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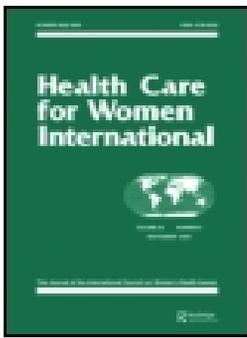
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"I'm not the woman I was": Women's perceptions on the effects of fibromyalgia on private life

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ABSTRACT

In this qualitative study we explored how gender shapes the women's experiences of living with Fibromyalgia and how it affects their private lives. Through thematic analysis of data from 13 in-depth interviews in Spain, we identified 7 themes which reflect that these women feel remorse and frustration for not being able to continue to fulfil the gender expectation of caring for others and for the home. This research contributes to a better understanding into what suffering from

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fibromyalgia implies for women and provides insights into how family and providers can support women with fibromyalgia in order to achieve a beneficial lifestyle.

Keywords fibromyalgia, women´s health, gender, family relations, qualitative research

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In this qualitative study we explored how private life is conducted by 13 women diagnosed with fibromyalgia (FM) from Spain. In this article we seek to integrate a gender perspective to gain a better understanding on how FM had an impact on the private lives of these women. Applying a gender perspective in FM research is crucial, as these women's daily lives are shaped by social factors such as gender. In the Spanish context, as in other traditional gender systems, gender equality exists in theory but not in practice, and progress falls short when it comes to sharing domestic tasks between men and women. Gender relations take place within the scope of the sexual division of labour: male breadwinner and female housekeeper, which means women have to take on work both inside and outside the home, as they still take on the role of caregiver to the rest of the family. It is critically important to understand how women with painful chronic other illnesses such as FM experience the changes in their private lives in order to improve the medical and behavioural recommendations (Bird & Rieker, 1999; Sánchez-López, Cuellar-Flores, & Dresch, 2012; Thorne, McCormick, & Carty, 1997).

Chronic pain and fatigue are highly limiting and common health problems in adult women (Carmona, Ballina, Gabriel, Laffon, & EPISER Study Group, 2001; Coster et al., 2008). Fibromyalgia (FM) is a chronic disease that mainly affects women: it has an estimated prevalence of 3.4% in females and 0.5% in males (2.4% among the general population), with a male/female ratio of 1:20 (Branco et al., 2010; Goldenberg, Burckhardt, & Crofford, 2004; Rivera et al., 2006). Its clinical characteristics were established in 1990 by the American College of Rheumatology and in 1992 the World Health Organisation recognised it as a disease in its

own right (Copenhagen Declaration, 1993; Wolfe et al., 2010). In addition to the fact that its etiology remains unknown, FM and people suffering from it are often questioned and misunderstood (Sim & Madden, 2008). The constant presence of FM symptoms, namely pain, fatigue and lack of strength, has a negative impact on patients' daily lives and on physical ability and functioning, that leads to a reduction in social, leisure and labour activity (Arnold et al., 2008; Campos & Vázquez, 2012; Jones, Rutledge, Jones, Matallana, & Rooks, 2008; Lempp, Hatch, Carville, & Choy, 2009; Sallinen, Kukkurainen, Peltokallio, & Mikkelsen, 2009).

The impact of FM in women's daily routines has been studied focused on their experiences of living with pain (Hallberg & Bergman, 2011; Kengen Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2011; Sallinen, Kukkurainen, & Peltokallio, 2011). The specific difficulties at home have been explored primarily in Northern European Countries (Hallberg & Bergman, 2011; Juuso, Skär, Olsson, & Söderberg, 2011; Soderberg & Lundman, 2001). Sallinen (2012) distinguishing between the women with FM who receive support and help from their family –who did not feel questioned and had been able to share the domestic workload–; and those women who continue with their work and home duties at the cost of their own health and well-being. Nevertheless, how gender-power relations shape the meanings of the changes of routine at home and with its members has not yet been explored in depth.

Few research studies include the gender-perspective even though FM is mainly a woman's illness (Soderberg & Lundman, 2001; Soderberg, Lundman, & Norberg, 1999). Gender, understood as the set of expectations, norms and values regarding how men and women should behave, strongly influences their health behaviour and ultimately their health status (Doyal, 2001; Rohlf, Borrell, & Fonseca, 2000). The biological body can be altered according

to context-bound societal gender ideals, for example through lifestyles (i.e. eating habits, rest, physical training, health habits) (Fausto-Sterling, 2008). This becomes specially relevant for chronic illnesses, with regard to key factors for primary, as well as secondary and tertiary prevention (R. Connell, 2012; Courtenay, 2000). Sociosymbolic constructions of femininity and masculinity, the way we sense ourselves as people, perceived to be male and female, affect how we behave, how we interact with others and how we feel (Annandale, 2010; Artazcoz et al., 2004; Gooren, 2011; Saltonstall, 1993). As a result, this has a direct repercussion on how people experience and live the consequences of a painful chronic disease (O'Neill & Morrow, 2008; Thorne, et al., 1997). Applying a gender perspective is useful for understanding private experiences not as individual decisions, but as a result of the socialization process that constructs femininity as culturally and socially opposite to masculinity (Burkitt, 1998; De Beauvoir, 1989; Öhman, 2008).

We believe that it is necessary to reach a deeper understanding of how women with FM experience the physical limitations derived from the symptoms of the disease at home, in order to provide a detailed and comprehensive description of the effects of FM on their private lives. This study is framed from a theoretical gender point of view as understood by Connell, whereby gender is defined as a pervasive system of stratification that shapes the use of time and space, structures relationships and interactions both between and among men and women, and signifies power (Connell, 1987). To the extent of our knowledge, this is the first time that this kind of study has been carried out in Spain. Our objective for this study is to explore how gender shapes women's experiences of living with FM and how it affects their private lives.

METHOD

Design and participants

This study was part of ongoing wider research into patients' experiences and health providers' perceptions on the personal and institutional consequences of FM in Spain. We hoped to gain insights into the social construction of the illness from the patients' and professionals' perspectives (Briones-Vozmediano, Ronda-Pérez, & Vives-Cases, 2014; Briones-Vozmediano, Vives-Cases, Ronda-Pérez, & Gil-González, 2013). In the present study we focused on women's accounts of daily events.

A total of 13 interviews were conducted with women diagnosed as having FM. All the participants were Spanish and caucasian and lived in a region in the east of Spain (Region of Valencia). They all had been clinically diagnosed with FM by a rheumatologist in the Spain National Health Service, which was used as inclusion criteria when considering patients for study. Their age range was from 24 to 61 years of age (Table 1). All of those interviewed were in paid employment prior to the illness; however, at the time of the interview the majority (=8) remained inactive due to the progression of FM (Table 1).

Sampling

A convenience sampling was conducted in which the informer selection process was carried out according to pragmatic and feasibility criteria, given the difficulties in accessing the patients derived from the consequences of the disease itself (Ulin, Robinson, & Tolley, 2005). In order to recruit participants, we contacted Patient Associations in the Region of Valencia (Spain) and

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used the snowballing technique. Only one woman refused to take part due to her sense of discomfort derived from her symptoms.

Data collection

We perform in-depth semi-structured personal interviews to encourage its participants to play a more active role during the course of the interview, as well to disclose very private thoughts and personal concerns (Rubin & Rubin, 2005). The interview guide included a series of topics to encourage the women to express their own views and experiences (Table 2). There were no textual formulations, predetermined sequential order or answer options. The interview guide was drawn up after reviewing the literature and taking into account the experience and knowledge of the research team. The interviews were carried out by the first author from January to June 2009 and lasted between 60 and 90 minutes. The women were interviewed in their homes and we carried out interviews until data saturation, meaning that no new information emerged in the final interviews (Strauss & Corbin, 1990). Then we taped and transcribed the interviews verbatim.

Ethical considerations

In keeping with the Declaration of Helsinki and Belmont Report principles, the purpose and procedure of the study were explained, an opportunity to ask questions was provided, and written informed consent was obtained from each participant prior to data collection (Bigatello, George, & Hurford, 2003). We sought ethical approval from the Ethics Committee of the University of Alicante (Spain).

Data analysis

The authors read all the interviews several times independently, and then together they compared and combined their analyses. All data were imported into qualitative analysis software (Atlas.ti) and examined using thematic analysis as described by Braun (Braun & Clarke, 2006). To identify themes across the data set and make sense of the patterning of responses, we generated initial codes from the data, which identified meaningful sentences or paragraphs; codes were sorted forming themes and grouped together. First we grouped the codes according to predefined themes related to housework and family relationships. During this process new themes emerged that were included as well. These themes were discussed, negotiated and redefined by the authors, which resulted in ending up with seven themes. The themes captured the way in which women with FM feel the consequences on their private lives. Finally we conducted and wrote a detailed analysis of each individual theme, as identifying the story that each theme tells. The quotes presented were chosen based on their clarity and representativeness.

RESULTS

We identified seven themes during data analysis: (a) “After having polished a bit, I have to lie down for a week”; (b) “I have to do it, because I can’t live in a filthy house”; (c) “As long as I can do it, I want to do it”; (d) “Dress me, I can’t do it myself”; (e) “He just helps with the basics”; (f) “How can you love me now, if I’m not the person I was?”; and (g) “You lose your sex drive, and then there are long faces.” These themes reflect women’ perceptions and experiences with how they felt trying to carry out their daily routine at home, doing the

household chores as their top priority, and trying to not disturb their family's routine neither feeling a disabled person. The themes are organized around three dimensions: housework, family relationships, and marital relationships.

Housework

“After having polished a bit, I have to lie down for a week”

But that's the way it is, from the minute I start to do something and I get this crippling pain I lie down a bit and try again later on ... and so on. (*Woman 2*)

Women interviewed described a number of physical complaints derived from the symptoms which prevented them from carrying out housework as they normally would. Picking things up, applying force, bending over, or going up the stairs was done with difficulty and was perceived as having to be overcome without inducing undue strain. Cleaning was considered as the most difficult chore for the interviewees. Specific activities such as sweeping, mopping the floor or ironing demanded repetitive movements which were detrimental to their physical well-being, making their pain and/or fatigue worse. Even so, they carried on doing the chores in spite of medical advice to refrain from doing so. They themselves admit that their drive to overcome their limitations ends up having a detrimental effect on their physical well-being, due to their self-imposed requirement:

I know that if I get up I won't rest – I'll immediately start to do things and I don't particularly want to tire myself out more than I normally am. (*Woman 10*)

They also mention the physical consequences of carrying out other chores such as doing the laundry (washing, pegging out and ironing) or cooking. Pain and fatigue take their toll on the

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accomplishment of these chores, by either making it difficult or by preventing them getting done, but they are also a direct result of having carried them out in the first place:

You can't iron ... because when you do watch out, that I did find out ... The pain that I felt at that time is where the pain was when I ironed. (*Woman 3*)

Time management is a strategy used by women suffering from FM which enables them to get on with the housework. Chores are prioritized, the most urgent ones being dealt with first. The physical effort involved in doing housework leads to subsequent aches and pains, so therefore they have to conform to a less than perfect end result.

The women interviewed are fully aware of the fact that any excessive physical exertion will directly affect their health. Therefore, they alternate between rest periods and housework: The variation of chores is also helpful – they may do one specific chore in the morning and another in the afternoon, or they may take advantage of their better days to get the jobs done. Only the absolutely necessary chores that they considered to be so (such as putting the washing machine on) are done on the days when they are not well.

“I have to do it, because I can't live in a filthy house”

The undertaking of household chores gives them a sense of satisfaction and achievement: a lack of cleanliness in the home sets off feelings of helplessness and frustration. They feel restricted as regards doing the housework. Acceptance of their loss of autonomy and the restrictions imposed on doing the housework seems difficult but unavoidable:

Me, I like things to be really clean. But afterwards I realized that, being as I am I can't carry on... I have to be satisfied with the way I've got them. (*Woman 1*)

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The need to remain active and feel useful instead of prioritizing their rest is apparent from the interviews of the women suffering from FM. The interviews reveal that having a clean home stands out as a priority in their daily routine amongst the women interviewed. Sometimes this involves depriving themselves of rest or of undertaking activities which would benefit them more, as go to the gym or go out for a walk, which is medically recommended to improving their malaise.

The inability to fulfill the tasks traditionally assigned to women sparks off remorse. Therefore, some of the women interviewed used derogatory terminology when referring to themselves and to the new attitude that they are forced to adopt with regard to cleanliness: “At home, I always say that since I’ve got fibro I’ve become more of a pig” (*Woman 9*).

The fact that they value their level of fitness or define their pain from the ability to do household chores gives an indication as to the importance that this type of activity has for their sense of identity and self-esteem:

I went downhill fast, because, I used to say ‘As long as I can cook a stew, here I stand, as long as I can wash a couple of dishes up, here I stand’, and my body said “Well you’re not going to do any stews, or any dishes,” and I plainly remember that day. (*Woman 3*)

“As long as I can do it, I want to do it”

Women interviewed state that they view housework as something they are used to do brings a feeling of normality into their lives: Even if they have had to hire help, they viewed it as a last resort, as they would have preferred to do the task themselves: “They’re things that I’ve always done and I have to do them, I want to do them” (*Woman 1*).

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The inability to carry out domestic chores leads to profound guilt. The fact that housework is solely their responsibility is so ingrained in their mindset that they cannot imagine anyone else carrying out the task. Besides, it makes them feel useful and it takes their mind off their illness: “My husband tells me ‘get a cleaner’, but I don’t want to” (*Woman 10*).

Nevertheless, the women interviewed who work outside the home view the hiring of a cleaning lady as a necessity. These women need to be able to be free of the burden of the home in order to get on with their job and take the rest they need due to their illness. They do not want to give their job up. Those interviewees who can’t afford a home-help think that having a cleaning lady would be beneficial to their well-being since it would save them the inevitable aches and pains. Their testimonies reveal the choice they have to make between hiring a home-help or paying for alternative therapies, which seems relieve their pain:

Obviously, if I pay for a massage, I’m not going to pay to have the kitchen cleaned, and if I have the massage and then clean the kitchen, I’ve ended up the same as when I started. (*Woman 9*)

Family relationships

“Dress me, I can’t do it myself”

Women interviewed expressed that their self-esteem and sense of worth was also diminished if they could no longer carry on looking after others, such as their children, due to the physical limitations:

I can’t make the most of my grandchildren – I can’t look after them, I can’t change their nappies /.../ I just can’t ... I see grandmothers older than I am, and they take them to

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nursery school, they do ... they play with them. I can't do it, I can't even bend down to the floor, because if I do, I can't get up again. (*Woman 1*)

One of the coping strategies used by FM patients is to find a way to carry out caring tasks which avoids subsequent pain; for example, they changed their daily routine to be able to take care of their children:

It was easier for me to get into the bath with him, enclose us both in with the bath screen, and for us to have a shower together, rather than me trying to struggle with him from outside the bath, that way I didn't have to hold him up, he didn't slip and slide around, and it was a lot easier for me. (*Woman 4*)

Older children have to be made aware of the fact that their mothers are no longer completely self-sufficient, and that they may need help even for simple things such as personal hygiene. A general lack of understanding of this fact was perceived by the women who were interviewed, but they attributed it to their child's youth:

When it comes to the family, it's hard to accept and deal with. I remember the day I got up and found that my legs wouldn't work, and my children put my knickers on. I'll never forget the look of disbelief on their faces as they pulled my knickers up, and the sight of seeing my bum. They said "something really serious is going on here. (*Woman 9*)

The women interviewed have had to teach their children how to cook or clean. This made them feel useful as they couldn't do it themselves. There is a general unwillingness on the part of the interviewees' children with regard to having to help with the housework. This woman demonstrates how her daughters only lend a hand when they can see that it's absolutely

necessary, and when their mother is in dire need or even at risk. Besides, they do not wish to be a burden to their children and thus refrain from complaining so as not to worry them:

Well, they ask “how are you feeling,” “fine,” and I’m probably feeling unwell and I still say “fine.” Of course, my kids come home to have lunch or dinner, we get together, “How are you feeling, Mom?,” “fine.” I’m not likely to say “It hurts here, there, it aches...”, when the kids come to see me? I don’t say anything. (*Woman 10*)

“He just helps with the basics”

Interviewees expressed that they often avoided seeking help because they do not like feeling dependent, that they are imposing on or that they are a burden to their family. Another reason for not asking for help is that they think that they can do the job quicker themselves, or that they would have to nag to get it done and explain how to do it. Nevertheless, there comes a time when women with FM become aware that they need help from others, what they say resigned.

The older participants of our study do not ask help of their husbands, and excuse them due to various reasons. In this sense, the pronoun ‘me’ demonstrates how these women perceive the cleanliness of the home as their responsibility:

Maybe they don’t know how, but then again they probably don’t want to learn (she laughs). From the start – he’s 60 now ... yeh, but at times I say to myself what’s a 60-year-old man going to do round the house ... if I say, these days, “peg the washing out for me,” he does it, he brings the washing

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in, on Sundays he might make the bed for me, little things like that. But it's not like ... he can't cook, so he can't do any cooking. (*Woman 10*)

One of the reasons for conflict in the relationship with husbands derives from them not fully dealing with the housework being as women with FM cannot continue doing it as they used to: "so when he gets home, he's dead beat, so I can't say so-and-so needs doing, dear" (*Woman 4*).

Husbands of women with FM may criticise and blame their wives for an untidy house, or allude to the fact that they have been at home all day doing nothing, which makes women with FM feel deeply misunderstood:

But sometimes he still forgot, and when he got home: "Bloody hell woman, can't you pick your own dirty knickers up off the floor?," things like that. He was incapable of realizing that, although I knew perfectly well they were there, I couldn't bend down, upsetting things like that. (*Woman 7*)

Although not usually the case, some evidence is to be found that some husbands are willing to take on the task. These husbands would offer to do the task themselves if the situation was seen to be serious. The redistribution of household chores among family members can also affect the care of dependent relatives, as in the case of one interviewee, whose husband stood in for her in the care of her aging mother:

My husband is the only one that says: if you can't do it, I will. Don't you clean that, I'll clean it. For example. Or ...I'll do that, I'll do the vacuuming – you can't do it ... and my husband has realized lately and he's helped me a lot. He helps me in the house, and things that I used to do before, well he does them. (*Woman 1*)

Marital relationships

“How can you love me now, if I’m not the person I was?”

FM forces marital relationships to change dynamics. Relationships are thrown off-balance due to the difficulties that arise fundamentally from the patient’s partner’s incomprehension: “There were a lot of problems in our relationship, because if he’s not in your shoes, he can’t possibly know what you’re going through” (*Woman 7*).

FM patients point out that they do not usually have either the will or the strength to engage in leisure activities outside the home, be that with their partner, family or friends. This leads to recrimination on the part of patients’ partners:

My husband has changed so much. So very much, he says that I’m an old woman, that I’ve become an old woman, and that obviously I don’t feel like going out any more the way that I used to, that ... But it stands to reason, you go out when you feel like going out, if you don’t feel like it they can’t make you go. (*Woman 6*)

The changes in the relationship could imply that women’ partners make plans outside the home with other people, which do not include them. Other partners choose to socialize less and adapt to the passivity of their sick partners. In order to avoid feelings of guilt as regards their partners’ social lives, women with FM interviewees either bear the strain of keeping up with the social life they had before the onset of the illness, or encourage their partners to go out on their own with other people. Interviewees feel that their partners are either unsatisfied or bored due to the general apathy caused by the illness.

Husbands or partners also have to adapt to their loved one's new situation. The adaptation process usually starts by a phase of incomprehension, leading to arguments between the couple involved, and eventually ends up with the acceptance of the new circumstances. These women endeavor to gain empathy by offering explanations, although their partners could not understand but merely adapted to what was required of them. The women interviewed did not feel that they were totally misunderstood by their husbands, which they know is usually the case amongst FM patients:

I know people whose husbands and other family members say “she’s putting it on, to get out of doing the cleaning or the ...” and I know what’s what, it makes my blood boil.
(*Woman 12*)

Women interviewees stated that their husbands' cynical attitude towards the fact that their wives were reluctant to socialize with friends almost led to a break up. FM patients are aware of the fact that living with someone who has lost their capacity to be totally self-sufficient can place a strain on the relationship.

Physical ill-being caused by the illness led to a negative mood, which was cited as one of the other main problems that affect the relationship. They notice how their character degenerates and how they are susceptible to mood swings, which are taken out on their partner, because he or she is the person who is closest to them. They are aware of the fact that their behavior could end up in a break up:

If you're lucky enough to have someone who'll stand by you and understands what you're going through, or has an inkling at least, OK, but if not ... each go their separate ways, that's how it is. (*Woman 13*)

Besides, women with FM could feel responsible for the fact that their husbands have to bear the role of sole breadwinner, and have to do overtime to supplement their earnings.

“You lose your sex drive, and then there are long faces”

The effects of FM also have a negative effect on patients’ sex lives. Women state that their libido has diminished. Women interviewees put this down to the medication they were on, together with other side effects such as vaginal dryness or the susceptibility to bacterial infections. They point out that the predominant symptoms of FM – tiredness, pain, limited movement – are the main obstacles which either impede sexual relations or make them less enjoyable. On the other hand, one interviewee stated that the enjoyment derived from sexual relations had a beneficial effect on her physical well-being. As a way of coping with the symptoms, they found a solution in being creative and finding different ways of performing the sexual act without pain:

I have to do it when I’m not tired – it’s not so much the frequency, but of finding other ways of doing it, whereby it’s not painful, not because of having sex, but of the correct position. (*Woman 4*)

This general decrease in frequency is another reason for marital conflict. Patients’ drop in libido leads to a lack of understanding as far as their husbands are concerned:

And now I think my husband has taken it on board a bit more, but at first he found it difficult and he used to use emotional blackmail: If you don’t want to do it I won’t help you to ... So ... he didn’t say it, but he did it. (*Woman 6*)

This being the case, women with FM feel guilty in that they are unable to satisfy their husbands sexually: “Of course, you sometimes say to yourself, this poor chap, he has to go without” (*Woman 9*).

Both husband and wife have to adjust to their new way of life. This process is a difficult one to come to terms with and puts the relationship in jeopardy. The interviewees reported the lack of information regarding the illnesses’ far-reaching effects. They explain how they felt responsible for ruining her marriage as they were unaware that their low sex-drive was another symptom of their illness. Women interviewees stress the importance of communication with their partners in order to achieve a sense of understanding on their part. They even affirm that they have had to seek the professional advice of a sexologist, in an effort to improve their relationship and their intimacy.

DISCUSSION

In this study we describe how gender shapes women’s experience of FM and how this affects their private lives. Results show the dual position women with FM need to take: as both caregiver of the home and the family and as a sick person herself who needs help from them. Women felt that FM intertwined with and alters the gendered expectation of caring for others, which is perceived as being important and necessary, whilst being well aware of the limitations imposed on them by the disease. These limitations induced women to feel less useful to the family, and gave rise to feelings of remorse and frustration among them due to not being able to rigorously fulfil gendered expectations, namely doing the household chores and caring for the family, including the wife-role. We have framed the findings within Connell’s gender-power

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theory, focusing on how gender is constructed within productive relations -housework-, emotional relations -family and marital relationships-, and symbolic relations – how their feminine identity is shaped by FM.

This study builds upon historical research on coping or adapting to the consequences of chronic illness. As in the case of many debilitating chronic diseases, the trajectory of fibromyalgia sufferers leads to subsequent losses of self: losing self-esteem and self-identity as a result of diminished control over their lives (Charmaz, 1983). When a woman is affected by FM, she starts a process of changes in life, which can be regarded as an invisible transition from being a healthy woman to being a woman living with FM (Siv Söderberg & Lundman, 2001). It is known that changes in life introduced by FM signified the loss of a previous life and identity (Kelley & Clifford, 1997; Raymond & Brown, 2000), and, in general, women's experiences of illness impacted the way they felt about themselves and their feelings of femininity (Johnson & Repta, 2012). Our participants perceived that FM altered their private lives, and their femininity identity, namely internalized norms and perceptions about what it is to be an ideal woman in their context (Bird & Rieker, 1999). The women interviewed have constructed themselves as “women” in terms of being essentially housekeepers, closely related to Connell's concept of emphasized femininity, which implies empathy, nurturance and compliance, as well as a subordinated position in relation to men (Connell, 2012). Emphasized femininity in the case of women with FM means having no time to rest, giving priority of the cleaning of the house and caring for others before their own needs. The fact that women seemed to experience the same kinds of issues regardless of ailments is not new; authors such as Charmaz (1991) documented

that women suffering from health issues continued to do most of the housework themselves to avoid burdening others some years ago.

The women interviewed proclaimed that, paradoxically, housework aggravated their health situation but had an improvement on their sense of usefulness. Therefore, in this case, the traditional feminine role as housekeeper acts as a strategy to keep their self-esteem and self-worth instead of feeling as a burden to the family. This finding aligns with another study, whereby the authors found that women tried to normalize life by focusing on daily chores in an attempt to distract their minds and alleviate the pain that dominates their daily lives (Juuso et al., 2011). Other authors also showed that women with FM felt well despite pain and fatigue when they had the strength to do ordinary chores independently, such as taking care of their children, cooking dinner or cleaning the home, adjusting chores to their physical ability (Juuso, Skär, Olsson, & Söderberg, 2012). We go further and we think that, relating these findings with that of gender theory, women tried to normalize life by doing daily chores as a way of maintaining their power in the home and their feminine identity, traditionally understood as housekeeper. In this case, women's housework is not simply a fulfilment of an inescapable gender role, it is the performative construction of femininity in the face of disease (Courtenay, 2000). But it is also the performative construction of refusing the sick-role by engaging into a culturally-recognizable activity –in the face of the possibility of sickness taking over the identity here. In their insistence to continue with daily responsibilities women with FM construct a “toughness,” an identity of non-whimpy patient (Barker, 2002). Perhaps what we traditionally see as the sexist oppression of sexual division of labour gives women here a unique opportunity for resistance. According to Asbring (2001), the largest repercussion of FM on women was the change from an active life to a

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passive one, and the women who featured in our study were dissatisfied with the new, more passive, attitude they have had to take on as regards the running of the home.

The women interviewed experienced a transition between ceasing feeling to be the caregiver of the family to having to resort to seeking help, and seeking help from their family seems to be an uncomfortable solution for these women. We found a role-conflict because social obligations and expectations of the active domestic role traditionally assigned to them, assuming the tasks of carer, collide with the more passive sick role, which implies allowing themselves to be helped by others and delegating role obligations (Christopoulos, 2001; Parsons, 1975). As Charmaz (1991) stated, women and their families tend to assume that they had to function as before, whereby the sufferer carried on fulfilling the "Supermom" role, instead of allowing herself the time to rest and relying upon children and husband to do the housework.

Women did not like to ask for help with the chores because they did not like to feel neither dependent or disabled, so they try to not disturb their family's routine. Our participants also stated that not being able to look after other family members prevented them from feeling useful. Literature specifically linking care with femininity shows that i) the family relationship is more important to them than having a perfect house (Kengen Traska et al., 2011); and ii) it is more appropriate for women to care for family members so the discomfort there might also come from a sense of betrayal of this aspect of gender normativity (Wood, 1994). Our interpretation of the results shows that the view of womanhood of the women interviewed is highly related to motherhood and taking care of others (Poduval & Poduval, 2009). For example, the interviews of the women with FM show how emotions are kept hidden so as not to worry their children. That has a cultural explanation in that feminine identity is based on the sacrifice of one's own needs in

order to care for those of others, as gendered norms dictate that women's needs come second – self-sacrifice and caring for others come first (Sulik, 2007).

Results align with previous studies showing that the loss of autonomy of those affected and their dependency on others triggered off misunderstandings and inter-personal conflicts within the home (Aïni, Curelli-Chéreau, & Antoine, 2010). As other authors found, the handicap caused by FM makes the relationship with their family and partner (Aïni et al., 2010; Cunningham & Jillings, 2006; Soderberg & Lundman, 2001). Women interviewed described additional difficulties in the marital relationship and the need of support from their husbands; support from their partners tended to be anecdotic; nevertheless, in other studies husbands adopted the role of carer (Rodham, Rance, & Blake, 2010; S. Söderberg, Strand, Haapala, & Lundman, 2003). According to the women interviewed, a lack of understanding could lead to break-up of the marriage. It might be due to the women's incapacity which implied an additional burden for the rest of the family, and also because the husbands lacked information about FM (Lempp et al., 2009; S. Söderberg et al., 2003). In keeping with Charmaz (1983), claiming that pain, fatigue or other disabling symptoms may lead to conflict. It becomes apparent from the women's interviews that not only they themselves, but their partners as well, must go through a period of adaptation to redefine who they are from the onset of the illness, as the identity and the relationship established between them changes

Their loss of identity as the women they used to be, together with the loss of autonomy in sexual relations, leads them to the point of feeling as if they were a different wife. Participants from other studies also felt that the deterioration of sexual relations between the couple leads to the deterioration of the relationship as a whole (Aïni et al., 2010). Women interviewed felt they were

breaching their marital “obligations”, because their lack of energy due to FM prevents them from engaging in sexual relationship, leading to a feeling of guilt and inadequacy. In fact, feelings of self-blame are common in women with chronic illnesses (Charmaz, 2003). Despite not being able to sexually satisfy their partners is also reported by other participants, which is defined as not being 'proper wives' (Hinchliff, Gott, & Wylie, 2009 we argue that this behaviour has its roots in the gender expectative of putting others' needs first, specially those of men (De Beauvoir, 1997 [1949]).

Implications

The need to support a FM patient is well recognized. Our findings suggest that it is vital for their partners to fully understand the implications and subsequent consequences of FM and their impact on the private sphere, as the patient's emotional stability depends on these factors. The interviews reflected these women's need for greater moral and effective support from both their family and spouse.

In the context of couple relationships in Spanish society, the reality is that work undertaken by women outside the home and the earnings gained by their labour has not resulted in any modification of the way roles are meted out within the marital home, which has a direct repercussion on women's health. Physicians and family practice nurses can support women with FM and their relatives by advising or training them to share household tasks, thus providing the patient with more time to rest. Nurses can inform women that experiencing pain and frustration is normal and can collaborate with these women to explain to their family that they need rest and comprehension. Health professionals can help women with FM by advising them that they

should not sustain any work overload and that they should delegate within their family. Nurses can provide knowledge on how family members should act to help their mother or wife with FM. Healthcare services should offer greater support for these patients in the form of providing information to the family and increased awareness of the disease. (Thorne et al., 1997). Such information may help health professionals to improve the clinical management and the health status of these women (Campos & Vázquez, 2012).

Since the changes in sexuality experienced by women with chronic illnesses are a major concern for maintaining their relationships, explicit information on the consequences and effects of the illness, together with open communication between the couple, are necessary to face the challenges placed upon them (Kralik, Koch, & Telford, 2001; Webster, 1997).

Methodological considerations

Fibromyalgia is not unique, but an example of how debilitating chronic illnesses disrupt the daily lives of persons suffering from them. Previous theories on the consequences of chronic illnesses from a gender perspective are applicable to FM (Charmaz, 2003). Nevertheless, specific literature on FM from a gender perspective, which is the main input of the present article, is scarce. In this qualitative study we represent the views of a small number of women with FM from Spain. Nevertheless, the sample is not small scale, because qualitative data should be not be viewed as alien to rigorous analysis (Pope, Ziebland, & Mays, 2000). We applied the criteria described by Lincoln & Guba to enhance trustworthiness in qualitative research (Lincoln & Guba, 1985). The authors negotiated findings, relying on triangulation to enhance reliability. Triangulation of researchers and participants was used to enhance credibility, involving different

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women profiles (occupation, family situation, age) and researchers from different disciplines; our positionality as researchers and interviewers was from sociology and gender studies applied in the field of public health. Throughout the study process we tried to keep ourselves aware of our pre-understanding, through critical peer discussions concerning our evolving understanding of the phenomenon in view (Lindseth & Norberg, 2004).

Although the findings are not necessarily generalizable they represent direct insights from the perspective of women with FM and could be transferred to similar situations. We also made an effort to contextualise the results in order to help readers evaluate as to what extent our results might be applicable to other, similar settings. In order to enhance dependability, to respond to issues emerging from the data we used an emergent design and responded to constant change even when that implied modifications to the planned schedule or the interview guides. To remain faithful to the meaning of the text, the original Spanish version was used for coding, and translation into English only took place when themes were identified.

Some information was not possible to obtain, since the general objective of the larger study did not include them, such as the socio-economic level and education of each participant, their religious beliefs or family history to better understand their adhesion to gender norms. In future studies with similar objectives as this, it could be interesting to include other interviewees such as other family members, e.g. sons and daughters or husbands (Rodham et al., 2010; S. Söderberg et al., 2003).

CONCLUSION

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Women with FM who were interviewed have given insights into how they experience and cope with the consequences of suffering from FM in their private lives, which are influenced by gendered norms that constrain women to be the carer of the home and the family. Women interviewed feel less useful, guilty and frustrated for not continuing to be able to fulfil the gendered expectation at home due to the limitations derived from symptoms. We have shown that women with FM responded to those specific challenges often renegotiating their identities as women.

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TABLE 1 Participants' characteristics

Interview code	Age	Profession*	Marital status	Children
Woman 1	61	Inactive (<i>Orange packing factory worker</i>)	Married	1 boy, 1 girl
Woman 2	52	Unfit for Work	Divorced	1 boy
Woman 3	53	Inactive (<i>Waitress in a family-owned bar</i>)	Married	2 boys, 1 girl
Woman 4	33	Inactive (<i>Cook</i>)	Married	1 boy
Woman 5	52	Cleaner	Married	1 boy
Woman 6	44	Administrative assistant	Married	2 girls
Woman 7	38	Hairdresser	Lives with partner	No
Woman 8	29	Call centre operator	Lives with partner	No
Woman 9	45	Primary School teacher	Married	2 boys
Woman 10	59	Unfit for Work (<i>Hospital orderly</i>)	Married	2 boys
Woman 11	55	Unemployed (<i>Shoe factory</i>)	Married	2 boys

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		<i>worker)</i>		
Woman 12	51	Inactive (<i>Shoe factory worker</i>)	Married	1 boy, 2 girls
Woman 13	24	Inactive (<i>Waitress in a restaurant</i>)	Lives with a same sex partner	No

*In case of current inactivity, the former profession is indicated in italics.

TABLE 2 Topics to explore during interview to ascertain changes brought about in the FM sufferers' private sphere due to the onset of their disease	
Opening topic	- the limitations found to carry on their routines
Section 1	<ul style="list-style-type: none"> - the repercussion of being diagnosed with FM on their daily lives - factors aggravating the disease at home - the strategies carried out for doing household chores
Section 2	<ul style="list-style-type: none"> - the changes in family relationship - the problems encountered with the family - the women' degree of satisfaction with their private lives
Closing topic	- proposals to improve their quality of life at home