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Exploring the lived experiences of patients with fibromyalgia in the United Kingdom: a study of patient-general practitioner communication

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ABSTRACT

Objective: Fibromyalgia is often viewed as a contested illness, with individuals facing scepticism from healthcare providers, which can hinder their diagnostic and treatment experiences. This study aimed to explore the lived experiences of individuals with fibromyalgia in the United Kingdom, focusing on their interactions with general practitioners.

Materials and methods: Six participants (one male, five females; mean age, 44.0 ± 13.7 years), all formally diagnosed with fibromyalgia, were recruited *via* social media. Interpretative Phenomenological Analysis was used to analyse the data, enabling the interpretation of participants' nuanced experiences. Semi-structured interviews were conducted to gather detailed accounts of their diagnosis, treatment, and communication experiences.

Results: Two primary themes emerged from the analysis. 'Challenges in obtaining accurate diagnosis and adequate treatment', reflected participants' feelings of invalidation and including sub-themes of 'medical mystery and misdiagnosis' and 'sex bias in healthcare'. 'Importance of trust in fibromyalgia management', highlighted the crucial role of trust in improving care, with sub-themes of 'positive impact of active listening' and 'improved trust over time'.

Conclusion: This study highlights the need for a more patient-centred, compassionate, and collaborative approach to fibromyalgia management. Addressing trust, diagnostic accuracy, and sex bias may lead to better overall outcomes for fibromyalgia patients.

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Fibromyalgia; patient-practitioner communication; patient-centred care; interpretative phenomenological analysis

Introduction

Fibromyalgia is a complex and chronic disorder primarily defined by widespread musculoskeletal pain that persists for ≥3 months, without an identifiable underlying cause. Unlike other musculoskeletal or autoimmune conditions, fibromyalgia is also

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characterised by specific symptoms, such as persistent fatigue, non-restorative sleep, and cognitive dysfunction, often referred to as ‘fibro fog’ which impairs concentration and memory (Doebl et al., 2022; Mease, 2008). Fibromyalgia is distinguished from other pain disorders by its widespread, diffuse pain that is not localised to a particular joint or region, and by heightened sensitivity to stimuli. In addition to physical pain, fibromyalgia disrupts patients’ emotional and social wellbeing, often leading to depression and anxiety (Alvarez et al., 2022; Fernandez-Feijoo et al., 2022). While conditions, such as rheumatoid arthritis or lupus involve inflammatory markers or organ-specific pathology, this is not the case for fibromyalgia making diagnosis reliant on clinical criteria rather than laboratory tests (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2024). In the United Kingdom (UK), ~5.4% of the population is affected by fibromyalgia, with a notably higher prevalence among women aged 35–45, highlighting the need for sex- and age-specific research and interventions (NICE, 2024; Rahman et al., 2014; Wolfe et al., 2018).

Despite advancements in the medical understanding of fibromyalgia, patients frequently encounter significant hurdles in the diagnostic process. The absence of objective diagnostic criteria often results in delays and considerable frustration as diagnostic tests typically return normal results, leaving patients without clear explanations (Baron et al., 2014; Goldenberg, 2009). Evidence suggests that it takes 5 years on average for a patient to be diagnosed with fibromyalgia (Millea & Holloway, 2000). While existing studies have explored diagnostic challenges (Al Sharie et al., 2024; Costa & Ferreira, 2024), there is still a lack of detailed insight into how these diagnostic difficulties specifically affect patient experiences during consultations with general practitioners (GPs).

Fibromyalgia is officially recognised by the World Health Organization as a rheumatological disorder (WHO, 2004), necessitating a multidisciplinary team consisted of primary care physicians, rheumatologists, and pain management specialists (Alciati et al., 2021). However, the integrated care model often strains the National Health Service (NHS), particularly when compounded by comorbidities, such as chronic fatigue syndrome, anxiety, and depression (Hyland et al., 2019; Kleykamp et al., 2021; Soni et al., 2020). The overlap with these conditions not only prolongs diagnosis but also exacerbates the healthcare burden, highlighting the need for more effective management strategies. Previous research has predominantly examined the medical aspects of fibromyalgia (Dizner-Golab et al., 2023; Salaffi et al., 2024), with less emphasis on how these complexities influence patient-practitioner interactions and overall care. Moreover, patients with fibromyalgia are often subjected to stigma, with fibromyalgia viewed as a ‘women’s illness’, and the reliance on antidepressants rather than targeted treatments (e.g. pain management therapies) has contributed to inconsistencies in diagnosis and symptom management (Gyorfi et al., 2022; Lian et al., 2020). These misconceptions coupled with the poorly understood pathophysiology of fibromyalgia create biases in care that have yet to be thoroughly examined in the context of patient experiences with GPs.

It is important to note that certain antidepressants, particularly selective serotonin reuptake inhibitors (SSRIs) and serotonin-norepinephrine reuptake inhibitors (SNRIs), are evidence-based treatments that help modulate central pain sensitisation in fibromyalgia (Häuser et al., 2009). However, despite their demonstrated efficacy, the reliance on antidepressants has contributed to the perception that fibromyalgia is primarily a psychiatric condition rather than a chronic pain disorder requiring a multidisciplinary approach. This misconception could lead to inconsistencies in care, with some patients receiving pharmacological treatment in isolation rather than as part of a comprehensive pain management strategy.

Effective patient-practitioner communication is crucial for building trust, facilitating collaborative decision-making, and improving health outcomes (King & Hoppe, 2013; Stewart, 1995). In the context of chronic pain management, this communication becomes even more vital. A systematic review by Georgopoulou et al. (2018) examined various aspects of patient-practitioner communication in rheumatology and found that higher levels of trust in the practitioner, along with active patient participation in medical consultations, were associated with lower disease severity, better global health, less organ damage accrual, greater treatment satisfaction (with fewer medication side effects), and more positive beliefs about disease control and future health. However, the dynamics of patient-practitioner communication in chronic pain care is complex. Matthias et al. (2010) identified three broad themes regarding providers' experiences: (1) the importance of the patient-provider relationship, with providers emphasising that strong, productive relationships are essential for effective pain care; (2) the challenges providers face, including pressure to prescribe opioids, scepticism about patients' pain reports, concerns about secondary gain or drug diversion, and difficulties managing 'difficult' or 'abusive' patients; and (3) the emotional toll of chronic pain care, with providers describing feelings of frustration, lack of gratification and guilt. Indeed, Butow and Sharpe (2013) highlight effective patient-practitioner communication as a key factor in promoting adherence to treatment recommendations within pain management. Hence, strengthening this communication can help mitigate both patient and provider challenges, ultimately leading to better health outcomes and more effective pain management strategies.

Patient-practitioner communication in the context of fibromyalgia is often challenging. Patients frequently report feeling dismissed or invalidated, with their emotional and psychological challenges overshadowed by a focus on physical symptoms (Galvez-Sánchez et al., 2019; Koesling & Bozzaro, 2021). This disconnect between patients' lived experiences and the predominantly biomedical model used by GPs exacerbates feelings of invalidation and impedes effective patient-practitioner communication (Deslauriers et al., 2021; Nishikawara et al., 2023). Although existing research has documented these patient-practitioner communication issues broadly (Byrne et al., 2023), there is a pressing need for a more focused examination of how these patient-practitioner communication dynamics specifically affect patient experiences and the management of fibromyalgia during consultations with GPs.

The aim of the present study was to address this need by exploring how patients with fibromyalgia experience and interpret their interactions with GPs using Interpretative Phenomenological Analysis (IPA). IPA is uniquely suited for examining the subjective meanings patients attach to their condition. While previous studies using IPA explored the significant impact of fibromyalgia on patients' lives and the barriers they face in accessing care (Ashe et al., 2017; Frumer et al., 2023), the present study offers a novel perspective by delving into the nuances of patient-practitioner communication and their effects on trust and management of fibromyalgia. The current study seeks to provide new insights into the lived experiences of patients with fibromyalgia, identify specific patient-practitioner communication challenges, and suggest strategies to enhance patient-centred care by addressing the research question: 'In what ways do patients with fibromyalgia experience and interpret their interactions with GPs, and how do these interactions influence their trust in healthcare and overall management of their condition?'.

Materials and methods

Participants and sampling

The current study recruited six participants with a formal diagnosis of fibromyalgia to conduct an in-depth, idiographic analysis (Smith & Osborn, 2015). Of the six participants, five were female [83% of the cohort; mean age ± *SD*, 44.0 ± 13.7 years old] and one was male [17% of the cohort; age, 41 years old]. The duration range of their fibromyalgia diagnosis was 2–15 years (mean ± *SD*, 5.6 ± 2.9 years). The eligibility criteria included: (i) ≥18 years old; (ii) formal fibromyalgia diagnosis for ≥1 year; and (iii) born in the UK. Opportunistic sampling was used to gain comprehensive insights into the lived experiences of participants with fibromyalgia (Smith & Osborn, 2015). Participants were recruited *via* advertisements on social media including Facebook, X, and LinkedIn. Recruitment efforts aimed to capture a diverse range of experiences, with specific attempts to include male participants due to the underrepresentation of men in fibromyalgia research. Despite these efforts, the sample remained predominantly female, reflecting the higher prevalence of fibromyalgia among women. Ethical approval was obtained from the Health, Psychology, and Social Care Research Ethics Committee of the University of Derby, UK (ethics approval no. ETH2324-1954). The study adhered to the Code of Ethics and Conduct of the British Psychological Society 2021. All participants provided written and oral informed consent for their participation in the study. The demographic characteristics of the sample can be found in Table 1.

Table 1. Demographic characteristics of the sample.

Participant	Pseudonym	Sex	Age, years	Ethnicity	Duration of fibromyalgia diagnosis, years
1	Sophie	Female	31	White/British	4
2	Emily	Female	32	White/British	5
3	Rachel	Female	40	White/British	10
4	Margaret	Female	59	White/British	4
5	Linda	Female	58	White/British	5
6	James	Male	41	White/British	2

Demographic questionnaire

All participants completed a demographic questionnaire to collect essential information, including participants' age, sex, and fibromyalgia diagnosis status. Additionally, they were asked about their willingness to be contacted *via* email to arrange an interview. If they consented, they provided their email addresses for future communication. The specific questions included in the demographic questionnaire are provided in Appendix A.

Interview schedule

The interview schedule was designed to explore the lived experiences of participants with fibromyalgia, focusing on their interactions with GPs. Questions were created by the authors of the present study to elicit in-depth responses regarding the challenges and uncertainties in their diagnostic journey, communication with GPs, and the impact of these interactions on their treatment, trust, and overall well-being. The schedule was structured to cover a broad range of topics, ensuring a comprehensive understanding of the participants' experiences with the healthcare system. To ensure rigour and relevance, the interview questions were generated through a comprehensive review of relevant literature and iterative refinement of questions to ensure they addressed the core research aims. All interviews were conducted by the first author (CM). The interview schedule can be found in Appendix B.

Procedure

Upon procurement of ethics approval, six participants with fibromyalgia were recruited using opportunistic sampling. Participants completed a demographic form, consented to be contacted *via* email to schedule an interview, and a mutually convenient time for the interview to be conducted *via* Microsoft Teams was arranged. The interviews, which lasted between 40 and 60 min, involved open-ended questions designed to elicit detailed responses. After the interview, participants were given the opportunity to ask questions, were provided with a summary of the study's aims, and thanked for their participation.

Transcription

Interviews were audio recorded *via* Microsoft Teams and transcribed using the transcription feature of the platform. Transcripts were then securely stored in a password-protected file to ensure data privacy and confidentiality. Identifiable information was removed to anonymise the transcripts. Before every interview, participants verbally consented to audio recording and transcription.

Analytic method

IPA was employed to analyse data from the six semi-structured interviews with the participants with fibromyalgia. IPA was chosen for its alignment with the focus of the study on participants' subjective experiences and its capacity for detailed and reflective analysis (Larkin & Thompson, 2011; Smith, 1996). This approach enables flexible questioning and rapport-building, which are crucial for discussing sensitive topics, such as patient-practitioner communication in the context of fibromyalgia (Miles & Gilbert, 2005; Eatough et al., 2008).

IPA integrates phenomenology, hermeneutics, and an idiographic perspective (Pietkiewicz & Smith, 2014). Phenomenology seeks to understand consciousness and lived experience (Murray & Holmes, 2014), while hermeneutics focuses on interpreting these experiences. IPA uses a double hermeneutic approach, where participants interpret their reality, and researchers, in turn, interpret those interpretations. The researchers' preconceptions are acknowledged as essential for understanding participants' perspectives (Eatough et al., 2008). The current study followed an inductive, critical realist approach informed by interpretative phenomenological epistemology (Hood, 2016).

The analysis adhered to the six-step idiographic approach outlined by Pietkiewicz and Smith (2014): (i) Transcripts were thoroughly examined to identify recurring themes; (ii) themes were then organised into clusters through an iterative abstraction process; (iii) sub-themes were delineated for each main theme; (iv) a detailed table was created to map superordinate themes and sub-themes to specific data points within the transcripts; (v) the entire analytic process was meticulously documented to ensure transparency and rigor; and (vi) this documentation culminated in the development of the final manuscript.

Results and interpretation

The analysis of the data revealed two key themes that highlight the experiences of participants with fibromyalgia: (i) Challenges and dismissal encountered in obtaining an accurate diagnosis and adequate treatment; and (ii) crucial role of trust and communication in managing fibromyalgia. Given the complexity of these findings, discussion points are integrated within the themes to provide a richer interpretation of the results. These themes reflect the complex interplay between participants' experiences and healthcare practices, highlighting areas of both concern and opportunity within the medical system. The first theme explores the difficulties faced by participants, with two sub-themes including 'medical mystery and misdiagnosis' and 'sex bias in healthcare'. The second theme addresses the importance of effective communication and trust, with two sub-themes including 'positive impact of active listening and communication' and 'improved trust over time'.

Theme 1. Challenges and dismissal encountered in obtaining an accurate diagnosis and adequate treatment for fibromyalgia

Participants frequently expressed anxiety about feeling rejected by GPs and not being heard or believed. It was consistently reported that contrary to their expectations, GPs often dismissed their symptoms, struggled to determine the underlying cause of their illness, or even questioned the legitimacy of their condition. This lack of acknowledgment led participants to feel abandoned, as they were often left to independently seek information and solutions, highlighting a troubling absence of collaborative care. These experiences underpin the first sub-theme: 'Medical mystery and misdiagnosis', where participants' frustrations with unclear diagnoses and ineffective medical support are deeply rooted in their interactions with GPs.

Sub-theme 1.1. Medical mystery and misdiagnosis

Participants often described themselves as 'medical mysteries' to GPs, indicating a shared frustration, lack of answers, and a sense of being referred to a number of different specialties in the healthcare system without a definitive diagnosis. Sophie shared:

> *'One doctor actually called me a medical mystery because he couldn't find out what was up with me, but refused to refer me to different consultants… Some accused it of just being anxiety as well.'*

Sophie effectively outlines the challenges that fibromyalgia patients face within the healthcare system, where inconclusive tests, unresolved diagnoses, and limited treatment options often contribute to feelings of sadness and despair (Undeland & Malterud, 2007). Being labelled a 'medical mystery' and the refusal to refer Sophie to specialists reflect a biomedical approach that hinders communication and invalidates participants' experiences. The tendency to dismiss Sophie's symptoms as 'just anxiety' further illustrates the broader issue of attributing physical ailments to psychological factors, which only increases the emotional distress of patients (Nishikawara et al., 2023).

The sense of medical uncertainty was also reflected in Linda's experience:

> *'I felt the doctor was more confused than me.'*

Linda's statement highlights a disruption in the expected patient-practitioner dynamic, where rather than receiving clarity from a medical professional, she perceives the doctors as equally—if not more—uncertain about her condition. This reversal of epistemic authority can contribute to frustration and a lack of trust in the healthcare system. Hence, the ambiguity surrounding ME/CFS often leaves patients feeling abandoned in their search for validation and care, which may contribute to feelings of frustration, uncertainty, and distrust toward the medical system (Dennis et al., 2013). Emily echoed the frustration of navigating a laborious diagnostic process:

> *'Going, oh, we think it says, we think it's that…no blood showing* arthritis [referring to blood tests]. *Vitamin deficiency…no this is chronic widespread pain… they simply didn't know enough about it… I had lots of pain around my joints… swelling… muscular pain… which they couldn't understand for somebody so young to have these kinds of issues.'*

Emily's description of tentative an uncertain language—including phrases, such as *'we think it says, we think it's that'*, mirrors Linda's experience of encountering medical confusion rather than medical authority. Emily's frustration is palpable as she describes how her symptoms including joint pain, swelling, and muscular pain were poorly understood, particularly given her young age. This reference to her age highlights a potential implicit bias that complicates the recognition and validation of symptoms, revealing a disconnect between patient experiences and medical expectations. Such misunderstandings contribute to a prolonged and distressing diagnostic journey for numerous patients with fibromyalgia (Hasselroth et al., 2021). James' also noted his experience of interacting with a GP:

> *'The next thing the doctor told me it was all in my head. There was nothing wrong. That dismissal from healthcare professionals and still to this day some dismissal from certain healthcare professionals who don't really recognise fibromyalgia for what it is…'*

The statement *'The next thing the doctor told me it was all in my head. There was nothing wrong.'* illustrates the invalidation patients with fibromyalgia, experience when their symptoms are dismissed as solely psychogenic. Such dismissals not only disregard the physical reality of James' suffering but also reinforce a damaging cycle of misunderstanding within the healthcare system. The assertion that *'there was nothing wrong'*, can leave patients feeling isolated and helpless, as their lived experiences are dismissed. Despite growing awareness of fibromyalgia, persistent scepticism among some GPs highlights the urgent need for improved education and recognition of the condition. Validating patients' experiences is essential for fostering trust and enhancing patient-centred care (Cunningham & Jillings, 2006).

Sub-theme 1.2. Sex bias in healthcare

In addition to diagnostic difficulties, several female participants felt that sex bias significantly impacted the adequacy of their treatment. Research suggests that practitioners may downplay women's pain, particularly when it involves 'medically unexplained' symptoms (Samulowitz et al., 2018). This aligns with findings from previous studies indicating that conditions affecting women are often met with scepticism, leading to doubts about the legitimacy of their pain (Bernardes & Lima, 2011; Samulowitz et al., 2018). Female participants frequently reported feeling disbelieved or dismissed, with a common perception that their sex contributed to more frequent dismissive attitudes from male doctors. The experience of Rachel reflects this sentiment clearly:

> *'Male doctors at my practice, they're more likely to believe a male over a female patient… makes you feel like you're not believed… so certain doctors I simply don't trust. It has meant me going through several doctors.'*

Here, Rachel alludes to a perceived bias in the treatment of male and female patients by male GPs. The assertion that male GPs are *'more likely to believe a male over a female patient'* reflects a troubling sex bias that erodes trust and complicates patient care. Rachel's experience of needing to consult multiple doctors illustrates a broader issue of trust degradation, where patients feel forced to seek multiple consultations to have their symptoms validated (Cunningham & Jillings, 2006). This lack of trust may not only intensify feelings of isolation and frustration but also highlights the emotional toll of navigating a biased healthcare system. The sex bias issue is further exemplified by a specific response from a GP (sex of GP unknown), as detailed by Rachel:

> *'It's just a female problem… it doesn't affect men as well.'*

The statement '*It's just a female problem… it doesn't affect men as well*' from a GP effectively encapsulates the sex misconceptions surrounding fibromyalgia. By categorising fibromyalgia as *'just a female problem',* the GP not only dismisses Rachel's condition but also reinforces damaging sex stereotypes that undermine the legitimacy of both the diagnosis and the patient's experiences (Samulowitz et al., 2018). This comment highlights a broader issue within the medical field where women's health concerns are often minimised or inadequately addressed compared with those affecting men (Hoffmann & Tarzian, 2001). Such dismissive attitudes reflect a lack of comprehensive understanding and awareness about fibromyalgia, which can severely impede accurate diagnosis and effective treatment. Sophie similarly reported experiences of sex-based dismissal, further demonstrating how these misconceptions can affect the quality of care and patient trust:

> *'No, they didn't* [when asked if they felt understood by GPs when explaining symptoms]. *They just poo pooed it* [i.e. dismiss]. *It was 'fine'. It's 'menopausal'… 'I've got an underactive thyroid gland.'*

This quote captures the frustration of encountering dismissive and superficial responses from GPs. The term *'poo pooed it'* highlights Sophie's experience of having her symptoms trivialised and attributed to menopause or an underactive thyroid gland, without a thorough examination. This attitude not only fails to address the complexity of Sophie's condition but also reflects a troubling pattern of oversimplifying or misunderstanding women's health concerns (Samulowitz et al., 2018). Similar experiences of denial and invalidation were reported by Margaret, further highlighting the prevalent issues within patient-practitioner communication regarding fibromyalgia:

> *'For those* [GPs] *that have told me, 'We don't believe in the whole thing of fibromyalgia'… I simply won't go back to him… because either they've not done the research… or they're just fobbing it off* [i.e. dismissing] *saying, 'well, it's not real.'*

The aforementioned quote highlights the profound impact of GPs' disbelief in fibromyalgia. When a GP dismisses fibromyalgia as *'not real'*, it reflects a lack of acceptance and respect for the condition, deeply affecting Margaret's sense of support and trust. Margaret's decision to avoid further consultations with such GPs highlights that the feeling of abandonment and frustration when their condition is not taken seriously. The term *'fobbing it off'* suggests a superficial engagement with the participant's concerns, revealing a broader issue of insufficient knowledge and understanding about fibromyalgia among some GPs (Byrne et al., 2023).

While sex bias was a recurring concern among female participants, dismissive attitudes were not exclusive to women's experiences. James, a male participant, also reported feeling invalidated by his GP:

> *'The next thing they told me* [GP] *it was all in my head. There was nothing wrong. My bloods were all OK.'*

Although sex bias was not explicitly mentioned in James' case, his experience reflects the same pattern of medical dismissal described by female participants. His account highlights how disbelief and minimisation by GPs can extend beyond sex, reinforcing the broader issue of inadequate recognition and understanding of conditions like fibromyalgia.

Theme 2. Crucial role of trust and communication in fibromyalgia management

Effective management of fibromyalgia extends beyond medical treatments and interventions, hinging markedly on the quality of the patient-practitioner relationship (Alamo et al., 2002). Trust and communication emerged as vital components in shaping these interactions. For patients navigating the complexities of fibromyalgia, consultations often carry the weight of high expectations not just for medical guidance, but for understanding, empathy, and validation of their lived experiences. When these expectations are unmet, it can lead to frustration and a sense of abandonment. However, trust, cultivated through consistent and empathetic engagement, can profoundly transform patient experiences. The participants of the present study highlighted that when healthcare providers, albeit not always referring to their GPs, took the time to listen, demonstrated empathy, and communicated effectively with them, they were able to build and sustain trust, ultimately leading to more effective fibromyalgia management.

Sub-theme 2.1. Positive impact of active listening and communication

Participants who perceived their healthcare provider, albeit not always referring to their GP specifically, as actively listening, empathetic, and collaborative reported greater satisfaction and improved health outcomes. Active listening, characterised by full attention, genuine interest, and avoidance of interruptions, is a fundamental communication skill (Teutsch, 2003). This skill is especially significant for patients with fibromyalgia, as it helps to affirm the patient's experiences and mitigate the stigma often associated with fibromyalgia, such as being dismissed or disbelieved (Egeli et al., 2008; Nishikawara et al., 2023). Such findings are echoed by Sophie, albeit not with a GP, but with a medical team of rheumatology specialists:

> *'Rheumatology was the one that seemed to listen… I felt like they listened, and they were like, 'It is actually you experiencing this, and it's not just in my head.'*

Active listening is crucial in validating the experiences of patients with fibromyalgia (Teutsch, 2003). Here, the rheumatology medical team's attentive and affirming approach significantly impacted Sophie's perception of her care. Linda similarly reflects on the more empathic and validating nature of rheumatologists compared to other healthcare professionals:

> *'I have rheumatoid arthritis too. This was diagnosed first and gave some relief. They had more experience, I would say. A lot more empathetic because of this.'*

For patients with fibromyalgia, who often face challenges with invisible symptoms that are easily dismissed (Byrne et al., 2023; Nishikawara et al., 2023), the act of actively listening and acknowledging their experiences can transform their care experience. The rheumatology medical team is described as having listened and validated Sophie and Linda's experiences, indicating a shift from feeling disbelieved and isolated to being understood and supported. This validation not only alleviates the emotional burden associated with the condition but also builds trust in the healthcare relationship. Indeed, rheumatologists, who specialise in conditions like fibromyalgia, may demonstrate a deeper understanding and empathy towards these patients, as they are more familiar with the complexities of chronic pain conditions and express higher confidence in diagnosing fibromyalgia (Blotman et al., 2005). This specialised knowledge can lead to more attentive and compassionate care, as reflected in Sophie and Linda's experiences.

Emily also reported the building of a relationship, this time with her GP specifically and not a team of specialists, who demonstrated active listening and empathy, given their own personal experience with a chronic condition.

> *'One of them* [speaking about their GP], *she's absolutely brilliant… ['listens and works collaboratively'] … That we can actually work with it and actually go forward… Because she suffers with* [GP also suffers a chronic condition] … *another chronic health condition as well. So she does understand a bit about like the complexity of chronic health, chronic health conditions. She will actually take the time to listen to me…'*

The reflection of Emily highlights the profound impact of a GP's empathetic and collaborative approach on her experience of care. The emphasis on the GP's willingness to *'listen'* and work *'collaboratively'* highlights the critical importance of these attributes, particularly for patients with fibromyalgia, where symptoms are often invisible and misunderstood (Wilson et al., 2022). Emily's admiration for her GP, who also lives with a chronic condition, illustrates how shared experiences can enhance empathy and deepen understanding, reinforcing the value of personal connection in healthcare. The GP's ability to truly listen, despite their own health challenges, reflects a deep commitment to understanding the complexities of fibromyalgia and addressing Emily's unique needs. This approach resonates with the biopsychosocial model (Engel, 1981), which advocates for an integrated understanding of chronic illness by considering biological, psychological, and social dimensions. Emily's positive experience demonstrates the importance of extending beyond superficial consultations to fully engage with the multifaceted nature of fibromyalgia. By taking the time to listen, GPs can foster a collaborative relationship that builds essential trust and empowers patients. This holistic approach not only improves patient satisfaction but also significantly enhances the management and outcomes of chronic conditions like fibromyalgia (Chen & Swaminathan, 2020; Egeli et al., 2008).

Sub-theme 2.2. Improved trust over time

Building trust with patients with fibromyalgia often relies on GPs demonstrating empathy and collaboration (Egeli et al., 2008). Participant accounts indicate that when GPs show genuine empathy, actively involve patients in decision-making, and make them feel valued, trust in the therapeutic relationship greatly improves. This finding aligns with research highlighting the importance of patient-centred communication, which shows that patients who feel heard and respected are more likely to trust their GPs (Kwame & Petrucka, 2021). The experience of Rachel effectively captures this dynamic:

> *'Once they started taking me seriously… they got me to keep a diary… I've got a lot more trust in them now… I think that's made things better.'*

This quote highlights how trust in a GP can be significantly enhanced through specific actions and attitudes. The shift in Rachel's trust began when the GP started taking her seriously, marking a crucial turning point where their concerns were validated. The request to '*keep a diary*' was more than a clinical tool; it was a proactive step towards involving Rachel in the active management of her condition. This approach not only signified the GP's commitment to understanding Rachel's symptoms but also transformed Rachel's experience from feeling dismissed to feeling actively engaged in her care. The increased '*trust*' reflects how such personalised and attentive care can move the relationship from mere clinical interaction to a supportive partnership. This shift illustrates how active listening, engagement, and personalised care strategies can improve the patient-practitioner relationship and lead to better management and outcomes for patients with fibromyalgia. Similarly, Emily noted:

> *'They did various other tests… and the physio… I felt like they listened… Yes. So, it is getting better.'*

The reference to '*various other tests*' and '*the physio*' highlights the GP's commitment to exploring comprehensive diagnostic and treatment options. This proactive strategy demonstrates a dedication to understanding and addressing Emily's symptoms from multiple angles, contrary to a more superficial or dismissive approach. Emily's feeling that '*they listened*' indicates that this thoroughness was coupled with genuine attentiveness and engagement, enhancing the overall care experience. The affirmation that '*it is getting better*', reflects the positive impact of this approach on both Emily's health and their trust in the GP. This further elucidates how combining detailed investigation with empathetic listening can strengthen the patient-practitioner relationship and lead to improved management of fibromyalgia (Nishikawara et al., 2023). The experience of Rachel further exemplifies this shift in patient-practitioner dynamics:

> *'That we can actually work with it and actually go forward. Rather than taking one step forward, like 10–15 steps back, at least we'll be actually working towards something that we can actually physically work with.'*

The comparison of '*one step forward, like 10–15 steps back*' may initially reveal Rachel's disillusionment with earlier interactions that failed to make meaningful progress. By contrast, the current experience of being able to '*work with it*' and '*actually go forward*' represents a significant shift towards a more constructive and optimistic path. Rachel's sense of moving forward reflects how effective collaboration with GPs, combined with a clear and consistent approach, can significantly enhance their sense of agency and optimism. Emphasising a tangible and cooperative strategy reinforces the importance of a productive partnership in fibromyalgia management. The experience of Margaret also highlights how trust and effective communication are essential for successful outcomes:

> *'So, like in my journey of, like, fibromyalgia, it has meant me going through several doctors [GPs] to be able to get the help that I need. But I'm lucky that I have a couple of doctors [GPs] that I will go to that I can discuss with.'*

Margaret reflects on a challenging healthcare journey, noting the need to '*go through several doctors*' to find adequate support for their fibromyalgia. This search represents the difficulties several patients with fibromyalgia face in locating GPs who genuinely understand and address their complex needs (Lempp et al., 2009). However, Margaret highlights a positive development, finding '*a couple of doctors*' with whom they can have open discussions. This shift from a fragmented experience to forming meaningful relationships with a couple of trusted GPs marks a significant improvement in their care. The ability to '*discuss with*' these doctors signify the establishment of a supportive and communicative partnership, which is essential for effective management and emotional support. This transition highlights the importance of building strong, trusting relationships with GPs to enhance overall care and well-being.

Discussion

The present study explored the lived experiences of six participants with fibromyalgia in the UK, focusing on their relationships with GPs during consultations. Specifically, the study answered the following research question: 'In what ways do participants with fibromyalgia experience and interpret their interactions with GPs, and how do these interactions influence their trust in healthcare and overall management of their condition?' through the identification of two primary themes, each with two associated sub-themes: (i) Challenges and dismissal encountered in obtaining an accurate diagnosis and adequate treatment, which included the sub-themes of 'medical mystery and misdiagnosis' and 'sex bias in healthcare'; and (ii) Crucial role of trust and communication in managing fibromyalgia which included the sub-themes of 'positive impact of active listening and communication' and 'improved trust over time'. These themes and associated sub-themes highlighted the difficulties fibromyalgia participants face in the healthcare system and the essential role of trust and communication in improving the patient-practitioner relationship in fibromyalgia consultations.

The findings of the current study reinforce the profound challenges patients with fibromyalgia encounter in securing an accurate diagnosis and appropriate treatment, the significant impact of fibromyalgia on daily life, and the critical importance of trust and effective communication in managing the condition. These results are consistent with previous research (Koesling & Bozzaro, 2021), which also identified the difficulties patients with fibromyalgia face in achieving an accurate diagnosis, accessing suitable treatment, and establishing trustworthy relationships with their GPs. The study reveals that conflicts between GPs and patients with fibromyalgia can persist in primary care, but clear, efficient communication and reciprocal patient-practitioner relationships have the potential to mitigate these challenges. Addressing key concerns, such as the uncertainty patients with fibromyalgia experience during GP consultations is an important first step. The ongoing sense of invalidation and the inability to receive clear answers from GPs can result in negative outcomes as reflected in the patients' experiences. By contrast, the findings of the present study indicate that patients believe GPs do not experience the same uncertainty, raising questions about whether GPs are best suited to manage fibromyalgia. Addressing this mismatch requires substantial training and a significant shift towards patient-centred care (Arnold et al., 2016).

Participants with fibromyalgia in the present study faced significant challenges within the healthcare system, as they reported feeling ignored, dismissed, and/or disbelieved by GPs. These findings align with prior research by Kachaner et al. (2023), who found that patients with fibromyalgia frequently feel misunderstood by their doctors, leading to isolation and frustration. The patients included in the present study described difficult interactions with their GPs, characterised by a reliance on the GP and a lack of acknowledgment of their experiences. This care pathway appears suboptimal, with potential for adverse outcomes. Dismissive attitudes from GPs create a negative cycle for patients with fibromyalgia. Delayed fibromyalgia diagnosis, often due to insufficient investigation, not only prolongs patient suffering but also prevents timely treatment with Moshrif et al. (2023) reporting an average of 5.6 years from the onset of symptoms to diagnosis, suggesting that GPs should refer to specialists sooner. Moreover, encountering dismissive attitudes erodes trust in GPs. Patients may feel ignored, frustrated, and deterred from seeking further help, leading to disengagement from the healthcare system, which can result in poorer health outcomes (Warda et al., 2023).

The present study also identified sex bias as a barrier to effective diagnosis and treatment, with female patients reporting more dismissive attitudes and disbelief, particularly from male GPs. While GPs often struggle with the complexities of fibromyalgia, leading to dismissive attitudes, rheumatologists, due to their specialised knowledge and experience, may be better equipped to listen attentively and validate the experiences of patients with fibromyalgia. This disparity in care highlights the importance of referring patients with fibromyalgia to specialists who can offer more understanding and targeted support. This is consistent with Bernardes and Lima (2011), who found an association between ‘medically unexplained’ conditions and a tendency among GPs to question women’s pain. Prior research indicates that women are more likely to be perceived as exaggerating or somatising their pain, especially in chronic conditions like fibromyalgia, which lack clear biological markers (Favretti et al., 2023). This bias can lead to underestimating the severity of women’s pain and dismissing their symptoms as psychological rather than somatic (Briones-Vozmediano et al., 2018). Such sex biases undermine trust and communication between patients and GPs, making it harder for women to receive the care they need. Drossman et al. (2021) emphasise the importance of trust in patient-practitioner interactions for effective treatment outcomes, such as medication adherence. Patients who feel unheard or disbelieved due to sex bias may struggle with open communication and adherence to treatment regimens, potentially leading them to seek alternative care or self-manage their symptoms. Integrating implicit bias training into healthcare education could help address these issues, as research suggests such training can effectively reduce biases against patients with ‘invisible’ chronic pain conditions like fibromyalgia (Gopal et al., 2021).

The patient experiences reported in the present study further emphasise the importance of building trust and effective communication through active listening and validation. Patients with fibromyalgia who felt heard and believed by their healthcare providers, albeit not always their GP, reported enhanced trust and communication. While empathy is a desired outcome in UK medical education, its explicit inclusion in GP training curricula remains inconsistent (Winter & Pearson, 2023). This is concerning given empathy is crucial for encouraging patients to disclose their symptoms fully and participate actively in treatment discussions. Furthermore, patients prefer a collaborative approach to treatment planning, where they feel involved in decision-making). Patient-centred care, which promotes collaborative shared decision-making and respects patient autonomy, has been shown to build trust, engagement and ultimately lead to better health outcomes (Grady et al., 2017;

Sherwood et al., 2018). Such approaches also contribute to job satisfaction and well-being among GPs, further enhancing the quality of care delivered. Therefore, the adoption of more collaborative care models would empower patients with fibromyalgia to become active participants in their care, increasing their sense of control and well-being (Hickmann et al., 2022).

Trust emerged as a critical component of effective fibromyalgia management. The current study highlighted the importance of GPs who demonstrate empathy, thoroughly investigate symptoms, and persist in seeking solutions. However, patients' narratives also serve as a cautionary tale, highlighting the potential for frustration during initial consultations. This points to a significant challenge for healthcare systems, emphasising the need for smoother transitions and greater patient autonomy in selecting trusted GPs. Several factors can undermine trust in fibromyalgia management, including the ambiguous nature of fibromyalgia diagnosis and potential scepticism from GPs (Byrne et al., 2023). Additionally, the frustration of not feeling heard or believed can lead patients to seek a more validating GP, disrupting continuity of care and delaying effective treatment. Promoting continuity of care is one approach to addressing these challenges. Continuity of care allows patients to develop trust in a single GP over time, which is vital for effective management of chronic conditions like fibromyalgia. Enhanced communication between GPs and specialists, supported by GP electronic health records, a key feature of the improved digital services for enabling the integrated care system proposed by NHS England, can facilitate this continuity. However, it is crucial that GPs resolve patient concerns adequately to maintain this trust.

Limitations

The present study has several limitations. The sex composition of the sample - predominantly female with only one male participant - limits the extent to which the findings capture the full spectrum of experiences among individuals with fibromyalgia. Given that fibromyalgia is more commonly diagnosed in women, research often underrepresents men, yet their experiences may differ in meaningful ways, particularly in terms of stigma, diagnosis, and treatment. Furthermore, little is known about the background of the participants, and the lack of diversity in the sample restricts the depth of the themes and subthemes identified. A broader variety of participants would provide a more comprehensive perspective and uncover additional nuances in patient experiences.

While the interview schedule was not specifically focused on GP-patient interactions, it allowed participants to discuss their experiences with a range of healthcare providers. This approach revealed important differences between GP and specialist care, with the latter often perceived more positively. However, the broad scope of the interview schedule may have diluted the focus on GP interactions. Additionally, the reliance on retrospective self-reporting introduces potential recall bias, which could have affected the accuracy of the experiences reported. The study also did not collect data on variables, such as the duration of illness or time to diagnosis, factors that could influence patient experiences, and the nature of patient-practitioner relationships.

That said, the analysis meets key quality criteria indicators outlined by Nizza et al. (2021). First, a compelling, unfolding narrative was constructed that progressively developed key themes from patients' experiences. Second, the patients' words were closely analysed to emphasize the emotional and practical impacts of fibromyalgia on their healthcare journey. Third, the analysis attended to both convergence and divergence in these experiences, noting shared frustrations with GPs while also highlighting more positive interactions with specialists.

Future research

To improve patient experiences and outcomes in fibromyalgia management, future research should prioritise several critical areas. Firstly, greater attention should be given to the role of sex in shaping patient-practitioner interactions. Given that fibromyalgia is more commonly diagnosed in women, men's experiences with diagnosis, treatment, and communication are often underexplored. Future studies should aim for a more sex-balanced sample to examine whether men face unique barriers, such as delayed diagnosis or increased scepticism from healthcare providers. Addressing these disparities could lead to more inclusive and effective care strategies.

Secondly, building trust and addressing sex bias in the patient-practitioner relationship is essential. Enhancing GP training to include more comprehensive communication strategies and a deeper psychological understanding of patients with fibromyalgia could help mitigate these biases. Mixed-methods research that combines qualitative and quantitative approaches would provide a more accurate picture of the prevalence and impact of these under-explored experiences. An important avenue for future research would also be to explore GPs' perspectives on patient-practitioner communication with fibromyalgia patients, which could reveal insights into how to improve these interactions and the overall patient experience.

Finally, investigating patient-centred care approaches could lead to increased patient satisfaction and improved health outcomes. Advocacy efforts and policy changes within healthcare systems could accelerate the shift away from a purely biomedical model toward a biopsychosocial approach that acknowledges the complex interplay of biological, psychological, and social factors in chronic conditions like fibromyalgia. Future research should also explore how different demographic and socioeconomic factors influence patient experiences, ensuring that fibromyalgia care is equitable and responsive to diverse needs.

Conclusions

The present study examined the experiences of patients with fibromyalgia with their GPs, focusing on the difficulties in diagnosis and treatment, as well as the importance of trust and communication in care. The findings revealed that patients often feel dismissed and invalidated, particularly due to sex bias and the complexities of diagnosing fibromyalgia. However, trust and effective communication, especially through active listening, enhanced patient-practitioner relationships and improved care outcomes. The present study highlighted the need for a shift towards patient-centred care models that emphasise empathy, collaboration, and reduction of biases. Such an approach is not merely beneficial but essential for truly supporting patients with fibromyalgia or other chronic conditions and significantly improving their quality of life.

Ethical approval

Ethics approval was obtained from the Health, Psychology, and Social Care Research Ethics Committee of the University of Derby (ethics approval no. ETH2324-1954). All participants gave their written and verbal informed consent to take part in the present study.

Patient consent for publication

Not applicable.

Disclosure statement

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Data availability statement

Data are available from the corresponding author upon reasonable request.

References

Al Sharie, S., Varga, S. J., Al-Husinat, L., Sarzi-Puttini, P., Araydah, M., Bal'awi, B. R., & Varrassi, G. (2024). Unraveling the complex web of fibromyalgia: A narrative review. *Medicina*, *60*(2), 272. https://doi.org/10.3390/medicina60020272

Alamo, M. M., Moral, R. R., & de Torres, L. A. P. (2002). Evaluation of a patient-centred approach in generalized musculoskeletal chronic pain/fibromyalgia patients in primary care. *Patient Education and Counseling*, *48*(1), 23–31. https://doi.org/10.1016/s0738-3991(02)00095-2

Alciati, A., Cirillo, M., Masala, I. F., Sarzi-Puttini, P., & Atzeni, F. (2021). Differences in depression, anxiety and stress disorders between fibromyalgia associated with rheumatoid arthritis and primary fibromyalgia. *Stress and Health*, *37*(2), 255–262. https://doi.org/10.1002/smi.2992

Alvarez, M. C., Albuquerque, M. L. L., Neiva, H. P., Cid, L., Rodrigues, F., Teixeira, D. S., Matos, R., Antunes, R., Morales-Sánchez, V., & Monteiro, D. (2022). Exploring the relationship between fibromyalgia-related fatigue, physical activity, and quality of life. *International Journal of Environmental Research and Public Health*, *19*(8), 4870. https://doi.org/10.3390/ijerph19084870

Arnold, L. M., Choy, E., Clauw, D. J., Goldenberg, D. L., Harris, R. E., Helfenstein, M., Jensen, T. S., Noguchi, K., Silverman, S. L., Ushida, T., & Wang, G. (2016). Fibromyalgia and chronic pain syndromes: A white paper detailing current challenges in the field. *The Clinical Journal of Pain*, *32*(9), 737–746. https://doi.org/10.1097/AJP.0000000000000354

Ashe, S. C., Furness, P. J., Taylor, S. J., Haywood-Small, S., & Lawson, K. (2017). A qualitative exploration of the experiences of living with and being treated for fibromyalgia. *Health Psychology Open*, *4*(2), 2055102917724336. https://doi.org/10.1177/2055102917724336

Baron, R., Perrot, S., Guillemin, I., Alegre, C., Dias-Barbosa, C., Choy, E., Gilet, H., Cruccu, G., Desmeules, J., Margaux, J., Richards, S., Serra, E., Spaeth, M., & Arnould, B. (2014). Improving the primary care physicians' decision making for fibromyalgia in clinical practice: Development and validation of the fibromyalgia detection (FibroDetect®) screening tool. *Health and Quality of Life Outcomes*, *12*(1), 128. https://doi.org/10.1186/s12955-014-0128-x

Bernardes, S. F., & Lima, M. L. (2011). On the contextual nature of sex-related biases in pain judgments: The effects of pain duration, patient's distress and judge's sex. *European Journal of Pain*, *15*(9), 950–957. https://doi.org/10.1016/j.ejpain.2011.03.010

Blotman, F., Thomas, E., Myon, E., Andre, E., Caubere, J. P., & Taïeb, C. (2005). Awareness and knowledge of fibromyalgia among French rheumatologists and general practitioners. *Clinical and Experimental Rheumatology*, *23*(5), 697–700.

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*(14), 1679–1685. https://doi.org/10.1080/09638288.2017.1306759

Butow, P., & Sharpe, L. (2013). The impact of communication on adherence in pain management. *Pain*, *154 Suppl 1*(Supplement 1), S101–S107. https://doi.org/10.1016/j.pain.2013.07.048

Byrne, A., Jones, K., Backhouse, M., Rose, F., Moatt, E., & van der Feltz-Cornelis, C. (2023). Patient and primary care practitioners' perspectives on consultations for fibromyalgia: A qualitative evidence synthesis. *Primary Health Care Research & Development*, *24*, e58. https://doi.org/10.1017/S1463423623000506

Chen, A. T., & Swaminathan, A. (2020). Factors in the building of effective patient–provider relationships in the context of fibromyalgia. *Pain Medicine*, *21*(1), 138–149. https://doi.org/10.1093/pm/pnz054

Costa, L. P., & Ferreira, M. D. A. (2024). The (in) visibility of fibromyalgia through its symptoms and the challenges of its diagnosis and therapy. *Revista Brasileira de Enfermagem*, *77*(2), e20230363. https://doi.org/10.1590/0034-7167-2023-0363

Cunningham, M. M., & Jillings, C. (2006). Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research*, *15*(4), 258–273. https://doi.org/10.1177/1054773806291853

Dennis, N. L., Larkin, M., & Derbyshire, S. W. (2013). 'A giant mess'–making sense of complexity in the accounts of people with fibromyalgia. *British Journal of Health Psychology*, *18*(4), 763–781. https://doi.org/10.1111/bjhp.12020

Deslauriers, S., Roy, J.-S., Bernatsky, S., Blanchard, N., Feldman, D. E., Pinard, A. M., Fitzcharles, M.-A., Desmeules, F., & Perreault, K. (2021). The burden of waiting to access pain clinic services: Perceptions and experiences of patients with rheumatic conditions. *BMC Health Services Research*, *21*(1), 160. https://doi.org/10.1186/s12913-021-06114-y

Dizner-Golab, A., Lisowska, B., & Kosson, D. (2023). Fibromyalgia–etiology, diagnosis and treatment including perioperative management in patients with fibromyalgia. *Reumatologia*, *61*(2), 137–148. https://doi.org/10.5114/reum/163094

Doebl, S., Hollick, R. J., Beasley, M., Choy, E., & Macfarlane, G. J. (2022). Comparing the impact of symptoms and health care experiences of people who have and have not received a diagnosis of fibromyalgia: A cross-sectional survey within the PACFiND study. *Arthritis Care & Research*, *74*(11), 1894–1902. https://doi.org/10.1002/acr.24723

Drossman, D. A., Chang, L., Deutsch, J. K., Ford, A. C., Halpert, A., Kroenke, K., Nurko, S., Ruddy, J., Snyder, J., & Sperber, A. (2021). A review of the evidence and recommendations on communication skills and the patient–provider relationship: A Rome foundation working team report. *Gastroenterology*, *161*(5), 1670–1688.e7. https://doi.org/10.1053/j.gastro.2021.07.037

Eatough, V., Smith, J. A., & Shaw, R. (2008). Women, anger, and aggression: An interpretative phenomenological analysis. *Journal of Interpersonal Violence*, *23*(12), 1767–1799. https://doi.org/10.1177/0886260508314932

Egeli, N. A., Crooks, V. A., Matheson, D., Ursa, M., & Marchant, E. (2008). Patients' views: Improving care for people with fibromyalgia. *Journal of Clinical Nursing*, *17*(11c), 362–369. https://doi.org/10.1111/j.1365-2702.2008.02505.x

Engel, G. L. (1981). The clinical application of the biopsychosocial model. *The Journal of Medicine and Philosophy*, *6*(2), 101–123. https://doi.org/10.1093/jmp/6.2.101

Favretti, M., Iannuccelli, C., & Di Franco, M. (2023). Pain biomarkers in fibromyalgia syndrome: Current understanding and future directions. *International Journal of Molecular Sciences*, *24*(13), 10443. https://doi.org/10.3390/ijms241310443

Fernandez-Feijoo, F., Samartin-Veiga, N., & Carrillo-de-la-Peña, M. T. (2022). Quality of life in patients with fibromyalgia: Contributions of disease symptoms, lifestyle and multi-medication. *Frontiers in Psychology*, *13*, 924405. https://doi.org/10.3389/fpsyg.2022.924405

Frumer, L., Marom Harel, H., & Horesh, D. (2023). Why does it hurt so much? Emotion regulation mediates the association between fibromyalgia symptoms and psychological distress. *Healthcare*, *11*(10), 1368–1368. https://doi.org/10.3390/healthcare11101368

Galvez-Sánchez, C. M., Duschek, S., & Reyes Del Paso, G. A. (2019). Psychological impact of fibromyalgia: Current perspectives. *Psychology Research and Behavior Management*, *12*, 117–127. https://doi.org/10.2147/PRBM.S178240

Georgopoulou, S., Prothero, L., & D'Cruz, D. P. (2018). Physician–patient communication in rheumatology: A systematic review. *Rheumatology International*, *38*(5), 763–775. https://doi.org/10.1007/s00296-018-4016-2

Goldenberg, D. L. (2009). Diagnosis and differential diagnosis of fibromyalgia. *The American Journal of Medicine*, *122*(12 Suppl), S14–S21. https://doi.org/10.1016/j.amjmed.2009.09.007

Gopal, D. P., Chetty, U., O'Donnell, P., Gajria, C., & Blackadder-Weinstein, J. (2021). Implicit bias in healthcare: Clinical practice, research and decision making. *Future Healthcare Journal*, *8*(1), 40–48. https://doi.org/10.7861/fhj.2020-0233

Grady, A., Carey, M., Bryant, J., Sanson-Fisher, R., & Hobden, B. (2017). A systematic review of patient-practitioner communication interventions involving treatment decisions. *Patient Education and Counseling*, *100*(2), 199–211. https://doi.org/10.1016/j.pec.2016.09.010

Gyorfi, M., Rupp, A., & Abd-Elsayed, A. (2022). Fibromyalgia pathophysiology. *Biomedicines*, *10*(12), 3070. https://doi.org/10.3390/biomedicines10123070

Hasselroth, R., Björling, G., Faag, C., & Bose, C. N. (2021). "Can someone as young as you really feel that much pain?"–A survey on how people with fibromyalgia experience healthcare in Sweden. *SAGE Open Nursing*, *7*, 23779608211026145. https://doi.org/10.1177/23779608211026145

Häuser, W., Bernardy, K., Uçeyler, N., & Sommer, C. (2009). Treatment of fibromyalgia syndrome with antidepressants: A meta-analysis. *JAMA*, *301*(2), 198–209. https://doi.org/10.1001/jama.2008.944

Hickmann, E., Richter, P., & Schlieter, H. (2022). All together now–patient engagement, patient empowerment, and associated terms in personal healthcare. *BMC Health Services Research*, *22*(1), 1116. https://doi.org/10.1186/s12913-022-08501-5

Hoffmann, D. E., & Tarzian, A. J. (2001). The girl who cried pain: A bias against women in the treatment of pain. *The Journal of Law, Medicine & Ethics*, *29*(1), 13–27. https://doi.org/10.1111/j.1748-720x.2001.tb00037.x

Hood, R. (2016). Combining phenomenological and critical methodologies in qualitative research. *Qualitative Social Work*, *15*(2), 160–174. https://doi.org/10.1177/1473325015586248

Hyland, M. E., Bacon, A. M., Lanario, J. W., & Davies, A. F. (2019). Symptom frequency and development of a generic functional disorder symptom scale suitable for use in studies of patients with irritable bowel syndrome, fibromyalgia syndrome or chronic fatigue syndrome. *Chronic Diseases and Translational Medicine*, *5*(2), 129–138. https://doi.org/10.1016/j.cdtm.2019.05.003

Kachaner, A., Harim, M., Combier, A., Trouvin, A. P., Avouac, J., Ranque, B., & Piot, M. A. (2023). Management perspectives from patients with fibromyalgia experiences with the healthcare pathway: A qualitative study. *Frontiers in Medicine*, *10*, 1231951. https://doi.org/10.3389/fmed.2023.1231951

King, A., & Hoppe, R. B. (2013). "Best practice" for patient-centered communication: A narrative review. *Journal of Graduate Medical Education*, *5*(3), 385–393. https://doi.org/10.4300/JGME-D-13-00072.1

Kleykamp, B. A., Ferguson, M. C., McNicol, E., Bixho, I., Arnold, L. M., Edwards, R. R., Fillingim, R., Grol-Prokopczyk, H., Turk, D. C., & Dworkin, R. H. (2021). The prevalence of psychiatric and chronic pain comorbidities in fibromyalgia: An ACTTION systematic review. *Seminars in Arthritis and Rheumatism*, *51*(1), 166–174. https://doi.org/10.1016/j.semarthrit.2020.10.006

Koesling, D., & Bozzaro, C. (2021). Chronic pain patients' need for recognition and their current struggle. *Medicine, Health Care and Philosophy*, *24*(4), 563–572. https://doi.org/10.1007/s11019-021-10040-5

Kwame, A., & Petrucka, P. M. (2021). A literature-based study of patient-centered care and communication in nurse-patient interactions: Barriers, facilitators, and the way forward. *BMC Nursing*, *20*(1), 158. https://doi.org/10.1186/s12912-021-00684-2

Larkin, M., & Thompson, A. R. (2011). Interpretative phenomenological analysis in mental health and psychotherapy research. In *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 99–116). Wiley.

Lempp, H. K., Hatch, S. L., Carville, S. F., & Choy, E. H. (2009). Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: A qualitative study. *BMC Musculoskeletal Disorders*, *10*(1), 124. https://doi.org/10.1186/1471-2474-10-124

Lian, Y. N., Wang, Y., Zhang, Y., & Yang, C. X. (2020). Duloxetine for pain in fibromyalgia in adults: A systematic review and a meta-analysis. *The International Journal of Neuroscience*, *130*(1), 71–82. https://doi.org/10.1080/00207454.2019.1664510

Matthias, M. S., Parpart, A. L., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Sargent, C., & Bair, M. J. (2010). The patient–provider relationship in chronic pain care: Providers' perspectives. *Pain Medicine*, *11*(11), 1688–1697. https://doi.org/10.1111/j.1526-4637.2010.00980.x

Mease, P. J. (2008). Assessment of patients with fibromyalgia syndrome. *Journal of Musculoskeletal Pain*, *16*(1–2), 75–83. https://doi.org/10.1080/10582450801960347

Miles, J., & Gilbert, P. (Eds.). (2005). *A handbook of research methods for clinical and health psychology*. Oxford University Press.

Millea, P. J., & Holloway, R. L. (2000). Treating fibromyalgia. *American Family Physician*, *62*(7), 1575–1582, 1587.

Moshrif, A., Mosallam, A., Abu-Zaid, M. H., & Gouda, W. (2023). Evaluating the effect of delayed diagnosis on disease outcome in fibromyalgia: A multi-center cross-sectional study. *Journal of Pain Research*, *16*, 1355–1365. https://doi.org/10.2147/JPR.S381314

Murray, S. J., & Holmes, D. (2014). Interpretive phenomenological analysis (IPA) and the ethics of body and place: Critical methodological reflections. *Human Studies*, *37*(1), 15–30. https://doi.org/10.1007/s10746-013-9282-0

National Institute of Arthritis and Musculoskeletal and Skin Diseases (2024). *Fibromyalgia: Diagnosis, treatment and steps to take*. Retrieved September 5, 2024, from: https://www.niams.nih.gov/health-topics/fibromyalgia/diagnosis-treatment-and-steps-to-take

NICE (2024, April). *CKS is only available in the UK*. https://cks.nice.org.uk/topics/chronic-pain/background-information/prevalence/

Nishikawara, R. K., Schultz, I. Z., Butterfield, L. D., & Murray, J. W. (2023). "You have to believe the patient": What do people with fibromyalgia find helpful (and hindering) when accessing healthcare? *Canadian Journal of Pain*, *7*(2), 2176745. https://doi.org/10.1080/24740527.2023.2176745

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369–386. https://doi.org/10.1080/14780887.2020.1854404

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, *20*(1), 7–14.

Rahman, A., Underwood, M., & Carnes, D. (2014). Fibromyalgia. *BMJ*, *348*(5), g1224. https://doi.org/10.1136/bmj.g1224

Salaffi, F., Farah, S., Bianchi, B., & Di Carlo, M. (2024). Central sensitization in psoriatic arthritis: Relationship with composite measures of disease activity, functional disability, and health-related quality of life. *The Journal of Rheumatology*, *51*(2), 144–149. https://doi.org/10.3899/jrheum.2023-0177

Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). "Brave men" and "emotional women": A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Research & Management*, *2018*(1), 6358624. https://doi.org/10.1155/2018/6358624

Sherwood, A., Brinkmann, J., & Fatone, S. (2018). Review of benefits to practitioners of using good patient-practitioner communication. *JPO Journal of Prosthetics and Orthotics*, *30*(1), 5–12. https://doi.org/10.1097/JPO.0000000000000165

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11*(2), 261–271. https://doi.org/10.1080/08870449608400256

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, *9*(1), 41–42. https://doi.org/10.1177/2049463714541642

Soni, A., Santos-Paulo, S., Segerdahl, A., Javaid, M. K., Pinedo-Villanueva, R., & Tracey, I. (2020). Hospitalization in fibromyalgia: A cohort-level observational study of in-patient procedures, costs and geographical variation in England. *Rheumatology*, *59*(8), 2074–2084. https://doi.org/10.1093/rheumatology/kez499

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *Canadian Medical Association Journal*, *152*(9), 1423–1433.

Teutsch, C. (2003). Patient–doctor communication. *The Medical Clinics of North America*, *87*(5), 1115–1145. https://doi.org/10.1016/s0025-7125(03)00066-x

Undeland, M., & Malterud, K. (2007). The fibromyalgia diagnosis–Hardly helpful for the patients? A qualitative focus group study. *Scandinavian Journal of Primary Health Care*, *25*(4), 250–255. https://doi.org/10.1080/02813430701706568

Warda, E. R., Taye, A., Perskin, M., & Taylor, L. (2023). Does missing trust lead to overuse or underuse of health care services? *American Journal of Managed Care*, *29*(8), 388–392.

WHO (2004). *2020 ICD-10-CM Diagnosis Code M79.7: Fibromyalgia*. www.icd10data.com. https://www.icd10data.com/ICD10CM/Codes/M00-M99/M70-M79/M79-/M79.7

Wilson, N., Beasley, M. J., Pope, C., Dulake, D., Moir, L. J., Hollick, R. J., & Macfarlane, G. J. (2022). UK healthcare services for people with fibromyalgia: Results from two web-based national surveys (the PACFiND study). *BMC Health Services Research*, *22*(1), 989. https://doi.org/10.1186/s12913-022-08324-4

Winter, R., & Pearson, G. M. (2023). Exploring the challenges of frailty in medical education. *The Journal of Frailty & Aging*, *12*(2), 134–138. https://doi.org/10.14283/jfa.2023.12

Wolfe, F., Walitt, B., Perrot, S., Rasker, J. J., & Häuser, W. (2018). Fibromyalgia diagnosis and biased assessment: Sex, prevalence and bias. *PLOS One*, *13*(9), e0203755. https://doi.org/10.1371/journal.pone.0203755

Appendix A. Demographic questionnaire

1. What is your age?
2. What is your gender? (Please select one: Male, Female, Transgender, Non-binary, Prefer not to say)
3. Have you received a formal diagnosis of fibromyalgia? (Yes/No)
4. May we contact you *via* email to arrange a follow-up interview? (Yes/No)
   If you consent to being contacted, please provide your email address below.

Appendix B. Interview questions

1. *Onset and diagnosis*
   - Can you describe your experiences leading up to the diagnosis of fibromyalgia? Were there any particular aspects of the diagnostic process that stood out to you?
   - If there was any uncertainty surrounding your diagnosis, how did you navigate it? How did healthcare practitioners communicate with you about your diagnosis?

2. *Healthcare seeking behaviour*
   - What factors influenced your decision to seek healthcare for your symptoms?
   - How did you feel about your ability to communicate the nature and impact of your symptoms to healthcare practitioners?

3. *Communication with healthcare practitioners*
   - Can you share any instances where you felt your symptoms were understood by healthcare practitioners? How did these experiences affect you?
   - How did healthcare practitioners communicate with you during the diagnosis and management of your fibromyalgia? Were there any challenges in these interactions?
4. *Diagnostic uncertainty and trust*
   - If you experienced uncertainty or ambiguity during the diagnostic process, how did you cope with it?
   - Reflecting on your experiences, how would you describe the level of trust between you and your healthcare practitioners?
5. *Treatment and management*
   - Have there been any moments where you questioned the effectiveness of your treatments? If so, how did you and your healthcare practitioners address these concerns?
   - How has your relationship with healthcare practitioners affected your decisions regarding treatment plans?
6. *Impact on daily life*
   - How has your experience with the diagnostic process impacted your daily life and relationships?
   - Can you describe situations where you felt your fibromyalgia was understood by those around you? How did these situations affect your well-being?
7. *Coping strategies*
   - What coping mechanisms have you found most helpful in managing the emotional aspects of your fibromyalgia?
   - How has your relationship with healthcare practitioners influenced your approach to coping with fibromyalgia?
8. *Reflection on healthcare system*
   - What recommendations do you have for healthcare practitioners to enhance the diagnostic and communication process for individuals with fibromyalgia?
   - Based on your experience, do you have any recommendations for healthcare practitioners to improve the diagnosis and communication process for individuals with fibromyalgia?