance related to sexual issues, indicating the family doctor, a sexologist or nurses as appropriate figures. Nurses trained in sexology could provide formal support for FSD in FM, giving advice on positions, the use of physical means or the exploration of alternative methods of sexual expression (Tristano, 2009). A comprehensive and individualized assessment of FSD in FM could help to manage symptoms and improve the coping process.

### **Limitations**

Our results could have varied depending on the sample chosen. Future research on social support for FSD in women with FM could include partners, homosexuals or healthcare professionals.

### **CONCLUSION**

Sexually-active women experience negative changes in their sexual life after being diagnosed with FM. A decrease in the frequency and the quality of sexual relations is a problem that affects both women's and their partners' quality of life. FSD seems to be hidden in the framework of a stigmatized illness. Together with treatment or therapy, women need socio-family support. This is mainly found in their partners and

organizations for patients with FM. However, they feel that they are misunderstood, unable to respond to the sexual demands of their partner and fear being abandoned. The lack of formal support is another recurring issue in their lives. Healthcare professionals trivialize FSD in FM, which is immersed in a conspiracy of silence. Although the women and their partners try to adapt, they require information and support that they cannot find. Women with FM look towards the family doctor, nurses or sexologists as healthcare professionals who would be an appropriate figure to improve guidance and support in the management of sexual problems.

### **Relevance to clinical practice**

FM has negative consequences for a woman's sexual life; FSD is a focal stimulus that can affect family, partner, work and social relationships. Women with FM need support to cope with sexual problems, which they mainly find in their partner and patient organizations. Although health professionals are involved in the physiological adaptation, patients complain about invisibility and a lack of information. Nurses could improve patients' coping process through supporting their physiological adaptation, strengthening their role, self-concept and interdependence modes, and encouraging self-management of FSD in FM.

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**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

**Table 2.** Themes, subthemes and units of meaning.

Theme	Subtheme	Units of meaning
1. Searching for understanding in socio-family support.	1.1 The partner: the first link of support for FSD in FM	- Involved from diagnosis
		- A reliable partner
		- Need for information
		- Demand for shared training/education
	1.2 Breakdown of relationships: living with the threat	- Issues related to body image
		- Compliments falling on deaf ears
		- Not being good enough
		- Living with the fear of breaking up
	1.3. Patient associations as a source of social support for FM	- From a lack of understanding to separation
		- Only someone with FM can understand another person with FM
- The association as a pillar of understanding		
- The woman as the cornerstone of the family		
2. Lack of formal support regarding FM patient's sexuality.	2.1 FM, a stigmatized illness	- Lack of credibility
		- Moral legitimacy questioned
		- Credibility questioned
	2.2 Sexuality trivialized, not on the professional agenda	- Professionals ignore sexuality
		- Patients do not ask questions either
		- Need for information
		- Consultation related to physical problems
		- A question of trust
		- Demand for healthcare professionals trained in sexology
		- Nurses as a possible figure to look after sexual health