

Living with Fibromyalgia: A Phenomenological Study of Pain, Fatigue, and Coping

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Article Info

Article type:

Original Research

How to cite this article:

Rostami, M., Bulut, S., Coelho, O., & Riyono, B. (2024). Living with Fibromyalgia: A Phenomenological Study of Pain, Fatigue, and Coping. *Journal of Personality and Psychosomatic Research*, 2(1), 16-23.
<https://doi.org/10.61838/kman.jppr.2.1.4>



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ABSTRACT

This phenomenological study aims to explore the lived experiences of individuals diagnosed with fibromyalgia (FM), focusing on their experiences of pain, fatigue, and the coping mechanisms they employ to manage these symptoms. Employing a qualitative phenomenological approach, data were collected through semi-structured interviews with 25 participants who have been diagnosed with FM. Participants were recruited from various fibromyalgia support groups and clinics, ensuring a diverse representation in terms of age, gender, and duration of diagnosis. Interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analysis to achieve theoretical saturation. Three main themes were identified from the interviews: Pain, Fatigue, and Coping Mechanisms. Under the Pain theme, categories included the nature and characteristics of pain, its impact on physical function, and pain management strategies. The Fatigue theme comprised chronic exhaustion, cognitive fatigue, and its impact on daily activities. For Coping Mechanisms, emotional strategies, physical coping tactics, and social support were highlighted as key categories. These themes underscore the complex interplay between the physical symptoms of FM and the psychological and social strategies employed by individuals to manage their condition. The study highlights the pervasive and multifaceted nature of pain and fatigue in fibromyalgia, significantly impacting individuals' daily lives and functional abilities. It also reveals the importance of effective coping strategies, both adaptive and maladaptive, in managing these symptoms. These findings emphasize the need for a holistic and personalized approach to the management and support of individuals living with FM, incorporating both pharmacological and non-pharmacological interventions.

Keywords: *Fibromyalgia, Phenomenological Study, Pain, Fatigue, Coping Mechanisms, Qualitative Research.*

1. Introduction

Fibromyalgia (FM) is a complex, chronic condition characterized by widespread pain, profound fatigue, sleep disturbance, and cognitive difficulties, impacting an estimated 2-4% of the global population. The etiology of FM remains elusive, complicating both diagnosis and management, with patients often undergoing a lengthy process of uncertainty before receiving a definitive diagnosis (Smith, 2011).

The prevalence and impact of fibromyalgia have been increasingly recognized in medical literature, with recent studies indicating a notable incidence among patients with early osteoarthritis, suggesting a potential overlap in their pathophysiological mechanisms (Hallberg & Carlsson, 2000; Velasco-Furlong et al., 2020; Vincent et al., 2013). Moreover, the relationship between fibromyalgia symptoms and various biopsychosocial factors, including religiosity and spirituality, has been explored, revealing complex interactions that influence the physical and mental outcomes in FM patients (Aloush et al., 2021). This underscores the multifaceted nature of fibromyalgia, necessitating a holistic approach to its management.

Catastrophizing, or the tendency to focus on and exaggerate the threats from pain, has been identified as a prognostic factor for pain and physical function in FM, highlighting the significant role of psychological factors in the condition's severity and progression (Angst et al., 2022). Similarly, abnormalities in pain expectation, as evidenced by electrophysiological indices, suggest that FM patients may process pain differently, further complicating their treatment (Barjola et al., 2022). The digital era has ushered in new platforms for support, with social media, particularly Instagram, emerging as a vibrant community for those seeking understanding and connection over their shared experiences with fibromyalgia (Berard & Smith, 2018). Technological advancements have enabled the development of novel learning models using concave and convex kernels, predicting the quality of sleep and level of fatigue in fibromyalgia, illustrating the potential of machine learning in personalizing patient care (Sabeti et al., 2019). The role of physical activity and fitness has been scrutinized in relation to fibromyalgia symptoms and severity, with findings suggesting significant associations that underscore the importance of an active lifestyle in mitigating symptom severity (Segura-Jiménez et al., 2016).

Medications such as duloxetine have shown effectiveness in managing specific fibromyalgia symptoms like tiredness, although responses vary significantly among patients, indicating the need for personalized treatment plans (Bradley et al., 2010). The intersection between psychiatric disorders and fibromyalgia has been documented, with a notable onset of FM and chronic fatigue syndrome following the manifestation of psychiatric conditions, which may point towards shared underlying mechanisms (Creed, 2023). Non-pharmacological interventions, including transcutaneous electrical nerve stimulation, have demonstrated potential in reducing pain, fatigue, and hyperalgesia, while restoring central inhibition in FM, suggesting the value of integrating such therapies into comprehensive treatment strategies (Dailey et al., 2013). The association between fibromyalgia and conditions like overactive bladder has been explored through systematic reviews and meta-analyses, indicating a higher comorbidity rate that impacts the management and quality of life of affected individuals (Goldberg et al., 2022). Innovations in treatment approaches, such as the use of acupuncture, have been examined through bibliometric analysis, reflecting a growing interest in alternative and complementary therapies that may offer relief to FM patients (Li et al., 2022). Group exercise and education programmes have also been evaluated for their impact on symptoms and physical fitness in FM, suggesting the potential benefits of such interventions in improving patient outcomes (Loftus et al., 2021).

The demographic shift towards an aging population has brought attention to the prevalence and characteristics of fibromyalgia in the elderly, a group that presents unique challenges in diagnosis and management due to the commonality of symptoms with other age-related conditions (Gómez-Argüelles et al., 2022). The coping strategies employed by individuals with fibromyalgia, including both adaptive and maladaptive mechanisms, have been the subject of extensive research, shedding light on the resilience and resourcefulness many patients exhibit in the face of persistent symptoms (Hallberg & Carlsson, 2000).

Emerging research has begun to unravel the complex interconnections between early life trauma, disease severity, and psychological resilience in fibromyalgia, offering insights into potential therapeutic targets that address both psychological and physical aspects of the disease (Kizilkurt et al., 2021). The COVID-19 pandemic has further complicated the landscape for FM patients, exacerbating both mental and physical wellbeing and underscoring the need for adaptive strategies in unprecedented times

(Lazaridou et al., 2022). The intricate relationship between psychological factors, stress, and key symptoms of fibromyalgia has been highlighted in the literature, pointing towards the significant influence of mental health on the manifestation and severity of FM symptoms (Malin & Littlejohn, 2016). The advent of telerehabilitation and mind-body techniques offers promising avenues for addressing both physical and psychological outcomes in FM, facilitating access to therapeutic interventions regardless of geographical constraints (Paolucci et al., 2022).

The complexity of fibromyalgia is further elucidated through studies examining the distinct alterations in the functional anatomy of the cerebral cortex in pain-sensitized osteoarthritis and FM patients, suggesting a unique neurobiological underpinning that differentiates FM from other chronic pain conditions (Pujol et al., 2022). Understanding fibromyalgia as an afferent processing disorder offers a unique perspective on the syndrome, emphasizing the role of central sensitization in the generalized pain and symptomatology observed in patients, which may guide future therapeutic strategies (Smith, 2011). Emotional recognition difficulties in fibromyalgia, compared with other conditions such as obesity, shed light on the cognitive and affective dimensions of FM, suggesting potential areas for cognitive-behavioral interventions (Vaioli & Scarpina, 2021).

The dichotomy of sedentary time and physical activity's impact on FM symptoms highlights the delicate balance required in managing physical engagement without exacerbating symptoms, pointing to the need for tailored exercise regimens (Segura-Jiménez et al., 2016). The psychological ramifications of the COVID-19 pandemic on individuals with fibromyalgia have been systematically reviewed, revealing profound impacts on their well-being and exacerbating the challenges faced in managing their condition (Sheykhgafshe et al., 2021).

The proposed model for understanding fatigue in fibromyalgia, termed the "4 U's rule," encapsulates the ubiquity, unpredictability, unrelenting nature, and unknown etiology of fatigue in FM, offering a framework for exploring this pervasive symptom (Velasco-Furlong et al., 2020). The exploration of fatigue beyond pain in fibromyalgia research has revealed its multidimensional impact on patients, highlighting the necessity of addressing fatigue as a primary symptom in FM management (Vincent et al., 2013).

The potential of hyperbaric oxygen therapy in ameliorating pain among overweight or obese patients with

fibromyalgia indicates the ongoing search for effective, non-pharmacological treatment options, presenting a novel avenue for symptom relief (Winfield-Vargas et al., 2021).

Through this study, we aim to contribute to the understanding of fibromyalgia by providing a phenomenological study on pain, fatigue, and coping, based on the lived experiences of individuals diagnosed with the condition. By integrating these insights with the broader research context, this study seeks to enhance the knowledge base surrounding fibromyalgia, facilitating more effective and empathetic approaches to care and management for those affected by this challenging syndrome.

2. Methods and Materials

2.1. Study Design and Participants

This study employed a qualitative research design, specifically utilizing a phenomenological approach to explore and understand the lived experiences of individuals diagnosed with fibromyalgia. Phenomenology focuses on the meanings of experiences for individuals, thus enabling an in-depth exploration of their encounters with pain, fatigue, and their coping mechanisms.

Participants were recruited using purposive sampling from various fibromyalgia support groups and clinics. Inclusion criteria required participants to have a formal diagnosis of fibromyalgia by a healthcare professional. The study aimed for diversity in age, gender, and duration of diagnosis to capture a broad range of experiences. Theoretical saturation was achieved after conducting interviews with 20 participants, at which point no new themes were emerging from the data, ensuring the comprehensiveness of the phenomena under investigation.

Participants were informed about the study's purpose, their rights to confidentiality and anonymity, and their right to withdraw at any point without consequence. Informed consent was obtained from all participants. To protect privacy, pseudonyms are used in reporting results.

2.2. Measures

2.2.1. Semi-Structured Interview

Data were collected through semi-structured interviews, allowing for the flexibility to explore participants' personal narratives deeply. The interview guide was developed based on a preliminary literature review and included open-ended questions on three main areas: the nature of their pain, experiences of fatigue, and coping strategies. Interviews

ranged from 45 to 90 minutes, conducted in quiet, private settings chosen by the participants to ensure comfort and confidentiality. All interviews were audio-recorded with participants' consent and later transcribed verbatim for analysis.

2.3. *Data Analysis*

Data analysis followed the principles of phenomenological analysis, focusing on identifying and describing the essence of the shared experiences among participants. Transcripts were read and re-read, enabling immersion in the data. Initial codes were generated, focusing on descriptive, linguistic, and conceptual elements. These codes were then grouped into themes that captured the core experiences of living with fibromyalgia. Trustworthiness was ensured through methods of triangulation, peer debriefing, and member checking, where participants provided feedback on the findings.

Table 1

Subthemes and Concepts of Fatigue

Main Theme	Subtheme	Concepts (Open Codes)
Fatigue	Chronic Exhaustion	Unrelenting tiredness, Sleep doesn't help, Hits suddenly, Worsens by evening
	Cognitive Fatigue	Forgetfulness, Trouble focusing, Slowed thinking, Mislacing things
	Emotional Fatigue	Feeling overwhelmed, Lack of motivation, Emotional numbness, Quick to anger
	Impact on Daily Activities	Struggle with chores, Need for breaks, Can't finish tasks, Reduced work hours
	Coping Strategies	Strategic resting, Energy management, Prioritizing tasks, Seeking understanding
	Perception and Misunderstanding	Invisible to others, Minimized by others, Frustration with misconceptions, Desire for recognition
	Recovery and Flare-ups	Recognizing triggers, Variability of recovery, Impact of stress, Importance of routine

3.1. *Fatigue*

The exploration of fatigue among individuals with fibromyalgia revealed seven distinct subthemes, emphasizing its multifaceted impact. Chronic exhaustion was described as a relentless tiredness that sleep could not alleviate, with one participant noting, "No matter how much I rest, the fatigue clings to me like a shadow." Cognitive fatigue emerged as a significant challenge, marked by forgetfulness and difficulty focusing, leading another to express, "My mind feels foggy, and I lose track of simple tasks." Emotional fatigue, characterized by feelings of overwhelm and a lack of motivation, was summed up by a respondent: "It's like my emotions are too tired to surface."

3. **Findings and Results**

The study encompassed a diverse group of 25 participants diagnosed with fibromyalgia, comprising 20 women and 5 men, reflecting the higher prevalence of the condition among females. The ages of participants ranged from 24 to 65 years, with a mean age of 45 years, highlighting the broad age spectrum affected by fibromyalgia. Most participants (16 out of 25) were employed either part-time or full-time, indicating a significant portion managed to maintain employment despite their condition. Regarding marital status, 12 participants reported being married, 8 were single, and 5 identified as divorced or separated, suggesting a variety of social support structures. Education levels among the participants varied, with 8 holding a college degree, 10 having completed some form of higher education (e.g., vocational training or associate degrees), and 7 possessing a high school diploma as their highest level of education.

The impact on daily activities was highlighted, with individuals struggling to complete chores or maintain work hours. "I've had to cut my workdays short because I just can't keep up," shared one participant. Coping strategies varied, including strategic resting and energy management, with one individual stating, "I've learned to listen to my body and rest before I hit my limit." The subtheme of perception and misunderstanding captured the invisibility of their condition, with a poignant remark: "People don't see my fatigue, so they think it's not real." Finally, recovery and flare-ups were discussed, with participants identifying stress as a significant trigger and emphasizing the importance of routine in managing their condition.

Table 2

Subthemes and Concepts of Pain

Main Theme	Subtheme	Concepts (Open Codes)
Pain	Nature and Characteristics	Sharp, throbbing, Widespread, Migratory, Intermittent
	Impact on Physical Function	Difficulty standing, Limited walking, Challenges with fine motor skills, Need for assistance
	Emotional and Psychological Impact	Fear of future pain, Anxiety about limitations, Depression due to pain, Anger and frustration
	Pain Variability and Triggers	Weather changes, Physical activity, Stress, Lack of sleep
	Management and Mitigation	Medications, Heat therapy, Cold compresses, Physical therapy, Acupuncture
	Communication Challenges	Difficulty explaining pain, Disbelief from others, Seeking empathy, Importance of validation

3.2. *Pain*

The theme of pain encompassed six subthemes, providing insight into its complex nature. The nature and characteristics of pain were widely discussed, with descriptions of pain as "sharp, throbbing, and sometimes migrating across my body." The impact on physical function was profound, limiting mobility and necessitating assistance for basic tasks. "I need help with things I used to do on my own," lamented one individual. The emotional and psychological impact was significant, with respondents

reporting fear, depression, and frustration directly linked to their pain experiences.

Variability and triggers of pain were noted, including environmental factors and physical stressors. "A change in the weather can leave me bedridden," revealed a participant. In terms of management and mitigation, a range of strategies was employed, from medications to alternative therapies, with one person highlighting, "Physical therapy and acupuncture have become my lifelines." Communication challenges were common, with individuals struggling to convey the severity of their pain to others, encapsulated by the statement, "Explaining my pain feels like speaking a different language."

Table 3

Subthemes and Concepts of Coping

Main Theme	Subtheme	Concepts (Open Codes)
Coping	Emotional Strategies	Seeking emotional support, Expressing feelings, Using humor, Practicing gratitude
	Physical Coping Tactics	Gentle exercise, Adjusted daily routines, Use of ergonomic tools, Scheduled rest periods
	Social and Community Support	Family understanding, Joining support groups, Online forums, Sharing stories
	Self-care and Wellness	Mindfulness, Balanced diet, Yoga and meditation, Regular check-ups, Pursuing hobbies
	Navigating Healthcare	Advocating for oneself, Building a healthcare team, Treatment plan adjustments, Seeking second opinions
	Information and Resource Seeking	Reading up on fibromyalgia, Attending workshops, Consulting specialists, Online webinars
	Resilience and Positive Adaptation	Developing resilience, Positive reframing, Setting new goals, Embracing change
	Environmental Adjustments	Home modifications, Workplace accommodations, Reducing sensory overload, Tailoring social activities

3.3. *Coping*

Coping with fibromyalgia introduced eight subthemes, illustrating diverse strategies and support systems. Emotional strategies such as seeking support and practicing gratitude were vital, as one interviewee put it, "Talking about my feelings helps me not feel so alone." Physical coping tactics, including gentle exercise and adjusted routines, were crucial for managing symptoms. "I've found that a little bit of yoga can go a long way," said a respondent.

Social and community support was a cornerstone of coping, with many turning to support groups and online forums for advice and camaraderie. "Finding a community that understands has been a game-changer," shared an individual. Self-care and wellness practices, from mindfulness to pursuing hobbies, played a significant role in participants' lives. Navigating healthcare effectively, through advocating for oneself and building a supportive healthcare team, was emphasized as essential for optimal management.

Information and resource-seeking behaviors were common, with participants actively educating themselves about fibromyalgia. Resilience and positive adaptation were themes of growth and acceptance, with one participant reflecting, "I've learned to see my condition as a part of me, but not all of me." Environmental adjustments, such as home modifications and workplace accommodations, were highlighted as necessary for reducing physical strain and sensory overload.

4. Discussion and Conclusion

This phenomenological study explored the lived experiences of individuals with fibromyalgia (FM), focusing on three main themes: pain, fatigue, and coping mechanisms. Our findings reveal that pain and fatigue are pervasive and debilitating aspects of FM, significantly impacting daily life and functional abilities. Pain was characterized by its heterogeneous nature, with variability in intensity, location, and triggers. Fatigue emerged as a profound and unrelenting symptom, affecting cognitive, emotional, and physical domains. Coping mechanisms varied widely, encompassing physical strategies, emotional support seeking, and the utilization of online communities for support and information sharing.

In our qualitative phenomenological study of individuals living with fibromyalgia (FM), we identified three main themes that encapsulate the lived experiences of our participants: Pain, Fatigue, and Coping Mechanisms. These themes were further divided into specific categories that provided detailed insights into the multifaceted nature of FM. The Pain theme was divided into categories such as Nature and Characteristics of Pain, Impact on Physical Function, and Pain Management. The Fatigue theme included categories like Chronic Exhaustion, Cognitive Fatigue, and Impact on Daily Activities. Lastly, the Coping Mechanisms theme encompassed Emotional Strategies, Physical Coping Tactics, and Social Support as its categories, highlighting the diverse strategies employed by individuals to manage their condition.

The Pain theme revealed a complex and varied experience among participants, with the Nature and Characteristics of Pain category revealing concepts such as intensity, duration, and location variability. The Impact on Physical Function category highlighted the limitations in daily activities and mobility, while the Pain Management category showed a reliance on both pharmacological treatments and alternative therapies. These findings

underscore the pervasive and unpredictable nature of pain in FM and the ongoing struggle to find effective management strategies.

Fatigue emerged as equally debilitating, with the Chronic Exhaustion category capturing feelings of unrelenting tiredness that significantly impacts life quality. Cognitive Fatigue brought attention to the mental aspects of FM, including concentration difficulties and memory issues. The Impact on Daily Activities category underlined how fatigue restricts participants' ability to engage in personal, social, and professional activities, emphasizing the need for energy-conserving strategies.

The Coping Mechanisms theme highlighted the resourcefulness of individuals with FM. Emotional Strategies included seeking emotional support and using humor to navigate the emotional turmoil of living with FM. Physical Coping Tactics detailed the use of gentle exercise, adjusted daily routines, and physical therapy, while Social Support revealed the importance of family, friends, and online communities in providing understanding and solace. These categories illustrate the adaptive and proactive approaches participants take to manage their symptoms and maintain a sense of normalcy in their lives.

Pain, as a predominant theme in FM, presents in a heterogeneous manner, aligning with Pujol et al. (2022), who reported distinctive alterations in the cerebral cortex associated with pain sensitivity. This neurophysiological insight complements our findings on the subjective experiences of pain variability and its profound impact on daily functioning (Pujol et al., 2022). The significance of pain expectation abnormalities, as investigated by Barjola et al. (2022), further illuminates the complex interplay between physiological processes and subjective pain experiences in FM (Barjola et al., 2022).

Fatigue emerged as a pervasive and debilitating aspect of FM in our study, echoing Vincent et al.'s (2013) insights into fatigue as a critical, yet often underappreciated, symptom (Vincent et al., 2013). The "4 U's rule" proposed by Velasco-Furlong et al. (2020) for understanding FM fatigue provided a valuable framework for interpreting our participants' experiences, highlighting the unpredictable and unrelenting nature of fatigue in FM (Velasco-Furlong et al., 2020).

The role of coping mechanisms in managing FM was central to our findings. Participants employed a range of strategies, from physical coping tactics to emotional and social support seeking, similar to the adaptive coping strategies described by Hallberg and Carlsson (2000) (Hallberg & Carlsson, 2000). Moreover, our findings on the

importance of social media platforms for support and community, as noted by Berard and Smith (2018), underscore the evolving landscape of social support in the digital age (Smith, 2011).

Aligning with the broader literature, our study highlights the importance of addressing psychological factors in FM. Angst et al. (2022) identified catastrophizing as a prognostic factor for pain and physical function (Angst et al., 2022), resonating with our findings on the psychological impact of FM and the importance of resilience, as also seen in the work of Kizilkurt et al. (2021) (Kizilkurt et al., 2021). The association between psychiatric disorders and the onset of FM (Creed, 2023) further emphasizes the need for a comprehensive approach that addresses both physical and psychological aspects of FM.

The multifaceted nature of FM management was evident in our participants' experiences, with many turning to a combination of pharmacological and non-pharmacological treatments. The effectiveness of duloxetine in managing tiredness subgroups in FM (Bradley et al., 2010) and the benefits of transcutaneous electrical nerve stimulation (Dailey et al., 2013) reflect the diverse therapeutic options explored by our participants. This aligns with recent trends in FM treatment, including the exploration of acupuncture (Li et al., 2022) and the potential of telerehabilitation (Paolucci et al., 2022), highlighting the growing emphasis on personalized, multifaceted treatment plans.

In conclusion, this study underscores the complexity of fibromyalgia, highlighting the significant challenges faced by individuals in managing pain and fatigue, as well as the importance of effective coping strategies. Our findings emphasize the need for a holistic and personalized approach to FM management, acknowledging the multifaceted nature of the condition and the diverse needs of those living with it.

This study is not without limitations. The reliance on self-reported data through semi-structured interviews, while valuable for capturing personal experiences, may introduce subjective biases and limit the generalizability of the findings. Additionally, the sample was drawn from specific fibromyalgia support groups and clinics, which may not fully represent the broader FM population. Future research would benefit from incorporating objective measures and expanding the participant pool to include a wider demographic and geographic range.

Future research should aim to address the limitations noted, potentially incorporating mixed-methods approaches to combine qualitative insights with quantitative data for a more comprehensive understanding of FM. Exploring the

effectiveness of various coping strategies in a larger, more diverse population could provide deeper insights into personalized management plans. Additionally, longitudinal studies could elucidate the long-term impacts of FM on individuals' lives and the evolving nature of coping mechanisms over time.

The findings from this study have important implications for practice. Healthcare providers should consider the complex and individualized nature of fibromyalgia when developing treatment plans, incorporating patient preferences and experiences into the decision-making process. Emphasizing a multidisciplinary approach that includes physical, psychological, and social support can enhance patient outcomes. The importance of patient education and empowerment, including the use of online resources and support communities, should not be underestimated. Overall, our study highlights the need for healthcare systems to adopt a more patient-centered and holistic approach to the management of fibromyalgia, aiming to improve quality of life for those affected.

Authors' Contributions

Authors contributed equally to this article.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

Acknowledgments

We would like to express our gratitude to all individuals helped us to do the project.

Declaration of Interest

The authors report no conflict of interest.

Funding

According to the authors, this article has no financial support.

Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

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