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Running title: Physiotherapy for fibromyalgia

## **Physiotherapy for fibromyalgia: A phenomenological study of patients' experiences**

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**Abstract:** Fibromyalgia is a chronic condition characterised by widespread pain, fatigue and other disabling symptoms. It affects up to 5% of the United Kingdom population. Fibromyalgia patients are often referred to physiotherapists for exercise-based therapy. The physiotherapist-patient relationship can be impacted by referral delays, differing expectations for intervention and outcomes. A better understanding of patient perceptions could raise practitioner awareness and support effective relationships. A purposive sample of twelve participants was recruited via Fibromyalgia Action UK and interviewed in depth about their experiences of physiotherapy for fibromyalgia. Interpretive phenomenological analysis (IPA) guided this study. Four themes were generated. “The physiotherapy journey” reflected experiential phases in participants’ care, including three sub-themes, “Journey to physiotherapy: waiting and expectations,” “Journey through physiotherapy: positivity or private care,” and “Journey beyond physiotherapy: struggling or succeeding with self-care.” Three themes reflected participants’ mixed experiences of and aspirations for physiotherapy care: “Maintaining movement and wellbeing,” “Treating all of me,” and “An understanding collaboration.” Increased awareness and understanding of patients’ experiences could help physiotherapists work in a truly patient-centred, compassionate and collaborative way with their patients.

**Keywords:** Physiotherapy, fibromyalgia, patient experiences, interpretive phenomenological analysis

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## **Introduction**

Fibromyalgia is a chronic condition characterised by widespread pain, fatigue, and other debilitating symptoms (1). Fayaz et al (2) estimated the worldwide prevalence of fibromyalgia meeting the 2010 American College of Rheumatology (ACR) criteria as 5.4%. The NHS estimates that up to 1 in 20 people in the United Kingdom (UK) are affected (3), equating to over three million people, based on a UK population of over 68 million (2021 World Population Review). The etiology of fibromyalgia is not fully established (4). Causal explanations such as overstimulation of the central nervous system (5) cannot be confirmed through clinical, laboratory or radiological examinations (6,7). Even the existence of fibromyalgia is contested by some (8). Diagnosis is based on the severity of a cluster of symptoms and the diagnosis process is complex and lengthy, with on average 2.1 to 2.7 years between symptom onset and diagnosis in the UK (9).

Therapeutic recommendations for fibromyalgia include analgesia, exercise, and cognitive therapy (10). Physical exercise has been found effective in relieving fibromyalgia symptoms (11,12) and as multi-site pain is a defining symptom (1), physiotherapists are often involved with fibromyalgia patients both before and after diagnosis. Physiotherapy approaches vary, but one of the most common in the UK involves graded exercise (13), often accompanied by patient education sessions, and sometimes hydrotherapy, acupuncture, and psychological rehabilitation (10). Similar variation in practice is apparent within other health systems, for example, in the United States (14) and Germany (15).

Treatment guidelines for fibromyalgia are based on outcome efficacy (10), but patient perspectives are important to a biopsychosocial (in contrast to biomedical) model of care and recommended in treatment of chronic pain conditions (16). They are also considered essential to the development and practice of patient-centred care (17). Patient-centred care is increasingly a focus and aim of healthcare models and research in medicine generally and in physiotherapy (17,18) and has been highlighted as vital in the management of chronic pain conditions, such as fibromyalgia (19). Patient perspectives are also particularly relevant to improving healthcare where research highlights practitioner scepticism, disbelief or frustration, and patient experiences of feeling humiliated, misunderstood or stigmatised (4,8,20).

The relationship between physiotherapist and patient can be complex. Delays in diagnosis, access to treatment and prior low expectations of physiotherapy can affect the positivity of the relationship at its outset (21). Ongoing issues include complaints by physiotherapists that patients don't adhere to treatment plans and by patients that physiotherapists don't appreciate their pain (6); an increase in pain for some patients during or after exercise-based treatment (22,23); practitioners who feel under-prepared, under-resourced or lack confidence with fibromyalgia care; and a concern that patients have unrealistic expectations of a cure (16).

Despite these issues, physiotherapy is often valued by patients (21), particularly when physiotherapists demonstrate awareness of the patient's perspective (24) or are perceived as an "ally", supporting them in their experience of fibromyalgia (25). Mengshoel and Grape (6) argued for a supportive partnership approach. Furness et al (21) conducted a qualitative analysis of 205 fibromyalgia patients' online survey responses, finding that patients valued a "patient as partner" over a "physiotherapist as expert" approach, in keeping with recent findings about what patient-centred care means to patients (18). Physiotherapists who aim for better therapeutic alliances and rapport with their patients need an awareness of the experience of fibromyalgia. Experiential accounts from people with fibromyalgia can build understanding and support equality in the professional relationship, leading to greater satisfaction for all parties and improved treatment outcomes. There is little current qualitative evidence regarding the experience of physiotherapy from the perspective of the patient with fibromyalgia. This study builds on our earlier work (21) and sets out to bridge that gap.

### **Aim**

To explore the experiences of people in the UK with fibromyalgia of the physiotherapy they have received.

### **Methods**

A phenomenological approach was taken, in which recent experiences of physiotherapy among people in the UK with fibromyalgia were explored in in-depth semi-structured interviews. Interpretive Phenomenological Analysis (IPA) originated in health psychology (26) and is based in a critical realist ontology and epistemology (27). According to the critical realist perspective, reality has stable and enduring features that exist independently of human conceptualisation, though individuals experience that reality differently. In-depth interviews allow access to and offer an understanding of these differences. IPA offers qualitative insights into the individual realities of patients, their experiences, perceptions, and attitudes, which contribute to a broader healthcare evidence base (28).

### **Sampling**

Sampling was purposive, meaning the aim was to deliberately seek and recruit people with relevant experience (26). Participants were adults who had received physiotherapy for fibromyalgia in the UK in the past five years. They were recruited from a larger sample who had completed a separate short-response survey about physiotherapy (to be reported elsewhere) and expressed interest in participating in an in-depth interview about their experiences. Informed consent was obtained from each individual participant involved in this study. The study was advertised online via Fibromyalgia Action UK, a patient support charity.

### **Materials**

A semi-structured interview schedule was developed, with items based on factors identified as important in the literature and our previous research (4, 21). For example, participants were asked about their experiences of, thoughts and feelings about physiotherapy, the perceived effects of the treatments, their communication and relationship with physiotherapists, and what they would like physiotherapists and researchers to know. In keeping with the IPA approach (26), the schedule was designed not to limit topics of conversation but to encourage participants to talk at length.

### **Data collection**

Data collection occurred during the Covid-19 pandemic, therefore secure online platform interviews or telephone interviews were arranged for each participant and conducted by a non-physiotherapist researcher with IPA interview experience. Reimbursement was offered in the form of shopping vouchers. Interviews were of 40-80 minutes' duration, based on how much each participant had to say. Participants were offered a break in case of discomfort and fatigue, which are common in people with fibromyalgia, but none took up this offer. Information about relevant support services was offered verbally and via email after the interview.

### **Data analysis and interpretive lens**

Interviews were securely transcribed in full, identifying data removed, and each participant assigned a pseudonym. IPA analysis involved the careful reading and line by line semantic analysis of each individual transcript to identify the key experiences for each participant, followed by cross-case analysis to identify emerging patterns and generate final themes (26). IPA analysis offers an account of participant lived experiences of phenomena which closely reflects the data through the analysts' interpretive process and lens. The beliefs and background of the researcher are not seen as biases to be eliminated but as a lens through which to make sense of other individuals' experiences (26).

To acknowledge our lens, we are a collaborative team of social scientists, physiotherapists, and biomedical scientists. The main analyst was a psychologist and experienced IPA researcher, and a sociologist and a physiotherapist specialising in chronic pain contributed impressions of a subset of data, followed by discussions to agree themes. Given our backgrounds and awareness of existing literature, the shared lens through which we conducted the research meant our questions and analysis focused primarily upon on participants' experiences of pain and symptom management, and their personal, psychological and relational experiences of physiotherapy. However, we aimed to remain fully open to any experiences, perspectives and issues the participants wished to share.

### **Ethical Compliance**

The project was based on ethical guidelines set out by the British Psychological Society (29) and approval was granted by the University Converis Research Ethics Approval process (ER21715151).

## **Results**

The twelve participants included ten females, one male and one participant who did not specify gender, ranging in age from 22 to 61 years. All were White British and lived across the UK, including Scotland, Wales, and ten different counties in England. Education levels varied from level 1 (National Vocational Qualification) to level 7 (master's degree). Five were working full-time, one part-time, one was a student, two were unemployed, and three described themselves as off work on sick leave.

## **Findings**

IPA analysis of the interview data generated four themes, representing participants' experiences of physiotherapy for their fibromyalgia symptoms.

“The physiotherapy journey” reflected experiential phases in participants' accounts, and included three sub-themes, “Journey to physiotherapy: waiting and expectations,” “Journey through physiotherapy: positivity or private care,” and “Journey beyond physiotherapy: struggling or succeeding with self-care.”

The remaining three themes reflected participants' experiences of various aspects of the care itself: “Maintaining movement and wellbeing,” “Treating all of me,” and “An understanding collaboration.”

### **The physiotherapy journey**

Participants reflected on their unique physiotherapy journeys, including the time leading up to therapy, experiences during care and events afterwards, and data from all twelve participants contributed to this theme. Pre-physiotherapy journeys included gaining access to or experiencing delays. Once therapy was underway, some accounts reflected participants' growing appreciation of or confidence in what NHS physiotherapy offered, and others reflected participants' ongoing search for what felt right to them outside the NHS. Following discharge – or a Covid-19 enforced cessation of care – for those unable to pay, the journey was often a lonely one, trying to apply physiotherapy advice which often felt less relevant with time, or searching for ways to live well with fibromyalgia beyond and without physiotherapy input.

### **Journey to physiotherapy: Waiting and expectations**

Experiences of access to physiotherapy varied. Some reported an unproblematic referral process and rapid access to care; others experienced more complex and lengthier pre-physiotherapy journeys. For example, Gail was seen within four weeks, whereas Sophie waited for “months and months” for one physiotherapy referral, commenting: “I find that's a problem. Obviously, they're so overwhelmed and so busy, but with fibromyalgia, you need the help there and then.”

Participants varied in the positivity of their mindset when approaching physiotherapy, based on expectations or concerns about its suitability. Examples

include Jim who “went into it with an open mind,” and Hayley, who began with low expectations: “I hadn’t had the best experiences with other physios previous to that, from injuries when I was working.”

Some, like Hannah, experienced pre-physiotherapy anxiety: I was like, “I’m not really sure what to expect of this. Are they going to expect me to, I don’t know, run a marathon at the end of this, or something like that?” I was curious, but also maybe a bit hesitant.

In contrast, a few had elevated expectations: Gail began her physiotherapy journey expecting that it “was going to solve everything for me.” Her early disappointment gradually shifted to a state of acceptance that “it is more around maintenance now.”

### **Journey through physiotherapy: Positivity or private care**

Participants in this study typically found the experience better than they had initially expected. Hayley found she “got more and more confident as it went on,” and Rachel said: I genuinely didn’t know what to expect. I didn’t have very high expectations in the first session, at all, but that has changed and improved over time ... I would recommend it.

Charlotte mentioned “looking forward to” her physiotherapy sessions, feeling “completely engaged,” wanting “to get absolutely everything I could from it.” Pam spoke of overdoing things in her enthusiasm: “I engaged a bit too much I think. In terms of exercising, I really wanted to do well, so I exercised all the time.”

Some commented on their positive experience of sessions and between-session advice: “He gave me a lot of little things to bring home as well, so he’s been brilliant. He really has. I wouldn’t hesitate to go back” (Julie). However, others were left wanting more support between sessions, which were sometimes a month apart: It wasn’t the best, because you saw him for that hour or half an hour appointment, and then you didn’t speak or hear from him until your next appointment. It would have been helpful if I was able to email him or ring him with questions that I had (Hayley).

Following unsatisfying experiences with the approach or duration of NHS physiotherapy, three participants had embarked on a new avenue in their physiotherapy journey, private care, often driven by a desire to find therapy that was right for them and the belief that it could be found. Rather than simply accepting what is on offer, “you need to find out what specifically within physiotherapy works best for you” (Gail). The following extracts are from the interview with Gail, comparing her NHS and private care: I don’t want to be negative about the NHS service because I know the situation, they are under pressure, I get all that. It was more that I did not feel like anything I was saying was validated. I know different things help different people but for me hands on therapy works better and I feel like I have reached that point all these years that I know now what is going to happen, what is not going to help me. So, I started seeing somebody else privately and I’m having a lot more hands on massage therapy ... he was very therapeutic. As soon as I went in I felt relaxed and I

genuinely felt like he believed me ... I have an hour with the physiotherapist. Previously it would be half an hour with the NHS.

Following NHS therapy, patients were routinely discharged, sometimes before they felt ready, or arrived at an abrupt end to care due to the Covid-19 pandemic; however, there were geographical differences in the end of care experience. Rachel's local service offered physiotherapy with "no end point put on it" and expected it to "continue on until I felt I was no longer needing that ... I got the impression that that was very much up to me, when I felt I'd had enough out of it, that's when it would be stopped." This unusual approach gave Rachel a sense that she had some control over and would get what she needed from physiotherapy.

### **Journey beyond physiotherapy: Struggling or succeeding with self-care**

Those who had opted for private physiotherapy felt confident about the future, at least for as long as they could afford to pay: Once I found what works for me, this definitely is what I would continue long term, providing I can ... If I couldn't afford to have these sessions then I know that my quality of life would definitely decrease and I would struggle (Gail).

Among those whose physiotherapy ceased after the limited prescribed sessions, most felt alone with their condition and symptoms, and commented on the lack of aftercare or contact:

I don't find that afterwards, there is a lot of, "This is what you do next." It's just like, "Well, those exercises seem to be working. Just keep doing them." But I'm like, "What? For the rest of my life?" It's just like, I don't know, "Bye" (Sophie).

In response, Sophie had developed her own ways of managing her condition, partly based on the original physiotherapy input:

It makes me feel better as well mentally, knowing that you have got something there. I call it my little toolbox of things. It's not just one thing that works on its own. You have to work through your little toolbox and use it all together to have an effect, to have a good effect. So, it's good to know it's there and that I can use it. Like I say, it's just what I do now automatically. ... I think, "I'm hurting," I get up and I just do some of the exercises. I don't even think about it half the time, I just do it because it feels more natural to do them now.

Sophie had achieved a sense of proficiency that physiotherapists would perhaps wish for all fibromyalgia patients, but was alone in experiencing this degree of confidence. Others were keen, however, to live as well as they could and meet life goals, including Kate:

But he did say, as I walked out of the course ... "You've really got a lot out of this, haven't you?" and I said, "I have, and I'm going to try and

put it all into practice, because I need to change my life, I need to be able to live and work alongside this.”

Emily had been similarly proactive: “I’ve changed my own lifestyle so that I can bring my stress levels” but acknowledged limitations: “There are certain things that I can do but there is only so much I can do.” Emily mentioned having had “no follow-up” and wanted “A contact number that if you’re having a bad time or you’re having a really bad flare-up ... you can catch things before they get too bad.” Hannah described her struggle to maintain exercise over time – “being my own service,” and her sense that initial advice became less relevant or harder to apply:

I felt like because I didn’t have the therapy any more, and like I wasn’t seeing anyone about that anymore, it was harder and harder to do it by myself ... you come across things that you haven’t come across before, then you are not really sure how to apply the tools you’ve gotten, and how to apply them to this new situation, and it can be then quite hard to figure it out on your own.

In summary, the journey to, through and beyond physiotherapy varied according to what was offered in participants’ local area and what they could pay. Low expectations prior to care were often followed by positive experiences and high motivation. For a minority, the journey to find ideal physiotherapy led them to private practitioners, and these participants appeared happy with their post-NHS physiotherapy journey. Others were divided between those who were succeeding in their efforts to live well without physiotherapy and those who struggled with feeling alone, unsupported and anxious about managing their symptoms, long-term.

### **Maintaining movement and wellbeing**

This theme reflected these participants’ experiences that the key benefit of physiotherapy was enhanced movement. All participants spoke about pain, but their accounts suggested that the impact of physiotherapy on pain was variable and some experienced no changes in pain. Others found their pain unchanged but experienced relief from the discomfort of stiffness and tension, and a few identified some direct benefits from physiotherapy on their pain. However, even where pain was unaffected, being able to move more freely gave participants a greater sense of control over their situation. It made it easier to perform day-to-day activities, utilise their space at home, go out and take some light exercise. Participants experienced movement as important to their quality of life and psychological health, hence physiotherapy maintained not only movement but also wellbeing. Data from nine of the participants contributed to the development of this theme.

Like others, Gail’s experience was that the benefits of physiotherapy lay more in relieving stiffness and promoting relaxation than in pain reduction:

It doesn't help the pain, but it helps with the muscle tightness ... I think it's because I feel more relaxed afterwards, like, it does release ... some of the tension and the stiffness because I think I hold myself - with the pain you hold yourself in such a rigid stiff way and then the knots get in because I can only sleep on my back, that the whole body becomes stiff and achy.

A few could see some clearer pain effects. Hannah noticed that physiotherapy "lessened the pain and the amount" and also delayed the onset of pain "so I could walk for way longer or do certain things for a lot longer without the pain." Julie had experienced pain during physiotherapy but, later, noticed beneficial effects: "It was very painful when he did it. It might have been painful for two or three days, and then it was bliss, because it helped." The pre-existing severe pain experienced by many patients made some very anxious about the physical movements required during physiotherapy, as Kim explained: "We're frightened because everything hurts so much, we're frightened of doing something to make that hurt more, and it doesn't." Fatigue, another common symptom of fibromyalgia, also made the exercise hard to engage with, though Sophie did as much as she could: "Sometimes fatigue can hit really bad, and you just don't have the energy to do it. So, it's just persevering and doing what you can when you can."

Sophie explained the complex physical and psychological benefits, for her, of physiotherapy:

I think it works because, when you are in pain, you clench up and you tense up and you shallow breathe. All these things are just creating tension and more stress than you already have. So, I think the physio works, like I said, because you are moving and that improves a lot of things ... If you start to feel a little bit of relief, your mood improves and then that helps with pain.

This account reflected similar experiences among other participants: physiotherapy movements worked by releasing the bodily tension resulting from pain and lifting mood, both of which improved the pain experience. Participant well-being was further impacted by being able to do more of the activities which were important to them. For example, Hayley spoke of experiencing no change in her pain and only the smallest of physical gains from physiotherapy but was appreciative nonetheless of "just being able to get up in the mornings is nice and have a little wander round my flat." Rachel was similarly tentative about physiotherapy's effects on her pain, but spoke about being better able to get out, which was especially important to her:

In terms of my overall ability to get out and do things more, has it improved, yes. Being able to get out and walk more is really, really important to me ... You know, I do like being able to get outside just to clear the head and everything.

The importance of and pleasure taken in movement and its impact on well-being was mentioned by most. Charlotte experienced significant improvement in movement over the course of treatment, which gave her joy:

It started where I could barely do the walking and by the end of it, all I wanted to do was run on the treadmill. One day, they weren't looking and I, kind of, cranked it up and had a run and it felt absolutely amazing.

Kim commented: "I think a lot of the effect was more mentally than physically, in a way." The combined physical and psychological impact of treatment was also reflected in Jim's account. He felt that physiotherapy kept him just ahead of the condition, described as "the woods behind me ... getting closer." He saw physiotherapy as essential maintenance to prevent an otherwise inevitable progression and worsening of the symptoms:

My good experiences have been with physio because they've actually done something ... The illness, I find, is that, if you're not careful it takes over, great weeds growing up your legs, it's like a vine and it actually grows up and up. If you don't notice it's growing up you, and you don't stop it and get it out and strengthen whatever joint it is, or the problems you got ... it just gets worse.

In summary, this theme reflects the perceived impacts of physiotherapy on these participants. For most, even where they noticed little reduction in their pain, the experience of reduced stiffness and increased movement and the impact on daily activities made a significant difference to their well-being. Participants saw physiotherapy as helping them to maintain a tolerable level of physical and psychological well-being and some control over their symptoms.

### **Treating all of me**

This theme was based on data from six participants, whose perception of best care involved more than exercises to maintain movement. This group included the three participants whose accounts were not reflected in the previous movement-focused theme, all of whom had experience of physiotherapist-led pain management courses, as well as others who had been treated by specialist pain physiotherapists. "Treating all of me" reflected experiences of a holistic approach to care which went beyond exercise and movement, and offered a range of treatments, built knowledge and coping skills, and integrated expertise from different professions.

Emily had several exercise-based physiotherapy interventions for her fibromyalgia, but realised she needed more:

I got my physio appointment. Again, then it was just exercises given. That's what I find, my experience is, "There are a couple of exercises. Off you go." I know myself now I need physical contact. I need that

massage. I need the reflexology. I need work done from head to toe to actually relieve everything that's gone on in my whole body.

On her journey, Emily had found a range of private alternative treatments, including those mentioned here and Reiki which, combined, helped her manage her symptoms. However, her most recent referral to a physiotherapy-led pain management clinic had offered a different NHS-based experience, which she had found extremely helpful:

I got sent to the pain management program ... Last year I had that, where you had your physio, your psychiatrist, doctors, all different fields to teach you how to learn how to deal with the pain and how to cope... you've got the psychology part of it to help you deal with the psychological problems. Plus, you've got the physio part of it to help you with the mobility problems.

Emily appreciated the interdisciplinary involvement and holistic approach, and Kate reported very similar positive experiences of this approach to fibromyalgia care:

And this course was the best thing I ever did. [It was] called Living with Fibromyalgia and it was run by a physio. We were really taught about how to deal with pain. They brought in different consultants to talk to us. We went through general stretches. We were actually taught mindfulness and meditation. And really, we were taught how to live alongside our pain.

Others with holistic care experiences, reflecting a complex approach which addressed both mind and body and focused on the whole person, had been treated by specialist chronic pain physiotherapists. For example, Rachel's physiotherapist had offered "general guidance on things like sleep ... diet ... it was quite broad ranging, covering a range of topics rather than, sort of, focusing on one particular area of the body." Kim believed that "everything together gave me a better understanding, probably, of my body" and helped them "learn a new way to live and to find exercise that I can do rather than that I want to do."

In summary, this theme reflected the positive experiences of those participants who had encountered more holistic, integrated forms of care provided or facilitated by physiotherapists, and their sense of personal gains and learning as a result.

### **An understanding collaboration**

This final theme reflects experiences of relationships with physiotherapists and represents data from all participants. It includes experiences of being seen, heard, listened to, understood and of collaboration, which built trust and confidence. For the majority this reflected their most recent or best experience of physiotherapy and compared favourably with alternative experiences, which all

participants described, of poor physiotherapy or healthcare encounters. Those experiences included not being believed, distress and shame in the face of negative attitudes and treatment.

Several participants spoke about the importance of being believed and heard. Hayley compared her recent physiotherapist who “recognised there was the problem and that I needed the help” with previous experiences with healthcare professionals, where “I have basically been told that I am faking. ‘It is rubbish. It doesn’t exist.’” Emily spoke about a recent encounter with a physiotherapist:

He was really, really listening and asking questions and giving you the time to actually communicate, to say this is what’s going on ... He was taking into account all the other things that were happening obviously because it’s not just pain that you get.

Gail had encountered both a dismissive, inflexible, expert-led approach and a more understanding, adaptable one, and was clear which she had preferred:

I found it more difficult to engage with the NHS physio because I honestly felt as though what I was saying, it just wasn’t being believed ... There are certain exercises that I have been- if the pain is too bad and I just physically can’t do it and I would explain that to the NHS physio and it would be, “Well, you’ve got push through that pain.” I think it is like, “If I could push through it, I really would.” I don’t think he realised the extent of the pain or the after-effects of doing it... That would just be dismissed and like I wasn’t trying hard enough. Whereas this physio, he will adapt then. He will say, “Right, well, if that is not good for you, let’s see what else can do.” It’s just that difference.

Some of the inflexible, problematic relationships participants had experienced were put down to a lack of knowledge or awareness. For example, inflexibility was seen as a function of a generic area-focused approach to physiotherapy, characteristic of some non-specialist physiotherapists, compared with the greater awareness and holistic approach of pain specialists:

My chronic pain physios were more looking at my body as a whole, trying to find, sort of, an exercise that would exercise all of me without impacting on any of the pains anywhere, rather than specific exercises for back pain. (Kim)

Similarly, Pam recognised a lack of specialist knowledge about fibromyalgia in previous stigmatising experiences with physiotherapists:

I still believe a physiotherapist has a really important role in fibromyalgia, but it’s also very important to remember that there are limitations, that a person with fibromyalgia has the limitations and it’s

not laziness. It's not depression in itself. It's not anxiety. It's something else.

Where participants spoke about enjoying collaborative relationships with their physiotherapists, this was facilitated by a recognition of the expertise each person brought into the relationship. Collaboration also required a realisation that treatment would not work if it didn't address the patient's needs, which could only be established through discussion, as Sophie commented, "If you feel listened to then you feel like you are going to work alongside that person for your own health." Rachel reflected on the two-way process of effective collaboration:

And then there was a discussion about, sort of, what my expectations were out of it. Also, a sort of, chat about what they could provide and what they could offer and how that fitted in with what I particularly wanted ... I think the guy I've been seeing; he very much understands the syndrome. He obviously deals with a lot of fibro patients through the pain clinic. So, he's very, very used to the nonspecific aches and niggles that you get and very understanding and empathetic of that. And he also understands, sort of, the fatigue side of it as well and the need to pace... It's very much open to, "What do you feel you can do? What can we perhaps just start to look at doing? Maybe just push this a little bit or back off on that particular exercise." So, it's been very much led by me, I felt, rather than him and he's just been there to, sort of, try and give me ideas and encouragement and a bit of advice along the way.

For Rachel, the collaboration meant she was able to bring her expectations, wishes and experiences with the exercises, and the physiotherapist was able to offer knowledge, understanding, empathy and a non-judgmental approach. Sometimes less experienced physiotherapists had been "willing to listen," "honest ... [and] willing to learn" (Rachel); however, others were perceived to struggle with the flexibility and collaborative approach these participants valued: "A lot of it was more him talking to me rather than me talking to him, which I have noticed seems to be a pattern amongst physios. (Laughter) They like to do the talking and not get your input on a lot of things" (Hayley).

In summary, this theme reflected the importance to participants of the quality of their relationship with physiotherapists. All had both negative and positive experiences, with the former characterised by feeling dismissed and unheard, a lack of empathy and understanding, and an inflexible, expert-led approach. The positive experiences, which were often the most recent or came from private or pain specialist physiotherapists, were characterised by listening, compassion, confidence and flexibility and the ability to create a truly collaborative approach to fibromyalgia treatment.

## **Discussion**

This is the first in-depth qualitative study to our knowledge focusing in detail on UK fibromyalgia patients' experiences of physiotherapy. It revealed that the period of treatment lasting a few weeks or months is only part of the overall physiotherapy journey which includes lengthy pre-therapy waits and post-therapy efforts to maintain gains. Key elements which determined the experience, meaning and perception of physiotherapy for these participants were its effects on movement and wellbeing, representing, for most, the primary outcomes; a holistic approach which treated the whole of the person, rather than focusing on a single pain location; and a collaborative relationship in which the person felt heard and understood rather than dismissed and stigmatised. Participants had mixed experiences during their long journeys and were clear about what worked for them and what did not, and what constituted a positive experience of physiotherapy for fibromyalgia. Understanding this could help practitioners and providers tailor their service to what patients really want, appreciate and value.

Pre-physiotherapy expectations can influence treatment outcome and patient satisfaction. The variation shown here – positive through cautious to low - is reflected in previous work (30), which also shows that some patients are hoping for a complete cessation of pain. A few previous studies have offered insights into the pre-physiotherapy journey. In our earlier work (21), one theme reflected experiences of “The long and the short” of physiotherapy, where the “Long” represented the pre-therapy stage of delayed diagnosis, long waits for referral and struggles with access, and the “Short” reflected participant assertions that “a few physiotherapy sessions are not enough.” Similar findings emerge elsewhere (8).

However, insights into the journey post-therapy and how encounters (or their absence) with physiotherapists have influenced that journey are harder to find in the literature. In our study, a perceived valuable outcome of physiotherapy was enhanced movement, and small gains had made a substantial difference to how participants could live and enjoy their lives. However, reflecting on their post-therapy journey, most struggled to maintain the benefits. Similarly, Valencia et al (31) reported that flexibility and quality of life gained during treatment tended to reduce or be lost six months after therapist involvement ceased. Some here could afford and had opted to self-fund ongoing care, and clearly valued what they received. Private physiotherapists could spend longer, working out with the patient what worked for them. By contrast, NHS physiotherapy is limited in its scope by funding and time constraints. A lack of time and funding for long-term care and the need for patients to pay when funded care runs out is common, across different areas of physiotherapy, and other geographical and healthcare contexts (32).

Our findings suggested that these participants were trying hard but often struggling to maintain their health and any gains achieved through physiotherapy. The idea that life with fibromyalgia is a struggle, and that maintenance of health requires daily effort are reflected in the retrospective accounts of women who have recovered from fibromyalgia (33). Those findings revealed women's involvement with and sense of responsibility for their well-

being, and their hard work towards health, characterised by small steps forward and frequent setbacks. Our findings showed similar high commitment to and engagement with physiotherapy and, when this was experienced as unsatisfactory or ended, a proactive approach in searching for and finding alternatives or in striving to maintain health alone. The loneliness of the post-physiotherapy struggle as reflected here is worth highlighting. Although UK NHS physiotherapists operate within a context of unavoidable constraints, awareness of the long effortful journey ahead of the fibromyalgia patient during care and after discharge could help physiotherapists work with and prepare their patients. It might also offer food for thought for service providers, who might wish to consider the possibility of some form of ongoing support. The desire for a contact point in case of changes, problems and for advice was mentioned by many participants as something they believed would make a significant difference to the post-physiotherapy journey.

Those participants who saw their care as integrated and holistic found this a very satisfying experience. Its complexity reflected the complexity of the condition in addressing physical, cognitive, emotional and intellectual needs. Previous research suggests physiotherapists may feel more confident with biomedical, mechanical aspects and less so with cognitive, psychological and social factors (16), restricting their ability to offer holistic care. However, research has also demonstrated that, with appropriate training, physiotherapists can effectively deliver a more holistic, psychologically informed pain intervention, reporting enhanced confidence and practice as a result (34). The present study suggests that where service providers offered multi-professional pain management interventions, led or facilitated by physiotherapists, but with interdisciplinary involvement, these were well received and contributed to satisfaction with care.

In keeping with other studies demonstrating the importance of a listening relationship to chronic pain patients (21,30), the patient-physiotherapist relationship was an essential element of the physiotherapy experience. A validating, understanding, respectful, compassionate and collaborative relationship was a vital part of a positive care experience for patients, even in the context of minimal physical changes. In our previous work (21) positive experiences seemed to reflect an ideal rather than a lived experience, whereas in the present study most could identify at least some positive encounters and articulate what these meant to them. Considering the conceptual and theoretical discussion in the literature around patient-centred care, our approach in this study is aligned with the trace mentioned by Hansen et al (17) of complex, experiential evidence about physiotherapy. The hopes and positive experiences of the physiotherapy relationship expressed here are highly reminiscent of values associated with the concept of patient-centeredness, including shared knowledge and power, responsiveness and acknowledgement of autonomy (35). Thus, although we did not set out to explore patient-centred physiotherapy, in the context of current understandings of this concept in the physiotherapy literature, findings suggest this is exactly what these patients wanted. Patient-centred physiotherapy implies a practitioner who is active in getting to know,

communicating with, motivating and empowering the patient, compared with traditional biomedical approaches (18). Ahlsen et al (36) found two different narratives among physiotherapists treating patients with chronic muscle pain. One spoke of treatment goals, restoration of health and the ability to work, and ‘the successful patient’ who self-managed to comply with advice. The other reflected an open-ended approach focused on the patient’s singular experience and expertise, interests and values, and on determining a path which was meaningful for them. Patient-centeredness means more than effective communication skills. It requires a willingness to let go of ideal outcomes in favour of a process and direction which is meaningful and desirable to the patient. This is reflected in both this study and our previous work, where patients preferred a “patient as partner” approach from their physiotherapist, rather than an “expert”-led one (21).

The strengths of the current study include its qualitative approach and detailed insights. Our participants had fibromyalgia and physiotherapy in common but were otherwise a varied group: male and female perspectives, those of different ages and varying UK localities and health authorities are reflected here. The sample is small, limiting generalisability; however, small samples are desirable in IPA studies which focus on in-depth experiential accounts (26). Our participants were all White British adults, and it would be beneficial to have heard the experiences of a more diverse sample. Participants were recruited from those completing a physiotherapy survey on the Fibromyalgia Action UK website. Users of this website include people who feel passionately about fibromyalgia and could be considered to reflect critical perspectives of treatment, as evidenced in previous work (21). Thus, people responding to this research call might be those with strong opinions, both positive and negative, about their experiences, and people who did not complete their course of physiotherapy sessions may have self-excluded.

The implications of these findings for physiotherapists, service providers and trainers should be considered. Previous studies have explored potential improvements in practitioner preparation, such as fibromyalgia-specific taught content, communication skills role-play and service user involvement in training (20,37). The current findings suggest that more service providers could consider whether ongoing support could be offered to patients after discharge, potentially applying the variety of remote technologies now available to practitioners. Students and practitioners could be supported with the following:

- Building a patient-practitioner relationship based on awareness, openness, listening and collaboration
- Setting patient-centred goals based on their experiences, limitations and aspirations, rather than those of the practitioner
- Highlighting movement as an outcome and discussing with patients how this might work in their life, circumstances and environment
- Helping patients to prepare for and maintain gains on their post-physiotherapy journey.

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