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Diviney M, Dowling M (2015) "This is not in my head': lived experience of Fibromyalgia'. *Primary Healthcare*, 25 (9):18-23.

Introduction

Fibromyalgia (FM) is a chronic illness characterised by widespread pain and fatigue (Briones-Vozmediano et al 2013). Additional somatic symptoms such as poor sleep, depression, headaches, and cognitive impairment are also often present (Sumpton and Moulin 2008). The debilitating effect of the condition on patients' quality of life and the experience of pain have been identified as having the most significant impact (Nuesch et al 2013). Typically the prevalence of the condition has been shown to affect women more than men (Haviland et al 2011).

Health care professionals require a deep understanding of the 'illness experience' of FM in order to achieve best outcomes for these patients (Wuytack and Miller 2011). This is especially the case for primary health care nurses because FM is considered one of the most challenging issues for primary care today (Marter and Argruss 2008). Moreover, it is argued that the care of patients with FM should be managed at primary care level and not by a specialist rheumatologist (Ghazan-Shahi et al 2012).

Our understanding of the lived experience for those with FM is limited. While a number of phenomenological studies have explored patients' experiences of pain with fibromyalgia (Paulson et al 2002, Råheim and Håland 2006, Juuso et al 2011),

and fatigue with fibromyalgia (Söderberg et al 2002), only four known phenomenological studies have specifically focused on exploring the lived experience of patients with this chronic condition. Two of these studies explored Swedish patients' lived experience (Hellström et al 1999, Söderberg et al 1999), and one was with patients in Belgium (Wuytack and Miller 2011). Hellström et al's (1999) study aimed to describe the way in which fibromyalgia patients (n=17 females and n=1 male) understood their illness. The researchers' reported the patients' long journey to diagnosis and their experiences of the illness being viewed as psychological. Similarly, Söderberg et al's (1999) study of women (n=14) lived experience of fibromyalgia reported the women's struggles to be believed and a general lack of knowledge about the illness. The most recent phenomenological study was undertaken in the UK (Dennis et al 2013) with twenty participants (18 females and 2 males). Dennis et al (2013) reported on their difficulty in describing a 'definitive fibromyalgia' experience.

Methods

The study reported here was guided by van Manen's phenomenological approach (van Manen 1990). Men and women with a diagnosis of fibromyalgia were invited to partake in the study via the FibroIreland, a social media website page. The inclusion of men in the sample was important because men's experience of fibromyalgia has not been as extensively explored as women's.

Nine people were interviewed (5 females, 4 males). Phenomenological studies typically adopt small purposeful samples. All participants (Table 1) were interviewed and an interview guide was used to ensure consistency. The first interview question asked participants to tell in their own words what it was like to live with a diagnosis of fibromyalgia. Subsequent questions focused on asking about their journey to diagnosis, how they felt when diagnosed, symptoms they experienced and management strategies. All interviews were audiotaped and transcribed verbatim. Data analysis was guided by van Manen’s lifeworld approach (van Manen 1990). A holistic reading approach was adopted in which the transcripts were read and re-read to grasp the core meaning of the transcripts collectively. Essential views were depicted and core themes established. Finally, statements that best depicted the individual themes were identified. The participants’ lived experience was then interpreted under four existentials, i.e. lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relations (relationality).

Ethical approval for the study was granted by the authors’ local University research ethics committee. All participants were asked to adopt a pseudonym, but some requested that their first name be used. Written consent was sought prior to each participant’s interview.

Table 1: study participants

Participants	Age	Time since first diagnosed with Fibromyalgia
Geraldine	59	18 months
Sarah	45	2 years

Alannah	20	3 months
Bob	30	4.5 years
Deirdre	48	6 years
John	44	3.5 years
Marie	48	5 years
Paul A	45	3.5 years
Paul B	45	1.5 years

Findings

Lived time

All nine study participants had experienced a long and complex journey to a final diagnosis of FM.

"Yeah, it was a very long journey... all doctors could tell me was it was absolutely nothing medically wrong with me. They couldn't find anything" (Paul A).

"...it's very much, in my experience, a diagnosis by exclusion so I was tested for everything under the sun..." (Bob)

For some, life was 'on hold' and unpleasant:

"...my life has pretty much been kind of put on hold...it's a bit like, when will there be, when can I kind of restart my life, you know". (Alannah)

"I've often thought actually over the last months that life would actually be easier if you were diagnosed with most forms of cancer. Or HIV or something of that nature...". (John)

Lived space

Many of the participants felt that people had difficulty in grasping the severity of the illness, despite the debilitating symptoms because those with FM *"look perfectly*

normal". Nevertheless, it was also acknowledged that a better understanding of the condition as a whole was emerging:

"Funnily it's getting better and people are now beginning to say 'Oh yeah I've heard of that but I don't know anything about it' so that's what I'm seeing the difference between say when I was first diagnosed and now" (Marie).

The need generally for more knowledge and education regarding the illness was expressed:

"It's I think really the more and more people that get in the TV, the more doctors understand it, the nurses, the medical field instead of just specialists. That if General Practitioners understood it yes, it would be a lot better for everybody and it would help I think more and more people with fibromyalgia to - not get better but of course feel better at least you know." (Paul A)

The participants' experiences with health care professionals were mostly negative and they believed that a lack of understanding and knowledge of the illness was to blame.

"Well, I think that you know, they [Doctors] have a very, very limited knowledge about it....there's definitely a lot of doctors who probably have, you know, an outdated view on it" (Alannah).

"Even though I think they [Doctors] are becoming more aware of it they still run away from it. I think they don't understand it and they don't want to get into it because it's too complicated..." (Marie).

"I don't think my doctor is really understanding; I would actually love to have a doctor who was more understanding of fibromyalgia and knew anything more about it..." (Sarah)

"It's really weird, the interesting thing is no medical professional I have met has demonstrated any interest at all in my medical history, which I find really interesting. I'm trying to help them diagnose, by giving them perhaps some of the signposts that their professional experience should then be able to kind of unpack and they're not interested...." (John)

Lived body

A common theme among participants' experiences was living with an invisible illness which had an immense physical and emotional impact on the body.

"Generally the first word you tend to say is pain and then they look at you and I look perfectly normal, I don't look like I'm in pain, you know" (Marie)

The cardinal symptoms for the majority of individuals were pain and fatigue.

"Well the pain is the worst thing but the pain causes other things and the spasm attacks that is like pain in the muscles" (Paul B).

"The pain. The pain is there constant. and it is there 24/7" (Deirdre)

"I mean from my own perspective the biggest thing is the fatigue side of it,"... "You get up tired, you go to bed tired..." (Paul A)

"...fatigue then feeds into other things such as memory loss, forgetting topics of conversation, forgetting conversations entirely, mixing up names..." (Bob)

Five of the participants also had other symptoms besides pain and fatigue, including sleep problems, restless leg syndrome and depression.

"...I would never really have had depression before but I can feel myself being very depressed sometimes because of it." (Sarah)

"My concentration is now appalling and, you know...I really have to concentrate incredibly hard, and I find myself just drifting..." (John)

Participants generally believed that conventional treatments did not significantly benefit symptom management and they often experienced side-effects from prescribed treatments.

"Everything I've tried has only made something else worse or like the time I was taking tablets and my hair would fall out, Neurontin, I think that one was" (Sarah)

Self-management and a holistic approach to treatment were discussed by all participants, albeit with varying effects. All of the participants had adopted techniques, through 'trial and error' and alternative therapies.

"Because it's not just about giving someone medicine, it's all other things that they would need to incorporate in a health management plan really." (Sarah).

Exercise was identified by six participants as being a huge component of self-management.

"Well exercise definitely...That has helped and in fact on days I don't run I'm really sore." (Marie).

"even though at the beginning it was kind of counterintuitive, you're in pain so you should exercise, but it does make a difference, so I do have to, you know, first thing in the morning..." (Bob).

Some also talked about stretching as a method of self-management and all of the participants who undertook the practice deemed it effective:

" I find when I do concentrate on the stretching that it does help with the stiffness, you know, get up in the morning, and do a little bit of stretching before I start the day definitely helps with the pain and it helps with the sleep as well and it helps with the exercise I do" (Paul A).

Lived relations

Loss and isolation were dominant experiences for participants.

"I've lost relationships with girlfriends and friends who just didn't quite understand the restrictions that were now on my life... my whole self-esteem and self-worth, the whole lot, took a hell of a lot of a beating...there's a grief process that you go through as well and I'm still doing that..." (Bob)

"...I have no social life, I don't go out. If I went out and I was out past twelve o'clock, it would probably take me the guts of two weeks to recuperate from that." (Marie)

"...once it goes a certain time I can't be arsed to talk, I'm too tired...I want to go home and go to bed." (Geraldine)

" I haven't suffered from depression over the years, but when you're so incredibly tired and unwell, you really do not want to have people around you; you don't want to be in social situations. And I'm actually very, very social and I had a very, very good active social life up to a few years ago, I would say." (John)

"people don't understand like your life changes from a 10 to 0 or 1 totally, all of a sudden you feel alone, you feel nobody listens to you." (Paul B)

"I kind of isolated myself because I was embarrassed and I, like I said, I had to leave school at fifteen and then I did try a couple of years later to do a course, I only lasted a few weeks, I was literally falling asleep in college" (Alannah)

Furthermore, particularly amongst the four male participants, the theme of role reversal was apparent:

" I think from a male perspective having fibromyalgia, I think it can be difficult, because you sort of want to be seen in your family as the bread winner and, you know, being physically strong, and fibromyalgia just ... I know from being a sportsperson before I got fibromyalgia, and then when I got it, the change in my energy levels, my strength was just unbelievable." (Paul A)

"particularly as a young man to be told that you have a condition that is 90%, diagnosed 90% in women and 10% in men; it's very kind of, it stops you in your tracks and it's scary and it's very difficult to comprehend at a grossly young age how to go about managing it and living with it and it's the constancy of it, the fact that it's never going away." (Bob)

However, the role of support groups as a means of support, acknowledgement of the illness coupled with the exchange of information, emerged positively in the participants' experiences:

"I think the group, meeting other people with it, knowing that it is not a psychological thing it is real, you know." (Paul B)

"In the very beginning the fibromyalgia group was absolutely fantastic. It was just amazing to walk into a group of people who believed you, listened to you, understood, had the same thing, were able to give you tips." (Marie)

Discussion

A key finding identified in 'lived space' was the long and arduous journey that participants embarked on before finally being given a diagnosis. Brown et al (2012) reminds us that evidence from the US shows that it takes on average five years for a patient to be diagnosed with FM, and in that time they make more visits to their family physician when compared to other groups of patients. Early diagnosis at primary care level is therefore important. Primary care physicians however have difficulty in diagnosing FM (Perrot et al 2012) and they often reach a diagnosis based on elimination (Briones-Vozmediano et al 2013).

Primary care practitioners could be helped by the use of more simple assessment tools newly developed to diagnose fibromyalgia, i.e. the Fibromyalgia Rapid Screening Tool (FIRST) (Perrot et al 2010) and the VASFIQ Brief Symptom Scale (Boomershine et al 2011). These tools can simplify the assessment process which in turn could promote a more positive experience for patients anxious for acknowledgment of their symptoms and a diagnosis.

Most of the study participants were upset with being told that their illness 'was all in their head'; a finding also reported elsewhere (Rodham et al 2010). However,

managing FM patients can be overwhelming for primary care physicians (Brown et al 2012). It is not surprising therefore that two recently published studies have reported that the majority of medical professionals surveyed believed FM to be a psychosomatic as opposed to a physical illness (Ghazan-Shahi et al 2012, Amber et al 2014).

Loss and isolation were also evident in the participants' stories. Loss of self-esteem is common and FM patients often experience difficulty attaining educational or career objectives, due also to cognitive impairment that can present. Moreover, due to the symptom burden of the condition it is sometimes difficult for those with FM to be around others and hence a breakdown in friendship and relationships can occur.

As mentioned earlier, FM patients have increased visits to primary care practices because of delayed diagnosis and their many symptoms (Brown et al 2012). Nurses in primary care are ideally placed to support FM patients; however, it is interesting to note that FM patients report little regular contact with primary care nurses (Lempp et al 2009). In the study reported here, FM patients' lack of contact with nurses was also evident. While there are significant time constraints to assuming an additional role for practice nurses supporting FM patients within general practice, there are useful tools that could be used by primary care nurses to assess the impact of FM on patients. For instance, the Fibromyalgia Impact Questionnaire (FIQ) (Burkhardt et al 1991) only takes 5 minutes to complete and assesses the patient's ability to perform large muscle tasks, and ability to perform normal tasks and difficulties such as anxiety

and depression. Using a tool such as this not only identifies key areas of concern that need immediate addressing but can also improve communication with FM patients because issues identified by them as distressing can be explored further with the primary care nurse and general practitioner. Patients needing urgent intervention could then be referred to specialist rheumatology services. Furthermore, education for practice nurses in the use of the FIQ could be provided by specialist outreach rheumatology services, such as the one in Norfolk (Abdelhamid et al 2012).

There may also be a role for some primary care nurses to manage referrals to specialist rheumatology nurses for the diagnosis and management of FM patients. Specialist rheumatology nurses, who diagnose FM, when compared to rheumatologists, have been shown to provide a service that saves waiting times provides greater patients satisfaction and is cost-effective (Kroese et al 2008). Moreover, Ryan et al (2012) illustrated how a nurse-led chronic musculoskeletal pain clinic for FM patients in the community had a positive impact. In this service, there is a nurse-led diagnosis after an initial 30 minute appointment and from this first visit an individualised plan of care is devised for each FM patient. Ryan et al's (2012) study showed that 78% of patients using the service reduced their visits to their GP in the following 12months.

In conclusion, it is disappointing that FM patients interviewed in this study expressed similar experiences of a lack of understanding from health care professionals as those reported in other phenomenological studies undertaken over fifteen years ago

(Hellström et al 1999, Söderberg et al 1999). A key priority should be to improve communication between FM patients and health care professionals at primary care level. Ullrich et al.'s (2014) study which surveyed FM patients (n=256) found that they want open and patient-centred communication with health care professionals which is emotionally supportive to their personal circumstances. Open, reciprocal communication with patients living with a chronic disease can lead to their feeling empowered (Hawks 1992). A part of that communication process should acknowledge patients as experts (Taylor and Bury 2007). Some FM patients may gain particular benefit from attending an 'Expert Patients Programme', in particular, younger patients, those lacking in confidence and those with poor coping skills (Reeves et al 2008). Recent guidelines outline that the core of FM management should be the promotion of healthy lifestyle practices with active patient participation (Fitzcharles et al 2013). Primary care nurses are ideally placed to provide support on healthy lifestyle practices. They have been proven to provide effective health care (Keleher et al 2009) and their expertise could be put to greater use in the delivery of responsive, person-centred supportive care to FM patients.

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