

A qualitative exploration of experiences of physiotherapy among people with fibromyalgia in the United Kingdom

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TITLE PAGE

A qualitative exploration of experiences of physiotherapy among people with fibromyalgia in the United Kingdom.

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ABSTRACT

Introduction: Fibromyalgia is a common condition characterized by widespread pain and debilitating symptoms. It is a complex, varied and unpredictable condition, which can frustrate and complicate the relationship between patient and practitioner. There is currently little evidence regarding fibromyalgia patients' perspectives on physiotherapy in the United Kingdom (UK).

Objective: To investigate the experiences of physiotherapy from the perspective of people with fibromyalgia in the UK.

Methods: A UK-based mixed-methods survey gathered broad-ranging data from 941 people in the UK with fibromyalgia, regarding living and working with, and being diagnosed and treated for the condition. Qualitative data regarding experiences of physiotherapy were extracted from the full survey dataset, which included responses from 205 participants.

Results: Thematic analysis generated two themes, each with two subthemes. "Access to the Physiotherapist: 'The Long and the Short of It'" had subthemes of "The Long: Delayed diagnosis, referral and access" and "The Short: A few physiotherapy sessions are not enough". "The Experience of Physiotherapy: Care on whose terms?" included subthemes of "Physiotherapist as 'Expert'" and "Patient as Partner".

Conclusion: Physiotherapy characterized by understanding and respect was experienced more positively than inflexible, 'expert' approaches. Findings suggest implications for emotional responses, communication skills and practitioner training.

Keywords: Fibromyalgia; Physiotherapy; Qualitative; Patient perspectives; Survey.

INTRODUCTION

Fibromyalgia is a common condition in the United Kingdom (UK). Fayaz et al. (2016) estimated the prevalence of fibromyalgia meeting the 2010 American College of Rheumatology (ACR) criteria as 5.4% (95% CI 4.7% to 6.1%). It is a chronic condition characterized by widespread pain and a range of other debilitating, activity-limiting symptoms (Wolfe et al, 2011). Nonetheless it remains a contested disorder (Mengshoel, Sim, Ahlsen and Madden, 2018). Current explanations include overstimulation of the central nervous system (Chinn, Caldwell and Gritsenko, 2016), which cannot be ascertained through clinical, laboratory or radiological examinations (Mengshoel and Grape, 2017; Wang et al, 2015). The process and implications of diagnosis have been hotly debated and diagnosis is currently based on presence and severity of a cluster of symptoms (Mengshoel, Sim, Ahlsen and Madden, 2018).

From the onset of symptoms, the average time to diagnosis with fibromyalgia in the UK is between 2.1 and 2.7 years (Choy et al, 2010). Diagnosis is typically made by a rheumatologist, often after treatments such as physiotherapy have failed to resolve the symptoms. Once diagnosed, evidence-based guidelines recommend pain medication, exercise and cognitive therapy (Macfarlane et al, 2017). As exercise is a core part of both the treatment of pain and guidelines for fibromyalgia care, physiotherapists are well-placed professionally and highly likely to be involved with care of those with fibromyalgia. As the 2010 ACR diagnostic criteria require multiple sites of pain (Wolfe et al., 2011) many people with fibromyalgia will have come into contact with a physiotherapist both prior to and following diagnosis. Thus, most fibromyalgia patients are likely to have formed an opinion on treatment by physiotherapists.

Physiotherapy practice with those with fibromyalgia can involve a range of different treatments, informed by a range of treatment philosophies. Guidelines suggest that physiotherapists could offer approaches such as graded exercise (inclusive of hydrotherapy), acupuncture, education, multi-modal psychologically-informed rehabilitation and support choices around medications (MacFarlane et al, 2017). Considerable variation was identified by McVeigh et al. (2004), for example, in a cross-sectional study of practice in Northern Ireland. Physiotherapists disagreed on the primary role of physiotherapy in managing fibromyalgia, ranging from increasing function (32%), improving patient education (29.3%) and pain reduction (24%). Exercise was the most commonly used treatment (a graded exercise program being more common than hydrotherapy), but some also offered heat, massage, electrotherapy, acupuncture and patient education sessions. Similar variation in practice is apparent within other health systems, for example, in the United States (Bennett et al, 2007) and Germany (Häuser et al, 2012).

Updates to guidance on the management of fibromyalgia are built upon a growing evidence base for efficacy (MacFarlane et al, 2017); however, in considering treatment effectiveness it is also important to explore patient perspectives. The paradigm shift from a biomedical to a biopsychosocial model (as proposed by Gifford, 2000) has attracted research focusing on the lived experience of patients interacting with physiotherapists and treatments. This may be particularly important when supporting individuals with fibromyalgia as studies have reported skepticism, disbelief and humiliation from misunderstanding health professionals (Furness, Vogt, Ashe, Taylor, Haywood-Small and Lawson, 2018; Mengshoel, Sim, Ahlsen and Madden, 2018). Physiotherapists' aims to normalize functional physical abilities through rehabilitation can be frustrated by the variable unpredictable nature of fibromyalgia

symptoms. Mengshoel and Grape (2017) note that the physiotherapist-patient relationship may not always be an easy one, with physiotherapists complaining that patients don't adhere to their treatment plans, and patients arguing that physiotherapists don't understand the experience of living with fibromyalgia. Taylor, Steer, Ashe, Furness, Haywood-Small and Lawson (2019) reported that low ratings of physiotherapy as a treatment of fibromyalgia were caused by, among other things, increased pain during activity related treatment and low adherence.

Evidence suggests that the beliefs and central concerns of chronic pain patients are not always fully understood by physiotherapists but when they demonstrated awareness of the patient's perspective, this improved patients' experience of the consultation (Sanders, Foster, Bishop and Ong, 2013; Stenner, Palmer and Hammond, 2018). Similarly, a systematic review by Synnott et al. (2015) of physiotherapist perceptions of patients with low back pain suggested a preference for dealing with mechanical and biomedical rather than psychosocial issues, for which practitioners felt under-prepared and under-resourced. Low levels of confidence have been reported in various studies of health professionals in relation to assessment, treatment and support of fibromyalgia patients (Busse, Kulkarni, Badwall and Guyatt, 2008; McVeigh et al, 2004). Further issues may arise from patient high expectations of treatment (as cure): Synnott et al. (2015) noted that physiotherapists found patient expectations a very challenging part of their role.

In response to the complexity of the condition and its care, there may be a tendency to stigmatize this group as demanding, attention-seeking and poorly motivated (Undeland and Malterud, 2007). For example, studies in different national contexts have found that professionals have negatively characterized fibromyalgia patients (primarily women) as

having 'a profile of complaining' (Briones-Vozmediano, Öhman, Goicolea and Vives-Cases, 2018), 'neglected' in close relationships (Billis et al, 2007) 'self-focused' or 'willing to be ill' (Sanders, Foster, Bishop and Ong, 2013). These attitudes to some extent mirror the general social context, in which the impairments associated with fibromyalgia are often invisible, unrecognized and unacknowledged (Ashe, Furness, Taylor, Haywood-Small & Lawson, 2017).

A range of factors, therefore, risk engendering negative feelings between physiotherapist and patient in the context of fibromyalgia, with detrimental impacts for both parties and the professional relationship. Approaching fibromyalgia patients for their perspectives on the physiotherapy treatment they have received might help improve the awareness and insights of practitioners, suggest areas for improvement in practice and training, and thereby enhance the experience and effectiveness of care. There is little current qualitative evidence considering the experience of physiotherapy as an intervention from the perspective of the patient with fibromyalgia, and this study sets out to bridge that gap.

METHODS

Objective

The aim was to investigate the experiences of physiotherapy from the perspective of people with fibromyalgia in the United Kingdom, using a qualitative survey design.

Data collection

Data for the current study was extracted from a large dataset resulting from a mixed methods online survey, the [University] In-depth Fibromyalgia Survey, conducted by the authors in 2016. That survey gathered extensive quantitative and qualitative data from a large UK sample of people with fibromyalgia, recruited via online networks, about their experiences of living with, working with, being diagnosed with and being treated for fibromyalgia and associated treatments. The authors have previously reported participant perceptions about the cause of their fibromyalgia (Furness et al., 2018) and their ratings of treatment effectiveness and side effects (Taylor et al., 2019). Survey questions were informed by an in-depth interview study (Ashe et al., 2017) and existing literature. The qualitative questions covered experiences of diagnosis, health professionals and specialist clinics; accessing treatments; satisfaction with treatments; financial, work and family issues; social responses; and support network experiences. The survey was approved by the University Research Ethics Committee and applied the British Psychological Society's guidance for research with human participants (BPS, 2014).

The current study explored survey participants' perceptions of physiotherapy. Relevant data were identified using the search term "physio*" and included qualitative responses from 205 participants. These arose in response to a range of questions, including: "How easy was it to get your diagnosis?" "What has been the experience of getting the treatments and

referrals you need from the NHS?" "How satisfied are you with the available treatments and why?" "Do doctors and health professionals understand the impact of fibromyalgia?" and "If you were designing a treatment for you today, what would it include?"

Length of responses in the resulting dataset ranged from a few words (e.g. regarding ideal care, pt. 57 wrote "Acupuncture, hydrotherapy and physio. Everyone is different") to long descriptive and comparative accounts of physiotherapy (e.g. pt. 560 who wrote 921 words). The dataset upon which the findings are based comprised 15,329 words in total.

Participants

941 people responded to the survey, of whom 94.8% were women, 95.9% White, 52% were married / cohabiting, 40.1% were employed and 30.5% had a University education. Mean age was 47.7 years (range 18-87) and mean time since diagnosis 5 years (ranging from <1 to 37 years).

Of these, 205 referred explicitly to physiotherapy in qualitative responses. This group was very similar demographically to the larger sample: 96.5% female, 95.1% white, 62.7% married / cohabiting, 40.9% employed and 37.5% had a University education. Mean age was 47.1 (range 18-76) and mean time since diagnosis was 5 years (<1 - 37 years).

Analysis

Responses were analyzed inductively for themes, using Braun and Clarke's approach (2006) of immersion in data through reading, data coding and categorization based on comparative analysis, and creation of themes. The first author developed categories and themes, which were discussed and refined within the team. Themes reflected semantic content of participant responses, awareness of previous theoretical and empirical work, and the

individual and collective interpretations of the researchers, whose backgrounds include Health, Developmental and Social Psychology, Biomedical Science and Physiotherapy. Data extracts were selected to represent themes, each of which is accompanied below by information about the participant, including their number, gender, age and time since diagnosis (e.g. pt. 57, F, 76, 4 y = participant number 57, who is female, aged 76, and was at the time of the survey, 4 years since diagnosis).

RESULTS

Two themes, each comprising two subthemes, were generated. The themes reflected variations in and problems with the accessibility and experience of physiotherapy care, which impacted on patient well-being and satisfaction with care.

Theme One: Access to the Physiotherapist: “The Long and Short of It”

This theme articulates the experiences of participants in gaining access to physiotherapy, as encapsulated in the following quotation:

Physio has proved beneficial but would like this to be more readily available (pt. 394: F, 50, 6y).

Physiotherapy was commonly utilized for fibromyalgia, and many welcomed a referral and benefited from care, but remained dissatisfied with what they had received. Two key subthemes within this theme reflected “The long and the short” of the narratives relating to physiotherapy access. They were “The Long: Delayed diagnosis, referral and access” and “The Short: A few physiotherapy sessions are not enough”.

Subtheme 1a - The Long: Delayed diagnosis, referral and access

This subtheme addressed participant experiences of barriers to physiotherapy, which made accessing it difficult and long-winded, and included problems getting diagnosis, being referred for care, and physically accessing treatment centers. Because of shortcomings in knowledge about fibromyalgia, the complexity of symptoms in each individual patient, and the condition's questionable credibility in the minds of some clinicians, most patients spoke of the route to diagnosis as a long, painful and frustrating one.

As you will know no patient is alike in this most mysterious and ill-understood illness (pt. 799: F, 74, no time since diagnosis provided (NTSD)).

Wish they could try it for a week, but with lack of understanding and the symptoms being so widespread I know why they are skeptical (pt. 744: F, 56, 3y).

For these participants, physiotherapists had often performed a positive role in the diagnosis journey:

A private physiotherapist gave me literature re fibromyalgia which I then passed to my GP, who then referred me to rheumatology, where I was officially diagnosed (pt. 199: F, 66, 16y).

I have been and seen many doctors over the years and there was only one who took it seriously, but this was due to the physio writing a firm letter and telling him to help me, basically (pt. 801: F, 32, 1y).

These extracts demonstrated how physiotherapists' insights, actions and support had helped identify symptoms and facilitate referrals, resulting in the long-awaited diagnosis for some. For others diagnosed with fibromyalgia, some had been refused physiotherapy and most had a very long wait to be seen:

When I suggested physiotherapy, it was rebuffed as being a “waste of time” (pt. 204: F, 48, 1y).

The appointment is set for 10 months since I was referred to it, which is ridiculous (pt. 90: F, 27, 1y).

I am currently waiting to join a 4-week fibromyalgia exercise class offered by the physiotherapist. There is a long waiting list and I will have to wait 4-8 months for this (pt. 911: F, 44, 1y).

The conditional nature of NHS funding was considered a culprit here, with chronic, incurable conditions like fibromyalgia under-funded in relation to need.

Unfortunately, my belief is that Fibromyalgia is not really taken seriously as it is an “invisible” condition so is therefore not a priority (pt. 166: F, 62, 5y).

Accessibility problems were not limited to referral, but included geographical, physical and environmental factors which failed to account for the disabling effects of fibromyalgia and thus made it extremely difficult for some to access physiotherapy, particularly in a hospital setting:

I cannot easily get to hospital and need my partner to take me ... I once used to ambulance transport service, but it was such a long day and the ambulance was so bumpy I was in agony even before I left the hospital. This was worse by the time I got home, and I would not use this service again (pt. 252: F, 44, 5y).

I've just started another round of physio however even parked in a disabled park it is too far to walk from the entrance to the physio. No porters are available. Physio is

not a great help so on balance it's best not to go. I'm often in too much pain to go out on a regular basis (pt. 703: F, 52, 6y).

It's always about access for me. My local hospital relocated its Physiotherapy dept. to the further edge of the hospital grounds, a good 800 meters from the main gates, bus stops and car park. Built on a hill, you've done a workout simply by getting there. It's things that planners consider insignificant that give me the most difficulty (pt. 496: F, 59, 11y).

Many participants wrote about the years they had spent, trying to get their symptoms acknowledged and diagnosed, then the months, waiting for the referral to and treatment by physiotherapists, followed finally by the long, physically taxing journeys to get to and from their appointments. Put together, data in this subtheme spoke clearly about the patience, persistence and effort required by people with this disabling condition in being granted access to the basic elements of treatment.

Subtheme 1b - The Short: A few physiotherapy sessions are not enough

Participant accounts demonstrated that physiotherapy was part of the standard package of care for most people diagnosed with fibromyalgia, alongside medication. Other non-pharmacological treatments were rarely on offer via the UK's National Health Service (NHS), although a few had either been offered or self-funded alternative treatments, such as cognitive behavioral therapy (CBT) or hydrotherapy. NHS funding priorities were again seen as the issue which limited care:

The only treatments that I have had through the NHS are medicines and physiotherapy (pt. 73: F, 44, 1y).

Treatments don't last and the NHS cannot fund what they cannot cure (so I have been told many times) (pt. 577: F, 41, 10y).

Many participants wrote about the mismatch between the chronic, fluctuating, varied nature of the condition and the short-term, limited non-pharmacological interventions offered on the NHS:

It is a shame that a lot of non-drug treatments, e.g. hydrotherapy, physiotherapy, are only available for a maximum of 6 weeks on the NHS (p. 205: F, 67, 16y).

Six sessions of CBT, 3 sessions with a physio. When is someone going to realize that sticking plasters don't fix a broken leg? (p. 160: F, 52, 9y).

I did have a good experience with a gentle exercise class which a physio referred me to, but it was only for 13 weeks, which was a shame. I wish it could have carried on because I was finding it helpful (pt. 446: F, 31, 2y).

Those who had found their physiotherapy input effective were clearly disappointed by its brevity. Among those who hadn't, a few had paid for their preferred forms of alternative care. Likewise, a few in our sample, who could afford to do so, had decided to pay for longer-term physiotherapy input:

Fibros need constant regular lifelong treatments to be of long term benefit. I have to pay for my own physio. If this was funded on NHS then I would have it more regularly, resulting in me having a better quality of life (pt. 560: F, 41, 10y).

There were frequent references in the dataset to the lack of long-term care for this lifelong condition. As shown above, some found physiotherapy effective but were offered only short-term input unless they were prepared to pay.

Theme Two: The Experience of Physiotherapy: Care on whose terms?

This theme was developed from a strong sense through the data that the agenda followed by physiotherapists in caring for people with fibromyalgia often differed from the personal needs and expectations of the recipient. It is important to note first, however, that, as demonstrated above and in the quotations below, the experience of physiotherapy (and, indeed, other professional care) for some of these participants had been positive:

Physio was not necessarily improving my condition but was having a good short-term relief for my pain (pt. 580: F, 48, 3y).

Very satisfied as I have found OT and physio very helpful and I have a lovely GP. I think I am fortunate that I was already under rheumatology (pt. 796: F, 42, 2y).

My consultant is a pain consultant and is amazing, so is my physio (pt. 105: F, 33, <1y).

There seemed to be a group of participants for whom the care they had received from all professionals was perceived in a positive light. However, in some of these accounts (e.g. pt. 796, above), there was a sense that they saw themselves as lucky, perhaps having heard others' less positive accounts through the support network.

Indeed, most data – and certainly all data from our participants who wrote at greater length – suggested dissatisfaction with aspects of their physiotherapy care. The data seemed to

reflect two different styles of care, which were associated with differences between actual and ideal experience. These are encapsulated in two subthemes, “Physio as 'Expert'” and “Patient as Partner”.

Subtheme 2a - Physiotherapist as 'Expert'

This subtheme comprises participant perceptions of an inflexible approach in some physiotherapists, based on being in a powerful position and having a sense of “expertise”. Participants suggested that physiotherapists often assumed that they knew best and disregarded patients' expressed needs and experiences. Care on the physiotherapist's terms was described as taking an inflexible or one-size-fits-all approach, characterized (by various participants) using terms such as “explaining”, “ordering”, “pushing”, “inflexibility”, “not understanding”, “not listening”, “ignoring”, “neglecting”, “judging”, and being “condescending”, “inflexible” and “dismissive”. Communication appeared to run in one direction, from the practitioner to the patient:

The physio I saw was very good at explaining various options for me, but I felt he didn't really understand how much pain I was actually in (pt. 276: F, 60, 7y).

Patients felt pressured to comply with exercise regimes prescribed by their physiotherapist. However, they believed their pain and other symptoms were often exacerbated rather than improved by these interventions. Finding it very difficult to complete these activities and suffering increased pain or other symptoms as a result left them anxious and unhappy with their care. Although most responses were focused on the physiotherapist in this regard, some also referred to other practitioners:

The OT and physio, I have felt, are condescending and too full of “you must do this” without taking into consideration the symptoms of the disease and how it affects you. The be told you MUST go for a walk every day when some days you do not have the energy to get out of bed makes you feel they do not believe your symptoms and the struggle you have on a daily basis. Yes, we know exercise, pacing and relaxation are good for you but, when you are in constant pain, it seems unattainable (pt. 21: F, 57, 5y).

I have attended physiotherapy where the therapist has ignored my need and followed what she felt was the issue - result, increased pain (pt. 125: F, 55, 8y).

Some of the exercises actually caused more damage - the physio was not prepared to listen and “knew better”. Pushing patients past their capabilities is never going to have a good outcome, physically or mentally (pt. 17: F, 55, 2y).

It made me more ill than I have been in years as it wasn’t recognized that, with fibromyalgia, pushing exercise during flare-ups only exacerbates symptoms and prevents the body getting back on an even keel. This was quite traumatic. However, when I used the strategies some time later at my own pace and did not push myself, I did make some progress in increasing activity. The nurse specialist in pain and the physio were more of a liability than a help. I have had other physios who have also made me worse with manipulating and stretching my body, leaving me with terrible pain and fatigue for days afterwards (pt. 730: F, 43, 20y).

Sometimes patients were unable or chose not to comply with instructions due to their pain and other symptoms; however, this decision was sometimes met with an unsympathetic response:

When I explained that I didn't have the energy or forgot to do [the exercises] I was put into the "too difficult" category. I was discharged after 3 sessions and told to come back when I had more energy (pt. 238: M, 49, 1y).

Participants described what they perceived as physiotherapists' apparently poor understanding of the condition, and practice characterized by an inability to accommodate the varied, individual and complex nature of their condition:

On the NHS physiotherapists will only treat the "part" you were referred with not any other bit which may have flared (pt. 112: F, 50, 8y).

All the physio is aimed at is making you get rid of walking aids and because you're not paralyzed you're made to feel you're "not disabled enough / the wrong kind of disabled / not allowed" to use a wheelchair (pt. 135: Genderfluid, 27, 1y).

Empathy, counselling, expert advice on what exercise is most beneficial to fibromyalgia patients, not physiotherapists that are used to dealing with pulled muscles. They are two very different [types of] expertise (pt. 52: F, 23, 1y).

These quotations are typical of many in the dataset and suggest frustration with clinical skills and professional priorities which don't match patients' individual needs and with the system which limits what can be done. Thus, for some patients their experience of physiotherapy had been care which lacked understanding yet adopted an expert stance, with which patients were expected to comply, despite worsening symptoms.

In contrast, others spoke of positive or ideal care, which acknowledged and accommodated both the complexity of fibromyalgia (termed “*The 'Fibro Spectrum'*” by pt. 749: F, 55, 9y) as well as patients' expertise in their own symptoms. This is reflected in the second subtheme, “Patient as Partner”.

Subtheme 2b - Patient as Partner:

The “Patient as Partner” approach to physiotherapy was empathic, consultative and involved partnership. In participant accounts it was characterized by “gentleness”, “reassurance”, “understanding”, “respect”, “dignity”, “support”, and underpinned by a “holistic” “person-centered” perspective. This was the care many wrote about when asked to outline their ideal, rather than something they had experienced.

A physio that offers more than guidance ... Someone who understood the mental impact as well as the physical, and had an alternative approach to medication and physio techniques (pt. 53: F, 49, 2y).

A few participants described actual experiences of excellent care, which fitted this ideal. These were often (but not exclusively) private practitioners who offered bespoke care, often beyond standard physiotherapy interventions. Flexibility, listening, understanding and trust were key components of the relationship and patient satisfaction, and people were prepared to pay for the high-quality care they received:

I pay for trigger point therapy. I have a fully qualified senior therapist who has been treating me for over 10 years. She knows my body and what it likes and doesn't like, cause one wrong move or more than it needs, it overturns any good and I flare up badly and can even cause spasms and injury... I have found that I can only tolerate

physio that gets to the point of the problem... over 10 years of regular monthly physio totals £3600 (ongoing) (pt. 560: F, 41, 10y).

I do pay for an exercise class with a physiotherapist, whom I trust (pt. 620: F, 58, NTSD).

Had acupuncture on the NHS by a physio. [It] really helped (pt. 668: F, 41, 3y).

Others had found excellent physiotherapists but the specialist elements of their care (and those perceived to be most therapeutic) had proven too expensive to continue:

[I had] a direct referral to community physiotherapy to a physio who specialized in working with people with fibromyalgia in the hydrotherapy pool... I had to stop as the charges kept going up and I couldn't afford it any more, which has had a negative effect on my quality of life (pt. 576: F, 48, 6y).

In many cases, finding a great physiotherapist often seemed to happen after a long journey of less-than-optimal care. Accounts suggested people were prepared or had been obliged to pay, and that others had been forced to give up their excellent care experience due to spiraling costs. These positive experiences left participants very pleased with their physiotherapy care and, when asked to describe their ideal care, long-term, flexible, individualized physiotherapy was often mentioned, typically as part of a multi-disciplinary approach under one roof.

Physio sessions ... perhaps one every month or so? The symptoms change so often and there's always something new (pt. 636: F, 32, 2y).

Really good, tailored physio (pt. 866: F, 26, 1y).

They should have all of the required experts on hand to help... They should also offer a safe place for sufferers to come together to help each other as Fibro is a very socially isolating illness (pt. 286: F, 55, 1y).

Although participants generally recognized that the 'under one roof' model of care was an ideal and may not be achievable, most felt that physiotherapy which met the varied and fluctuating needs of patients and treated them as partners in care was a realistic aim.

DISCUSSION

This study explored the perceptions of a large sample of people with fibromyalgia of physiotherapy care. Findings suggested that many were either happy with their treatment or had negative experiences to report but still valued physiotherapy as an important part of fibromyalgia care. Delays in getting diagnosed, being referred for and receiving physiotherapy, as well as problems accessing service locations were frustrating for most respondents. Many found aspects of the practitioner – patient relationship unsatisfactory: physiotherapists who listened, understood and respected patients' expertise in their own symptoms, lifestyles and bodies were experienced far more positively than those who took an inflexible, 'expert' approach.

Although a physiotherapist is not expected to diagnose the condition, it was interesting to note that physiotherapists treating participants for pain had sometimes identified symptoms and supported patients in getting an appropriate referral, which was considered helpful, given the typically long wait for a diagnosis. This suggests there is reasonable awareness of the condition among some physiotherapists of symptoms and a desire to advocate on patients' behalf.

Nonetheless, findings suggested a mixed view of physiotherapy in our sample. Some experiences had been positive but others, less so: the long wait, the brevity of physiotherapy input, the lack of understanding and empathy in some, and care which seemed inflexible and unresponsive to individual need. The qualitative findings supported and provided considerable additional detail to the quantitative findings regarding physiotherapy care from the full survey, reported elsewhere (Taylor et al., 2019). In that survey, 51% reported trying and rated their physiotherapy. Mean effectiveness was 3.59 (SD 3.00) on a 0-10 Likert scale (0 = not effective to 10 = very effective), and mean side effect rating was 4.94 (SD 3.33) (0 = 'no side effects' and 10 = 'terrible side effects'). 39.8% reported that physiotherapy worked best for muscular pain; however, 45.5% believed it made their pain worse. Hence quantitative survey findings indicated rather negative perceptions of physiotherapy, which were reflected at greater depth in the qualitative themes reported here.

Broadly speaking, evidence in the literature suggests that physical exercises help improve pain, disability and other symptoms of fibromyalgia (Busch et al, 2007; Joshi, Joshi and Jain, 2009; Valim et al, 2013). Exercise is recommended to improve wellbeing (e.g. for women, de Almeida Silva et al, 2019) and forms the mainstay of physiotherapy care alongside patient education (MacFarlane et al, 2017). However, the experiences of these survey participants suggested a more complex picture of the relationship between pain, symptoms and physiotherapy, and there seems some mismatch between "objective" (outcomes) and "subjective" (experiential) evidence. This may indicate that aspects of the delivery of physiotherapy can create a difference in the experience, such that the "how" of delivery

becomes as important to the experience and perceived effectiveness of the intervention as the “what”.

A key theme in the data related to the long wait for and then short duration of physiotherapy. The issue of waiting times has been raised previously in UK-based work (Consulting, 2011). The current participants were also often unhappy that they didn’t receive ongoing support or regular maintenance treatment, and similar concerns have been expressed by physiotherapy patients in other contexts (Calner, Isaksson and Michaelson, 2017). The current findings to some extent mirror aspects of meta-ethnographic findings of Mengshoel, Sim, Ahlsen and Madden (2018), that the long wait for a diagnosis is followed by its short-lived usefulness, given the lack of curative treatment.

The long wait for and short duration of physiotherapy, both of which are beyond the power of the practitioner, may set up negativity towards them as the point of contact with the service. The need for enduring patience, the frustration and disappointment of receiving no clear answers, and the disempowering effects of impatience or skepticism from others are common themes in the literature surrounding fibromyalgia (Ashe et al., 2017; Furness et al., 2018). Mengshoel, Sim, Ahlsen and Maddden (2018) note that relationships between patients and health professionals, on the long trajectory through debilitating symptoms, fibromyalgia diagnosis and ineffective treatments, are sure to be strained. The various access issues highlighted by these findings are a matter for service providers and commissioners; however, the individual physiotherapist should appreciate their impact when meeting and treating their fibromyalgia patients and take an empathic approach to patient frustrations and apparent negative attitudes.

Responses articulating disappointment or dissatisfaction with aspects of care were suggestive of unmet expectations. Expectations of therapy feature strongly in the literature. Patient expectations may be focused on the process and / or the outcome of therapy (Constantino et al, 2011; Haanstra et al, 2013), in other words what will happen and its effect on the condition. Previous evidence suggests that positive outcome expectations may be linked to success and satisfaction (Bishop, Mintken, Bialosky and Cleland, 2013; Metcalfe and Klaber-Moffett, 2005). Although there is minimal information detailing fibromyalgia patients' expectations of physiotherapists, Kamper et al. (2018) explored the expectations of physiotherapy within a similar group in Canada, chronic pain patients. They found some expectations which fell within clinical practice guidelines, such as examination, advice, information about management and side effects. They also found that expectations for diagnosis and causal explanations, which fell outside the physiotherapist's expertise and, therefore, presented practitioners with a challenge. However, other expectations related more to the interpersonal relationship with the physiotherapist: two thirds also hoped to discuss problems in their life, an expectation which accords with a biopsychosocial approach to pain (Wong et al, 2017).

The need for understanding might be exacerbated by some of the psychological sequelae of fibromyalgia, for example, the high levels of stress, frustration, anxiety and depression in this group (Hadlandsmayth et al, 2017). These factors may both create a sense of being poorly heard and understood and make it more difficult to be on the receiving end of care by a physiotherapist who doesn't appear to listen. Studies have found that meeting interpersonal expectations for good dialogue, communication, involvement and respect generates better satisfaction among patients (Hills and Kitchen, 2007; Stenberg, Fjellman-

Wiklund and Ahlgren, 2012). A collaborative approach might mean entering into a dialogue about the patient's expectations and hopes, acknowledging that service limitations and the complexity of fibromyalgia may prevent them being fully met, but attempting to build with the patient a realistic treatment package based on practitioner's expert knowledge and the patient's self-knowledge, needs and goals.

To meet the complex needs of fibromyalgia patients, aspects of education and training for physiotherapists could be improved. The need for greater support and focused training for physiotherapists treating people with fibromyalgia has also recently been highlighted elsewhere (Roitenberg & Shoshana, 2019). In the current study, participants observed that physiotherapists seemed to struggle when they didn't "fit" a regular pattern of presentation, treatment and recovery, with some similar themes reported elsewhere, for example, in the context of treating lower back pain without clear structural cause (Askew et al, 1998). This threat to their competence can lead to patient-blaming and a lack of empathy (Cohen et al, 2011; Thomson, 2000). Synnott et al. (2015) argues that education which encompasses an understanding of mechanisms underlying complex chronic conditions could help the trainee develop sympathetic attributions and empathy, to the benefit of their future professional relationships, patient compliance and treatment efficacy.

Briones-Vozmediano and colleagues (2018) also highlight the needs for health professionals to be equipped through training with greater knowledge, understanding and competence. Previous studies have highlighted physiotherapists' concerns about their own skills and confidence in dealing with these complex cases, and it is suggested that explicit training in communication, using, for example, role play, might help address this (Daykin and

Richardson, 2004). Service users might also play a direct role in training in various ways (Thomson and Hilton, 2011; 2013). In that study, the service users believed students understood more about the patient experience and learned what service users could bring to the care relationship (expertise in their own experience to complement the physiotherapists' therapeutic expertise). They had valued the sense of partnership, being able to challenge attitudes and contribute to future care. Students' perceived learning reflected similar aspects: enhanced understanding, challenged assumptions and new knowledge. Hearing real patients and learning communication skills during training would help practitioners build their abilities to listen actively and communicate to their patients their understanding of the condition and its impact on their life and wellbeing. Trainees could learn to rely a little less upon their own professional expertise, assumptions and normal practice and develop the confidence to listen to, validate and legitimize patient experiences as well (Laerum, Indahl and Skouen, 2006).

From a methodological viewpoint, there are limitations to the study. Although these themes were generated from a large sample compared with most qualitative studies, the richness and detail of the data were less than for individual interviews and varied a great deal; we were also unable to ask follow-up, probing or clarifying questions. These survey participants belonged to a fibromyalgia online support group and may represent a particular tranche of the broader population of people with this condition. Self-selection bias is a potential limitation because some individuals may be more likely to respond to a survey than others (Biele et al., 2019; Wright, 2005). It may be that survey participants were more actively engaged in wanting better care, getting personal support for and fighting the cause of fibromyalgia. Therefore, it is possible that results reflect more negative experiences and

perceptions of physiotherapy care than might exist among the broader population of people with fibromyalgia, who do not belong - or feel no need to belong - to an online support network. We did not formally aim for representativeness, nor are we likely to have achieved it. However, these themes complement existing qualitative and quantitative evidence in the field of fibromyalgia and other complex conditions and have the benefit of breadth and depth, compared with most existing research, as open-ended data from a relatively large sample. This is the first UK-based qualitative exploration of this issue of which authors are aware and it is interesting to note that the experiences both of having fibromyalgia and aspects of physiotherapy care are strikingly similar across studies from different countries.

CONCLUSION

The study aimed to explore the experiences of physiotherapy among people with fibromyalgia in the UK. Physiotherapy was often valued by participants but long delays, the brevity of NHS physiotherapy care, and inflexible or impersonal approaches by some physiotherapists impacted negatively upon their experience of care. Access and funding issues are a matter for service providers and commissioners; however, the insights raised by these findings have implications for individual practitioners. A greater awareness of the emotional impact caused by diagnostic, referral and access issues, a sympathetic (if realistic) attitude toward patient expectations and frustrations, and a willingness to prioritize listening, dialogue and collaboration with their patients could address some of interpersonal shortcomings identified by these participants. In so doing, physiotherapists could help support and empower their patients as they adjust to life with fibromyalgia, enhancing both their emotional wellbeing and increasing the likelihood of compliance with a mutually

agreed, individualized plan of care. Additional focused training for working with fibromyalgia is recommended.

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DECLARATION OF INTEREST STATEMENT

No potential conflict of interest is reported by the authors.

DATA AVAILABILITY STATEMENT

Data are available on request from the authors.

REFERENCES

Ashe S, Furness PJ, Taylor SJ, Haywood-Small S, Lawson K 2017 A qualitative exploration of the experiences of living with and being treated for fibromyalgia. *Health Psychology Open* July-December, 1-12.

Askew R, Kibelstis C, Overbaugh S, Walker S, Nixon-Cave K, Shepard KF 1998 Physical therapists' perception of patients' pain and its effect on management. *Physiotherapy Research International* 3: 37-57.

Bennett RM, Jones J, Turk DC, Russell IJ, Matallana L 2007 An internet survey of 2,596 people with Fibromyalgia. *BMC Musculoskeletal Disorders* 9: 27-37.

Biele G, Gustavson K, Czajkowski NO, Nilsen RM, Reichborn-Kjennerud T, Magnus PM, Stoltenberg C, Aase, H 2019 Bias from self selection and loss to follow-up in prospective cohort studies. *European journal of epidemiology*, 34: 927-938.

Billis EV, McCarthy CJ, Stathopoulos I, Kapreli E, Pantzou P, Oldham JA 2007 The clinical and cultural factors in classifying lower back patients within Greece: a qualitative exploration of Greek health professionals. *Journal of Evaluation in Clinical Practice* 13: 337-345.

Bishop MD, Mintken PE, Bialosky JE, Cleland JA 2013 Patient expectations of benefit from interventions for neck pain and resulting influence on outcomes. *Journal of Orthopaedic and Sports Physical Therapy* 43: 457-465.

Braun V, Clarke V 2006 Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101.

Briones-Vozmediano E, Öhman A, Goicolea I, Vives-Cases C 2018 “The complaining women”: health professionals’ perceptions on patients with fibromyalgia in Spain. *Disability and Rehabilitation* 40: 1679-1685.

British Psychological Society 2014 BPS Code of Human Research Ethics (2nd Edition).
Leicester: British Psychological Society.

Busch AJ, Barber KA, Overend TJ, Peloso PM, Schachter CL 2007 Exercise for treating fibromyalgia syndrome. *Cochrane Database of Systematic Reviews* 4: CD003786.

Busse JW, Kulkarni AV, Badwall P, Guyatt GH 2008 Attitudes towards Fibromyalgia: A survey of Canadian chiropractic, naturopathic, physical therapy and occupational therapy students. *BMC Complementary and Alternative Medicine* 8: 24.

Calner T, Isaksson G, Michaelson P 2017 “I know what I want but I’m not sure how to get it”—Expectations of physiotherapy treatment of persons with persistent pain. *Physiotherapy Theory and Practice* 33: 198-205.

Chinn P, Caldwell W, Gritsenko F 2016 Fibromyalgia pathogenesis and treatment options update. *Current Pain and Headache Reports* 20: 25-34.

Choy E, Perrot S, Leon T, Kaplan J, Petersel D, Ginovker A, Kramer E 2010 A patient survey of the impact of fibromyalgia and journey to diagnosis 10: 102-110

Cohen M, Quintner J, Buchanan D, Nielsen M, Guy L 2011 Stigmatization of patients with chronic pain: The extinction of empathy. Pain Medicine 12: 1637-1643.

Constantino MJ, Arnkoff DB, Glass CR, Ametrano RM, Smith JZ 2011 Expectations. Journal of Clinical Psychology 67: 184-192.

Consulting JJ 2011 A survey of NHS Physiotherapy waiting times, workforce and caseloads in the UK 2010-2011. Chartered Society of Physiotherapy.
<http://www.csp.org.uk/publications/>

Daykin AR, Richardson B 2004 Physiotherapists' pain beliefs and their influence on the management of patients with chronic low back pain. Spine 29: 783-795.

De Almeida Silva HJ, de Almeida Lins CA, Nobre TTX, de Sousa VPS, Caldas RTJ, de Souza MC 2019 Mat Pilates and aquatic aerobic exercises for women with fibromyalgia: a protocol for a randomised controlled bling study. BMJ Open 9: e022306. doi:10.1136/bmjopen-2018-022306

Fayaz A, Croft P, Langford RM, Donaldson LJ, Jones GT 2016 Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. BMJ Open 6: e010364. doi: 10.1136/bmjopen-2015-010364

Furness PJ, Vogt K, Ashe S, Taylor S, Haywood-Small S, Lawson K 2018 What causes Fibromyalgia? An online survey of patient perspectives. Health Psychology Open journals.sagepub.com/doi/full/10.1177/2055102918802683

Gifford LS 2000 Topical issues in pain 2. Biopsychosocial assessment and management. Relationships and pain. Falmouth, UK: CNS Press.

Haanstra TM, Hanson L, Evans R, van Nes FA, De Vet HC, Cuiipers P, Ostelo RW 2013 How do low back pain patients conceptualize their expectations regarding treatment? Content analysis of interviews. European Spine Journal 22: 1986-95.

Hadlandsmyth K, Dailey DL, Rakel BA, Zimmerman MB, Vance CG, Merriwether EN, Chimenti RL, Geasland KM, Crofford LJ, Sluka KA 2017 Somatic symptom presentations in women with fibromyalgia are differentially associated with elevated depression and anxiety. Journal of Health Psychology <https://doi.org/10.1177/1359105317736577>

Häuser W, Jung E, Erbslöh-Möller B, Gesmann M, Kühn-Becker H, Petermann F, Langhorst J, Thoma R, Weiss T, Wolfe F, Winkelmann A 2012 The German Fibromyalgia consumer reports- a cross sectional survey. British Musculoskeletal Disorders 13: 74-79.

Hills R, Kitchen S 2007 Satisfaction with outpatient physiotherapy: Focus groups to explore the views of patients with acute and persistent musculoskeletal conditions. *Physiotherapy Theory and Practice* 23: 1-20.

Joshi MH, Joshi R, Jain AP 2009 Effect of amitriptyline vs. physiotherapy in management of fibromyalgia syndrome: What predicts a clinical benefit? *Journal of Postgraduate Medicine* 55: 185-189.

Kamper SJ, Haanstra TM, Simmons K, Kay M, Ingram TG, Byrne J, Roddick JM, Setliff A, Hall, AM 2018 What Do Patients with Chronic Spinal Pain Expect from Their Physiotherapist? *Physiotherapy Canada* 70: 36-41.

Laerum E, Indahl A, Skouen JS 2006 What is "the good back-consultation"? A combined qualitative and quantitative study of chronic low back pain patients' interaction with and perceptions of consultations with specialists. *Journal of Rehabilitation Medicine* 38: 255-262.

Macfarlane GJ, Kronisch C, Dean LE, Atzeni F, Häuser W, Fluß E, Choy E, Kosek E, Amris K, Branco J, Dincer et al. 2017 EULAR revised recommendations for the management of fibromyalgia. *Annals of the Rheumatic Diseases* 76: 318-328.

McVeigh JG, Archer S, Hurley D, Basford JR, Baxter GD 2004 Physiotherapy management of fibromyalgia syndrome: a survey of practice in Northern Ireland. *International Journal of Therapy and Rehabilitation* 11: 71–78.

MengshoelAM, Sim J, Ahlsen B, Madden S 2018 Diagnostic experience of patients with Fibromyalgia – A meta-ethnography. *Chronic Illness* 14: 194-211.

MengshoelAM, Grape HE 2017 Rethinking physiotherapy for patients with fibromyalgia- lessons learnt from qualitative studies. *Physical Therapy Reviews* 22: 254-259.

Metcalfe CJ, Klaber-Moffett JA 2005 Do patients' expectations of physiotherapy affect treatment outcome? Part 2: Survey results. *International Journal of Therapy and Rehabilitation* 12: 112-119.

Roitenberg N, Shoshana A 2019 Physiotherapists' accounts of fibromyalgia: role uncertainty and professional shortcomings. *Disability and Rehabilitation*

<https://doi.org/10.1080/09638288.2019.1632939>

Sanders T, Foster NE, Bishop A, Ong BN 2013 Biopsychosocial care and the physiotherapy encounter: physiotherapists' accounts of back pain consultations. *BMC Musculoskeletal Disorders* 14: 65-74.

Stenberg G, Fjellman-Wiklund A, Ahlgren C 2012 "Getting confirmation": Gender in expectations and experiences of healthcare for neck of back patients. *Journal of Rehabilitation Medicine* 44: 163-171.

Stenner R, Palmer S, Hammond R 2018 What matters most to people in musculoskeletal physiotherapy consultations? A qualitative study. *Musculoskeletal Science and Practice* 35: 84-89.

Synnott A, O'Keeffe M, Bunzli S, Dankaerts W, O'Sullivan P, O'Sullivan K 2015 Physiotherapists may stigmatise or feel unprepared to treat people with low back pain and psychosocial factors that influence recovery: a systematic review. *Journal of Physiotherapy* 61: 68-76.

Taylor SJ, Steer M, Ashe SC, Furness PJ, Haywood-Small S, Lawson K 2019 Patients' perspective of the effectiveness and acceptability of pharmacological and non-pharmacological treatments of fibromyalgia. *Scandinavian Journal of Pain*. 19(1):167-181.

Thomson, D 2000 The Experience of "Problem" Patients as Experienced by Senior Physiotherapists in the Context of their Working Lives. *Advances in Physiotherapy* 2: 2-13.

Thomson D, Hilton R 2011 An evaluation of students' perception of a college programme involving patients, carers and service users in physiotherapy education. *Physiotherapy Research International* 17: 36-47.

Thomson D, Hilton R 2013 Service users' perceptions regarding their involvement in a physiotherapy educational programme in the UK: a qualitative study. *Physiotherapy* 99: 153-158.

Undeland M, Malterud K. 2007 The fibromyalgia diagnosis-hardly helpful for the patients? *Scandinavian Journal of Primary Health Care* 25: 250–55.

Valim V, Natour J, Xiao Y, Pereira AF, Lopes BB, Pollak DF, Zandonade E, Russell IJ 2013 Effects of physical exercise on serum levels of serotonin and its metabolite in fibromyalgia: a randomised pilot study. *Revista Brasileira de Reumatologia* 53, 538-41.

Wang SM, Han C, Lee SJ, Patkar AA, Masand PS, Pae CU 2015 Fibromyalgia diagnosis: a review of the past, present and future. *Expert Review of Neurotherapeutics* 15: 667-679.

Winkelmann A, Bork H, Dextl C, Heldmann P, Henningsen P, Krumbein L, Pullwitt V, Schiltenswolf M, Häuser W 2017 Physiotherapy, occupational therapy and physical therapy in fibromyalgia syndrome: Updated guidelines 2017 and overview of systematic review articles. *Schmerz* 31: 255-265.

Wolfe F, Clauw DJ, Fitzcharles MA, Goldenberg DL, Häuser W, Katz RS, Mease P, Russell IJ, Winfield JB 2011 Fibromyalgia criteria and severity scales for clinical and epidemiological studies: a modification of the ACR Preliminary Diagnostic Criteria for Fibromyalgia. *The Journal of Rheumatology* 38: 1113-1122.

Wong JJ, Côté P, Sutton DA, Randhawa K, Yu H, Varatharajan S, Goldgrub R, Nordin M, Gross DP, Carroll LJ et al. 2017 Clinical practice guidelines for the non-invasive management of low back pain: A systematic review by the Ontario Protocol for Traffic Injury Management (OPTIMa) Collaboration. *European Journal of Pain* 21: 201-216.

Wright KB 2005 Researching internet-based populations: advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *J Comput Mediat Commun* 10: 1034.