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Knowledge and strategies for coping with fibromyalgia

Saberes e estratégias no enfrentamento da fibromialgia

Conocimiento y estrategias para el enfrentamiento a la fibromialgia

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ABSTRACT

Objective: To analyze the knowledge about fibromyalgia of people with this diagnosis and its repercussions in coping with the disease.

Method: Qualitative research, based on the Social Representation Theory framework. Thirty people over 18 years old and from the state of Rio de Janeiro, Brazil, participated. Snowball sampling was applied to recruit participants and a semi-structured interview was used to produce data, between April 2020 and January 2021. Statistical and lexicographic analysis was performed using Alceste.

Results: Most participants were women (93%); aged 41 to 60 years old (67%); of whom 63% were married; had been diagnosed 10 years ago or more (40%); and 40% participated in support groups. They did not know the name of the disease and its causes, but they mentioned its symptoms, mainly pain. Objectification of fibromyalgia occurs in painful symptoms and the lack of signs in the body generates misunderstanding among the people they live with. They share experiences in support groups to cope with the disease.

Conclusion: The subjective phenomenon of pain generates distrust about the disease. Diagnosis difficulties delay treatment and insufficient information generates judgments and stereotypes for patients. Prejudices and rejections have repercussions on coping with the disease.

Descriptors: Fibromyalgia. Chronic pain. Nursing. Qualitative Research.

RESUMO

Objetivo: Analisar os saberes sobre a fibromialgia de pessoas com este diagnóstico e suas repercussões no enfrentamento da doença.

Método: Pesquisa qualitativa amparada no referencial da Teoria das Representações Sociais. Participaram 30 pessoas acima de 18 anos, do estado do Rio de Janeiro, Brasil. Aplicou-se *snowball sampling* para recrutar os participantes e entrevista semiestruturada para produção de dados, entre abril de 2020 e janeiro de 2021. Realizou-se análise estatística e lexicográfica pelo Alceste.

Resultados: A participação majoritária foi de mulheres (93%); idade de 41 a 60 anos (67%); 63% eram casados; com diagnóstico há 10 anos ou mais (40%); 40% participavam em grupos de apoio. Desconheciam o nome da enfermidade e suas causas, mas citaram os seus sintomas, majoritariamente a dor. A objetivação da fibromialgia ocorre nos sintomas dolorosos, por sua vez, a falta de sinais no corpo gera incompreensão nas pessoas com as quais se convive. Compartilham experiências em grupos de apoio para enfrentar a doença.

Conclusão: O fenômeno subjetivo da dor gera desconfiança quanto à enfermidade. As dificuldades do diagnóstico retardam o tratamento, e a insuficiência de informações gera julgamentos e estereótipos para os doentes. Os preconceitos e rechaços repercutem no enfrentamento da doença.

Descritores: Fibromialgia, Dor crônica, Enfermagem, Pesquisa Qualitativa.

RESUMEN

Objetivo: Analizar el conocimiento sobre fibromialgia de personas con este diagnóstico y sus repercusiones en el afrontamiento de la enfermedad.

Método: Investigación cualitativa, basada en el marco de la Teoría de la Representación Social. Participaron 30 personas mayores de 18 años, del estado de Rio de Janeiro, Brasil. Se aplicó un muestreo de bola de nieve para reclutar participantes y se utilizó una entrevista semiestructurada para producir datos, entre abril de 2020 y enero de 2021. El análisis estadístico y lexicográfico fue realizado por Alceste.

Resultados: La participación mayoritaria fue de mujeres (93%); de 41 a 60 años (67%); el 63% estaban casados; diagnosticado hace 10 años o más (40%); el 40% participó en grupos de apoyo. Desconocían el nombre de la enfermedad y sus causas, pero citaban sus síntomas, principalmente dolor. La objetivación de la fibromialgia se produce en los síntomas dolorosos y la falta de señales en el cuerpo genera incomprensión en las personas con las que se convive. Comparten experiencias en grupos de apoyo para afrontar la enfermedad.

Conclusión: El fenómeno subjetivo del dolor genera desconfianza sobre la enfermedad. Las dificultades de diagnóstico retrasan el tratamiento y la información insuficiente genera prejuicios y estereotipos en los pacientes. Los daños y rechazos repercuten en el afrontamiento de la enfermedad.

Descriptores: Fibromialgia. Dolor crónico. Enfermería. Investigación cualitativa.

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INTRODUCTION

Fibromyalgia (FM) is a chronic rheumatic disease when persistent for more than three months. It is multifactorial and has a complex etiopathogenesis that is not yet fully understood. It is characterized by diffuse musculoskeletal pain, mental fatigue, behavioral changes, concentration, and memory issues, and is generally associated with signs and symptoms such as anxiety, depression, sleep, mood, and gastrointestinal disorders. It can trigger numerous limitations and disabilities in patients[1].

Estimated data for the global population range from 2% to 4%; in the United States of America (USA) and Europe, the incidence rates are up to 5% in the general population, with more than 10% of patients treated at rheumatology clinics; in Brazil, FM affects up to 2.5% of the general population, being more frequent in the 35 to 44 age group. The predominance in women is up to nine for every man affected[2,3]; it affects 4.2% of women aged 40 to 50 compared to 0.2% of men, and women with lower education level. Furthermore, people under 60.6 years of age tend to have more acute symptoms of the disease[4]. Women are 1.5 times more likely to feel widespread chronic pain than men and are 10 times more likely to have 11 or more tender points on clinical examination, which may explain the higher prevalence of FM among women[5].

Predominantly, diagnosis is based on the evaluation of the presence of pain and sensitivity in these tender points, associated with the clinical judgment of the signs and symptoms reported by the individuals. The diagnosis of FM still varies widely, and there is no laboratory marker or imaging test to prove its existence, which encourages researchers to propose studies on guidelines for diagnosis and evidence-based treatments[2,5,6].

A study using data from a database of rheumatic diseases and fibromyalgia criteria (CritFM) from 2016 and a reanalysis of a German population study that applied revised 2016 criteria for fibromyalgia[6] indicates that there may be overdiagnosis of FM in women and underdiagnosis in men, thus causing inaccuracies in statistics related to symptoms, prevalence, costs, comorbidity and clinical outcomes – due to the slightly higher values of pain and severity of symptoms in women when compared to men. Women report more pain and, therefore, reach more CritFM, which may influence diagnostic data. The study suggests that overdiagnosis in women and underdiagnosis in men result from prejudices due to the widespread belief that the disease predominantly affects women; consequently, there is a potential for earlier examinations and greater diagnosis of the disease in women than in men. This same study suggests that there is an important element of social construction regarding FM and its identification, highlighting the medical and social dimensions of this disease[6].

In addition to all its biological variables and vast symptomatology, FM also involves psychosocial variables that permeate the entire health/disease process, negatively affecting the physical, cognitive, social, family and professional aspects of individuals[4]. People with FM perceive the disease as a stigmatized, invisible and difficult to understand disorder[7], which worsens the suffering of those living with the condition.

The lack of knowledge about the disease, its treatment and care practices persists, whether by those who have been ill, by society or even by healthcare professionals, as FM has a strong subjective burden. By permeating this territory of subjectivity and uncertainties that lead to delayed diagnosis and therapeutic divergences, FM brings suspicion, doubts, questions and stigma, with patients often being discredited in their health/disease process, even by family members and friends. This disease is immersed in biological and functional aspects, but also psychosocial, which implies expanding knowledge about this aspect in the experiences of those living with the condition so that it can increase the spectrum of its approach in the care and self-care practices of affected individuals.

Among the seven pillars of self-care is having health information and knowing oneself[8]; therefore, for effective self-care to occur, people with FM need to have more knowledge about the disease and, for it to be well understood, professionals must know what and how much knowledge patients have so that they can provide the necessary care.

In this research, fibromyalgia was taken as the object of social representations (SR), understanding that SR deal with interpretations of phenomena relevant to social subjects, thus generating knowledge and practices to better cope with these phenomena. Therefore, studying social representations unveils knowledge and practices about the object studied[9,10]. Therefore, the question is: what knowledge do people with FM have about this disease? The objective, in this sense, was to analyze the knowledge related to fibromyalgia among people with this diagnosis and its repercussions in coping with the disease.

METHOD

Qualitative, descriptive and exploratory study with application of the Social Representations Theory (SRT) – as theoretical and methodological framework – in its procedural approach regarding the processes of objectification and anchoring[9,10]. The guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were applied[11].

The selection criteria for participating in the study were being 18 years of age or older with a diagnosis of FM. Exclusion criteria included individuals with cognitive or speech impairments that could hinder data collection, and adolescents/young adults diagnosed with Juvenile Fibromyalgia Syndrome, as this variable requires a different analysis regarding the repercussions of the disease in daily life.

The data production period was from April 2020 to January 2021, and participants were recruited using the snowball sampling method, since, due to the pandemic, support groups for people with fibromyalgia suspended in-person meetings. The researcher then began collecting data from two informants diagnosed with FM, both residents of the state of Rio de Janeiro, who were called seeds. These seeds were part of the researchers' network of relationships, and through them, new participants with the study profile were contacted. All participants, including the seeds, were contacted by telephone, received preliminary explanations about the research, and interviews were scheduled upon their agreement to participate. The snowball sampling method is used when dealing with hard-to-reach populations or when an initial probabilistic sample is impractical, as it allows for a variety of participants[12].

Individual and in-person interviews were conducted at the participants' homes – by their request. The interviews lasted between 60 and 90 minutes, and were recorded using voice recordings, with the application of instruments with closed and open questions to collect personal, sociodemographic, health-disease process data, family history, clinical history, medication history, comorbidities, and other health-related data, to support the analysis of the social representations of the disease. After, questions were asked about knowledge and daily experiences, the impact of the disease, attitudes, behaviors, strategies and care practices adopted.

The collection was completed by reaching 30 participants, applying the consensus recommendation for qualitative samples combined with the saturation criterion to establish sufficiency in data and participant heterogeneity[13]. The interviews and their transcriptions were conducted by the main researcher and submitted for validation by the participants.

The research was conducted during the COVID-19 pandemic, and all prevailing safety protocols were applied. This also explains why participant recruitment and interviews were carried out over nearly 12 months.

The profile data were statistically processed, and the interview texts were transcribed and formed a corpus of 30 Initial Context Units (ICU), corresponding to the number of interviews processed by the Alceste software version 2012. This software performs contextual lexical analysis of a set of text segments, applies calculations on the co-occurrence of words in text segments to define word classes that represent different discourses regarding the object of investigation. The software identifies lexical oppositions and reaches the oppositions of different collective points of view that are expressed in the vocabulary of a text, enabling access to intergroup communication, the sharing of knowledge, and the production of social representations[14].

Text processing in the software promotes the grouping of semantic roots from the words used by participants in their statements to communicate their points of view on the object under investigation. The software generates figures, such as the Descending Hierarchical Classification (DHC), which highlights the most significant words in the class through statistical association, and each class is composed of text fragments that express the ideas that give meaning to the class, called Elementary Context Unit (ECU)[15].

To meet the stated objective, this article addressed Class 1, which relates to the participants' role regarding their experience with the disease and their knowledge about it. This interpretation was carried out by the researchers based on the DHC and ECUs generated by the software[15].

The project was approved by the Research Ethics Committee of the *Escola de Enfermagem Anna Nery* and the *Instituto de Saúde São Francisco de Assis* of the *Universidade Federal do Rio de Janeiro*, with Presentation Protocol No. 28347120,0,0000,5238 and Favorable Opinion No.3,918,414. All participants signed the informed consent form before participating in the research.

The identification of the statements followed the coding applied for processing in the software, each interview was identified as ICU followed by the sequential number of its occurrence, the sex/gender (female or male) and the age group of the participant.

RESULTS

Thirty people participated, with a predominance of females at 93% (n=28). Regarding the age group, 30% of the sample was between 20 and 40 years old (n=9); 67%, between 41 and 60 years old (n=20); and 3%, 61 years or older (n=1); 63% (n=19) were married and 70% (n=21) had a job. Diagnosis of fibromyalgia 10 years or more ago was reported by 40% (n=12) of the sample and the remainder was divided into 4 to 6 years (20%; n=6), 7 to 9 years (20%; n=6), 17% (n=5) from 1 to 3 years and 4% (n=1) with less than 1 year. Health monitoring was made mostly in the private network, by 93% of the participants (n=28). Regarding treatment, 97% (n=29) used medication and 3% (n=1) did not; 53% did not follow non-pharmacological treatments (n=16) and 47% used some type of non-pharmacological treatment (n=14). Participation in support groups was made by 40% (n=12), and all of them participated in virtual groups on social networks such as Facebook, WhatsApp and YouTube channels.

Regarding the interview data, the software subdivided the text into 4,034 ECUs, consisting of 8,138 distinct forms. The software reduced these words into distinct roots, composing 1,287 analyzable words and 309 supplementary words. A total of 2,934 ECUs were analyzed, resulting in 73% of the corpus being used.

Class 1 consisted of 1,296 ECUs and 76 analyzable words, corresponding to 44% of the corpus classified for analysis. Therefore, this class is highly relevant as it concentrates the largest number of ECUs. When analyzing the DHC of this class (Chart 1), the form "Pesso" (Perso) had the highest Phi value, corresponding to 0.31. This root is expressed in the full forms "*pessoa*" (person), "*pessoais*" (personal), "*pessoal*" (personal), "*pessoas*" (people). Following this, the terms "*ach*" (think), "*cois*" (things), "*gente*" (people), "*entend*" (understand) appeared. Therefore, it is understood that Class 1 communicates the agency, experiences and perceptions related to the disease. It addresses the experience and subjectivity of the person with FM, their understanding and perceptions, the knowledge and what they do not know about the disease and their feelings regarding the (mis)understanding of others.

Due to its representativeness, Class 1 was named "What I know: The interfaces of FM from the perspective of those who experience it". In the ECUs of this class, it was evident that the disease is objectified in pain, despite not being understood by others who do not feel it.

> *I don't think it's that difficult to treat fibromyalgia. From what I read, fibromyalgia is pain, I think it's pain.* (ICU 15, woman, 41-60 years old)

> *It affects a lot because, like, even within the family, sometimes they don't really understand that the pain is persistent. It's permanent, it's real, all the time. Then you feel like, it's that case, you're feeling it, but other people aren't, but you'd at least like others to understand!* (ICU 23, woman, 41-60 years old)

It was identified from the results that there is an attempt to understand the disease as a compensatory strategy in light of the numerous hypotheses and divergences about what FM is.

> *I don't know much. Listening like this, someone saw a video and passed it on to me. Oh, look, they're going to talk about fibromyalgia on TV today. Look, I don't know if I'm right, but I think it's emotional, I think. I've always absorbed many problems from everyone around me.* (ICU 11, woman, 41-60 years old)

> *It could be, I can't say if it's a deficiency of something, I don't know. I don't know what it is, honestly I don't know, because until I was forty years old, I was an extremely healthy person.* (ICU 16, woman, 41-60 years old)

> *Then the doctor thought it was psychological. Some people have psychological pain, that sometimes they feel, you know. Then I went to an endocrinologist. What you have, from what you describe, is fibromyalgia. Have you heard of it? No. Then she explained it to me roughly. I research it up, read something about it.* (ICU 10, woman, 41-60 years old)

There are misunderstandings and perceptions in relation to oneself and others due to the lack of signs in the body, which makes it difficult for others to see, especially because the main characteristic is pain, which is subjective.

> *But no one sees it, no one sees it. You are not hurt, you are not bleeding, you are not injured. I can't say why I developed it. Maybe it's because of my temperament, because of the way I was raised. Because, I don't know if I had an explosive temper, for example, if I would have it.* (ICU 9, woman, 41-60 years old)

> *You know the pain you feel, you know everything. The other person doesn't. They don't have it, but they also don't imagine it, you know?! So, to them, it's something that when that lay person, especially if they are a lay person, has no interest in knowing what it is, what you feel, you know?!* (ICU 16, woman, 41-60 years old)

> *And it's a very marginalized disease, right?! Because people don't understand how you can feel pain and live. It's like I said, sometimes people look at me and say: oh, but you don't have anything, you're not feeling pain.* (ICU 21, woman, 41-60 years old)

Chart 1 – Representative words of Class 1, according to the dendrogram of Descending Hierarchical Classification (DHC). Rio de Janeiro, RJ, Brazil, 2021.

CLASS 1 – 1,296 ECUs		
Reduced form	**Full Form**	**Phi Value**
pesso	*pessoa*(304) *pessoais*(2) *pessoal*(14) *pessoas*(300)	0.31
ach	*acha*(40) *acham*(16) *achando*(4) *achar*(15) *achava*(10) *achavam*(3) *ache*(1)	0.21
cois	*coisa*(314) *coisas*(261) *coisinha*(1)	0.18
gente	*gente*(493)	0.18
entend	*entenda*(3) *entendam*(1) *entende*(36) *entendem*(20) *entender*(53)	0.15
as	*as*(500)	0.14
ne	*ne*(461)	0.14
doenca	*doença*(101) *doenças*(10)	0.13
sei	*sei*(262)	0.12
lid	*lida*(3) *lidado*(1) *lidam*(2) *lidando*(2) *lidar*(25) *lidasse*(1) *lidei*(1) *lido*(9)	0.11
quest	*questão*(78) *questões*(7)	0.11
apoi	*apoia*(5) *apoiada*(4) *apoiam*(3) *apoiando*(2) *apoiar*(4) *apoio*(27)	0.10
vejo	*vejo*(71)	0.10
conhec	*conhece*(10) *conhecem*(5) *conhecer*(21) *conhecia*(1) *conheço*(22)	0.10
maior	*maior*(28) *maiores*(3) *maioria*(28)	0.10
mundo	*mundo*(74)	0.09
relacao	*relação*(29)	0.09
fibromialg	*fibromialgia*(284) *fibromialgica*(4) *fibromialgico*(4)	0.09
sej	*seja*(36) *sejam*(2)	0.09
gostaria	*gostaria*(22)	0.09
facil	*fácil*(36) *facilitar*(1)	0.09
conviv	*convive*(2) *convivência*(1) *conviver*(16) *conviveram*(1) *convívio*(5) *convívios*(1)	0.08
ouv	*ouve*(7) *ouvem*(1) *ouvia*(3) *ouvir*(22) *ouviram*(2) *ouvirem*(1) *ouviu*(4)	0.08
viv	*vive*(11) *vivem*(1) *vivencia*(3) *viver*(38) *vivesse*(1) *viveu*(3) *vivo*(11)	0.08
mesma	*mesma*(61) *mesmas*(5)	0.08
compar	*comparação*(5) *comparada*(1) *comparado*(1) *comparando*(2) *comparar*(8)	0.08
convers	*conversa*(16) *conversado*(1) *conversam*(1) *conversamos*(1) *conversando*(13)	0.08

Source: Alceste detailed report (2021).

They will respond in the way they understand. Oh, this woman is annoying, this woman is annoying, she complains about the pain every day, the same thing, this habit of complaining. (ICU 10, woman, 41-60 years old)

It's a very bad feeling, the people pity you, I don't like it. So I choose people I can count on, who I'm sure will treat me like a fibromyalgia sufferer without pity, because I don't want someone who, oh poor thing, she has fibromyalgia. (ICU 1, woman, 20-40 years old)

People living with FM highlighted the importance of sharing experiences among those who experience the same problem as an important strategy for coping. Although the reports pointed out differences in the way of dealing with the disease, the symptoms are similar, and care practices can be shared among these people.

A group with more people would be nice, it would be cool, because it would be an exchange of experiences, learning about the difficulties of others, it would be very good for us to know how to live with our difficulties related to fibromyalgia. (ICU 2, woman, 41-60 years old)

So, I use what I've learned and what I have. I'm very curious, I'm like a sponge in absorbing information. I filter things that are good and safe for me. And if I can help someone, sometimes, in the group, I rarely spoke up, but sometimes I spoke up, I spoke up to say what was happening to me. (ICU 21, woman, 41-60 years old)

I have to understand myself first with this disease, so that I can see my limitations and my ability to overcome them in certain situations. So, I stopped demanding things from myself that I wanted to do, because I started to see that the disease gives you limitations. (ICU 30, woman, 41-60 years old)

I just haven't gone back to Pilates yet because I'm afraid. Look, a lot of people don't even know that I have fibromyalgia. I have a normal life. A lot of people don't know. Here at home, it's normal, I have nothing to complain about. Oh, I don't know. Look, I think it's something very broad and not widely publicized! (ICU 8, woman, 41-60 years old)

Self-demand is a characteristic that overwhelms the lives of participants, and the demand to be strong, balanced, and perfect in what you do generates stress and harms their health.

I think I have to face many obstacles every day. I think my life has a heavier burden that I have to carry and, sometimes, I have to be so strong, so balanced to deal with certain things and also deal with other people's problems. (ICU 17, woman, 20-40 years old)

It's harmful to you. And this causes several changes, like fibromyalgia. Wow, I consider myself a very stressed person. It's really bad when you grow up thinking that everything has to be perfect, you know?! And if it's not perfect, it's better not to do it. (ICU 25, woman, 20-40 years old)

DISCUSSION

Chronic diffuse pain, overloads, and the emotional aspects of life are frequently used as possible definitions for FM and attempts to identify an explanation for why it was triggered. Life history, emotional and psychological baggage, accumulation and absorption of problems, perfectionism and self-demand are points that arise in the context of understanding and explaining the triggering of FM by people who live with it. Therefore, all these elements are associated in the representations about FM.

In the field of common sense knowledge, it is observed that, in the attempt to understand and explain what is unfamiliar, in this case, a disease whose definitions are constructed in the field of technical and scientific knowledge, people use their experiences and establish causal relationships based on them[9]. In light of the SRT, this transformation of the unfamiliar into the familiar occurs supported by cognitive processes called objectification and anchoring, in order to give concreteness to something abstract (objectify) and an intelligible context to give it meaning and explain it (anchor)[9].

FM is a neuropathic pain syndrome that can be triggered by stress and different stressful stimuli can cause it, including psychological suffering[16,17]. Therefore, pain is an important characteristic of this disease, and the results of this research pointed to an objectification of FM in pain, considered real, but misunderstood, this being the most cited concept by the participants, despite other symptoms listed to characterize this disease. Anchoring occurs in behavioral and emotional characteristics, as explanations anchored in these aspects are identified in the results[9]. Therefore, people report not knowing what fibromyalgia is (from a technical and medical point of view), but they know how to talk about it based on what they feel and how they feel it[10].

Pain is at the heart of the definition of FM, conceived as a syndrome characterized by chronic widespread pain, which mainly affects the musculoskeletal system, of still unknown etiology, predominantly present in women between 35 and 45 years of age. This pain is not associated to an injury, which classifies it as a type of dysfunctional pain. It is assessed by identifying painful points, called tender points[18].

Regarding the possible causes of pain, it is believed that it occurs due to a genetic predisposition or dysfunction of the central nervous system, from the insufficient action of pain suppression mechanisms. Changes in the perception and interpretation can reduce the pain threshold in people with FM. There are indications that disturbances in the balance of neurotransmitters in the insula of the brain may cause pain, as well as other characteristic symptoms of FM[19]. There is also a historical construction of pain throughout life, in which childhood stressors give rise to this biological response[18].

Pain is a subjective phenomenon, representing a significant clinical and diagnostic challenge that causes numerous impacts on the lives of people who experience it, influencing relationships, such as marital and family problems, reducing productivity or causing work absences, among others. These emotional impacts tend to increase the suffering of the body from the painful trigger[20].

Chronic pain affects not only the biological dimension, but also the psychological and behavioral dimensions, generating anxiety, depression, anguish, among other symptoms that have negative impacts on quality of life, such as reduced sleep quality, mood swings and appetite changes[21]. These damages directly impact the lives of those suffering from FM, as portrayed in the results of this study. In this sense, interdisciplinary teamwork has the potential to offer more effective care to people with FM, in which the nurse can act in the assessment of pain by applying the nursing process to guide care that minimizes the suffering of these individuals[21].

The results showed that people construct knowledge about the disease based on its consequences, such as generalized pain, and seek to establish relationships with the emotional field, with the overloads experienced, with the deficiency of something, through the way they react to emotions. The classic questions used to investigate social representations: Who knows or who speaks and from where? What and how do we know or speak? About what and with what effect?[10], are applied to understand the representations of fibromyalgia by the participants in this research, as their attempts were observed to find out what it is and why they became or were ill. The representations are reinforced by information from professionals, when they attribute the pain to a psychological reaction.

It is a fact that overloads and losses suffered throughout life tend to maintain and worsen pain, which results in a perception of loss of one's own health, generating suffering and discouragement, emotionally sensitizing the individual. Emotional factors should not be neglected, as FM causes emotional distress and psychological disorders that can worsen symptoms or even alter the perception of pain[22]. However, pain is real and not imagined; it is felt and should be understood as such by those who deal with and live with someone suffering from FM.

It is necessary to understand what FM really is and why the person become ill. Those who suffer from this disease realize that these professionals have difficulty in determining the diagnosis, as observed in one of the ECUs in which the patient reported that one of the doctors who treated her attributed the pain she felt to the psychological domain, and only another specialist suspected FM. In this case, the medical professional plays an important role in legitimizing the pain based on the diagnosis and in the necessary guidelines for the treatment of FM, acting as an important disseminator of information for the patient and their family network, promoting self-care and mutual support[23].

To expand their knowledge, people with FM use other means to obtain the information they so desire, such as the internet, television, articles on the subject and exchanging information with other people who have the same diagnosis. Through these searches, they form their knowledge, which is combined with technical information from professionals, the media and their own experience. However, when people obtain information through different means and sources, many of which are not technical and have no direct commitment to scientific dissemination, beliefs, stereotypes and prejudices circulate, permeate and consolidate representations[9]. In the case of FM, such information obtained from these different means can contribute to reinforcing behaviors and practices that do not help improve the quality of life of people with this condition.

Regarding knowledge about their own diagnosis, a study conducted in Brazil with eight women about their daily experiences and their impact on quality of life showed a lack of knowledge and compromised quality of life. According to the authors, this lack of knowledge extends to health professionals, given the difficulty and time spent on diagnostic confirmation, which negatively influences symptom control and improvement in the quality of life of these people[24].

A study conducted with 172 women, aged between 18 and 75 years, in a Rehabilitation Center in Turkey, showed that more than 80% of them knew that FM is characterized by widespread pain and is more common in women, however some misconceptions compromise accurate knowledge about the disease, such as it being an inflammatory disease that deforms joints and compromises fertility. The authors indicate that the results should be considered according to the participants' context, but state that health education programs are strong allies in the treatment of the disease[25]. In contrast, a Spanish study conducted with 121 women showed medium (49%) and high (41%) knowledge about the disease[26].

What this research and the referenced studies show is that health education should integrate planned care for patients, considering previous surveys on their knowledge about the disease and their ways of dealing with it in everyday life, with the dissemination of knowledge about FM, regarding its diagnosis, symptoms and care, so that beliefs or information not supported by science harm the quality of life of patients.

The internet is an important information searching tool for people with FM. Since 2017, searches for the term "fibromyalgia" have increased considerably in Brazil, a fact that may be linked to the cancellation of a musical performance by the artist Lady Gaga at the Brazilian event Rock in Rio, since the links also mention the artistic event and the singer's FM diagnosis, which gave greater visibility to the syndrome[27].

Despite gaining this notoriety at the time, the lack of knowledge about FM still persists. The results of this research even point to the individuality of the disease, in which only those who feel the pain can understand it. Therefore, due to the lack of knowledge and the uniqueness of FM, those affected feel misunderstood.

Disbelief regarding the pain is the most relevant complaint, and this disbelief occurs not only among family and friends, but also by healthcare professionals themselves, who communicate judgments about the behavior of patients such as lazy, unmotivated, and faking, and images of sick people constructed based on attributes such as annoying, irritable, with a habit of complaining, among other pejorative terms that negatively affect the emotional dimension of these people and impact marital, family and social relationships.

Judgments and images with stereotypic behaviors indicate social representations about fibromyalgia and people affected by it, due to figurative models that make the meanings correspond to the images[9] that socially construct the realities that classify people and behaviors into certain categories[28]. In the results, this stereotyping was evident in terms such as annoying woman, irritable woman, habit of complaining.

In light of the results, those who do not feel the pain of FM do not understand it, nor are they interested in seeking an understanding of this phenomenon. Because they are not familiar with the disease, no experiencing the pain and believe that it is not possible for a person to feel pain of this intensity and constancy, the family and social network tend to minimize it.

There is still a great deal of misunderstanding and lack of solidarity regarding the impacts and limitations that FM generates in people with the condition[22]. To better understand it, it is necessary to support the individual and give voice to their pain, which is often misunderstood due to diagnostic difficulties[29]. The results revealed a lack of support, which could greatly help in the treatment of these patients, and this is an important aspect to consider when assisting people with FM, as a different factor in the care provided to them. In the meantime, it is observed that multi and interdisciplinary approach, with health education activities focused on pharmacological and non-pharmacological measures, is applicable to this context[24], and here is an important field of action for nursing.

Considering symptoms as "merely psychological" promotes the idea of the fragmentation of the human being into body and mind, with the supremacy of the body. The Cartesian vision that permeates biomedical discourse and materializes in the processes of diagnosis, treatment, and cure contributes to discrediting and stigmatizing the patient. This ideology is identified in circulating representations about the body, placing emotions and sensations in opposition to it[30]. Discriminatory discourses still reverberate in the lives of these people, who suffer from society's discredit[31]. Moreover, the negative perception of the disease and the lack of social support worsen their symptoms and functioning [7].

A review study on the psychological aspects related to FM highlights the difficulties patients have in adapting to this disease, causing them social isolation, reduced physical activities, fatigue, interference in their sexual life and sleep, and stress – which aggravates the symptoms[22]. A systematic review study on the psychological consequences of the Covid-19 pandemic in patients with FM concluded that they presented problems with mental health, quality of life, sleep and social relationships, which led to recurrence of the disease and increased anxiety and depression. This result corroborates the idea that this group is very vulnerable and needs to be understood, attended to and cared for in its specificities[32].

The feelings generated by the lack of understanding of the disease are reaffirmed, and, due to this suffering, the results of this research indicated that people with FM seek strength and strategies to avoid worrying or caring too much about the interpretations and opinions of others as a form of self-preservation. One of these strategies is the decision not to talk about this subject with people who do not have this diagnosis.

People with FM prefer to share experiences, talk and discuss the disease with others who suffer from the same condition. One strategy to foster and expand opportunities for conversation is online groups, which favor the sharing of ideas and serve as an important source of information to expand knowledge, strengthen relationships and create an environment of mutual support[31].

Discussion groups for sharing experiences help in the practice of self-knowledge, being one of the strategies adopted to minimize the impacts of FM. Furthermore, the recognition of limitations and the search for overcoming, reducing self-demand and adopting alternative practices as a measure to enhance pharmacological treatment are also important aspects to be shared.

Studies indicate that physical exercises help in pain management and that regular practice of physical activity, aerobics, in and out of water, and muscle strengthening exercises do not increase the symptoms of the disease and have beneficial effects on physical and mental health[33], as well as a study of strength training in women with FM reduced pain and significantly reduced daytime sleep disorders, making it a viable treatment for patients with FM[34]. Regarding Pilates, present in the results of this research, a systematic review study indicates that evidence suggests its influence in pain control, being more effective than no intervention or minimal intervention in the treatment of FM[35].

A study conducted with 68 people with FM, 84% of whom were female, on associations between complementary therapies, quality of life and self-reported pain levels, showed that 66% used complementary medicine, such as vitamins, massage therapy and meditation, and had a better quality of life and lower pain levels compared to individuals who did not use it[36]. The mindfulness technique also showed good results in regulating emotional intensity with positive consequences for the clinical treatment of pain and emotion[37].

Generally, people with FM are more demanding and perfectionist, which further increases the overload and demands on themselves and others. Empowerment for self-care, through the development of self-knowledge and self-control, is an important strategy for these people to know how to identify pain triggers and their own body's signals as a means of self-protection[38], in line with the recommendations of the World Health Organization[8].

The particularities of the experience of pain by different people lead to individualities in the expression of feelings, sensations and reactions. Likewise, coping is also unique and singular. However, what is not understood should be minimally respected[29].

Only those who feel the pain can explain it, so one should not judge or discredit the painful complaints of others. In the meantime, support groups, formed by people living with the disease, are important spaces for talking, socializing, sharing of experiences and knowledge that strengthen their coping strategies and, above all, are an important setting for finding the desired understanding.

Finding other people with similar cases and symptoms, even in groups, online or in person, is an excellent strategy to encourage discussion about the management of chronic health conditions such as FM. These scenarios offer the opportunity to improve individuals' health through the exchange of experiences and knowledge, promoting more information about the disease, interaction, autonomy, improvement in social interaction and clinical results, reduction of hopelessness and the adoption of negative behaviors[9]. In these groups, people with FM feel more encouraged to express their pain, anguish, worries, fears, as well as share their coping strategies and routines, making the group a place of knowledge and solidarity collaboration through dialogue.

For this reason, there has been progress in creating online Facebook groups as a support strategy, with the proposal of offering support in the health/disease process and promoting the sharing of ideas. Among the advantages of these groups, the vast diversity of participants, the multiplicity of life stories and, consequently, the agility in the exchange of information and knowledge, the flexibility in terms of availability for interaction and participation, the geographic proximity, among others, stand out. Regarding the disadvantages, they involve the fluidity of social ties, the quality of the content and the reliability of information, discrimination and misunderstandings in the virtual environment, among others[39].

A study conducted in an interdisciplinary group with women with FM concluded that the support group is an excellent care strategy, which facilitates the sharing of experiences. In these spaces, people feel comfortable to vent, expose their problems and conflicts; they also receive support, attention and understanding, which is generally not achieved in their social and family environments[38].

The results showed that people with FM value the exchange of experiences with other people who have the same health condition/disease. Therefore, implementing

initiatives aimed at expanding this interaction and strengthen the relationships between these peers is an important care measure. When it comes to health promotion, especially in chronic conditions, encouraging interaction, intimacy and strengthening interpersonal relationships are effective strategies[31].

A study conducted with medical residents in the area of rheumatology concluded that these professionals feel frustrated in patient care, with a feeling of helplessness, and need greater psychological preparation in medical training and a more integrated approach involving medicine, psychology and physical therapy[40]. In order to minimize the damage caused by misinformation, the topic needs to be widely addressed, both in professional health training and in continuing education in the workplace, so that the multidisciplinary team is well prepared to provide adequate care and management for people with FM.

It is necessary to expand guidance and discussions on this topic with the family network, employers and society in general, as a proposal for social intervention in view of the magnitude of the impacts of misinformation for those living with the disease and those who live with people with FM. Thus, social media and other communication means are seen as effective tools available to society, and the importance of disseminating information about FM through them is emphasized. Furthermore, healthcare professionals working in an interdisciplinary team in the field of public health play an essential role in supporting and disseminating information that can minimize the suffering of patients and expand everyone's knowledge so that society can better understand the daily lives of those who suffer from this disease.

The limitations of this study are related to the predominantly female sample, and it was not possible to conduct an analysis by gender. Studies with qualitative samples of men diagnosed with fibromyalgia should be conducted to expand the potential for debate on the topic, concerning the care of this population group.

CONCLUSION

According to this research, participants were unaware of the name of the disease and its causes, but they mentioned its symptoms, primarily pain, which is a subjective phenomenon. Therefore, the objectification of fibromyalgia occurs in painful symptoms, while the lack of signs in the body leads to misunderstanding among individuals with whom these individuals live.

Given that the primary symptom characteristic of FM is a subjective phenomenon, there is a lack of understanding and distrust regarding the legitimacy of this disease, increasing the suffering of those affected by it.

The delay in diagnosis, in turn, delays treatment, and the lack of accurate and quality information increases the possibility of judgment and creates stereotypes about the behavior of patients, leading to prejudice and rejection, which impact on the way they cope with the disease. To mitigate this issue, discussion groups that disseminate accurate information, whether in person or virtually, are powerful strategies for caring for and minimizing the suffering of those with FM, contributing to their self-care.

Regarding the field of nursing and health, this study contributes to showing that knowledge, especially self-knowledge, is a valuable care strategy for people with FM. It is the starting point for achieving better results in the process of pain reduction, from proper and early diagnosis to the selection and implementation of effective therapeutic practices to provide well-being and quality of life to those individuals.

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