DOI 10.18471/rbe.v39.64306

LOSSES, GRIEF AND REFRAMING IN FIBROMYALGIA: A JOURNEY INTO THE FEMALE UNIVERSE

PERDAS, LUTO E RESSIGNIFICAÇÕES EM FIBROMIALGIA: UMA VIAGEM AO UNIVERSO FEMININO

PÉRDIDAS, DUELOS Y RESIGNIFICACIONES EN LA FIBROMIALGIA: UN VIAJE AL UNIVERSO FEMENINO

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How to cite this article: Vivas MCS, Feitoza LC, Correia CM, Suto CS, Macedo TTS, Rodrigues GRS, et al. Losses, grief, and resignifications in fibromyalgia: a journey into the feminine universe. Rev baiana enferm (2025); 39:e64306. doi: https://doi.org/10.18471/rbe.v39.64306

Objective: to understand the social representations of women about living with fibromyalgia. Methods: a qualitative study conducted with 42 women recruited from the pain outpatient clinic of a university hospital in Bahia, Brazil. Data were collected through semi-structured interviews and the Drawing-and-Story Procedure with a Thematic Focus. Interpretation followed the lens of Social Representation Theory. Results: participants self-identified as Black and mixed-race, aged 35-64 years, with monthly income up to one minimum wage. Living with fibromyalgia was represented by them as limitations, suffering, sadness, stress, pessimism, and social isolation. To cope with treatment and return to social life, they relied on courage, resilience, patience, and faith. Final Considerations: Women with fibromyalgia expressed an overarching desire to identify alternatives enabling them to experience illness in a way that fosters a better quality of life despite the disease and its restrictions.

Descriptors: Fibromyalgia; Women; Grief; Social Representations; Social Isolation.

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Objetivo: apreender as representações sociais de mulheres sobre viver com fibromialgia. Métodos: estudo qualitativo com 42 mulheres do ambulatório da dor de um hospital universitário da Bahia, Brasil, as quais responderam à entrevista e elaboraram desenho-estória com tema. Os resultados foram interpretados à luz da Teoria das Representações Sociais. Resultados: as participantes autodeclararam-se pretas e pardas, na faixa etária de 35-64 anos, com renda mensal de até um salário-mínimo. O viver com fibromialgia foi representado por elas como limitações, sofrimento, tristeza, estresse, pessimismo e isolamento social. Para enfrentar o tratamento e voltar à vida social, elas recorriam à coragem, resiliência, paciência e fé. Considerações Finais: o desejo de mulheres com fibromialgia era buscar alternativas que as ajudassem a vivenciar o processo de adoecimento com o intuito de alcançarem um estilo de viver melhor com a doença e suas limitações.

Descritores: Fibromialgia; Mulheres; Luto; Representações Sociais; Isolamento Social.

Objetivo: Comprender las representaciones sociales de las mujeres sobre la vida con fibromialgia. Métodos: Estudio cualitativo con 42 mujeres de la clínica ambulatoria de dolor de un hospital universitario en Bahía, Brasil. Respondieron a entrevistas y crearon un dibujo temático. Los resultados se interpretaron a la luz de la Teoría de las Representaciones Sociales. Resultados: Las participantes se autoidentificaron como negras o mestizas, de entre 35 y 64 años, con ingresos mensuales de hasta un salario mínimo. Representaron la vida con fibromialgia como limitaciones, sufrimiento, tristeza, estrés, pesimismo y aislamiento social. Para afrontar el tratamiento y reincorporarse a la vida social, se apoyaron en la valentía, la resiliencia, la paciencia y la fe. Consideraciones finales: Las mujeres con fibromialgia deseaban alternativas que les ayudaran a transitar el proceso de la enfermedad, con el objetivo de lograr una mejor calidad de vida con la enfermedad y sus limitaciones.

Descriptores: Fibromialgia; Mujeres; Duelo; Representaciones sociales; Aislamiento social.

Introduction

Fibromyalgia (FM) is one of the most common rheumatologic disorders worldwide, with prevalence estimates ranging from 0.2 % to 6.6 %(1) of the general population, and from 2.4 % to 6.8 % among women(2). In Brazil, the average prevalence is 2.5 %, with a higher incidence in the female sex and in the 35–44-year age group(3).

FM is a complex syndrome whose hallmark is chronic widespread musculoskeletal pain, generally accompanied by sleep disturbances, and physical and mental fatigue. Autonomic dysregulation, hyper-sensitivity to external stimuli, and psychiatric symptoms such as anxiety, depression, memory deficits, concentration difficulties, and morning stiffness may also be present(4). In the state of Bahia, Law No. 14,364/2021 instituted May 12 as the Day of the Person with Fibromyalgia, aiming to raise public awareness and stimulate initiatives that improve information and treatment access(5). At the federal level, Law 14,705/2023 establishes guidelines for care provided by the Brazilian Unified Health System (SUS) to individuals affected by this syndrome(6).

Fibromyalgia markedly impairs quality of life across personal, professional, and social domains. Therefore, feelings of despair arising from the illness trajectory shape pain perception, interfere with coping strategies, and trigger a sense of multiple losses and grief(7).

Chronic pain's impact on women's quality of life varies according to individual factors—age, education, income, illness beliefs, coping styles—and contextual variables such as perceived social support, resource availability, and cultural or religious influences(7). Reflecting on the repercussions of this condition and providing comprehensive, systematic care tailored to each woman's needs warrant heightened attention from health professionals.

The importance of this theme requires sensitization of healthcare professionals, as it affects the entire life of women with fibromyalgia, involving health, emotional, psychological, physical, social, and financial aspects, among others. Therefore, multiprofessional healthcare assistance is necessary, from a broad perspective, with the aim of achieving professional excellence and continuous improvement in these women's quality of life.

The present study aimed to apprehend the social representations held by women regarding the experience of living with fibromyalgia.

Method

The research protocol was approved by the institutional Research Ethics Committee. All participants received detailed information and provided written informed consent prior to data collection. Confidentiality and anonymity were ensured; participants were identified as "I" followed by an interview number. Example: I1, I2 ... I42. The study adhered to Brazilian National Health Council Resolutions 466/2012(8) and 580/2018(9).

Given the complexity and subjectivity of the object, the study is grounded in the Processual Approach of Social Representation Theory(10), which facilitates understanding of women with fibromyalgia, their relationships, and their coping with illness and treatment.

This is a descriptive qualitative research with a multi-methodological approach based on Social Representation Theory, which consists of studying subjective aspects of social phenomena and human behavior. The elaboration of this article followed the checklist of recommendations from the Consolidated Criteria for Reporting Qualitative Research (COREQ) for qualitative research.

Data collection instruments comprised three parts: (1) sociodemographic and clinical data; (2) the Drawing-and-Story Procedure with a Thematic Focus (DS-T); and (3) guiding questions. The questions were: "What does it mean for a woman to live with fibromyalgia?" "Do you miss anything from before the diagnosis?" "What can a woman with fibromyalgia do to confront the disease?" "Which strategies do you use to reframe your life after the diagnosis?"

Interviews were audio-recorded on an Android device after participants' consent and concluded when content saturation was reached—i.e., no new elements emerged after five consecutive interviews. Researchers conducted, transcribed, and analyzed all data.

During the DS-T session, each participant was asked to draw anything illustrating a day in the life of a woman with fibromyalgia; subsequently, she narrated a story about the drawing and assigned it a title.

The study was conducted at the Pain Outpatient Clinic of a University Hospital Complex in Bahia, Brazil, between March and June 2023. This institution is a reference for medium and high complexity care and is part of the Unified Health System (SUS). The clinic operates on Tuesdays from 7 a.m. to 7 p.m., serving patients with continuous or intermittent pain for more than six months, including those with fibromyalgia. In this outpatient clinic, medical, nursing, and psychological care are provided. Consultations and nerve blocks are carried out according to each patient's needs, along with referrals to other specialties and/or integrative practices.

The convenience sample comprised 42 women with a medical diagnosis of fibromyalgia undergoing follow-up at the Pain Outpatient Clinic in 2023. The non-probabilistic convenience sample voluntarily agreed to participate in the study after presentation of the research and invitation. Inclusion criteria were: female sex, ≥18 years, and ≥6 months since diagnosis. Exclusion criteria were treatment abandonment during data collection or any sensory/cognitive impairment hampering data collection.

Data techniques included semi-structured individual interviews in a private setting and the DS-T. The latter is an image-based communication modality that facilitates apprehension of statements tied to events, facts, and updated stories evoked by the depicted scene(11).

Data from interviews were organized through thematic content analysis(12), a method that comprises a set of techniques that analyze subjects' communication based on objective and systematic processes of description of message contents. Exhaustive reading of the material was performed, highlighting the main key ideas, which were categorically analyzed and structured. Drawings were analyzed using the same content-analysis technique(13). For result dissemination purposes, names were omitted, and speeches and drawings were identified through enumeration.

Results

Participants were aged 35–64 years (88.1 %) and predominantly reported stable marital relationships (52.38 %). Most self-identified as Black or Mixed-race (92.86 %). Although many reported having studied 13 years or more, only 7.14% completed higher education. Of these, 33.33% studied less than 9 years. Among participants, 26 (61.90%) reported having stopped performing paid work activities after the fibromyalgia diagnosis. Forty point four eight percent (n = 17) lived on ≤1 minimum wage per month—insufficient to cover basic needs.

Analysis revealed that, to copo with fibromyalgia and reframe life after diagnosis, women needed to understand and manage the changes imposed by the disease. The repercussions imposed by fibromyalgia were analyzed and grouped by thematic similarities into two categories that emerged from empirical data: Category 1 – Losses and Grief; and Category 2 – Coping. These categories were defined based on limitations (psychological, physical, financial), social isolation, resilience, and treatment.

Category 1 – Loss and Grief

Persistent pain eroded women's willingness to work, socialize, and perform daily activities, rendering their routine empty. Their routine becomes empty, as represented by I8's statement: "After fibromyalgia, I died to the world." And E9, under 35, who verbalized: "I celebrated my birthday in January and asked God for it to be the last. I truly hope it is!"

Intense pain, sadness, hopelessness, depression, sleep deprivation, loss of joy, and the absence of a healthy life were poignantly expressed:

> *"It's so much pain, so stressful; if we could, we wouldn't have fibromyalgia. It's a lot, a lot, a lot! Some days you lose yourself because it's overwhelming. Folks, you have no idea."* (I19)

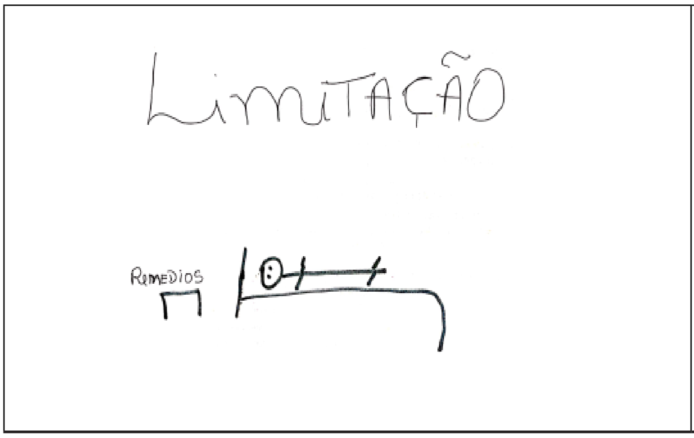
During the DS-T task, when asked to make a drawing depicting the daily life of a woman with fibromyalgia, I35 represented her painful routine, as can be observed in Figure 1.

Painful routine

> *"I feel pain and strange sensations. Sometimes I hear voices and sounds others don't. I see odd things—a flying fish, a shining person. At times I feel empty."* (I35):

Figure 1 – Drawing-story 1

It is observed that fibromyalgia restricts the patient to bed, making her totally dependent on medications, which can further intensify dependency and physical limitations. The experienced grief can be observed in Figure 2, through the use of only black pencil, strong and limited strokes by I32, even though pencils of various colors were made available.



Limitation

Medications.

Figure 2 – Drawing-story

Physical limitation is represented by fatigue, lack of motivation for routine activities, mobility difficulties, and inability to perform activities with the same naturalness as before the disease. The insecurity that permeates women's routines after fibromyalgia diagnosis, generating fragilities and incapacities, is expressed in the following fragment:

> *"A woman who thinks, many times, before doing anything. Thinks about climbing on a stool, because her back is hurting and she might fall, thinks before leaving home to go somewhere: will I feel pain? How long to sit? How long to stand? And will I take medications anywhere? I am a person full of limits in everything I do."* (I24)

> *Chronic pain and its implications are reported as impactful on freedom, physical, domestic, and work activities, according to the following statement:*

> *"It's a lot of limitation, it seems like you feel inside a cocoon. You feel like the most fragile person in the world."* (I27)

The lack of conditions to maintain work activity appears even before a firm fibromyalgia diagnosis. This syndrome limits women not only for activities performed outside the home, but also for basic daily activities, including domestic activities and self-care, as explained in the following interviews:

> *"I miss basic things, walking, taking care of the house, washing my clothes, making my food, which I did with pleasure. Sleeping."* (I9)

> *"Now I can't do everything in one day. I have to choose the day and time when I'm feeling well, doing it little by little."* (I16)

Women, to live with fibromyalgia, need to overcome themselves every day, as pain and limitations require constant use of medications, cause insomnia, and do not allow an active social life, according to the following report:

> *"It's a daily struggle, because you have to overcome yourself every day. It's very difficult to wake up every day and, first thing in the morning, you realize you're fully paralyzed. You have to take more time to get out of bed, to wake up to your day, to really start up. You have several limitations that you didn't have before."* (I32)

In Figure 3, it is still observed how the disease affects mobility, locomotion, hygiene, and self-care, in addition to causing social isolation, with constant visits to health organizations.

	*During the day: pain, medications, crutches, holding onto furniture pieces and crying.* *Night: pain, insomnia and, when I sleep, the pain wakes me up.* *My children sometimes taking me to bathe, to dress, etc.* *Going to the Emergency Unit or hospital, because social life no longer exists.* *Pain points and there are still pains in the rectum, hyperlordosis, spine, and neck.”* (I9)

Figure 3 – Drawing-story

According to one of the interviewees, social life no longer exists because, in addition to the physical limitations imposed by fibromyalgia, women also lack motivation to interact with other people, including due to low self-esteem, which restricts them to their own homes:

> *You're going to stay too much in a bed, you're going to feel very isolated.* (I19)

The severity and unpredictability of symptoms make life difficult for women with fibromyalgia in professional, domestic, and leisure activities, leading them to feel trapped in social isolation. One of the reasons for this isolation is linked to the fact that other people think their complaints are “nonsense,” among other situations.

> *“I understood what fibromyalgia was, that it wasn't something in my head, as many used to say, that fibromyalgia is a woman's thing, it's in your head, it's not a disease.”* (I32)

Family, work, and friend relationships become compromised due to changes caused by the disease. These relationships become increasingly distant each day until, sometimes, they cease to exist, according to the following reports:

> *“Family relationships are very complicated. They don't accept the way I am. Each day they distance themselves more.”* (I2)

> *Fibromyalgia is an invisible disease. Many times I was labeled as crazy, that it was all in my head.* (I35)

Low self-esteem, time dedicated to treatment, instability of feelings and sensations, all contribute to the social withdrawal of these women, according to the following statement:

> *It's difficult, very difficult, because it's a lot of pain. I can't concentrate on anything. I can't even go to church! I get there with so much pain, I can't sit, I can't stand. I can't even kneel!”* (I29)

Category 2 – Coping

The Coping Category is anchored in resilience and treatment. Some women remain trapped by limitations and all the negative elements that the disease brings to their lives, while others perceive that having resilience and facing fibromyalgia becomes the possible option and they need to transform some aspects of their experience to move forward.

In subsequent testimonies, women refer to knowing what they need to face fibromyalgia:

> *“Control diet, exercise, control emotions, have psychological follow-up, because it's very associated with the person's emotional state. Her lifestyle will have to change, adapt to her new reality.”* (I7)

> *“She can follow medical recommendations, seek healthy eating, seek leisure, seek a psychology specialist for help, seek to socialize, have friends, go out more. Everything related to leisure. Do physical activity, which relieves a lot.”* (I34)

In DS-4, the interviewee represents the coping experienced with optimism, without focusing only on the disease, trying to see what life has that is good, light, colorful, and joyful. It is by experiencing life with good humor that she seeks to overcome fibromyalgia.

Overcoming fibromyalgia

"See life as light and colorful, with good humor." (I13)

Figure 4 – Drawing-story 4

E23's statement and DS-5 by E7 (Figure 5) present the contrast experienced by women with fibromyalgia. While she draws crying, sadness, and pain, she also represents her daily life with strength, effort, and struggle. The representation evidences that women need to find their means of coping to continue living.

> *"Wake up in the morning and ask God's mercy to lift me up and not keep thinking about it. Keep trying to do my things slowly, trying to smile and joking* [...]" (I23)

Tough struggle

"Strength, effort and struggle combating crying, sadness and pain." I7:

Figure 5 – Drawing-story 5

Re-signification after diagnosis was observed in the pursuit of pharmacological, therapeutic, nutritional, and physical treatments, alongside faith, social reintegration, patience, and resilience:

> *"I only do what I can and enjoy. The machine is sick. Within my limits, I seek everything said to be good. That's what helps me."* (I4)

> *"I try. I start something now and can't—leave it, begin, get sad, stop, step away, try something else, rest, return, and try again."* (I10)

Knowledge about the disease was highlighted by the interviewees as crucial for coping:

> *"Making people understand and know a bit about the disease—it becomes easier to be helped."* (I21)

> *"First and foremost, understand what the disease is, study, grasp how it affects the person, because each individual is unique. Often what affects one doesn't affect another* [...]" (I32)

Each woman, in her own time and manner, will seek strength and wisdom to reframe her life and move forward, as they express:

> *Think positive, that this is not the last disease in the world. Take care of yourself. Move forward and do the treatments."* (I3)

> *"I perceive, in many women who haven't reached this point of reframing, that they are immersed in pain, focusing only on physical and psychological pain, like accepting it. This is fibromyalgia, I am limited and that's it. There are many, like me, who are already opening their minds. Do I have fibromyalgia? Ok, what can I do with this? Let's move forward, I can't go this way, I'll go that way; I'll see how I'm going to move, but I need to move* [...] *I'm now learning to deal better with this situation and see another person that I wasn't seeing in myself. See that I'm capable. This is because, before, I was immersed, trapped* [...] *I'm going to try to do what needs to be done to improve, even if it's one step each day.* (I32)

It is observed that there is a desire to seek alternatives that help experience this entire process. From the first symptoms to diagnosis confirmation, going through losses, experiencing grief, until being able to live better with the disease and its limitations, even if unconsciously, is the desire of most women in this study. This capacity to accept and adapt to changes is explained in the following statements:

> *"All of us have to accept, move forward, never give up, love ourselves and seek treatment. Everything has a solution.* (I3)

> *"There is no cure, but there is improvement".* (I4)

> *"I try to keep my head up, get up and try to live. Live in a way that you can, today, with other limitations, with pain, with many health problems."* (E27)

Some women in the study reported that faith was what propelled them to move forward and believe in better days. Faith helps not only to strengthen them for coping with the disease, but also helps, when they attend temples and religious activities, to reinsert themselves in groups, improving social life. For these women, this is one of the most important components in helping to cope with fibromyalgia:

> *"I try to have good friendships, adequate environment at home, activities to do, games, read the bible, activate the mind."* (I3)

> *I, thank God, have a God, I serve him, who takes care of me, my family, a husband who takes care of me and my children* [...] (I11)

Discussion

The results of this study corroborate the literature, which refers to higher prevalence of fibromyalgia in women over 30 years and rare diagnosis in young people(14). They also confirm that approximately 60.9% of women who use SUS services are Black or mixed-race, according to the National Health Survey by the Brazilian Institute of Geography and Statistics - IBGE(15). Education level is one of the most determining factors in income inequality of the Brazilian population, especially among women(16).

Fibromyalgia carries a very negative representation, being linked to the expectation of a better life, but loaded with pessimism, suffering, limitation, and sadness. Most women who suffer from fibromyalgia consider their routine stressful and painful, precisely because of the limitations resulting from physical pain, in addition to reporting living without hope, due to risks of having an uncertain disease evolution(17). Thus, they come to live according to the disease. It is explicit that the impact of fibromyalgia, for them, is incalculable, as chronic pain, limitations and restrictions for active social life, anxiety, suffering, and sadness generated by all experienced situations affect all aspects of life. Limitations, lack of support, absence of work activity that restores their dignity and collaborates with coping, make their daily life very difficult(7).

A study on pain perception and stress in fibromyalgia found that greater pain intensity, reduced functionality, greater stress perception, and greater impact on quality of life presented direct relation with depressive symptoms in these patients(18). Limitations imposed by fibromyalgia are related, on a large scale, to pain processes, as persistent pain generates various difficulties for women to manage their physical, psychosocial, and organizational demands at work and at home, causing a negative balance in their lives(19).

Living with pain daily is a cause of much affliction and impairs the continuity of women's work activities, who find themselves forced to leave an active life for a passive life, suffering from socioeconomic consequences, physical limitations, and loss of autonomy. Associated with all this is the need for behavioral changes, seeking knowledge and support for coping with the disease, which is often difficult to achieve(20).

Fibromyalgia treatment is based on all measures adopted for pain relief and physical and psychological suffering relief. It goes beyond drug treatment and requires lifestyle changes, differentiated nutrition, physical activities with professional supervision, and also regular therapy with a specialist. When women acquire knowledge and have a realistic perspective of the problem, it becomes easier to deal with the disease and develop coping mechanisms directed to their own individuality(21).

In fibromyalgia, various coping processes are necessary given the constant and incurable symptomatology in the individual's life. Thus, it is important to focus on interventions that assist in this coping, from educational strategies, reception, support groups, physical exercise practice, and medications(22). Faith in God, religious participation, and family function as support points for women to face the disease(23).

One of the forms of coping was reported by participant E32, when informing that reframing is initiated as women understand fibromyalgia and become co-participants in their treatment. When women think about reframing life after disease diagnosis, they seek to find coping means that make their days less stressful, even with treatment. It is important to clarify that reframing means attributing a new meaning to; giving a new sense to something(24), and each person has an original way of being, feeling, reframing, expressing themselves, and building new possibilities(25).

Reframing life after a chronic diagnosis is something very complex, difficult to experience, especially for women with fibromyalgia who, even today, experience many discriminatory processes in society. This is a disease full of stigmas, often seen, even by family members and friends, as fantastical or "head creation" and, in the case of this study, is also linked to an unfavorable economic situation, which makes all stages of the process difficult.

In this study, some women with fibromyalgia represent the disease as living in a "cocoon," in which they are isolated and protected from everything and everyone, awaiting the moment to learn to live with the disease and create courage to face treatment and society itself that still does not understand what it means to live with fibromyalgia. These women aggregate a very restricted belonging group. Even today, fibromyalgia is not an object of social representation for society, due to the difficulty of objectifying and anchoring a pathology that does not present physical manifestations that clinical and laboratory tests can prove. Thus, anchoring this syndrome is only possible for the belonging group of women who have the disease diagnosis.

This study made it possible to infer that women with fibromyalgia, who undergo treatment in university and public health services, anchor the repercussions imposed by fibromyalgia as losses and grief, by objectifying psychological, physical, and financial limitations and social isolation, as well as by facing the chronic illness process with resilience and treatment for pain relief. It is important to emphasize that repercussions, losses, and grief are directly linked to how women face fibromyalgia and the changes that occurred after diagnosis.

Study limitations consisted of the lack of data from women with fibromyalgia followed in private health institutions, which would allow a deeper analysis of coping forms, as well as having chosen the female gender as the research focus, which may have limited possible comparisons of specific aspects in the illness and fibromyalgia coping process between women and men.

This study contributes to making fibromyalgia socially visible, and to emphasizing that these patients need to have access to all types of available treatment, so they can be reinserted into a healthy and socially active life process, since they need to reframe their way of living, even though fibromyalgia is still an incurable disease.

The positive impact and contributions that the results of this study bring to people living with fibromyalgia, healthcare professionals, and society are emphasized, by allowing deepening of still scarce knowledge about the pathology, opening gaps for new studies, in addition to disseminating how women represent and face the disease. It may also contribute to helping women understand the changes brought by fibromyalgia diagnosis and reframe their lives to live with the diagnosis and certain quality of life.

Final Considerations

With this study, it was understood that most women represented living with fibromyalgia as living in a "cocoon," in which they are isolated and protected from everything and everyone, awaiting the moment to learn to live with the disease and create courage to face treatment and society itself. Women know what they need to do to alleviate suffering, but due to limitations imposed by the disease itself, they feel fatigued and unmotivated to execute necessary changes. These women need to be heard and welcomed, considering that it is necessary to look at them in their entirety, since this illness is associated with social, cultural, and gender problems, which ends up making coping difficult.

We suggest that new research be conducted with different belonging groups of women with fibromyalgia and based on other perspectives, such as men with fibromyalgia, family members, and healthcare professionals, with the aim of expanding knowledge, both of society and professionals, about difficulties and real needs for care and support networks.

Collaborations:

1 – conception and planning of the project: Marcia Santana de Carneiro Vivas e Gilmara Ribeiro Santos Rodrigues;

2 – analysis and interpretation of data: Luciana de Carvalho Feitoza, Cleuma Sueli Suto, Tássia Teles Santana de Macedo, Marcia Santana de Carneiro Vivas e Gilmara Ribeiro Santos Rodrigues;

3 – writing and/or critical review: Marcia Santana de Carneiro Vivas, Cintia Mesquita Correia e Gilmara Ribeiro Santos Rodrigues;

4 – approval of the final version: Marcia Santana de Carneiro Vivas, Carolina Vila Nova Aguiar and Gilmara Ribeiro Santos Rodrigues;

Conflicts of interests

There is no conflict of interest

Data Availability Statement

The derived data supporting the findings of this study are available from the corresponding author GRSR, upon reasonable request.

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Received on: November 4, 2024

Accepted: May 5, 2025

Published: September 01, 2025