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RESEARCH ARTICLE

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The lived experience of mothers living with fibromyalgia syndrome: A phenomenological inquiry

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Abstract

Introduction: Fibromyalgia syndrome (FMS) is a complex chronic pain condition that negatively impacts women's daily lives, particularly their roles as mothers and wives. A phenomenological qualitative study was conducted to explore the lived experiences of motherhood and daily life among women diagnosed with fibromyalgia.

Methods: A sample of 10 women affected by FMS was recruited between January and February 2020. Participants were interviewed in a face-to-face, in-depth interview using a semi-structured interview guide. Data were collected until saturation, and Colaizzi's method was used to analyse data.

Results: This qualitative analysis identified five themes: A trauma preceding diagnosis, Pervasive feelings of misunderstanding, A struggle to maintain strength among limitations, Challenges in fulfilling maternal roles, and Persistent sexual discomfort. The latter two themes emerged as the most prominent.

Conclusion: These findings highlight the significant impact of fibromyalgia on women's family lives and suggest the need for a more comprehensive care programme.

KEYWORDS
fibromyalgia, mothering, nursing, pain, phenomenology, qualitative

1 | INTRODUCTION

Fibromyalgia syndrome (FMS) is a complex chronic pain condition characterised by persistent and unknown widespread pain, fatigue, sleep disorders, stiffness, headache, perceived weakness, and other associated physical and cognitive problems. FMS prevalence rates are 2.7% in the global population, 2.64% in the European population, 3.1% in the American population, and 1.7% in the Asian population (Kocyigit & Akyol, 2022; Queiroz, 2013). In Italy, studies estimate the prevalence of this syndrome between 2.2% and 3.7% in the general population and 5.5% in women (Sarzi-Puttini, et al., 2020). Fibromyalgia Syndrome affects women most, with a ratio of 10:1, especially between 20 and 50 years old although early signs of FMS may appear in childhood. The aetiology of the disease is unclear, but fibromyalgia is a highly disabling disease (Giorgi et al., 2022).

This syndrome significantly impacts the quality of life of women. Affected individuals struggle to manage daily demands—including family, social, and occupational responsibilities—due to the pain and associated symptoms (Ben-Yosef et al., 2020; Cetingok et al., 2022; Lev & Goldner, 2022). This burden exacerbates anxiety and depression, further compromising physical, mental, and emotional well-being (Henao-Pérez et al., 2022; Yepez et al., 2022). Notably, mothers with FMS often experience strained relationships due to the condition's effects (Montesó-Curto et al., 2022). The diminished quality of life translates into increased healthcare costs due to frequent medical consultations and lost productivity, with studies

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reporting a 24.3% work withdrawal rate 5 years after FMS onset (D'Onghia et al., 2022; Sarzi-Puttini et al., 2020).

The lived experience of motherhood and daily life for women with fibromyalgia remains largely unexplored in the literature (Arfuch et al., 2022; Ashe et al., 2017; Juhlin et al., 2023; Peñacoba et al., 2018), potentially hindering optimal care provision. Employing phenomenology, a qualitative research approach focused on meaning-making through lived experiences, this study explored the lived experiences of motherhood and daily life among women diagnosed with fibromyalgia.

2 | METHODS

A phenomenological approach was employed, drawing upon the philosophical foundations of Husserl and Heidegger. Phenomenological inquiry is particularly suited for investigating experiences that are deeply personal and subjective, as it allows researchers to delve into the inner world of participants and uncover the meanings they ascribe to their experiences. This approach can contribute to improving care quality by providing insights into mothers' needs and preferences (Colaizzi, 1978; Giorgi, 1985; Lincoln & Guba, 1985).

2.1 | Sample/participants

Italian mothers with FMS were recruited until achieving data saturation, using a combination of quota and maximum variation sampling techniques. This allowed us to enroll only female sex participants with a role as mothers and to capture a range of experiences with regard to different aspects of their daily life. The inclusion criteria were a medical diagnosis of fibromyalgia, age 18 years or older, and at least one child. Exclusion criteria included communication difficulties, absence of children, and refusal to sign informed consent. Participants were recruited by a study nurse, from the internal medicine outpatient clinic and from a patient association in Palermo, Italy.

2.2 | Data collection

In-depth interviews were conducted face-to-face between January and February 2020. A semi-structured interview guide, created on the basis of existing literature (Boulton, 2019; Doebl et al., 2020), was employed (Table 1). The first pilot interview involving the head of the patient association was not included in the study. The interviews were conducted in private settings (participants' homes, the association headquarters, or the outpatient clinic).

The researcher, an internal medicine registered nurse the patients had never seen before, undertook an introspective analysis and documented her preconceptions, beliefs, values, and positions in a notebook. Before each interview, participants completed a structured questionnaire to provide background information on their lives. Participants were encouraged to freely discuss their experiences and perspectives on motherhood and FMS during the interviews. Notes were taken in a notebook throughout each interview. The interviews lasted for 40–90 min each, were conducted in Italian, and were recorded using a voice recorder. The researcher transcribed the interviews verbatim. Data collection continued until saturation was achieved.

2.3 | Data analysis

A descriptive phenomenological analysis was used as a theoretical framework and analytical method. Colaizzi's seven-step method was used to analyse the transcripts as described previously. Data analysis began after the first interview was transcribed verbatim, 24 h after data collection. Two researchers independently read each transcription several times. The researchers extracted significant statements from the transcriptions, formulated meanings, and summarised data as themes. The research team compared and discussed findings with the participants until a consensus on themes, subthemes, and quotations was achieved. Member checking was performed and all the participants agreed with the data analysis. The analysis did not include the first pilot interview (Lo Monaco et al., 2020).

2.4 | Validity and reliability/rigour

This study's rigour was assessed using Lincoln and Guba's criteria: credibility, confirmability, trustworthiness, and transferability (Lincoln & Guba, 1985). Credibility was established by using a data collector, a nurse unfamiliar to the participants, and by including direct quotes from participants to support the interpretation of the findings. The researcher recorded interviews with a single voice recorder for credibility and transcribed them verbatim. Reliability was enhanced by using two researchers to code the data and by having all participants interviewed using the same interview guide. Another researcher conducted external verification to ensure that the data, conclusions, comments, and notes were consistent with the raw data. The study's reporting adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

3 | RESULT

A total of 10 mothers meeting the study's inclusion criteria were recruited and enrolled in this qualitative study. All participants were married except for one, and their ages ranged from 34 to 60 years. The average age was 47.4 years (SD 8.2). All participants were native Italian speakers and provided informed consent prior to the interviews. A detailed description of participant characteristics is provided in Table 2.

Five themes emerged: A trauma preceding diagnosis, Pervasive feelings of misunderstanding, A struggle to maintain strength among

TABLE 1 Qualitative interview guide questions.

n°	Semi-structured questions
1	How much did fibromyalgia affect your motherhood?
2	Did you know you had fibromyalgia before the birth of your children?
3	At what stage of growing up did your children feel the most burden of your being affected by fibromyalgia?
4	Do you feel understood by your family?
5	Is someone supporting you the most?
6	What strategies did you use to live with fibromyalgia while raising your children?

TABLE 2 Characteristics of women included in the study.

Interview code	Age	Tender points	Occupation	Health-related job loss	Marital status	Education	Children
Pz. 1	34	18/18	Housewife	No	Married	Middle school	2
Pz. 2	54	18/18	Unemployed	Yes	Married	High school	3
Pz. 3	40	18/18	Housewife	No	Married	Middle school	2
Pz. 4	40	12/18	Housewife	Yes	Married	Middle school	3
Pz. 5	58	18/18	Nurse	No	Divorced	High school	2
Pz. 6	50	16/18	Merchant	No	Married	High school	2
Pz. 7	42	11/18	Employed	No	Married	High school	2
Pz. 8	44	12/18	Employed	No	Married	High school	2
Pz. 9	52	18/18	Merchant	No	Married	Middle school	2
Pz. 10	60	18/18	Housewife	Yes	Married	High school	1

limitations, challenges in fulfilling maternal roles, and persistent sexual discomfort (Figure 1).

Theme 1: A trauma preceding diagnosis

A recurrent theme emerged from participant narratives, suggesting a potential association between the onset of fibromyalgia symptoms and past traumatic experiences. Many participants attributed the development of their condition to personal experiences such as bereavement, abuse, or loss.

> I believe fibromyalgia started after my father's death (Pz. 6, with a resigned expression)

> I associate the onset of the symptoms with a particular event in my life. I'm divorced, and my illnesses came after my separation (Pz. 5)

> People think that fibromyalgia starts with a traumatic event, and, in my case, I realized that it was so. I always wanted to be a mother more than anything else […]. After years of heartache, we finally adopted a little girl who spent several months in our home. She was illegally placed with another family, and for me, it was a tragedy. From that moment on, I began to experience a terrible feeling of pain throughout my body (Pz. 10, in tears)

Theme 2: Pervasive feelings of misunderstanding

Our study identified feelings of being misunderstood as a prevalent theme, particularly regarding the perceived 'imaginary' nature of fibromyalgia pain. Participants reported experiencing a significant increase in negative emotions, including sadness, depression, and frustration, especially prior to diagnosis.

> Finally, since I have found a name for my tiredness, I am happy. I no longer feel crazy, and I feel understood (Pz. 6.)

> A long time ago, a physician told me that I had invented my disease, and he considered me an imaginary sick. In my family, I was not believed; they thought it was an excuse not to go to school […]. None understood me; my husband did not accept my condition completely; I felt lonely. It is useless for you to show your pain to others. The only one who understands me is my dog (Pz. 5)

> Not being understood by the family is excruciating pain. Some days ago, I read my husband a story about a

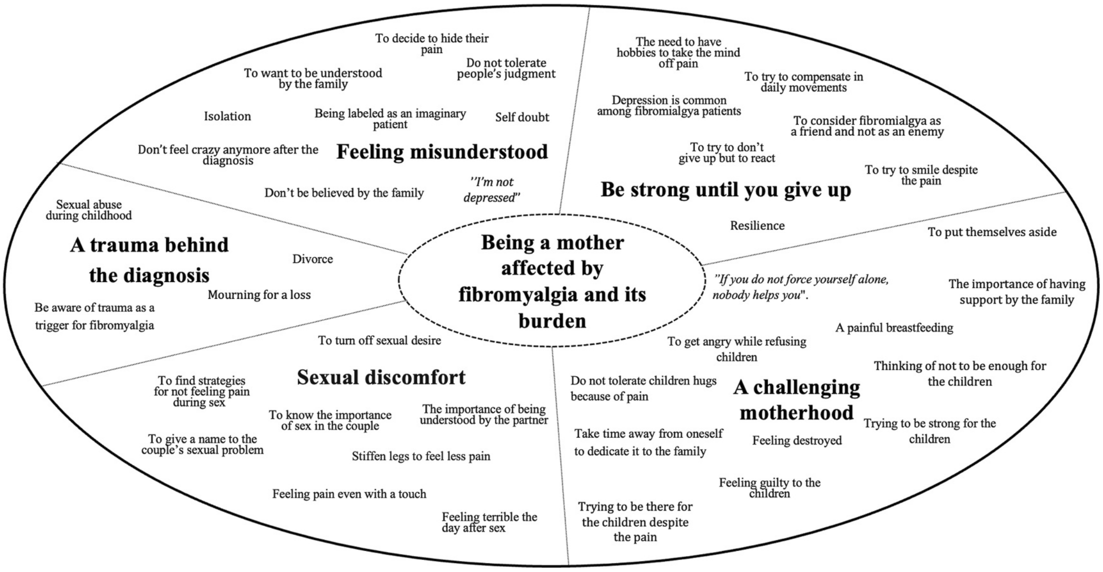

FIGURE 1 Ellipse of formulated meanings from significant informers' statements aggregated according to the main themes.

> woman affected by fibromyalgia, and he burst into tears; I asked him why he had this reaction. Then I realized that he recognized me in that story (Pz. 10, in tears)

> Before receiving the diagnosis of fibromyalgia, I isolated myself from the rest of the world because other people did not understand that I was limited. When I received the diagnosis, I was happy. I accepted it because everyone thought I was crazy, hysteric, or depressed, but I am not depressed. (Pz. 2)

Theme 3: A struggle to maintain strength among limitations

Women with fibromyalgia experience significant impairments in daily living. Patient-reported management strategies emphasise the importance of integrating pain management techniques into daily routines to regain a sense of control.

Juggling childcare, household chores, and employment is commonplace for women, but fibromyalgia can significantly impede their ability to fulfil these roles, potentially worsening their health. Resilience also plays a crucial role in supporting a sense of purpose and participation in meaningful activities despite the presence of depression, which is common in FMS. Employment appears to be associated with improved health outcomes in women with FMS, potentially due to the social support and sense of purpose it provides. However, the severity of FMS symptoms can significantly hinder employment continuity, often leading to job losses in physically demanding occupations.

> The pain caused by fibromyalgia cannot be described. I have learned to live with it, but some of us do not have the strength to go on and fall into depression […] many things help me to cope with pain better and to live better, for example, theatre: it helps me take my mind off pain […]

> I lost my job because of fibromyalgia; I worked for many years at the children's hospital as a children's entertainer. At the time, I was already suffering from fibromyalgia, but I did not know it. I was always tired, and I did not understand why. I was afraid that my discomfort could create problems for the whole team, and I quit my job (Pz. 10, tearfully)

> If you get down on it, you do not do anything. You only get depression, and everything gets worse and worse […] I cannot call the office and say: I am not coming today; I'm too tired because they do not care. As employees, we are just numbers. In the evening, my hands are purple and swollen (Pz. 8)

> I think that for living with fibromyalgia, it is crucial to think of it not as an enemy but as a friend. I am a nurse, and when in the hospital, someone asks me how I am, and I answer, "Like a flower," but they do not know which kind of flower I am referring to. It can be a cut flower, or a graveyard flower or a paper flower… they do not know […]What keeps me going is my job (Pz. 5)

> By now, I have understood how to manage pain and my limits; I have learned to say no, which is essential […] People define me as a resilient person. My motto is: "I do not give up even though I am drowning." to avoid negativities is good for me. (Pz.3)

> I continue to work because I cannot live without helping my husband in our business, but my physical condition would not allow me to. This gives me the strength to get up in the morning. (Pz. 1)

> I was a hairdresser. I was on my feet for over 12 hours, arriving home exhausted in the evening, but I could finish my working day. One day, I quit my job because I could not do it anymore (Pz. 2).

Theme 4: Challenges in fulfilling maternal roles

Mothers with fibromyalgia experience a substantial burden, potentially amplified when their condition negatively impacts children. This study identified feelings of guilt among participants.

The longitudinal demands of child-rearing, from pregnancy to adulthood, present a significant challenge for women with fibromyalgia, particularly those balancing careers and facing limited family support. Daily tasks such as bathing, meal preparation, transportation, and household duties, alongside career demands, can be particularly strenuous for these mothers, especially those experiencing debilitating symptoms that limit mobility and energy levels.

Empathetic support from family members plays a crucial role in enhancing the emotional well-being of mothers with fibromyalgia. Notably, for some, childbirth can serve as a powerful motivator to overcome challenges associated with the condition.

> Fibromyalgia affected my motherhood. It changed me. I do not tolerate my children hugging me because I feel pain when they touch me. They get angry when I refuse them. I try to explain that it is just because I am sick, and then I burst into tears because I feel guilty about them (Pz. 4)

> Whenever you say that you cannot do everything alone due to the chronic pain, but then they find housework done, they do not believe you. In the family, we are not believed (Pz. 5)

> I cannot help my children do their homework; when they want to repeat something, I cannot follow them, I lose concentration, and it is irritating (Pz. 8)

> There was a period in which I felt destroyed […] the arrival of my daughter was my salvation, thanks to her I can live, to go on (Pz. 10)

Theme 5: Persistent sexual discomfort

The impact of FMS on sexuality is a well-recognized concern within the literature. Studies suggest that women with FMS experience difficulties in interpersonal relationships, with a higher risk of breakdown. Furthermore, most of the participants reported altered libido associated with FMS, often manifesting as hypoactive sexual desire.

This association is likely due to the influence of pain on sexual health. Sexual satisfaction is a known predictor of relationship quality, and feeling understood by their partner is crucial for women with FMS to maintain fulfilling relationships.

> My husband sometimes touches me, and I feel pain. Sexually, the desire has dropped a lot, not because I do not love my husband, but because I feel pain everywhere. It is also embarrassing to tell him not to touch me because I feel pain. The day after sex, I feel terrible […] Having sex is essential for a couple because if this is missing, everything is missing. Some husbands leave their wives for this reason, and I always tell my husband never to leave me (Pz. 7)

> Fibromyalgia also affects our sexuality. Because of the pain, I cannot move, so I stiffen my legs during sex to feel less pain (Pz. 5)

4 | DISCUSSION

This qualitative study identified five key themes: (1) a trauma preceding diagnosis, (2) pervasive feelings of misunderstanding, (3) a struggle to maintain strength among limitations, (4) challenges in fulfilling maternal roles, and (5) persistent sexual discomfort.

While the literature does not establish a definitive link between trauma and FMS, a substantial proportion of participants attributed their condition to a specific traumatic experience, aligning with findings from other studies (Gardoki-Souto et al., 2022; Yavne et al., 2018). What is known is that most people receive a diagnosis of FMS following physical or emotional trauma or the birth or death of a child (Furness et al., 2018).

The second theme focused on the importance of being understood by people. The impact of this syndrome on women's daily routines has been studied and focused on their experiences of living with their pain (Climent-Sanz et al., 2023; Doebl et al., 2020). As our participant said, the biggest challenge for them was coping with daily life as if they had no symptoms.

Female participants expressed deep disappointment with physicians who failed to provide a correct diagnosis and dismissively labelled them as “imaginary sick people’, leading to significant frustration and misunderstanding. However, FMS has been recognized as a disability by the health care system (Berwick et al., 2022); being labelled as imaginary sick or depressed by family and friends has been, for women, the main problem in coping with the disease. In the literature, several studies have shown that depression is the result and not the cause of FMS (Montesó-Curto et al., 2022; Yepez et al., 2022).

Our participants were strong women in their roles as wives and mothers, able to care for their loved ones at the price of their health and well-being. Participants' concerns about misunderstandings were more related to their loved ones than to health care providers, emphasising the crucial role of families in the physical and psychological support of patients with FMS, as demonstrated in the literature (Ashe et al., 2017); in fact, their main desire was to be understood by their family.

The third theme, 'a struggle to maintain strength among limitations', showed how, daily, women with fibromyalgia adopt strategies to cope with the syndrome in their daily lives (Rubio Fidel et al., 2022). As most of our participants said, the key to coping with FMS was accepting their chronic condition and trying to forget the pain differently. For most of the women enrolled in our study, continuing work although the pain, was one of the most important strategies for coping with the disease. As our participants said, working or joining patient associations were opportunities for social relationships, personal development, and belonging to society. Patients' associations were also for them because they offered different activities. Feldenkrais (Hillier, 2015) and theatre were the favourite activities cited by the participants. One of the most discussed themes was 'challenges in fulfilling maternal roles', and the results of our study suggest that FMS compromises our participants' motherhood both for the whispered pain and the misunderstanding from their families. Women affected by fibromyalgia struggle to serve as wives and mothers, but they are usually told by their children and husbands that their disease is imagined. The reported speech of our women pointed to a worsening of family relationships and their feeling of guilt for not performing the gender roles that are expected of them (Paxman, 2021). Women suffering from FMS often note that their disease compromises their ability to perform as the wives and mothers they want to be because even the slightest touch from children or their husbands can be painful.

This study, based on interviews with 10 women diagnosed with FMS, explores their perspectives on how pain affects their libido, sense of pleasure, and overall sexual relationships. Research suggests that women with FMS experience higher rates of sexual dysfunction compared with the general population, potentially due to the impact of pain on physical and emotional intimacy (Granero-Molina et al., 2023; Ricoy-Cano et al., 2022; Santos-Iglesias et al., 2022), as shown by our results.

5 | CONCLUSION

Female fibromyalgia patients grapple with physical, emotional, and social challenges. Family dynamics and associated stressors are particularly pronounced in mothers with FMS.

By analysing women's narratives, we aim to contribute to understanding the complex interplay between FMS and women's health.

It was necessary to understand the challenges in the everyday life of mothers affected by FMS through women's experiences to provide comprehensive management of those patients who need all the strength to cope with their role as women, wives, and mothers. According to our findings, in our opinion, an early - diagnosis and a multidimensional and inter-professional approach are essential in managing these complex patients (Mattina et al., 2022).

Managing coexisting physical and psychological conditions such as pain, anxiety, and depression is challenging for healthcare professionals.

Our qualitative study identified five primary areas of burden, with 'challenges in fulfilling maternal roles' and 'persistent sexual discomfort' being the most prevalent.

One of the most important topics discussed during the interviews was their need to be understood by their partner, so therapeutic interventions should also be targeted to improve communication in couples.

It is also crucial to implement the figure of a carefully trained nurse case manager to support the inter-professional team and manage individual cases from diagnosis to contact with primary care. In an inter-professional approach, the nurse should inquire about any history of trauma, the family and social role of the patients, and everyday tasks because this information may provide a depth of understanding of the single case. Thus, the nurse case manager and other healthcare professionals can partner with the patient to develop a treatment plan, provide education, and provide appropriate referrals.

Healthcare professionals are crucial in offering comprehensive support, encompassing physical, emotional, and informational dimensions. A deeper understanding of these aspects is necessary to redesign multidimensional and interprofessional care programs with the involvement of nurse case managers to enhance the quality of daily life for women with FMS and their families.

While FMS is predominantly diagnosed in women, and research has explored the perceptions of illness among relatives of individuals with FMS, further studies could provide additional insights through the exploration of gender differences in the experience of FMS, as our study focused solely on mothers.

AUTHOR CONTRIBUTIONS

All authors equally contributed in this research, in particular: Marika Lo Monaco, Sharifa Alblooshi, Maria Luisa Landa, Giuseppe Natoli and Salvatore Corrao have made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; Marika Lo Monaco, Raffaella Mallaci Bocchio, Sharifa Alblooshi, and Salvatore Corrao been involved in drafting the manuscript or revising it critically for important intellectual content; Marika Lo Monaco and Salvatore Corrao given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content, and all authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST STATEMENT

All authors declare they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

The study was approved by the Ethics Committee "Palermo2" (protocol number 231/CIVICO/2018).

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