

## **A qualitative exploration of the experiences of living with and being treated for fibromyalgia**

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# A qualitative exploration of the experiences of living with and being treated for fibromyalgia

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## Abstract

This study explores the life and treatment experience of people in the United Kingdom with fibromyalgia in order to inform the development of treatments which are both effective and acceptable to users. Qualitative interviews were conducted with 14 participants with interpretative phenomenological analysis used as the theoretical framework and analytical method. The themes identified were as follows: *Inauthenticity of fibromyalgia*, *An Unconventional healthcare experience*, *Re-creating support networks*, *Challenging the working identity*, *Threatening the family dynamic* and *Fighting, accepting or accommodating?* The biopsychosocial impacts of fibromyalgia disrupted the identity, lifestyle, roles and relationships of our participants with such challenges further exacerbated by the contested nature of the illness.

## Keywords

chronic illness, fibromyalgia, interpretative phenomenological analysis, qualitative methods, treatment

## Introduction

Fibromyalgia syndrome (FMS) is a chronic pain condition which has a global mean prevalence of 2.7 per cent (Queiroz, 2013) and has been described as pervading every aspect of the individual's life – occupational, personal, future and social (Wuytack and Miller, 2011). Patients frequently also experience sleep disturbance, fatigue and psychological distress, limiting the person's capacity to work and often damaging their relationships with loved ones. Marcus et al. (2013) observed that half of couples, which included one person with FMS, were not satisfied with their relationship and that their bonds with their children were also affected.

The profound symptomatic impact of FMS may be exacerbated by the perceived inauthenticity of the condition (Lempp et al., 2009). Illness beliefs such as those outlined in Leventhal et al.'s (1980) self-regulation model (SRM) are a helpful tool to understand the status of an illness. Leventhal's model describes a problem-based approach to illness in which our method of coping (and subsequent appraisal of this coping strategy) is formulated in response to an interpretation of the illness threat.

Using this model, we can appreciate how inconsistencies in the identity, cause, consequences, timeline and curability of FMS might affect the interpretation of FMS and subsequently the emotional and coping responses. A 'double burden' is felt by those whose life is dominated by pain as their experience is not adequately acknowledged (Juuso et al., 2011). Such contested authenticity in diagnosis, treatment and healthcare experience lends to a sense of invisibility to the condition and for those living with it (Lempp et al., 2009). The recurring theme of dissatisfaction in the patient-doctor bond from both perspectives is located in FMS' uncertainty (Briones-Vozmediano

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et al., 2013) – without an agreement on aetiology or treatment neither party can successfully engage in the relationship, and frustration may occur.

Attendance at a pain clinic has been shown to reduce doctor and clinic utilisation in a retrospective UK analysis (Ryan et al., 2012). This underlines the benefit of timely referral to a clinic which specialises in managing and treating known aspects of FMS via a range of potential interventions (not limited to one medical specialism) all from one location. A range of treatments and interventions have been developed including pharmacological, alternative therapies, psychological, physical activity and interdisciplinary programmes. Evidence for the effectiveness of these in reducing symptoms is varied and inconsistent. Few intervention trials have measured patient satisfaction, yet there is evidence that outcomes sought by the patient and practitioners differ (Mease et al., 2008). In order to develop a treatment which will meet patient needs and enjoy long-term adherence, it is essential to understand the perspectives of the patient – their expectations, their lived experience of an intervention, its acceptability, fit with lifestyle and their perceptions outcomes and effectiveness (O'Brien et al., 2010; Stutts et al., 2009).

A phenomenological approach to the embodied nature of illness describes a breakdown of normal existence in which our usual lived, pre-reflective body is interrupted by consideration of our body as an object of medical observation (Merleau-Ponty, 2002). This new third-person, medical gaze observes a biological body which interferes with our desires and activities which constitute 'normal' life. This reconsideration may cause the individual to question their own abilities today but may also lead to a yearning for the life that has been lost. Chronic illness forces the individual and those around them into a reflection on how they live, their homes and their relationships (Bhatti et al., 2011). Qualitative differences in the outlook of those living with FMS were described by Mannerkorpi et al. (1999) which impact the management and coping styles employed. Whether a person is struggling, adapting, in despair or giving up needs to be not only addressed but also considered in a treatment plan.

In this study, we listened to the lived experiences of people with FMS with a particular focus on treatments they have tried and how these impacted their life. The overall aim was to ascertain the effectiveness and adverse reactions to treatments with the intention of designing a new intervention within the United Kingdom.

## Methods

This qualitative study explored the lived experience of 14 people with FMS with a particular focus upon treatments and interventions they had tried or been offered. The rationale of the study led to the utilisation of Interpretative Phenomenological Analysis as a theoretical framework

and analytical method. Interpretative Phenomenological Analysis is well-suited to the study of ideographic accounts of chronic illness but also as a tool to illuminate the connections between participant accounts (Smith et al., 1999). Although a literature review had previously been undertaken, the themes noted during analysis were grounded fully in the data rather than using any *a priori* themes or codes.

## Participants

A total of 14 participants were purposefully recruited in the South Yorkshire area of the United Kingdom. All participants had received official medical diagnoses of FMS and were over 18 years of age.

The administrators of three FMS support groups were contacted in March 2015 and given a full description of the research study and asked if they would promote the study to their members. Around 30 potential participants made contact with the first author and following further discussions and a full briefing, 14 were recruited to the study, and interviews took place between May and July 2015.

The participants were all white UK citizens aged between 29 and 58 years. All spoke English as their first language, and two were men.

## Data collection

Ethical approval was obtained prior to data collection from the Research Ethics Committee of Sheffield Hallam University, and all names and identifiable personal details have been anonymised in this article.

The first author conducted in-depth interviews in a private location of the participant's preference – either their own home or Sheffield Hallam University. The interviews were digitally recorded.

The interviews were semi-structured by the researcher with open-ended questions to gain an insight into the psychological and social world of the participant in line with the guidance given by Smith (1995); they were informed by a review of the existing literature but primarily exploratory in keeping with a grounded approach. The participants reflected upon their lived experience of FMS and the strengths and weaknesses of interventions in terms of perceived symptom relief, user-friendliness, acceptability, lifestyle fit and long-term effectiveness while also discussing their own needs, expectations and wishes with regard to FMS treatments. The interviews lasted between 60 and 90 minutes and were then transcribed.

## Analysis

The interviews were initially read several times by the lead author with a focus upon embedding himself within the experiences of the participants as far as possible. Three

accounts which were particularly rich in data were chosen to be interpreted using Interpretative Phenomenological Analysis by the lead and second authors. Points of interest and significance were noted during the reading of the first transcript which progressed during analysis into emergent theme titles (or particularly salient phrases) which captured the essential quality of the participants account (as far as is possible). The emergent themes were noted and clustered where appropriate under superordinate themes or salient phrases. The three chosen transcripts were analysed in this manner individually by both authors who then compared their master list of themes and comments. There was significant harmony between the analyses during cross-validation with several major themes agreed regarding the restructuring of social support, ambivalence towards the healthcare provided, fighting for help and the status of FMS within UK culture. Both authors independently identified several significant phrases within the dataset, which seemed to describe key aspects of the experience and were subsequently incorporated into theme names.

The first author continued analysis of the remaining 11 accounts as above. The relatively small sample size permitted an iterative process and a close interaction between the researcher and the text. Any new emergent themes were continually re-checked against the previous accounts to ensure a continuity of meaning, and saturation of new themes was reached before the analysis was complete.

## Results

Six main themes were generated through the analysis of the data: Inauthenticity of fibromyalgia, An unconventional healthcare experience, Re-creating support networks, Challenging the working identity, Threatening the family dynamic and Fighting, accepting or accommodating? The first theme (Inauthenticity of fibromyalgia) was central, and experiences reported under this theme influenced those encompassed by the remaining five. The continuing contested status of FMS within the UK National Health Service (NHS) and wider society, as perceived by participants, formed part (and sometimes the basis) of the tensions apparent throughout the remaining five themes.

### *‘Nothing the doctors couldn’t know ...’ – the inauthenticity of FMS*

Illness representations are governed by an unspoken social understanding which is rooted within a traditional, biomedical model of aetiology, diagnosis and treatment plan (Leventhal et al., 1980). Lacking clear cause, with diagnosis often a complex process and where no established treatment route exists, the authenticity of FMS in particular was considered to be contested. One participant described her husband commenting that there is ‘nothing the doctors couldn’t know’. For her husband, despite witnessing the

impact of FMS upon his wife for many years, the condition still lacked true medical status. Lacking the sense of support from health professionals, the participant’s search for validation can be directed inward, as described here:

I think if I knew why I had it, for me that would probably be enough. If somebody says you have this condition because you have got this, this, this and this – for me that would be enough to know that it’s not my fault because sometimes it feels like it’s my fault ... it’s got to be something I’ve done.

Alternatively it can be turned outward towards a general public who may struggle to comprehend the enormity of a condition which does not follow the traditional medical pathway:

I think they [the public] sort of know what you’re saying but don’t think it’s enough to have ... the concern over it. I can’t live a normal life and if you try to say that to people, they don’t understand cos they look at you and think, ‘You’re alright’.

A lack of public understanding about the cyclical nature of fibromyalgia, characterised by alternating flare-ups (temporary increases in symptoms) and periods of increased physical mobility, led to a feeling in nearly half the participants that FMS was stigmatised: that others perceived their condition as an excuse (for laziness or disability benefits) or a sign of weakness. Over time, a lack of acknowledgement and public understanding had led to frustration:

Should I walk around with a walking stick ... so that you leave me alone and you don’t judge me? Should I stay at home with me curtains closed and stare at the ceiling just so you don’t judge me?

The contested status led to a sense of the invisibility of FMS and the minimisation of debilitating symptoms. This was a recurring theme throughout the interviews, with many explicitly using the word invisibility when attempting to describe the internal reality of life with FMS: ‘They call it an invisible illness and it really is ... if you could see how I feel, I would be black and blue’. The invisibility of FMS is not a new concept: the term has been used in many previous qualitative studies, including Sim and Madden’s (2008) review of the FMS literature, and by FMS participants themselves, to refer to the lack of outward manifestation of the condition. The misunderstanding created by the mismatch between the inner experience and outward appearance could sometimes extend to the participant’s own experiences and expectation of themselves. For example, one participant remarked, ‘It being an invisible illness ... even to yourself, sometimes you don’t grasp the idea that you can’t do that!’ The fact that their FMS was often co-morbid with irritable bowel syndrome (IBS), musculoskeletal issues, depression and migraines left participants sometimes

uncertain about the distinction between symptoms of FMS and those of other conditions, further complicating the expression of their own FMS and the clarity of their interactions with health professionals.

A common experience recounted by these participants was frustration caused by the assertion or suggestion that the condition is ‘all in your head’. Without a clear biological aetiology, doctors may attribute symptoms to psychological factors, arguably undermining the overwhelming physicality of the experience for sufferers and giving rise to the sense of inauthenticity described by these participants. Such a response may lead to a suspicion of those who prescribe psychological therapies for pain. One of the participants in this study commented that if ‘all pain does come from your head so they’d be saying *everybody*’d be lying that they’re in pain ... *everybody* could control it’. A biopsychosocial model may prove more helpful to balance consideration of the psychological (e.g. depression) and social factors (e.g. changing social networks and isolation), as well as the debilitating physical symptoms associated with FMS (Ferrari, 2000).

The inability to exercise regularly or at all, depression and side effects of certain medications led to an ongoing battle with weight gain for most participants. Weight gain acts as a threat to self-esteem but could also form part of the public misconceptions of and attitudes towards FMS, based in an ongoing discourse within UK culture regarding mobility, obesity and entitlement to benefits or support. This discourse and the resulting attitudes were expressed in one participant’s experience: ‘[when I] went into [supermarket], one of the assistants saw me in a wheelchair, she went, “Yeah, like she needs a wheelchair, she’s just fat.”’

The experience of FMS for these participants was dominated by a perception that the condition is viewed and treated as inferior to others or is used to make judgements about the individual themselves. In keeping with previous accounts, and reflected in Sim and Madden’s (2008) ‘legitimacy’ theme, the sense that their condition and experiences lacked authenticity seemed to be the product of both negative social responses from individuals (family, friends and strangers) but also a lack of formal social and medical support and acknowledgement, which would be expected when living with a chronic illness

### ***‘I want answers, don’t just cover it up again’ – an unconventional healthcare experience***

This second theme is related to the *Inauthenticity* theme above but has a narrower focus upon experiences with the NHS and health professionals. These participants described a significant breakdown in the traditional medical journey from diagnosis to treatment. Chronic illness complicated this journey; however, there was still an expectation that health professionals would take their presented symptoms seriously and offer ongoing support in the management of

symptoms, expectations which were not met for many of the participants. Diagnosis for some was a long time coming, and required considerable persistence:

Keep knocking on t’door ... don’t stop knocking ... because like with me, nobody took any bloods, nobody took any tests, nobody did anything until seventeenth time or whenever it were.

Following diagnosis, support continued to require proactive efforts on the part of sufferers: comments included ‘I’ve had to ask for everything that I’ve had’ and ‘If you’re not moaning, then you just get left on shelf and you’re not thought of’. Indeed, diagnosis was not always positive: some found it could actually hinder future interactions with health professionals because of the tendency for any and all symptoms to be attributed to FMS. Several reported dismissive attitudes, curtailed consultations and a sense of futility regarding their healthcare:

You get to the point where ... if I pulled a muscle I would probably be unwilling to go to the doctors because you know they’ll just say ... ‘It’s part of your Fibro ... you just have to deal with it’.

The contested nature of the illness created difficulties in the validation of FMS patients’ experiences by their doctors. These participants felt they were being scrutinised or mistrusted by health professionals, especially around the requirement for and prescription of analgesic medications. Consultations were seen as a ‘battle’, ‘a fight’ in which patients were ‘seen as though you are a drug addict just wanting stronger pain meds’ and that their explanations of their symptoms were regarded as ‘faking it’ and ‘making stuff up’. This naturally placed strain on their relationships with the medical staff. Another unsatisfactory aspect of their healthcare lay at the heart of the FMS experience, namely, the lack of answers:

I just collapsed on the bathroom floor, I were just crying ... it were horrible and they gave me morphine, get pain away and they send you on your way. It were like, ‘But what’s wrong, why ... why am I in this pain? I want answers, don’t just cover it up again’.

Their lack of understanding was often attributed by participants to a deficit in FMS training for doctors; however, there was also a perception that there had been some improvements in knowledge among more recently qualified doctors: ‘I find it’s the older GPs [General Practitioner] that’s not had the training ... because we’re acknowledging Fibro more now’.

A primary referral from doctor to rheumatologist is a standard route in the United Kingdom for people with suspected FMS for diagnosis and initial treatment. The participants who discussed their experiences with rheumatologists



described little improvement from their consultations with general practitioners (GPs) – while one met a specialist who was knowledgeable and proactive with advice, the remainder were left either without satisfactory treatment options or had the authenticity of the condition questioned again: ‘She as good as said that it was all in my head’ ... she said ... ‘If you found a job you liked more then you might be better’.

Despite accounts of having to argue for analgesic medications, these were the treatment of choice for most doctors. This contrasts with a recent review of FMS and its treatment by Borchers and Gershwin (2015), who recommend a ‘multimodal’ approach in which pharmacological therapy plays only one part, accompanied by both psychological and physical therapies, noting that people with FMS ‘should not be turned into a poly pharmacy’ (p. 130). Within this sample, the most commonly attempted treatments and interventions (in order) were pregabalin, acupuncture, codeine, exercise, amitriptyline, gabapentin, dietary change and supplements, hydrotherapy, planning and pacing, psychological therapies and tramadol. Analgesics and anti-convulsants (such as gabapentin or pregabalin) were described as unsatisfactory because they produced debilitating side effects and they proved inadequate in relieving pain. Side effects commonly included nausea, disorientation and drowsiness while the benefits for pain relief diminished over time. Such limitations and impacts were well summed up by one participant in describing how a doctor’s role was to ‘poison you enough to make life bearable’. The use of analgesics was often a self-management process of achieving an acceptable level of pain relief while still being able to function:

I’m on a 20mcg patch of Buprenorphine ... when I went up to 35, completely pain-free but I was just out of it for three days so I’ve got the balance now where I know I can function at this level.

Participants expressed fears about analgesic tolerance and were actively engaged in avoiding or navigating addiction when living with chronic pain:

I was 35 ... 36 when I was diagnosed properly and I thought then that, ‘They’re putting me on morphine at this age ... where do you go from morphine?’ That’s it, that’s the endpoint.

I’ve been advised not to cut it out entirely because it’s codeine-based and I’ve been on it a long time. It’s not such a good idea to cold turkey after all this time.

One other important consideration regarding treatments was the difficulty of leaving home and attending clinics. This was a considerable problem for three of the participants with severe symptoms or restricted mobility, who had missed treatments. One participant struggled to attend meetings with healthcare professionals: ‘I didn’t get there

because I [was in] too much pain to actually get there ... then I kept forgetting. I kept forgetting appointments’.

Beyond analgesics, some had physiotherapy; however, these participants had negative perceptions of the discomfort of the treatment and a lack of knowledge and empathy from the practitioners; similar comments were made about massage therapy. Apart from yoga and tai-chi (being too strenuous), other alternative therapies received almost entirely positive endorsements for symptom and mood improvement, and a lack of side effects. Aromatherapy, meditation, relaxation tapes and hot baths/hot-water bottles were commonly used. The only drawbacks to such therapies were sometimes the prohibitive costs and the difficulty of finding practitioners who were willing to work with people with FMS. A recurring theme was that ‘most of them don’t want to do anything because they’re too worried about being sued basically’.

Two treatments prescribed via the NHS – acupuncture and hydrotherapy – were seen as very effective; however, participants complained about their duration: ‘You only get ... six weeks and that’s it. So where’s the facility for it really?’ Several participants continued to access these services privately once the NHS treatment finished due to their positive results; however, this had a financial impact upon them and their families.

Finally, four of the participants had been referred to a pain clinic and described it as an incredibly beneficial experience. Many of these participants reported fighting for pain clinic referral, echoing the battles for medication described above. Those who had persisted and been successful in gaining a referral described a service which offered expertise and support in pain management and vital links to other services. The pain clinic was seen as an option to bypass obstructive GPs and get advice regarding dietary changes, relationship support and many other problems associated with the actual lived experience of chronic illness beyond medication and exercise. The pain clinic represented the closest approximation available for most participants of a specialist centre for FMS. Four of the participants independently questioned the absence of such a facility for FMS and linked this to the status of the condition alongside others. The desire was for ‘a one-stop shop’, with a range of useful treatments on offer:

[A hydrotherapy pool], CBT for those who want it, physiotherapy, a pain clinic doctor, a rheumatologist and the support group in with it ... you’d need the gym specifically for people ... not high weights, running machines ... you want a gentle walking machine, the steps ... and preferably a nurse as well that understands fibromyalgia.

The implications of the study of Briones-Vozmediano et al. (2013) on FMS management are pertinent for this theme yet underline the considerable change that is required to achieve equity in healthcare experience for those with

FMS. The authors suggest significant modifications are required to improve clinical competencies and doctor–patient relationships in the form of coherent, multidisciplinary strategies, health professional training and nurturing improved therapeutic relationships. One positive conclusion (from a United Kingdom perspective) is the reference to the use of pain clinics within the United Kingdom as offering interdisciplinary expertise in pain management. This is undoubtedly supported in this study; however, the validation received at the pain clinic is often in contrast to other interactions with health professionals.

Differences in medication beliefs and adherence in chronic illness were investigated by Horne and Weinman (1999), who highlighted the cost–benefit analysis undertaken by patients when considering and managing medications and their adverse effects. Decision-making will form part of a large-scale survey to follow this study, focused on the experience of available FMS treatments.

### *‘A Fibro-family’ – re-creating your support network*

Beyond the healthcare experience, the main sources of support for the participants were family and friends. The impact of FMS on friendship group activities was marked, and in some cases, FMS had completely restructured the support network. One individual described a regular experience of the participants, ‘I don’t ... associate with anyone outside. You might as well call it a Fibro-family because people just don’t get it’. Chronic illness can force a close examination of personal relationships and sometimes this was negotiated by some participants by de-emphasising or hiding symptoms: ‘You don’t tell people how you feel because they actually don’t want to know. They say, ‘How are you?’ but nobody actually wants to know how you are’. While those who were not judgemental and could accommodate FMS continued as close friends, in the end, the burden of illness led to some bonds being broken as ‘the ones that can’t cope pull away and you’d lose contact with them’.

The sample for this study was drawn from local support groups and the majority of those who were able to regularly attend the meetings stressed the key benefits as helping with isolation and meeting people who would be able to understand especially soon after diagnosis. ‘It was important at that stage to meet people. To know that there were other people out there ... who felt like I did’. The nature of the condition and cultural norms regarding membership of support groups (Grande et al., 2006) were described by all male participants of the study as potential barriers to male attendance, however, one described how FMS had forced a reassessment after an initial rejection of alcohol support groups earlier in his life:

I’m not normally a support group person but alcohol [was] something I wanted to leave behind whereas Fibro is something

that’s there in the future. I can choose to stop alcohol, I can’t choose to stop Fibro.

Wuytack and Miller’s (2011) phenomenological study of FMS described the pervasive action of FMS on women’s lives, and this was apparent in this study. The incomprehension of those who do not understand led to the breaking of bonds and a desire not to share experiences with others. Possibly due to the nature of the sample, the benefits of peer support were highly apparent and echo the work of Sallinen et al. (2011) whose study demonstrated the importance of such support networks in the reconstruction of identity following diagnosis, acceptance of fibromyalgia and ongoing coping mechanisms.

There was ambivalence towards online fora and support groups among participants who had used them previously, with half describing the positive nature of 24/7 support and the opportunity to share ideas about treatments; however, the other half described struggling with the sometimes aggressive nature of fora and the mixed emotions of seeing the deterioration of others with FMS: ‘I’ve found I get more depressed looking at them, thinking, ‘Jesus, am I gonna get that bad?’

Daraz et al. (2011) evaluated the available online information resources for people with FMS (from a primarily North American perspective) and concluded there was great variation in the quality available. This was apparent in a lack of comprehensive information on most existing websites, while higher quality websites often provided information with technical language inappropriate for the general population. Providing accurate and reliable online information not only empowers patients to make informed decisions about their own health when they might not be comfortable (or able) to discuss with health professionals directly (Sillence et al., 2007) but also can be a resource for other family members and the wider public to learn about the condition.

### *‘Who swiped my Mum?’ – threatening the family dynamic*

FMS also compromised the functioning of the family. Many of the participants relied heavily upon their partners and family for day-to-day tasks and as such; their family dynamic had changed with one participant remarking, ‘I’ve had to change so much over the years ... my children have had to change so much around me over the years’. Those participants who were married often referred to the strain it can place on this relationship and those closest to them: ‘It’s been 30 years but he’ll say things like, “didn’t know I were gonna marry a cripple,” he doesn’t mean it nasty ...’. Participants understood the strain their FMS symptoms placed on others, and this awareness caused distress:

Your pain goes up, your stress goes up and it then affects your memory and your concentration and how you ... feel and it

also affects how you are with other people because you can be very short-tempered with people and draw back from people and then after you've been like that, you feel very upset because you've been like that to people.

Participants struggled to juggle family demands and the needs of their condition. For example, although they believed it would benefit their symptoms, participants found that making even mundane changes to their diet was difficult to achieve due to financial constraints or the daily reality of family life. One participant described how her family 'get bored and they won't eat vegetable soups or a vegetable stir-fry. They want English dinners, home-made'. The physicality of parenting was another challenge, especially for those with younger children, for whom FMS sometimes acted as a barrier between them and their child:

I try not to let things get me down and I try to push myself to do stuff with the kids cos I don't want them missing out ... You get hit (with fatigue) and it's so hard ... I struggle to look after him because I was so tired all the time.

If my kids could hug me that would be great but they hurt.

Participants recognised that the experiences for the child of a parent with FMS could also be devastating, from frustration at the loss of the pre-FMS parent they knew, powerfully expressed by the son of one participant who asked her, 'who swiped my Mum?' to the fragmentation of the family unit: 'My older son moved in with his Dad cos he couldn't handle seeing me deteriorating in the way I was'.

When discussing the onset of FMS, most of the participants described a traumatic incident later in life; however, a few of the participants described particularly problematic childhoods, including abusive relationships. Such experiences could dramatically alter the relationships within the family across the generations.

It seems to come up again and again and again either domestic abuse from a husband or father or mother ... basically your whole central nervous system's sensitive ... by keep being hit again and again?

Many of the participants discussed the hereditary nature of FMS and described close relatives who had also had chronic pain conditions. For some, this was accompanied by fear for their own children's health and the construction of FMS as an ongoing, intergenerational condition within their family: 'My Dad had severe pain and my daughter has severe pain and she's only 12 ... she's already under the pain consultant and so it's coming up ...'.

Wuytack and Miller's (2011) and Marcus et al.'s (2013) studies discussed the negative impact of FMS on family bonds, and this was supported in this study. Cudney et al. (2002) and Liedberg and Henriksson (2002) mention that FMS symptoms negatively affect relationships with family

members, changing family roles and dynamics, sexual relations and support. The current findings provide detailed insights into how and why this occurs, demonstrating the day-to-day impact on being able to parent and maintain intimate relationships in the context of FMS. The experience of FMS appeared to create negative self-perceptions in these participants. These included the sense of being a burden, the belief that their having FMS interfered not only with the person's own activities but also those of family members and loved ones. Some also felt they were unable to offer the necessary level of support and care for children and were impacting negatively upon their development as a result.

### *'Taking part of my identity away' – challenging the working identity*

A focus group study by Arnold et al. (2008) detailed the profound impact FMS can have on the identity of an individual in not only their social but also their occupational function – the presence of FMS changes the way people live their lives. The intense and cyclical nature of FMS symptoms can make regular work incredibly difficult, and this appeared to have had a severe impact on the identity and self-esteem of these participants with FMS:

An occupational health consultant ... said to me, 'I don't think you'll ever be a physio again'. That's devastating to be told ... it's my career you're playing with here ... somebody's taking part of my identity away from me.

I expect being best okay? ... I'm a perfectionist and there is no way I'm weak and if I tell people I can't do things, then I don't see myself as being useful anymore ... people come to me for help.

Work was absolutely impossible for many of the participants and for the others, symptoms and medications dictated the extent to which regular work was possible. This created reliance on others, financial difficulties and guilt of not being able to provide for their family:

It was my responsibility that was what I was to do and then now I ... I ... [exhales] ... no, there's not a chance on earth. There's some days where I'll look at me husband and then I went, 'I'm so sorry ...' and I feel ... the guilt is horrendous.

The financial reality for many was the need to accept benefits but this damaged the pride of those used to working. A participant described it as 'soul destroying ... I hate being on benefits'.

The invisibility of the condition and an ongoing public discourse in the United Kingdom regarding the credibility of disability benefits can lead to stigmatisation of those with FMS. Garthwaite (2011) describes how media language can be employed to stigmatise those who receive sickness-related benefits as *unwilling* rather than *unable* to find appropriate work. Such rhetoric from the media and



politicians not only fuels public misunderstanding but also may reduce the openness of employers to people with disabilities. One participant felt as if society saw them as ‘a scrounger. I should get to work ... if you’re in a wheelchair you got sympathy but if they can’t see your condition they won’t believe there’s anything wrong’.

For the employed participants, the ability to continue working had become harder, not only due to increasing symptoms but also due to the increasing dependence upon co-workers’ and employers’ understanding:

I’m not going to be able to work in the true sense of a 9-5 or even guarantee I can work set hours ... unless I can get a really understanding (employer) which I’ve got currently.

These findings are in line with the study of Bossema et al. (2012) regarding those sorts of work environments those with FMS consider suited to their needs. The participants described needing work which is paced in such a way so that energy may also be conserved for time away from work.

### *‘The more I push, the more it fights back’ – fighting, accepting or accommodating?*

The relationship between these participants and their FMS developed over time with changes to both the status of the condition and the individual. A discord between body and mind was alluded to by several of the participants. FMS was described as being in control like ‘another person strapped to your side that restricts and controls you’ and ‘It’s almost like my body shuts me down’. The difficulty that many participants had in pacing activities to minimise the likelihood of flare-ups was based upon a feeling that they had to make the most of times when the symptoms were less intense. This natural reaction characterised the daily experience as an ongoing fight with FMS in order to maintain some form of agency. The lived reality of this fight is illustrated by extracts from two participants: ‘The more you let it, the more it takes’ and ‘the more I push, the more it fights back’. It seemed an unwinnable fight, which understandably led some to grieve the life they were meant to have and feel a profound sense of unfairness in their position:

Who gave me this body? I didn’t ask for this one.

Shut the curtains, shut the world out ... you have a pity on yourself because you think, ‘Why am I dealing with this?... Where’s my twenties gone because it was such a happy time.

For those further along the illness trajectory, the concept of acceptance was occasionally raised:

I think the biggest part of it was acceptance and ... I only accepted it last year. So what ... seven years fighting? ... I

don’t feel disabled, I don’t want to accept that. Eventually accepted it over the last year ... to tell the truth it hasn’t changed things that much that I thought it would.

Although the term ‘acceptance’ was used by participants, these discussions were centred on the need for time and distance to re-build confidence, accept new limitations and re-design life around FMS. Thus, the notions of adaptation or accommodation were perhaps more appropriate to these participants’ experience than acceptance, similarly to ‘adapting’ in Mannerkorpi et al.’s (1999) ‘patterns of living’ typology. The process of gradually accommodating to FMS often took the form of major adaptations to lifestyle with some adapting their home (including converting rooms downstairs), two needing crutches or walk-sticks and four using a wheelchair. The use of a wheelchair or scooter is often a highly emotive and divisive moment for individuals as ‘it’s like you’ve conceded. It’s like you’ve given up, but then what is sitting at home in a chair cos you can’t go anywhere ... that is conceding as well isn’t it?’

Three of the participants had clearly experienced times when acceptance was far from their minds: the hopelessness and burden of the excruciating symptoms and psychosocial strain had led to thoughts of suicide.

I’d wrote my letters, I’d done everything, I’d took my son to where I thought he was safe. Everything had just ... nothing mattered.

I attempted suicide ... It’s just going to get worse and worse and worse and living with that feeling and the knowledge that there’s nothing I can do that makes it better ... there are no medications out there that’s going to take this pain away ... the only way I can’t be like this is to be dead.

Despite occasional accounts of a deep sense of hopelessness, the interviews were characterised – in the gestures and the tones used – by pragmatism in the face of many of the barriers and difficulties these participants had faced. In the end, it seemed one had to persevere and take control of the situation oneself because support was often not available and even when it was ‘people could give you advice but you don’t have to accept it ... again it comes down to your own personal choice of what you do with the tools *available* (author’s italics) to you’.

Sim and Madden’s (2008) metasynthesis of FMS studies describes a dualism in the experience of pain which was also apparent within this study. While the experienced pain (and FMS generally) was often referred to as separate and uncontrollable (using a biomedical model which reduces the accountability of the person with FMS), participants also referred to the interconnectedness of the mind, body and environment in symptom progression and management. The Cartesian dualism and biomedical model are thus enlisted and then rejected in

these complex and ambiguous and conflicting understandings of the FMS experience.

## Discussion

This study demonstrated the immense disruption FMS had upon the lives of these participants, the challenges faced in accessing treatments and the inadequacy of many treatments. Pain and fatigue seemed at times to dominate their lives. Pain was extreme and idiosyncratic but would be misunderstood by others largely because of its permanence. In keeping with this, Sim and Madden's (2008) review reported that pain was the most commonly described symptom in the qualitative FMS literature, with a recurrent theme relating to the difficulties of adequately describing the pain experience and having it understood and acknowledged by others. These findings are replicated in more recent studies of FMS (Sorensen and Christiansen, 2017) and of chronic pain more generally (Stenner et al., 2015), with psychosocial impacts attributed to both the pain and its incommunicability to and incomprehension by others. In our findings, fatigue could be totally debilitating, and the personal benefits of activities were constantly balanced with their negative consequence. Participants in previous studies (e.g. Cudney et al., 2002) have described fatigue as the most disabling aspect of the condition, and for many, the two symptoms intertwine in that pain is exhausting and also interferes with sleep, creating chronic fatigue, with the resulting impact on daily activities and relationships (Sim and Madden, 2008).

Often for the first time in the participants' lives, their body had become discordant with not only their own intentions but also the social and physical world around them. Two themes outlined in Crowe et al.'s (2017) review of chronic pain studies, termed 'body as obstacle' and 'disrupted sense of self', which describe how bodily symptoms interfere with lifestyle and identity, have resonance with our themes describing changes to participants' family roles and working identity. Frustration and depression are commonly described consequences of these disruption of activities, goals and aspirations in previous work (e.g. Cudney et al., 2002; Dow et al., 2012), as they were here.

As described by Merleau-Ponty (2002), chronic illness can limit a person's ability to function and thus redesigns their sense of self. Changes to mobility alters the person's way of being in the world while their subjective embodied experience takes place within a social world now inhabited by health professionals and changed relationships with others. Carel (2014), however, asserts the ability of individuals to set fluctuating levels of illness to one side, in order to carry on as the pain recedes despite the knowledge that the symptoms will flare-up again. In this way, consequences were usually ignored by the participants of this study in order to make the most of the better times. Thus, most participants still seemed to be fighting FMS, and others were

starting to accommodate it in their lives, but few were even considering accepting it. Many had been forced to withdraw from work and from large parts of their social and family life as previously observed by Wuytack and Miller (2011). Women with FMS described in Liedberg and Henriksson's (2002) study how work offered a source of value, structure, fulfilment, and income but added to their burden and stress, and increased symptoms of pain and fatigue. Most wanted to stay in work but described structural barriers and interpersonal challenges in so doing, and those who had been forced to leave did so reluctantly and grieved the losses this created. Similarly, our participants had resented and railed against, rather than accepted, these enforced changes in their lives.

Opportunities to continue employment may well be controlled by issues outside the individuals control such as the need for adjustments to workload, hours and tasks. These accommodations require the help and understanding from management and colleagues and although complex, this study is helpful in re-directing the question of employment for people with FMS away from a focus on individual disability to a consideration of how organisations might support the desire to continue work. Such thinking is based upon a social model of disability (Oliver, 1990) in which environmental and social conditions constrain the individual's opportunity to participate in work and society, and which recognises the need for society to change to meet all citizen's needs, rather than requiring individuals to adapt as best they can to the status quo.

The chosen method produced rich data which has offered insights into the experience of FMS, which both support and extend previous findings. They also present a novel and helpful view of treatment experiences within the United Kingdom, which will be expanded upon in large-scale surveys. Although many of the interviews touched upon emotional and painful experiences, the participants described the study experience as useful and were extremely positive that their voices were heard and were included in research. A common perception was that FMS research (especially in the United Kingdom) was lacking, which was seen as further evidence of the diminished position of FMS relative to other conditions. The sample were drawn from local support groups, so these may be individuals who do not perceive they are receiving sufficient care from their family and healthcare providers, and in some cases, the participants were active in attempting to create the expertise and support service within their group that they felt was lacking. Many from the group were unable to work and so the sample may suffer more severe symptoms than the general FMS population. Furthermore, the participants had the confidence to participate in such a group so may be a more vocal, unsatisfied and symptomatic sample than the broader UK population with FMS. It may be argued that the issue of authenticity itself is a product of a sample of whose search for recognition of their illness meant they were more likely to participate.

The issue of the invisibility of the illness was keenly felt in this study, similarly to findings made by Lempp et al. (2009) and reported in the study of Sim and Madden (2008). The incongruity between what is felt by the individual and seen by the outsider forms one part of the common thread tying the accounts together – that of the authenticity of FMS within UK culture. The participants in this study shouldered the ‘double burden’ described by Juuso et al. (2011) in their experiences with doctors, (ex) friends, family and the general public.

Difficulties in doctor–patient relationships often began during the long wait for diagnosis, as reported elsewhere. For example, Söderberg et al. (1999) captured the lack of clarity pre-diagnosis, the initial positivity of diagnosis and dissatisfaction with treatment. Accurate diagnosis is important; however, the doctor–patient relationship is a long and potentially problematic one, especially in the context of under-developed understanding of the condition, varied treatment paths, many of which prove unsatisfactory, and financial constraints on providing more popular options. Our study highlights how these aspects contributed to a long-term disruption to the expected healthcare experience, resulting in growing mistrust of the medical profession, indeed, a mutual loss of trust (Juuso et al., 2011). For the person with FMS, diagnosis is a step in a process of discovery about the condition and living with it, which gradually unfolds and is never complete (Adamson, 1997). Navigating this process involves drawing on a range of resources, in which medical advice plays a vital, but not by any means the only, part (Madden and Sim, 2006).

Participants in this study perceived a lack of expertise and resource within the NHS which forced many into difficult decisions regarding private healthcare. The sense that for many patients the onus was upon them to repeatedly demand satisfactory treatment for such a debilitating condition was profound and suggests professionals could consider taking a more proactive approach to FMS. The notion of availability of resources referred to in the final data extract above – and presented in author’s italics – reflected the pragmatic notion that a patient is obliged to take responsibility for their own well-being in the current unsatisfactory state of affairs. The authors suggest that researching treatments, with the concomitant energy and skills required to access or to demand them, should not be the responsibility of a patient with a diagnosis of FMS.

Our participants were all drawn from online support groups and had, therefore, taken it upon themselves to seek out the support they lacked elsewhere. Sim and Madden’s (2008) review describes a theme in the literature, ‘Re-evaluation of life’, which includes the strain placed by FMS, its impact and misunderstandings, on social relationships, resulting relationship breakdown, loneliness and isolation. Raymond and Brown (2000) discussed the importance of support groups in coping with diagnosis, and Madden and Sim (2006) described the role of the support group as an ongoing co-creator of FM

diagnosis. Interesting in our findings was the notion that people would gradually and deliberately loosen ties with people in their social network who had been unable to support or validate them and replace these with a ‘Fibro-family’. Somewhat in contrast to certain previous findings (e.g. Crowe et al., 2017; Sorensen and Christiansen, 2017), which suggested that people were primarily motivated to maintain existing lifestyles and relationships, our data pointed to a movement in some participants to, instead, reformulate their lives, support networks and roles around fibromyalgia. The data suggested that an important part of new relationships was the sense of understanding and validation which was lacking elsewhere. These new ties suggest the gradual assumption of a new ‘Fibro’ identity, following disruption and damage to the previous ones, rewarded by a sense of ‘belonging’ (Juuso et al., 2013), and the positive, affirming experience of offering support to others (Schwartz and Sendor, 1999).

Using Leventhal et al.’s (1980) framework for illness representations, differences in the socio-cultural setting of an illness are expected to have a bearing upon the individual experience of that illness. In a recent study by Ruiz-Montero et al. (2015), subtle cultural differences were described in the experiences of women with FMS in Spain and the Netherlands in terms of illness perception, understanding and impact. Kool et al. (2009) considered that invalidation of FMS was a combination of the responses of family, colleagues and the healthcare system to FMS. Such findings underline the very social nature of this phenomenon and the multiple layers involved in the construction of illness authenticity.

The contested status of the condition has led to a social construction of FMS which negatively impacts the experience of those living with it (Lempp et al., 2009). The reframing of FMS would require both validation of the condition by health professionals and increased public awareness. Improving the experience for people with FMS by challenging issues of illness status is a monumental societal task; however, the lived experience of FMS could be improved by a proactive health service which acknowledges FMS and improves access to interventions which can alleviate symptoms. Acknowledging FMS means admitting the shortcomings of medical knowledge (Werner and Malterud, 2005), accepting and valuing the experiences and expertise of people with FMS (Donaldson, 2009), and supporting and empowering them (Kool et al., 2009). As Söderberg et al.’s (1999) participants reported, a simple, achievable feature of positive doctor–patient encounters is simply being listened to and trusted. Improving access ranges from signposting available treatments to research and funding to enhance what is currently available. Research into improved (or the creation of new) online resources which better balance accessibility with content may also be of benefit. Currently available interventions which could benefit people with FMS – as described by these participants – are clearly not being made available to



patients or are only accessed by those who have the skills and energy available to fight for them, which places many people with FMS at a distinct disadvantage. The findings of this study are being used to inform a national survey to quantify the experience, perceived effectiveness and adverse reactions to treatments currently available, with the intention of designing a new user-focused intervention.

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