

The Impact of a Peer Social Support Network From the Perspective of Women With Fibromyalgia. A Qualitative Study

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Abstract

Background: Fibromyalgia is a chronic and complex disease whose management by patients requires a high level of commitment. Patient empowerment therefore represents an important milestone in chronic disease treatment and control. We explored the impact of a peer social support network from the perspective of women with fibromyalgia.

Methods: A generic qualitative design was proposed for the study, for which women who had been diagnosed with fibromyalgia were purposefully selected. Six semi-structured interviews were conducted and the collected data were thematically analysed.

Results: Three key themes emerged regarding the peer social support network: (1) empowerment (it facilitated acceptance of the diagnosis and was a source of information); (2) effects on wellbeing and quality of life (it attenuated stigma, improved physical wellbeing, provided emotional support and was a socialization medium); and (3) valuable aspects (it transmitted feelings of being understood and listened to and it increased personal feelings of satisfaction).

Conclusions: A peer social support network for women with fibromyalgia exerts positive effects on their physical, mental, and social wellbeing and empowers them to better manage their disease. Healthcare for women with fibromyalgia should include strategies that connect them through peer social support networks.

Background

Fibromyalgia (FM) is a chronic and complex disease of unknown aetiology, characterized by generalized musculoskeletal pain, whose onset and specific location is often unclear [1]. FM prevalence worldwide is 2.7%, ranging from 0.4% to 9.3% depending on the country [2]; in Spain, prevalence is 2.73% in people aged over 20 years, with a clear predominance in women (4.2% vs 0.2% of men), and with maximum incidence among individuals aged 40-49 years (4.9%) [3].

People with FM have ongoing hypersensitivity to pain, which tends to occur mainly in muscle structures, although other symptoms and clinical manifestations frequently have symptoms of depression (30%), while psychological stress, anxiety, dysthymia, and simple phobia are even more frequent [5]. Emotional distress is typically accompanied by poor expectations of disease control. Other clinical manifestations of FM include altered sleep patterns, irritable bowel syndrome, fatigue, morning stiffness, memory problems, restless legs syndrome, urethritis, a subjective feeling of oedema, and cognitive impairment [6,7]. The multiple symptomatology of FM is characterized by overlaps with other diagnoses, although the initial diagnosis usually focuses on inflammatory joint diseases. The complexity associated with FM led the World Health Organization in 2010, to establish clinical classification criteria that primarily take into account the presence of generalized pain, the absence of any other disease explaining the pain, and the severity of the symptoms [8]. Giesecke's [9] classification, currently the most widely used for FM diagnosis, is based on variables corresponding to the three domains of mood, cognitive aspects, and biological aspects.

Since the main problem with FM is heterogeneity, treatment needs to be multidisciplinary and personalized [7]. Pharmacological treatment combined with psychological therapy has shown clear benefits: the pharmacological treatment tackles the symptoms of pain [10], while the psychological treatment helps manage emotional aspects, anxiety, and depression. Psychological treatments include education, cognitive-behavioural therapy, and relaxation techniques [11]. Physical exercise involving aerobic, strength, and flexibility activities has been described as an essential component of treatment, as it mitigates pain, improves mental health, and lessens the overall impact of FM on people's lives [12].

FM-focused health programmes combining physiotherapy and cognitive-behavioural therapy have been reported to show positive results in quality of life (QoL) perceptions of people with FM [13,14].

Management of chronic diseases like FM requires a high level of commitment from patients, so their empowerment represents an important milestone in treatment [15]. According to Nijs et al. [16], people with diffuse chronic musculoskeletal pain and poor control over FM show less tolerance and have more catastrophic thinking processes and weaker coping strategies. Several studies have shown that it is easier for people to take control of chronic diseases if they are involved in groups that share knowledge and resources [17,18]. People participating in social support networks (SSNs) achieve control in less time and experience fewer complications [17,19], and this clearly can enhance QoL perceptions [17,20].

A perception of social support is the thinking that support is available if and when needed, and is especially useful for people living with the same conditions [21]. Social support can be classified as follows: (a) information support (provision of information, guidance, advice, and recommendations); (b) tangible support (direct physical interaction); and (c) emotional support [22]. Studies have demonstrated gender-based variability in the provision and reception of social support; women tend to seek social support more than men, suggesting that women are more open and receptive to the positive benefits associated with social support [23].

SSNs are conceptualized as relationships between network participants, structure, and functionality. The relationship aspect refers to the links established between SSN participants [24]. One type of SSN is the peer support network, based on the notion that similarity between peers generates connection [25] and facilitates the sharing of information, experiences, and emotions [18]. Through SSNs, people with chronic illnesses feel encouraged to improve their coping strategies and their adherence to treatment [20,26]. With FM, for instance, a peer SSN can facilitate social interaction and motivate patient self-

care by augmenting knowledge of the disease [17]. While SSNs are considered key to dealing with chronic diseases [19], most existing studies refer to Anglo-Saxon settings and there is little literature on their impact on people in Spain.

We hypothesized that a peer SSN could have a beneficial effect on patients with FM. The aim of this study, therefore, was to explore the role played by peer support for people with FM provided through an

SSN created from women who had previously participated in psychoeducational groups. Exploring the impact of a peer SSN from the perspective of women with FM should enhance our understanding of the potential of SSNs so that we can reorient resources and adapt the healthcare offered to people with FM.

Materials And Methods

2.1 Design

A generic qualitative design [27] based on a constructivist naturalistic approach was adopted, aimed at analysing interpretations arising from experiences of participating in a peer SSN, created from primary care-based psychoeducational groups of women with FM. A qualitative methodology offers the possibility of understanding the complexity of a phenomenon from the differing points of view of informants [28], while a generic qualitative design is useful for research that – as opposed to phenomenology, fundamental theory, and ethnography – does not fall within the confines of a single established methodology [27]. The researcher using this approach can modify and adapt the study structure so that the qualitative design is tailored to the particular needs of the research.

2.2 Study area

The study was carried out in a Spanish primary health care setting which provides care to 32,600 people. This setting corresponds to the Girona Health Region [29], where FM prevalence is 1,5%. Primary care areas, the backbone of the universal Spanish health system, are composed of one or more primary care centres that coordinate health, socio-health, and hospital services, and provide community care to people with both acute and chronic health conditions. In relation to FM, in 2017, an interdisciplinary Expert FM Unit was established for the Girona Health Region to provide care to people with FM, chronic fatigue, and chemical sensitivity, in both community and hospital settings. Interventions include psychoeducational groups for people with FM led by primary care nurses specializing in FM.

2.3 Patient recruitment and data collection

The study, undertaken in February 2021, was based on six semi-structured interviews, conducted with individuals with confirmed FM diagnoses, selected using an intentional sampling procedure [30]. Patients were recruited through primary care teams. Inclusion criteria were individuals aged 18 and older, who spoke Spanish or Catalan, who had been diagnosed with FM, and who were participants in a peer SSN based on previous participation in psychoeducational groups. Sociodemographic data for the patients were collected to characterize the sample.

The semi-structured, flexible, and dynamic in-depth interviews [31] aimed to capture subjective perceptions of the experience of being part of an SSN for women with FM. After a review of the literature regarding the impact of SSNs on people diagnosed with FM, a specific script was designed, and several meetings were held by the research team to develop the final set of five questions for the semi-structured guidelines (Table 1). These guidelines focused on exploring the role played by the peer SSN for women with FM, determining how the SSN affected the women's QoL, and highlighting the most valuable social support aspects from the perspective of the participants.

Interviews lasting 45-60 minutes were conducted, according to Kvale's [31] recommendations, in a comfortable, stimulus-free setting in primary care centres, and were audio-recorded for subsequent transcription. Interviewers used a fieldwork diary to complete information, noting perceptions, sensations, and nonverbal language input, among other issues. Informed consent for study participation was taken prior to commencement of the interviews.

Table 1. Interviewing guide for people with fibromyalgia (SSN, social support network)

1. What has it meant to participate in a peer SSN?
2. What changes has participation in a peer SSN brought about?
3. What is the most valuable aspect of participating in a peer SSN?
4. How could it be explained what it represents to participate in a peer SSN?
5. Why would it be recommended people with FM to participate in a peer SSN?

2.4 Data analysis

Two members of the research team independently analysed the transcribed interviews so as to establish initially agreed categories of analysis (themes), following the six phases of thematic analysis considered by Broun and Clarke [32]. The line-by-line holistic thematic analysis aimed to organize information descriptively. Open source codes were grouped by similarity criteria so as to configure the analysis categories. A subsequent phase involved theorizing about the significance of both the themes and response patterns, and interpreting how those signifiers aligned in the context of the research phenomenon to be explained [27].

The Standards for Reporting Qualitative Research (SRQR) [33] checklist was used to ensure the rigour of the research. Among other items, the researchers applied the reflexivity criterion, involving reflection on the project approach, methods, and theoretical positioning, and recording, in the fieldwork diary, the personal motivations, assumptions, theoretical positions, and personal histories leading them to pose specific research questions, as well as their analytical perspectives on exploring the data [27].

2.5 Ethical considerations

The study was approved by the Ethics Committee of the Jordi Gol Primary Care Research Institute (IDIAP Jordi Gol) and respected the ethical principles of the most recent version of the Helsinki Declaration and good clinical practice guidelines as established in current Spanish legislation (Law 14/2007 on Biomedical Research). All interviewees received oral and written information on the study, were guaranteed the confidentiality of their data, voluntarily agreed to participate, and provided their written informed consent.

Results

Six semi-structured interviews were conducted, exclusively with women. Participants all had an FM diagnosis and were participants in a peer SSN for people with FM. Mean (SD) age was 57 (15.5) years (range 42-73 years). One woman was retired, two were not working, and three were working. Five women were married or living with a partner, and one was divorced. All six had children, living with their mother

in three cases. No major family burdens were reported, except that one woman cared for her grandchildren.

The analysis highlighted three themes related to the role played by the peer SSN for people with FM: empowerment, effects on wellbeing and QoL, and valuable aspects of the SSN. Table 2 describes the topics and categories that emerged after analysis of the interviews.

Table 2. Topics and categories identified in the thematic analysis (SSN, social support network).

	TOPIC 1	TOPIC 2	TOPIC 3
	Empowerment	Effects on wellbeing and quality of life	Valuable aspects of the SSN
CATEGORIES	-The SSN facilitates acceptance of the FM diagnosis	-The SSN attenuates FM stigma	-The SSN transmits a feeling of being understood
	-The SSN is a source of information for better FM management	-The SSN improves physical wellbeing by helping with symptom control	-The SSN transmits a feeling of being listened to
		-The SSN provides emotional support and bolsters self-esteem	-The SSN increases personal feelings of satisfaction
		-The SSN is a socialization medium	

Empowerment

The SSN facilitates acceptance of the FM diagnosis

Participants explained that the SSN helped them better understand their disease and that this was a key factor in accepting it. All the women had consulted numerous health professionals, and it had taken approximately six years to obtain a clear diagnosis.

"I went to several doctors, social security and others [private], to see what was going on and what I was going through. Because I didn't know." [P1_56 years old]

Symptoms were often attributed, prior to diagnosis, to psychological distress.

"I must have had fibromyalgia for a long time. They thought it was nerves." [P2_56 years old]

Sharing what was happening to them and what they felt meant that the women better understood the characteristics of FM, which made them feel less guilty on understanding that the FM was not the fruit of their imagination or their past life.

"What have I gained from the group? Well, understanding about this disease. What needs to be understood. That you're not to blame." [P1_56 years old]

Understanding the different clinical manifestations of FM helped the women better understand their disease.

"I got a lot out of it [the group], especially the fact that I now understand that not all FMs are the same. There are people who have FM who can still work, who lead a half-normal life, there are others who do not, that the FM poses obstacles [...]. Sometimes you know, you can't cope, you're sinking, but then you talk to them [the group] and you know it will pass, that this is how the disease is, and that better times are coming, and that helps you." [P3_64 years old]

Participants placed great value on being able to attribute their ailments to a specific disorder, so having a definitive diagnosis helped them to better manage their FM.

"Because the tunnel is dark, dark. When you have a diagnosis you begin to see that there is someone else behind all this, that there is a chance that it can improve." [P1_56 years old]

The SSN helped the women acquire a better awareness of FM. The women explained that, while a better awareness of the disease was very useful, they often lacked the courage to face up to it, which was why they were encouraged by the SSN.

"I hadn't told anyone because I thought it was something that I had to bear alone. But the group helped me understand the disease and what I had to say [to others], but as if it were a normal thing." [P4_73 years old]

The SSN is a source of information for better FM management

Regarding the sharing of doubts, experiences, information, and knowledge, the SSN was described as a valuable resource that increased the women's knowledge of FM, resolved their doubts, helped them tackle problems, and enabled decision-making and changes in their management of FM.

"Because they contribute things you might not have even thought about, and they make you think and see things differently" [P6_42 years old]

Figure 1 illustrates the information obtained through the SSN that was considered especially useful by the participants.

The women explained that their FM diagnosis was not always accompanied by the information needed to deal with the disease; rather, much of this information was acquired from peers in the SSN. Participants commented that health professionals needed to provide more detailed information on FM.

"When they diagnose you, they tell you what you have, but don't tell you what to do. They tell you to take painkillers when you are in pain, but they don't tell you anything else." [P4_73 years old]

However, participants did comment that it was primary care nurses who spent more time providing them with information.

"The primary care nurses never allot you just five minutes, nor do they change the subject."

[P1_56 years old]

Better knowledge about FM and about lifestyles adopted by SSN peers encouraged women to incorporate beneficial habits in their own routines and to improve how they managed the disease.

"I've learned the gym exercises we need to do ... I've also made changes in my eating habits. I'm adding things I didn't know before." [P2_56 years old]

However, one perceived barrier to acquiring knowledge was when people with negative perceptions participated in the SSN.

"What happens, though, is that sometimes we meet and someone is very negative, that makes things go wrong." [P1_56 years old]

Effects on wellbeing and QoL

The SSN attenuates FM stigma

Stigma in relation to FM was identified as a crucial factor with direct negative repercussions for people with this disease.

"For whoever has one of these diseases it's a stigma. I don't want it to be known. I have it, the group knows, but that's it. I wouldn't like it to come out." [P1_56 years old]

Participants explained that stigma was evident in the family and in friends, but especially in the work environment.

"For example, I didn't tell my friends and family until a year and a half had gone by, ... because it was a time when it was said that FM is for people who have a bit of depression that they don't know how to handle. I didn't mention it, not even to my children." [P4_73 years old]

The women's perceptions were that they were often labelled by co-workers as people with little desire to work.

"[They say] You make up stories, you're lazy, you're loafing, and that you don't want to work, to do anything. And you feel very useless. And sometimes that's what hurts you the most." [P2_56 years old]

FM was described as having a particular impact on strong people, who often cover up their symptoms over several years. The women considered the peer SSN to be a space where they felt liberated, as there they felt they could openly and uninhibitedly talk about the impact FM had on their lives, over and above the symptoms.

"It's like emptying the backpack you're carrying." [P2_56 years old]

SSN participation therefore reduced both the stigma of FM and the women's perceptions of guilt. The SSN afforded them a space where they no longer felt they had to suffer in silence but could give expression to their pain.

"I didn't say anything because I thought it was something I had to go through and I shouldn't say

... I didn't want to complain! This [group] helped me to say it, but as something normal." [P4_73 years old]

The women felt that the SSN enhanced their capacity to cope with their disease, to share their thoughts and feelings, and to deal with the stigma they perceived in their surroundings.

"The group has helped me to be more honest with myself. Not to hide the disease and not to think what others might say... it has helped me to be more myself, to trust more." [P4_73 years old]

3.2.2 The SSN improves physical wellbeing by helping with symptom control

The participants unanimously agreed that pain was a common feature of their FM.

"Maybe nothing hurts, but there's no energy to do anything. And there are times when everything hurts." [P1_56 years old]

The women reported experiencing constant pain, which usually increased at night. Being able to share their perceptions of pain with peers in the SSN helped them control the pain; in other words, the SSN acted as a protective factor.

"It hurts just the same, but your head is disconnected [from the pain]. And that moment of disconnection is very good for you." [P1_56 years old]

"We talk a lot about the pain ... and then we send each other motivational words ... this encourages you and makes the pain less." [P5_49 years old]

Similarly, in relation to mood disorders, participants reported that the SSN helped them control and regulate their anxiety. Broadly speaking, the SSN was a key source of emotional support that greatly helped with mood management.

"Uf, you know that just speaking here, I feel better!" [P2_56 years old]

"When someone is very down ... like, today I'm feeling really depressed ...well, we encourage each other, you know." [P5_49 years old]

The SSN provides emotional support and bolsters self-esteem

According to the participants, the peer SSN was a source especially of moral support, understood as having a purely emotional or psychological value.

"It helps me a lot ... emotionally, to be able to get support from people you know understand you." [P5_49 years old]

All the women recognized the importance of this support, especially those who had less family support.

"It's very obvious that, for different reasons, some people do not have the support of their family and so they look for it in the group... they need this support." [P3_64 years old]

The women commented that the stories of their SSN peers helped them identify better with others with the same disease, connected them with their own emotions, and helped them to cope better.

"The group helped me, because of my age, I saw younger people ... I was managing well, but seeing young people with a lot of pain made me think." [P4_73 years old]

People with more FM-related health problems tended to have more difficulty in opening up to their SSN peers. In this case, the support was provided more individually than at the group level.

"Some people are very down ...these we support privately." [P1_56 years old]

The WhatsApp group was considered to be a very powerful facilitator of exchanges of support among the SSN peers.

"In the WhatsApp group we ask: So, how are you today? or, how are you not today?" [P1_56 years old]

As for general emotional wellbeing, the participants expressed their satisfaction with the peer SSN as a resource that fostered self-esteem and positive attitudes. A more positive perspective on the disease proved to have beneficial effects on the women's health, improved their confidence, and helped them foster healthy relationships and lifestyles.

"There were days when I couldn't even get dressed, it was like there was a rage inside me ... It was typical to see people exercising there [in the group] ... and with their help I was more positive, seeing that there were things that I hadn't even thought I could do." [P6_42 years old]

All the participants reported that being able to help other people in the SSN, and especially those most affected by FM, had a positive impact on their own wellbeing, as they felt recognized, important, and necessary.

"For example, when I explained relaxation techniques to them and saw that they wanted to know more ... I saw that what I was telling them was good for them." [P2_56 years old]

The SSN is a socialization medium

In relation to socializing, the women explained that the SSN increased their socialization opportunities. Participants indicated that since the SSN was created, they participated in more activities and went out more, and, as a result, they were more motivated to take care of themselves and to care for their appearance.

"There came a time when we began to meet up even after the group had ended." [P4_73 years old]

"It was great sharing the experiences of the week with other people ... How did the week go? How was your week? It was that, sharing your illness with other people ... In that sense, for me it was very positive, very, very much so." [P3_64 years old]

The SSN made the women feel more accompanied. They explained that being part of the SSN and sharing with peers diminished feelings of loneliness, which, in turn, had a direct and positive impact on their wellbeing and QoL.

"Before finding the group.... it happens that you feel very, very alone." [P2_56 years old]

"Emotionally I don't feel so alone [...] The fact of sharing and having people who understand me makes me feel less alone." [P5_49 years old]

Participants also reported that the peer SSN had a positive impact on their relationships with other people in their lives, whether family, friends, co-workers, or other people in the community. The SSN was considered to facilitate socialization, both with their SSN peers and with other people outside the SSN.

"That helped me, to open up more... to the other people around me." [P4_73 years old]

Valuable aspects of the SSN

The SSN transmits a feeling of being understood

Participants reported that they felt a high degree of frustration, given that society largely does not understand what people with FM go through, and they related this to a feeling of being misunderstood and so not having their needs met. The SSN, they noted, helped them alleviate their feelings of frustration.

"The group helped me accept that there were things I couldn't do, it helped me a little, no, a lot

... because I've always been very active and was always doing lots of things. And feeling limited or that there were days I couldn't even get up, that was tough ... it's like, you know, this can't be happening to me." [P5_49 years old]

The SSN facilitated the women's identification with a peer group; the group as a source of empathy meant that the women felt emotionally understood by their peers. This empathy was described

"Finding a group to share what I'm going through helped me a lot ... Before joining it, I found that many people do not understand FM [...], but here you find people that explain things and tell you things ... and it makes you feel really understood. You can share your pain or they share their pain; you understand them and they understand you [...]. You find that there are people who feel the same as you." [P2_56 years old]

The women explained that, in general, sharing needs, desires, perceptions, and goals with other people in the SSN increased their sense of identity and belonging to the SSN.

"I feel like I belong to a likeminded group of people." [P2_56 years old]

The SSN transmits a feeling of being listened to

Participants reported that, in their family and social settings, they felt an absence of active listening, understood as an ability of others to know how to listen and understand. The women therefore appreciated their SSN peers for showing interest in them, making time for them, and actively listening to what they were saying.

"We do a lot of psychology, which ...well, maybe I need it more than the others, or maybe not ... but you see people in great need, they are listened to and they feel understood." [P6_42 years old]

The SSN increases personal feelings of satisfaction

An enhanced feeling of personal satisfaction was reported by the women as one of the most valued aspects of the peer SSN. They explained that, since becoming part of the SSN, they generally felt better about themselves and felt more encouraged to achieve goals in relation to their disease.

"The talks we had (with a lot of positive emotions), the laughter ... because it wasn't just talk about FM, it was many things ... the truth is we had a great time." [P3_64 years old]

"Well ... to say that it's very positive, at least for me, who's never been in any group ... It's very positive I would 100% recommend we continue together, it's great!" [P6_42 years old]

Discussion

In the context of a global approach to FM, this study explored the impact of a peer SSN on women with FM who had previously participated in primary care nurse-led psychoeducational groups. The main themes that emerged from the analysis were empowerment, effects on wellbeing and QoL, and valuable aspects of the SSN.

In relation to the empowerment of women with FM, the fact of accepting the diagnosis was considered crucial, as it highlighted the difficulty experienced by the women in obtaining a definitive diagnosis; according to Basu and Bayliss [34,35], diagnosis is complicated by the fact that FM, often misunderstood, has symptoms common to some rheumatic diseases. According to Undeland [36], obtaining a diagnosis marks a watershed in the lives of people with chronic illnesses, including FM. Borg [37] notes that there is a lack of evidence about how important becoming aware of FM is for patients. The women in our study acknowledged that the peer SSN helped them better understand their diagnosis, and also heightened their awareness of FM – both fundamental to acceptance of FM.

The women perceived the peer SSN to be an important source of information about FM. According to García-Ríos et al. [15] and Nijs et al. [16], having information and being knowledgeable about FM is crucial to disease management. Perceived as a barrier to the acquisition of FM knowledge through the SSN was the participation of people with negative perceptions regarding the disease. Three key aspects

of the SSN were identified as especially useful. First, participants referred to relaxation techniques and tips for better sleep, corroborating the literature attesting to altered sleep patterns as a main symptom of FM [1,15]. Second, participants noted the importance of physical exercise, coinciding with evidence reported by Segura-Jiménez [2] and García-Ríos [15] that physical exercise improves the pain, fatigue, and mental health problems associated with FM. Finally, diet was commented as being important, despite the lack of related evidence. People with FM often make dietary changes in an attempt to control symptoms, with certain dietary supplements reported to improve pain symptoms [38].

The peer SSN was also reported by interviewees to be a source of information that enabled better disease management. Bernandini [19] has reported that people with chronic diseases participating in SSNs achieved more rapid control of their symptoms and had a lower incidence of complications. Our findings would suggest that people with FM do not acquire this information, for instance, felt they should have received more complete information from their doctors, although knowledge received through primary care centre nurses was positively appraised. Armentor [39] reported that patients with FM often faced a lack of understanding from doctors, with Homma [40] attributing this to doctors considering the problem to be psychological. We observed that most of the women started off with high expectations of the healthcare they were to receive, yet, as Chen [41] points out, people with chronic illnesses need to develop realistic expectations regarding healthcare.

In relation to wellbeing and QoL, the women referred to stigma about FM as an important factor with negative repercussions. According to Schmitt [42], stigmatization, which particularly affects the work environment, has a negative effect on wellbeing. Participants, in indicating that FM was poorly understood and so stigmatized by society, corroborated the findings of Kool [43]. The peer SSN, however, was perceived by the women with FM as a protector against stigma.

Another important aspect of wellbeing and QoL was overall health. The women found that participation in the peer SSN had positive effects on their physical, mental, and social wellbeing, reflecting a holistic view in line with the World Health Organization concept of health [44]. Research confirms the positive

effects of SSNs on those three dimensions of health, e.g., Freitas and Annemas [45,46] on physical and mental health, and Prins [47] on social wellbeing.

In relation to physical wellbeing, the women agreed that pain was a common feature of living with FM, corroborating Mas et al. [48]. As for mental wellbeing, the women noted that the SSN fostered self-esteem and positive attitudes, both of which facilitated management of emotions and mood; this corroborates several studies describing the same outcomes [49,50]. Mental wellbeing is especially important for patients with FM, as Shuster [50] identified higher levels of depression and anxiety in these patients. Finally, in terms of social wellbeing, participating in the SSN enhanced the women's social relationships; this was especially relevant, as people with FM often experience changes in their life that leave them more socially isolated [51], which consequently increases their perceptions of pain [8,47,52]. The women in our study indicated that the SSN was a protective factor for pain by increasing opportunities for social interaction, recognized as a factor that raises the pain threshold.

Finally, in relation to comprehension of FM as a valuable aspect of the peer SSN, the women reported feeling misunderstood in their family environment, but encountered understanding in the SSN. Other authors have identified the understanding of others as a key aspect in coping with FM [46,53]. The women attached great importance to being listened to within the SSN; interestingly, Garcia-Campayo et al. [54] reports that being listened to by a peer group is more effective than being listened to by an individual. Another valued aspect of the SSN was the enhanced personal satisfaction felt by the women, deriving from a feeling of being integrated in and identifying with a group of peers.

The main limitation of this study was that it explored the perceptions of a group of women from the same geographical region and with similar socioeconomic findings of the study. Other studies are therefore needed, reflecting, for instance, more varied sociodemographic profiles.

The results of this research highlight the key role that can be played by peer SSNs in empowering women and facilitating their management of FM. Connecting women with FM in peer SSNs should be included as a care strategy, with health professionals including assessment and promotion of peer SSNs in their global approach to FM, and encouraging people with FM to participate in activities such as

psychoeducational groups. Further research is needed to explore the outcomes of such strategies in the framework of health policies, and to further explore the value of peer SSNs for people living with chronic diseases.

Conclusion

A peer SSN facilitates acceptance of an FM diagnosis and is a source of information that empowers women and facilitates their management of their disease.

A peer SSN exerts positive effects on the physical, mental, and social wellbeing of women with FM.

Valuable aspects of a peer SSN are that women feel understood and listened to, and feel a greater degree of personal satisfaction.

Healthcare for women with FM should include strategies based on encouraging their connection through peer SSNs.

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the Jordi Gol Primary Care Research Institute (IDIAP Jordi Gol) (reference 20/230-P) and respected the ethical principles of the most recent version of the Helsinki Declaration and good clinical practice guidelines as established in current Spanish legislation (Law 14/2007 on Biomedical Research). All interviewees and written information on the study, were guaranteed the confidentiality of their data, voluntarily agreed to participate, and provided their written informed consent.

Consent for publication

Not applicable

Availability of data and material

All data generated or analysed during this study are included in this published article.

Competing interests

The authors declare no conflict of interest.

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Authors' contributions

Conceptualization, G.R.-G., C.B.-F. and S.M.-J.; Data curation, C.B.-F., R.S.-S. and D.J.-C.; Formal analysis, G.R.-G., C.B.-F. and S.M.-J.; Investigation: G.R.-G., C.B.-F., E.B.-R., N.P.-V., R.N.-B. and S.M.-J.; Methodology, G.R.-G., C.B.-F., R.S.-S., D.J.-C. and S.M.-J.; Visualization, G.R.-G., R.S.-S., D.J.-C.; Writing-original draft, G.R.-G., C.B.-F. and S.M.-J.; and Writing-review and editing, G.R.-G., C.B.-F., R.S.-S., D.J.-C., E.B.-R., N.P.-V., R.N.-B. and S.M.-J. All authors have read and agreed to the published version of the manuscript.

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Figures

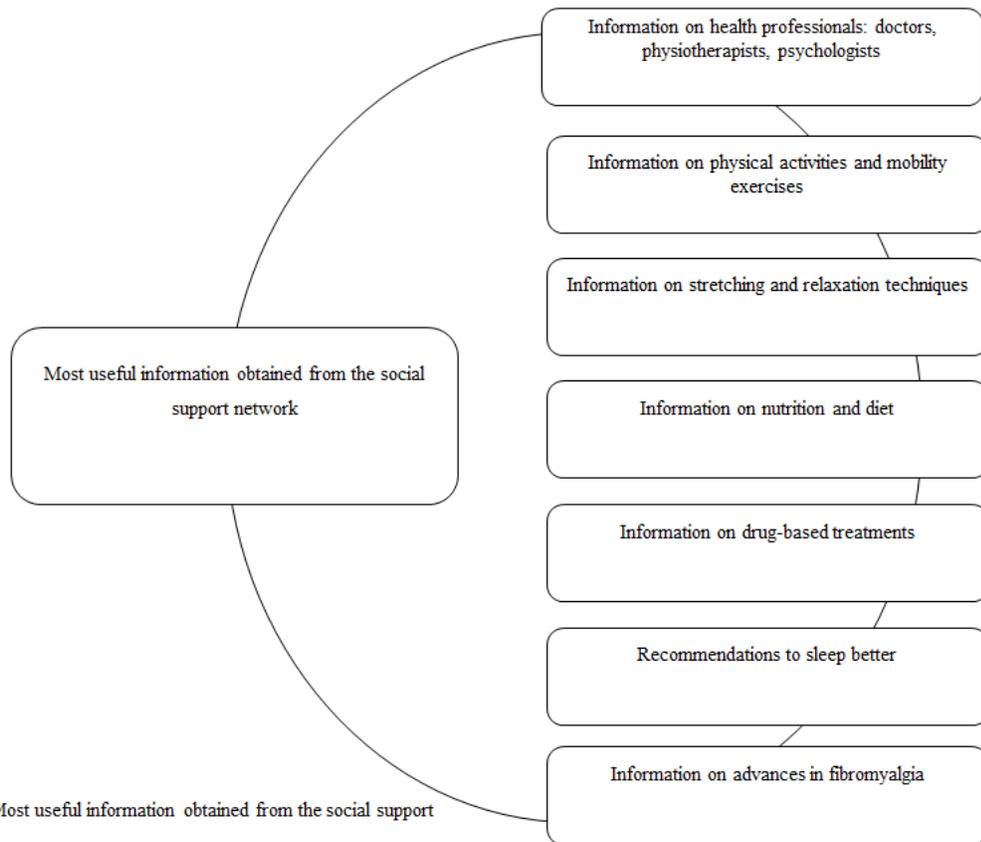


Figure 1. Most useful information obtained from the social support network.

Figure 1

Most useful information obtained from the social support network.