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ORIGINAL ARTICLE

Fibromyalgia patients' perceptions of diagnosis, life and the psychological impact of the disease

Percepção de pacientes com fibromialgia sobre diagnóstico, convívio e impacto psicológico da doença

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ABSTRACT

BACKGROUND AND OBJECTIVES: Fibromyalgia is characterized by widespread pain, sleep disturbances, and fatigue, affecting patients' lifestyles, work relationships and interpersonal interactions. This study aimed to investigate the perception of patients with fibromyalgia regarding their experience with the condition.

METHODS: Qualitative research was conducted using semi-structured interviews with ten women. Data were analyzed through content analysis and were organized into four categories.

RESULTS: The diagnostic process was reported as complex and lengthy, being often associated with feelings of helplessness, hopelessness, and suicidal ideation in some cases. Pain and cognitive impairments were linked to disruptions in personal and professional life. The lack of family support and the invalidation of the pain experience were associated with heightened emotional distress, as well as increased symptoms of anxiety and depression. Despite these challenges, some participants reported acceptance of their condition and improvement through multidimensional approaches, family support, and participation in support groups**.** Social misunderstanding of the pain experience was mentioned as a reason contributed to isolation, intensified stigmatization, and worsened depressive and anxious symptoms. These negative effects of fibromyalgia on quality of life, social interactions, and mental health highlighted the subjective nature of pain and the necessity of incorporating psychological care into the treatment of these patients.

CONCLUSION: Beyond its physical symptoms, fibromyalgia has a significant socioemotional impact, being commonly associated with depressive and anxious symptoms. These factors call for an interdisciplinary approach that addresses the disease's multiple dimensions, providing enhanced support for patients.

KEYWORDS: Chronic pain, Coping, Fibromyalgia.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A fibromialgia é caracterizada por dor generalizada, alterações no sono e fadiga, o que afeta o estilo de vida, relações laborais e interpessoais das pacientes. Este estudo objetivou investigar a percepção de pacientes com fibromialgia sobre sua experiência com a doença.

MÉTODOS: Pesquisa qualitativa com entrevista semi-dirigida, com 10 mulheres. Os dados foram submetidos à análise de conteúdo e organizados em quatro categorias.

RESULTADOS: O processo até o diagnóstico foi descrito como complexo e demorado, associado muitas vezes ao sentimento de desamparo, desesperança e, em alguns casos, ideação suicida. A dor e o comprometimento cognitivo foram relacionados a prejuízos na vida pessoal e profissional. A falta de suporte familiar e a invalidação da dor estiveram associadas à exacerbação do sofrimento emocional e da sintomatologia ansiosa e depressiva. Apesar das dificuldades, alguns pacientes relataram aceitação da doença e melhora com abordagens multidimensionais, suporte familiar e de grupos de apoio. A incompreensão social sobre a experiência álgica foi citada como motivo para o isolamento, intensificando a estigmatização e agravando quadros depressivos e ansiosos. Esses efeitos negativos da fibromialgia na qualidade de vida, nas interações sociais e na saúde mental endossam o caráter subjetivo da dor e a necessidade de incluir o cuidado psicológico no tratamento de tais pacientes.

CONCLUSÃO: A fibromialgia, além dos sintomas físicos, apresenta um impacto socioemocional significativo, estando comumente associada a sintomas depressivos e ansiosos. Esses fatores demandam uma abordagem interdisciplinar que compreenda e trate a doença em suas múltiplas dimensões, promovendo maior suporte às pacientes.

DESCRITORES: Capacidades de enfrentamento, Dor crônica, Fibromialgia.

HIGHLIGHTS

- The invalidation of pain and emotional suffering were reported as important factors in worsening the condition of fibromyalgia patients, while family support and support groups were reported as protective factors
- The multidisciplinary approach needed to treat fibromyalgia requires health professionals to comprehend the relationship between pain and psychological aspects
- Beliefs in the efficacy of exclusively pharmacological treatment, financial difficulties and access barriers compromise adherence to integrated treatment

INTRODUCTION

Fibromyalgia (FM) is a chronic disease of uncertain etiology whose main characteristics are the presence of generalized musculoskeletal pain, fatigue and sleep problems[1]. This disease affects between 2% and 4% of the general population and is more prevalent in middle-aged women[2]. The pain associated with FM has significant long-term impacts, impairing memory and social relationships[3], and reduces significantly quality of life[4].

The disease is characterized by a long diagnostic process, due to the lack of tissue lesions and specific clinical biomarkers that indicate its presence, which results in an average of five years for a clinical diagnosis to be made[5]. Misdiagnosis or late diagnosis can prolong suffering, delaying access to appropriate treatment[6].

Due to its symptoms and the difficulties in diagnosis, patients with FM often experience feelings of hopelessness when facing the fact that the disease has no cure, and are at greater risk of suicidal ideation and attempts when compared to the general population[7]. These factors can modify the perception of pain and hinder the adoption of effective coping strategies[8]. Due to the lack of biological explanation, FM is often discredited and made invisible by family, friends and work colleagues, generating additional suffering and compromising the search for support[9].

Within the family, women with FM face a double challenge: dealing with the symptoms of the disease and the expectations imposed by the domestic environment, including care and motherhood tasks[10]. When there is support and encouragement, the family can play a protective role, facilitating acceptance and adherence to treatment, reducing the burden and fatigue[11]. However, failure to adapt family roles can erode marital and sexual relationships[12,13]. In addition to family life, chronic pain also has a direct impact on work life, compromising financial stability and causing feelings of incapacity[14].

With interference in relationships and work, FM patients can be more vulnerable to psychological distress[15], chronic stress[16] and negative thoughts[17], resulting in a high prevalence of psychiatric disorders such as depression[18] and anxiety[19]. Around a quarter of these patients manifest symptoms of major depressive disorder throughout their lives, a considerably higher incidence compared to other clinical groups[20]. In addition to the impact on quality of life, psychiatric outcomes can aggravate the primary symptoms of FM[21].

Given this multidimensional nature, it is essential to develop multi-professional interventions aimed at promoting a more complete and in-depth view of treatment[22]. A chronic illness has a peculiar trajectory, being present throughout the patient's life, implying frequent adaptive challenges from discovery to habituation and symptom management[23]. The predominant literature on FM mainly focuses on the clinical and physiological aspects of FM[24,25], leaving a gap in studies on the patients' subjective experiences. Qualitative research offers a deeper understanding of the psychological, social and cultural challenges, enriching the biopsychosocial model of pain. Moreover, descriptive accounts also provide important insights for healthcare professionals, helping to plan patient-centered interventions and promote more empathetic and effective communications[26].

Finally, exploring the experiences of women with FM makes it possible to identify coping patterns and contextual factors that directly influence the perception of pain, contributing to both literature and clinical practice[27,28]. The present study's objective was to investigate the perception of patients with FM about their experience since being diagnosed with the disease.

METHODS

This is an exploratory, cross-sectional and descriptive study using semi-directed interviews and content analysis[29], developed in accordance with COREQ - Consolidated criteria for reporting qualitative research[30].

Participants

The study included 10 women diagnosed with FM, over 18 years old, patients of the rheumatology outpatient clinic of a general hospital in northeastern Brazil. The sample was composed by convenience using the snowball method[31] and was closed according to the criterion of saturation of the content of the interviews[32]. That is, as the data was collected and analyzed, a point was reached at which additional information did not bring new content or themes relevant to the research question.

Instruments

Sociodemographic and clinical questionnaire

Composed of closed and open questions, it covered the patients' gender, age, occupation, level of schooling and time since diagnosis.

Semi-directed interview script

An interview script was drawn up with seven questions about: discovering the diagnosis; living with the illness; relationship with work activities; social and family relationships; perceptions about treatment; expectations about the future; and the meaning made of the illness itself.

Procedures and ethical aspects

The interviews were carried out individually after the objectives had been presented and the Free and Informed Consent Term (FICT) had been signed. The questions were conducted by a trained researcher (first author) and a researcher with experience in the method (third author). After giving their consent, the participants filled the sociodemographic and clinical questionnaire and were interviewed face-to-face in a reserved place in the hospital itself. The interviews lasted an average of 25 minutes and were audio-recorded and transcribed. Personal information was withheld in order to protect the anonymity and protection of the participants.

The researchers had no prior contact with the participants and they all agreed to take part, so there was no need to repeat any of the interviews. The transcript and data were made available to the participants, but there was no request for access. The research was approved by the ethics committee (Opinion No. 3.581.860).

Data analysis

The data from the sociodemographic questionnaire was analyzed descriptively. The interviews were subjected to content analysis[29] and the data was organized into four categories that emerged after the readings: discovery of the diagnosis; symptoms and living with fibromyalgia; family and support network; and psychological impact (Table 1). To illustrate the results, the patients' accounts were added, omitting their names and indicating them by the interview number.

RESULTS

Profile of the participants

Ten women took part in the study, with a mean age of 51.7 years. Most of the participants were married (n=9), and one was widowed. As for schooling, half had completed elementary school (n=5), followed by higher schooling with post-graduate studies (n=2), graduate degree (n=1), technical degree (n=1) and complete high school (n=1). Half of the participants were working (n=5), four of whom were self-employed and one in regular employment. Of the five who didn't work, two were on sick leave, two were housewives and one was retired. All the participants reported being on pharmacological treatment. Half of the participants practiced physical activity three times a week (n=5), followed by twice (n=1), once (n=2), never (n=1) and five times or more (n=1). The average time since diagnosis was 6.5 years (Table 2).

Interview content

Discovering the diagnosis

Diagnosis was perceived as complex and time-consuming (n=8), due to the specific characteristics of the disease. Seven participants reported difficulties in reaching the diagnosis and four mentioned the presence of incorrect diagnoses or comorbidities, which initially overshadowed the hypothesis of FM (n=4). Three patients claimed to have lived with the pain for years before being referred to a rheumatologist. One of the participants reported not understanding what the disease was at the time she was diagnosed.

> *At first, it was normal because I didn't know what fibromyalgia was. The general clinician was not sure about the diagnosis. It was only after I went to the rheumatologist that I felt the impact.* (Interview 04).

Table 1. Registration units for coding and categorizing data

Categories	Definition	Registration Units
Discovering the diagnosis	Perception and experiences of discovering the diagnosis	Reports on the perception of the diagnosis and how it was received by the participant
Symptoms and living with fibromyalgia	Participants' perception of fibromyalgia symptoms	Reports on Fibromyalgia symptoms, living with the illness and treatment
Family and support network	Perception of the support received from family and people in their social group	Reports on family interaction and relationships and perceived social support.
Psychological impact	Perception of the emotional impact of the disease	Reports of symptoms of anxiety or depression, acceptance/learning and relief from the illness

Table 2. Profile of the participants

N. Participant	Age	Occupation	Schooling	Time since diagnosis
1	52	Housework	Elementary school	3 years
2	36	Away from work	Postgraduate degree	2 years
3	54	Autonomous	Complete high school	18 years
4	39	Autonomous	Elementary school	3 years
5	56	Autonomous	Postgraduate degree	12 years
6	49	Housework	Elementary school	6 years
7	70	Autonomous	Elementary school	5 years
8	48	Away from work	Graduate degree	7 years
9	47	Nursing technician	Technical degree	1 year
10	66	Retired	Elementary school	8 years

> *I spent 12 or 13 years going from doctor to doctor. I went to cardiologists, orthopedists, all kinds of doctors.* (Interview 09).

The diagnosis was accompanied by feelings of helplessness (n=3), hopelessness (n=3), suicidal ideation (n=3) and bouts of crying (n=2) generated by the chronicity of the disease. Three patients made the analogy of "falling into a hole" to express the loss of control at the moment of diagnosis.

> *I didn't accept the pain. I didn't think it would get better. How would I look after my daughter? How would I carry on a relationship? Everything revolved around this disease. I couldn't see any solution for getting better. The only solution I could see for my pain was to take my own life.* (Interview 02).

> *When the doctor told me I had fibromyalgia, I panicked! It was as if they'd opened a hole and I'd fallen in.* (Interview 09).

Symptoms and living with fibromyalgia

In addition to the characteristic pain at specific points in the FM, mentioned by all the participants, symptoms such as memory loss (n=5) and sleep problems (n=4) were also mentioned. All the participants mentioned interference in their work activities, due to the pain's influence on domestic activities and work involving physical effort. This limitation led to perceptions of inadequacy, with feelings of uselessness (n=1) and fear of social judgment (n=2).

> *I realized that I couldn't do what I used to do and I thought: 'What will become of me now? I felt useless. What am I going to do with my life. I'm going to change roles at work, and I'm already afraid of what they're going to say about me. They'll say: 'she's so lazy, she doesn't want to teach'.* (Interview 08).

Half of the participants were exclusively concerned with pharmacological treatments (n=5), including care for emotional issues (n=1). However, the patients who adhered to multidimensional treatment (n=3) reported a significant improvement in sleep quality and a reduction in the use of drugs. Regarding the practice of physical exercise, some obstacles were highlighted, such as fear of intensification or the appearance of new pains (n=3), distance from sports centers (n=2) and financial limitations (n=2). The financial situation was pointed out as an obstacle to acquiring the drugs prescribed to them (n=2). One of the patients said she used homemade alternatives (massages and teas), with no proven efficacy, to treat FM.

> *I'm worried most of the time, I can't get excited about anything. I wonder if I'll have the money to buy the medication. It's not all the medication you get at the clinic. Most of it I have to buy myself.* (Interview 10).

> *Physical activity increases pain. I used to do it every day, but the pain increased and I had to cut back. Now I just take walks. I can't even lift weights.* (Interview 09).

Family and support network

Three main contents were identified in this category: invalidation of suffering by family members (n=4), the importance of empathy shown by family members (n=4) and the importance of social support from support or religious groups and associations of FM patients to cope with the experience of pain (n=4).

The participants emphasized the lack of family support in carrying out domestic activities (n=3). One of them tried to make family members aware of the disease through an explanatory booklet[33] but reported disappointment at the lack of interest. Other patients wished to receive more attention from family members (n=2) and stressed the importance of the support groups they attended (n=4).

> *For me, one of the best treatments is to come to the patient support group. I've seen so much that, for me, sometimes it's better to come to the group than to get a glass of water and take some medicine.* (Interview 07).

Three patients revealed that FM interfered with their marital relationship and sex life. The lack of understanding on the part of the partners was described as exacerbating the emotional suffering of these patients.

> *My husband arrives and sometimes I'm cleaning something in the yard, and he says 'you're doing this now and later you'll be half-dead'. He doesn't really understand this disease and what gets to me the most is my emotions.* (Interview 03).

> *They didn't care at all. My husband was the worst. All he cared about was the sex, when you have this disease, you totally lose your libido.* (Interview 05).

Recurrent invalidation was also pointed out as an obstacle to expressing suffering. Two patients mentioned shame or fear of upsetting others, leading them to conceal their pain and submit to heavy housework to avoid embarrassment.

> *Sometimes when I'm doing the laundry, I have to stretch to pick up the clothes, I end up getting swelled up. I wash them and leave them in the bin. When my husband comes home, he complains: 'I've just come from working in the fields and now I have to do this?* (Interview 03).

> *I avoid complaining because nobody deserves to be around someone who complains too much. My children, who are teenagers, say: 'Mom, you complain a lot, you're impatient all the time. On the street we put on masks."* (Interview 08).

Psychological impact

All the participants had some depressive symptom and four said they had received a psychiatric diagnosis of depression (n=4). Among the most frequent symptoms were: helplessness (n=4), lack of pleasure (n=3), hopelessness (n=3), recurrent crying (n=3), fear of the future (n=2) and suicidal ideation (n=2). These symptoms were related to incurability and limitations in life.

> *I couldn't see any solution to improve the situation. The only solution I could see to my pain was to take my own life.* (Interview 02).
>
> *It was a terrible blow, you get emotionally shaken and I became very depressed, I even think about suicide.* (Interview 05).
>
> *At first, it was a shock because I got desperate. I had depression, I went through horrible bouts of depression. When the doctor said it was fibromyalgia, it was as if I'd been dropped out of a parachute and onto the ground.* (Interview 09).

There was also evidence of anxiety symptoms (n=6), such as restlessness (n=3), irritation (n=3), difficulty sleeping (n=2), constant fear (n=1) and anxiety attacks (n=1).

> *I get very distressed, that pain, it's anxiety really, afraid that something might happen. When I get more worried, the pain increases.* (Interview 03).
>
> *I'm always scared, I lie in bed and I feel like something is going to fall on me, some bug, I get nervous, I get up and lie down again. I get nervous and impatient. I can't laugh, I can't remember the last time I laughed. I used to be very happy. I'm worried most of the time, I can't get motivated. I feel restless, but I can't go on a walk, so I sit on the sofa and sit and stand up back again. Mentally, I get agitated.* (Interview 10).

Finally, the patients were asked about the future. There was a marked presence of depressive symptoms such as hopelessness (n=3), discouragement (n=2) and/or dysfunctional beliefs about the prognosis, such as the expectation of a cure (n=2). There were reports of a lack of plans for the future (n=3), as well as a focus on the present (n=3).

> *I think a lot about getting well, that I'll be able to beat the lupus and the fibromyalgia.* (Interview 01).
>
> *Some days I think about the future and I'm scared for my spine, seeing that it's so worn out. Sometimes I see myself in a wheelchair. I'm negative. When I renovated my house, I asked them to put in a wide door because if I'm in a wheelchair, how am I going to get into my bathroom?* (Interview 08).
>
> *There's no future for me anymore. My future is to wait for the time when God calls me and that's it. I can't make any more plans. There's no way, I don't work anymore, I live sick and depend on others. What kind of plans can a person like that make?* (Interview 10).

There were contents of acceptance (n=2), which involve recognizing and allowing pain to be felt, without the intention of avoiding or controlling it, and the search for healthy strategies using emotional regulation (n=1). The comprehension that the disease is not fatal or contagious was mentioned as a reason for relief (n=3).

> *I'm experiencing self-love, self-knowledge and this is helping me in the process of acceptance.* (Interview 02).
>
> *"My mind was set that I'm going to accept (the disease) and I'm going to accept myself the way life is contemplating me.* (Interview 07).

DISCUSSION

The present study's objective was to investigate the perception and experience of FM patients about living with the disease and its psychological impacts, from diagnosis and symptoms to coping strategies. The participants described the process of achieving the diagnosis as complex and time-consuming, marked by a long period of living with the pain before it was confirmed. They also reported that this period was often accompanied by negative feelings, such as helplessness, hopelessness and, in some cases, suicidal ideation. This delay reflects the challenge faced by patients and health professionals due to the absence of tissue lesions and specific laboratory markers, which can lead to misdiagnosis and inadequate treatment[34-36]. Furthermore, waiting and uncertainty intensify symptoms of anxiety and depression, making it difficult to cope with the disease. This, in turn, reinforces the importance of an accurate diagnostic assessment with the objective of avoiding and reducing emotional and psychological suffering, as well as enabling the early start of effective interventions[36-38].

Upon receiving the diagnosis, feelings of hopelessness, bouts of crying and suicidal ideation appeared, all signs of depressive symptoms[39], which may have been present before the diagnosis, both because of experiences with pain and because of the two-way relationship between the physiological mechanisms of pain and affective disorders[40]. This intersection between mental health and chronic pain highlights the subjective dimension of pain, being a broader experience than the pathophysiology of the phenomenon[41], in which psychological care from the beginning of treatment is essential[42].

The presence of hopelessness and the feeling of loss of control reinforce the need for clarity in the transmission of information by health professionals, ensuring a welcoming atmosphere and checking the patient's perception of the diagnosis and prognosis of the disease[43]. This care can prevent the emergence of dysfunctional beliefs about a cure or lack of control and improve adherence to treatment[44].

Pain, reported by all the patients, hinders sleep and cognitive functions, adding to the other stressors in the direct impact on quality of life[45-47]. One stressor highlighted by the participants was social invalidation in the family and at work. The feeling of being misunderstood and discredited can keep patients away from social interactions, causing losses in family and social relationships, as well as intensifying stigmatization and invisibility, which makes depression and anxiety worse[21,48,49]. Another effect of isolation is reduced social support, greater burden and poor adherence to treatment[50]. FM tends to be more socially invalidated than other rheumatological diseases[51], since it is a disease without biological markers, but with social characteristics and pain[52].

All participants pointed to interference in their work activities as a result of chronic pain and functional limitations[53]. This condition aggravates the feeling of stigmatization and isolation, considering the role of work in identity and social recognition[52]. The intrinsic relationship between the patients' pain and experiences of isolation and social rejection can be explained by studies of social pain, which indicate that this type of pain activates brain areas similar to those of physical pain and may be associated with an increase in the intensity of perceived pain[54].

Thus, validating pain and psychological suffering strengthens the patient's trust in the medical team, reducing internalized stigma and improving adherence to treatment[55]. In addition to professional support, some participants cited benefits associated with support from family members and groups, reinforcing the role of empathy and belonging in coping with the disease and perceiving pain[53]. When the social environment comprehends the limits imposed by the disease, it tends to provide more effective support for coping[50].

As for treatment, half of the participants still associated the treatment of FM exclusively with drugs, while three reported adhering to multidimensional treatment. This may be explained by the belief that drugs are more effective, which makes this a common phenomenon in patients with FM[56]. However, the literature reinforces the need for multidisciplinary interventions[57]. In the present study, patients who adhered to treatment along these lines reported improved sleep quality and reduced consumption of other drugs.

As shown in the literature, non-pharmacological approaches are effective in helping to regulate pain, highlighting the importance of health professionals adopting a holistic perspective to promote patient adherence to treatment[58]. Low adherence to physical exercise was related to the symptoms of FM and to financial difficulties and access to sports centers. These reasons are widely evidenced in the literature[59], explaining the need to create public policies that promote access for this population. Although starting this practice may momentarily increase pain, there is evidence of improvements in FM symptoms and mental health in the long term[60]. In this sense, health education is essential to clarify the benefits of this practice and reduce initial resistance[61].

The lack of physical exercise exacerbates symptoms resulting from FM, due to the consequent loss of function[62]. Some patients mention the use of alternative treatments without scientific proof of efficacy, which poses financial and health risks, mainly due to exposure to adverse effects that can aggravate symptoms[44]. This finding reinforces the need for clear guidance from health professionals regarding the search for evidence-based treatments[63].

All the participants had depressive symptoms and more than half had anxiety symptoms, which is in line with the literature on FM and mental health[64,65]. This scenario impacts the daily experience of intense pain, reduced quality of life and consequent impairment of mental health[64]. These psychological comorbidities not only reduce quality of life, but also worsen other symptoms such as fatigue and sleep disorders[1].

Despite the suffering reported, some participants showed signs of acceptance and learning, expressing relief at understanding that the disease was not fatal and contagious. According to the literature, acting with acceptance does not mean passively accepting pain, but opting for actions in line with one's values, even in the face of discomfort. This attitude is related to greater psychological flexibility, which is essential for aligning pain coping with patients' life goals and values[66]. Therefore, together with a welcoming and validating attitude, it is important for health professionals to help their patients comprehend and accept the existence of chronic pain in a realistic and functional way[61].

CONCLUSION

The perception and experience of women diagnosed with FM highlights the multifaceted nature of FM, intrinsically related to social experiences, with repercussions on family and work life, marked by the fear of being misunderstood or rejected. Throughout the course of the illness, feelings of sadness, helplessness, hopelessness and suicidal ideation were reported. In this context, lack of family support, invalidation of the pain experience and interference in relationships aggravate the emotional impact. The interaction between chronic pain, social life and mental health highlights the biopsychosocial nature of pain and reinforces the need for integrated interventions that address both the physical and psychological aspects of the disease.

One limitation of this study was the size of the sample, which is typical of qualitative studies. Despite this, the sample reflected the epidemiological profile of the condition: women aged between 40 and 55. The semi-directed interviews made it possible to deepen the understanding of the participants' experiences and generate new insights. Nevertheless, such instruments require caution regarding generalization and causal inferences. Considering that FM affects different dimensions of life, interdisciplinary studies are needed to broaden the comprehension of the disease and its impacts, integrating different areas of knowledge.

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