

SELF-PERCEPTION OF PATIENTS WITH FIBROMYALGIA ON THE PHYSIOTHERAPY TREATMENT

Autopercepção dos pacientes fibromiálgicos sobre o tratamento fisioterápico

Autopercepción de los pacientes con fibromialgia sobre El tratamiento fisioterápico

Original Article

ABSTRACT

Objective: To understand the self-perception of the patient with fibromyalgia regarding the pathology and physiotherapy and show it as an instrument for improving the practice of health professionals. **Methods:** A qualitative, exploratory and descriptive research conducted at a physiotherapy center in the municipality of Fortaleza, Ceará, in 2013. The study comprised 10 people with a clinical diagnosis of fibromyalgia undergoing physiotherapy treatment. Data were collected through semi-structured interview and underwent content analysis. The text could be grouped into the following themes: Relationship between pain and fatigue; Fibromyalgia defined as a personal, physical and mental pain; Physiotherapy, the functional workshop of the body; The idea of being healthy and uncertainty; and the humanized physiotherapist. **Results:** Pain was reported as the most disabling factor and, because of that, they feel tired and stressed. They understand the importance of physiotherapy in the process of adaptation to physical limits and coping with pain, and recognize the physiotherapist as a humanized professional. **Conclusion:** The reports show that patients undergoing physiotherapy recognize they are sick and know the importance of physiotherapy for their functional condition. The speeches give a feedback to the professional who identifies the objectives and factors that interfere with treatment, and may also suggest the need for interventions by other professionals.

Descriptors: Narration; Fibromyalgia; Physical Therapy Specialty.

RESUMO

Objetivo: Compreender a autopercepção do paciente com fibromialgia em relação à sua patologia e à fisioterapia e mostrá-la como um instrumento de aperfeiçoamento na prática dos profissionais de saúde. **Métodos:** Pesquisa com abordagem qualitativa, com características descritivas e exploratórias, realizada em um centro de tratamento fisioterápico do município de Fortaleza-Ceará, em 2013. Fizeram parte do estudo 10 pessoas com diagnóstico clínico de fibromialgia em tratamento fisioterapêutico. Os dados foram coletados através de entrevista semiestruturada e analisados à luz da análise de conteúdo. Pôde-se agrupar o texto com os seguintes temas: Relação entre dor e cansaço; A fibromialgia resumida como uma dor; pessoal, física e mental; Fisioterapia, a oficina funcional do corpo; A perspectiva do sadio e a incerteza; e O fisioterapeuta humanizado. **Resultados:** A dor foi relatada como o maior fator incapacitante e por isso se dizem cansados e estressados. Compreendem a importância da Fisioterapia no seu processo de adaptação de limites físicos e na convivência com a dor, e conhecem o fisioterapeuta como um profissional humanizado. **Conclusão:** Os relatos mostram que os pacientes, em atendimento fisioterapêutico, têm a percepção de sua condição como enfermo, sabendo da importância da fisioterapia na sua condição funcional. As falas dão um feedback, ao profissional, que identifica os objetivos e os fatores que interferem no tratamento, podendo sugerir também a necessidade de intervenções de outras especialidades.

Descritores: Narração; Fibromialgia; Fisioterapia.

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RESUMEN

Objetivo: Comprender la autopercepción del paciente con fibromialgia respecto su patología y la fisioterapia y presentarla como instrumento de perfeccionamiento en la práctica de los profesionales de la salud. **Métodos:** Investigación de abordaje cualitativo con características descriptivas y exploratorias realizada en un centro de tratamiento fisioterápico del municipio de Fortaleza-Ceará, en 2013. Participaron del estudio 10 personas con diagnóstico clínico de fibromialgia y en tratamiento de fisioterapia. Los datos fueron recogidos a través de entrevista semi-estructurada y analizados a la luz del análisis de contenido. Se agrupó el texto en los siguientes temas: Relación de dolor y cansancio; La fibromialgia resumida como un dolor personal, físico y mental; Fisioterapia, el taller funcional del cuerpo; La perspectiva del sano y la incertidumbre; y El fisioterapeuta humanizado. **Resultados:** El dolor fue relatado como el mayor factor incapacitante y por ello se dicen cansados y estresados. Los pacientes comprenden la importancia de la Fisioterapia en su proceso de adaptación de límites físicos y vivencia con el dolor y reconocen el fisioterapeuta como un profesional humanizado. **Conclusión:** Los relatos muestran que los pacientes asistidos por la fisioterapia tienen la percepción de su condición de enfermo consciente de la importancia de la Fisioterapia en su condición funcional. Las hablas ofrecen un feedback al profesional que identifica los objetivos y los factores que interfieren en el tratamiento lo que también sugiere la necesidad de intervenciones de otras especialidades

Descriptor: Narración; Fibromialgia; Fisioterapia.

INTRODUCTION

Fibromyalgia is classified as a musculoskeletal disorder associated with somatoform mental disorders. In France, it is known as “diffuse idiopathic multifocal pain syndrome”⁽¹⁾.

It is a chronic disorder. The first consultation with a doctor occurs months or years after the onset of symptoms, which remain stable for years. Diffuse muscle pain is its main symptom, and it affects mostly women aged 30-50 years. Anxiety and depressive symptoms – often observed in patients with fibromyalgia – are believed to be the basal causes of the syndrome; they are often seen as symptoms of the disease. Associations with neurotic hypochondriasis and hysteria have also been reported⁽²⁾.

The treatment of patients with this pathology requires a multidisciplinary approach that should consider patient's opinion. Pharmacological and non-pharmacological treatments can be combined to improve the quality of life through psychological, medical, social and occupational support⁽²⁾.

Thus, the physiotherapy treatment should aim at the recovery of functions and lifestyles, promoting health, well-being, and quality of life. Additionally, it should be part of the educative and multidisciplinary work of healthcare professionals, who must educate and inform about the need for other interventions. Thus, the physiotherapist must know when and how to refer patients to other services, like the psychological care. One of the ways is drawing attention to the history of patients since it works as a general model for understanding psychosocial phenomena⁽³⁾. To do so, the healthcare professional should listen to patients carefully in order to reconstruct the identity so that the therapy can have a successful effect, making patients feel themselves as subjects of the processes and autonomously accept the changes needed in their lives⁽⁴⁾.

Patients with fibromyalgia are commonly found in physiotherapy outpatient clinics; however, they face obstacles during the treatment due to its complexity and difficult diagnosis, the chronicity of multiple symptoms and the prognosis without a cure. The needs experienced by the authors of the present study arose the interest in observing what these patients had to say about the treatment.

Thus, this study aimed to understand the self-perception of fibromyalgia patients regarding their pathology and physiotherapy and present it as an instrument for improving the practice of healthcare professionals.

METHODS

This is a qualitative, descriptive and exploratory research conducted in a center for physiotherapy treatment of a *Unidade Básica de Saúde – UBS* (Basic Health Unit) belonging to the VI Regional Executive Secretariat of the city of Fortaleza, Ceará, in the period from August to September 2013.

The aforementioned institution has a multidisciplinary program composed of physiotherapists, rheumatologist, pharmacists, occupational therapists and psychologists assisting a group of 30 patients with fibromyalgia since 2009. In addition to information, drug prescriptions, and psychological follow-up, the patient with fibromyalgia receives the following types of physiotherapy treatments: self-stretching, hydrotherapy, pilates and normal outpatient care.

The research included people over 18 years old with the clinical diagnosis of fibromyalgia undergoing physiotherapy treatment for more than six months. Patients with any types of cognitive or speech disorders that could hamper the interview were not included. The sample comprised 10 patients out of 30 individuals in the institution who were indicated by the professionals and presented good speech,

discernment, and capacity to develop logical reasoning skills to answer the questions.

Data were collected using a semi-structured interview containing two sections. The first section collected data on the identification of the interviewees according to the following variables: sex, age, education, occupation; the second part contained the following questions, which were specially developed for this research: a) How do you define yourself as a person with fibromyalgia today? b) Describe how you understand fibromyalgia c) What do you think about the physiotherapy treatment? d) What are your expectations regarding your disease, what do you expect from the future? e) How do you see the attitude and knowledge of the physiotherapy professionals regarding your disease?

The interview was conducted by one trained researcher only in a private, comfortable room of the institution where the patients are treated. They took place on Friday afternoons, when the patient stayed alone with the researcher who read the questions and recorded the answers using a Philips DVT 4000 voice recorder following previous authorization by the interviewee. There was no time limit.

The data underwent content analysis⁽⁵⁾ and were then re-grouped into classes or categories. Thus, the following steps were taken for the categorization of data: pre-analysis; skimming of interviewees; establishment of the corpus; selection of units of context and registration; clipping; coding and classification; categorization and definition of symbolic categories⁽⁵⁾.

After that, five thematic categories emerged: relationship between pain and fatigue; fibromyalgia defined as a personal, physical and mental pain; physiotherapy, the functional workshop of the body; the idea of being healthy and uncertainty; and the humanized physiotherapist.

This research was approved by the *Comitê de Ética em Pesquisa com Seres Humanos da Universidade de Fortaleza - COETICA – UNIFOR* (Research Ethics Committee of the University of Fortaleza) under No. 191/11 in agreement with all the ethical aspects of Resolution 196/96⁽⁶⁾. All the participants signed a free informed consent form. In order to ensure anonymity, interviewees are identified as (P). P1, P2, P3...

RESULTS AND DISCUSSION

The data on the identification of the research subjects are presented below followed by the thematic categories that emerged in the study.

Data on the identification of the subjects

A total of 10 interviews were carried out with fibromyalgia patients: nine women and one man whose age

ranged from 40 to 60 years (mean age of 56 years). Only one patient worked as a street vendor; the others took care of the household. Regarding education, one patient was illiterate, eight had complete primary education, and one had a complete higher education.

An epidemiological study conducted with 500 women with a mean age of 50.16 years revealed that, in Brazil, many patients with fibromyalgia have low education levels and 1/3 of the patients have not concluded primary education. Additionally, with regard to occupation, 31% of the women were employed, 21 were housewives, and 34% were unemployed or retired⁽⁷⁾. These findings are corroborated by the data of the present research regarding the median of ages and the prevalence of unemployed patients.

The main complaint presented by the participants of the present study was the presence of constant pain, which will be described in the following lines regarding its definition, physical and emotional repercussions, and its implications for the treatment.

Relationship between pain and fatigue

In the category “relationship between pain and fatigue”, patients defined themselves as people who feel tired and fatigued due to constant pain. However, they learned to overcome pain and carry on with their lives in the functional activities, as they reported:

“Today I see myself in an advanced stage of the disease, tired and irritated because of pain. When the pain starts, it gets me angry, bored, stressed, tired. I try hard not to be like this, but the pain makes me feel like that” (P1)

In 1979, the International Association for the Study of Pain (IASP) coined an important definition for pain: “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. However, it is a known fact that there is a difference between the objective reality of a painful stimulus and the subjective response to it. When it comes to chronic pain, there is a reduced social contact, which leads the patient to focus on the pain most of the time. This tendency leads to a vicious cycle of pain, lack of exercise, fear, depression and more pain⁽⁸⁾.

“With the problem I have, I do what I can do, even if I can’t I will try. I know it’s aching a lot, but I do it, even if I have to spend the rest of the day lying, because there are many people who are worse than me. We have to learn how to live and deal with the disease.” (P7)

The decreased functional capacity that reported in the present research has also been evidenced in another study showing that the pain compromises the strength and the

performance of activities of patients with fibromyalgia, directly affecting their quality of life. Additionally, individuals who have more difficulties to perform activities of daily living walk shorter distances when assessing functional capacity⁽⁹⁾.

The fibromyalgia pain is different from any other sensory impressions. Its manifestations depend on social, psychological, cultural and other aspects, making its clinical expression highly variable and, consequently, requiring different therapeutic approaches⁽⁷⁾.

"I think that it keeps you from doing many things you would like to do but you can't, but if that is the choice [...] every day I feel better, but I don't know if it's because I really got better or because I got used to pain." (P4)

Research could not verify a direct relationship between pain and stress. However, the compromised functionality of patients with fibromyalgia was related to a greater perception of stress⁽¹⁰⁾.

The subjects assessed by the present research report that the pain transcends the physical aspect. Furthermore, they do not have many prospects for improvement because it is a complex pathology with a difficult social understanding; however, they seek help to overcome the difficulties.

Fibromyalgia defined as a personal, physical and mental pain

The category "fibromyalgia defined as a personal, physical and mental pain" refers to the concept that the fibromyalgia syndrome has a remarkably clinical diagnosis characterized by chronic musculoskeletal pain associated with several symptoms. It can be confused with many other rheumatic and non-rheumatic diseases. It requires an individualized and multidisciplinary approach with combined drug and non-drug treatment⁽¹¹⁾.

The patients of the present study defined fibromyalgia as a chronic pain that has no cure and affects both physical and mental health. A disease that is difficult to diagnose and confirm because it is not identified by exams. Each patient presented an individual perception of pain. According to the reports:

"What I understand is that it is an intense pain. It's a pain that gets me upset sometimes because I have already tried to take this away from me. Sometimes I felt sad, anguished, but I don't want to feel like this because I don't want to have depression, and, to avoid this, we need to learn how to live, how to deal with it! The pain is intense, only the person who feels it can understand!" (P7)

The diagnosis of fibromyalgia is essentially clinical, and there are no markers or specific tests for its diagnosis.

The auxiliary diagnostic tests are performed to exclude other similar diseases⁽¹²⁾.

"It's a pain you can feel on the finger, on the back, and it's not shown in an x-ray, the leg aches but the tomography does not show anything, the pain on the back doesn't appear in the MRI because it is a disturbing pain and sometimes it feels like a pain in the bone." (P10)

Between 2010 and 2011 the American College of Rheumatology (ACR) published the diagnostic criteria for fibromyalgia, taking into account other symptoms, besides diffuse pain, at the expense of the palpation of tender points. The patient is fully diagnosed with fibromyalgia if he/she presents a widespread pain index $\geq 7/19$ and a symptom severity score ≥ 5 , or widespread pain index between 3–6 and a symptom severity score ≥ 9 . The symptoms must have been present at a similar level for at least three months, and there should be no other clinical conditions that would explain this pain.

Physiotherapy, the functional workshop of the body

The category "physiotherapy, the functional workshop of the body" reveals that although patients know fibromyalgia has no cure, they report the good results obtained from the exercises and stretches proposed by the physiotherapist, especially the self-perception of functional aspects as walking, sleeping, and others.

"When I forget everything and start stretching I feel better, even to sleep; I don't lack sleep anymore, I sleep well, but I still wake up tired as if I didn't rest. To me, physiotherapy is the best solution." (P2)

Stretching is a term used to describe physical exercises that lengthen soft tissues structures and hence improve flexibility. The effects of stretching can be divided into acute and chronic. The acute and immediate effects result from the flexibility of the elastic components of the muscle-tendon unit. The chronic effects result in an adaptive remodeling of muscle structure, which increases muscle length helping it tolerate stress better⁽¹⁴⁾.

A study conducted in experimental conditions using stretches and physical exercises suggests that the physiotherapy treatment, especially muscle stretching, has a positive impact on fibromyalgia, improving sleep and stiffness of patients⁽¹⁵⁾.

"The physiotherapy was essential for me; if it did not exist I'd be a lot worse. I think I would not be walking properly because my knee aches a lot, and so does the sole of my foot; I couldn't even walk properly. After I came to the physiotherapy sessions and the treatments offered by the

people here, like pilates, stretching exercises, I saw there are many different things, and this helps a lot.” (P3)

Physiotherapy aims to reduce symptoms, improving the control of pain and the maintenance or improvement of patients' functional abilities. Additionally, physiotherapy should also play an educative role to keep the benefits of the interventions for longer and make patients less dependent on health care services. The adoption of more participative and functional lifestyles is suggested to help in the physical and emotional recovery of the patient⁽¹⁶⁾. This is corroborated by the following speech:

“Considering the time I’ve been here, I see that we shouldn’t quit physiotherapy, because if we stop, it’s like an old rusted car: you take it and drive away and away; then, it starts sputtering; after that, it stalls and then continues, you speed up and it’s alright... physiotherapy is very good, including pilates, because it moves this muscle here, and this, and that (patient touches and points to many parts of the body). So, moving the muscle improves something.” (P10)

Regular physical activity does not only contribute to physical improvement. It also has psychological benefits, improves and causes well-being and eliminates the fear of exercises. Active exercises induce the participation in the fight against chronic pain. Group exercises also reduce physical stress and encourage socialization⁽¹⁶⁾.

The idea of being healthy and uncertainty

The category “the idea of being healthy and uncertainty” shows that patients with fibromyalgia report expectations to be cured and live a normal and healthy life with the advance of medicine and religious perspectives. However, there were some comments about the uncertainty or lack of precision about their future.

“I wanna leave here cured, wanna go out running, start running again, jogging, I wanna lose weight! Go home on foot, exercise, get really good! That’s what I expect, I want to get really, really good with physiotherapy. I wanna leave here feeling great and wonderful, I wanna find a boyfriend.” (P3)

“I’m not sure about the next days. I had some improvements, and they made me feel very good, but then I felt it again and now I am in the moderate stage. I have already been in the mild stage, severe... So, I have been through the three stages. Today I am in the moderate-severe stage, so I can’t tell how I’m gonna feel tomorrow.” (P1)

The strategy for the real treatment of fibromyalgia requires a multidisciplinary approach with combined drug and non-drug treatments. The treatment must be planned

along with the patient and according to his pain intensity, functionality and characteristics; it should also consider biopsychosocial and cultural aspects. Chronic pain is a persistent health condition that changes life. Its treatment aims at its control and not at its elimination⁽¹⁷⁾.

“Life and behavior changes are always welcome. Family bonds are of great importance; I wonder about my family in the generations, the ones who might come, the children of my children. I wonder if I’ll be able to follow their growth and enjoy their childhood.” (P5)

A study shows that childhood traumas, mainly stressing factors, anxieties and neglect regarding patients with fibromyalgia are directly related to the muscular system status⁽¹⁸⁾.

“Well, as we get old our muscles and joints start getting stiff, but as we continue the exercises of physiotherapy we get better and better.” (P10)

The physical interventions associated with cognitive behavioral therapy, both the touch and the exercise, produce body perception responses in addition to motor, autonomic, neuroendocrine, emotional and behavioral responses regulated by the limbic system, which organizes the somatic expressions of emotional states and experiences of patients with pain. Therefore, the physiotherapist needs to be a therapist and educator for the patient, regardless of the choice for passive or active techniques. Education strategies for dealing with dysfunctional beliefs, abnormal behaviors, negative thoughts and attitudes can modulate pain and increase functional capacity of patients⁽¹⁹⁾.

The humanized physiotherapist

The category “the humanized physiotherapist” presents patients' reports about their experience with the physiotherapist, revealing a relationship based on affinity and trust. Professionals' concerns for the improvement of patient's condition and their professional attitude are the key to perform a successful treatment.

“The best healing comes from the way they treat us, we feel loved. I really think they have expertise; they are very good. [...] Every physiotherapist here develops a different treatment for every single patient, they have a different way for each patient and they do it in a very special way.” (P2)

Physiotherapy has been following the trend of specialization and, consequently, has been faced with conflicting issues. The construction of an ethical subject must be prioritized where professionals deal with human beings who experience moments of anguish and pain. The

physiotherapist uses the touch as a therapeutic resource, and it is impossible to touch someone without developing a bond. The physiotherapist's practice requires a great involvement with the human being in addition to technical and scientific knowledge. Efforts should be made to conciliate ethics and science, for there are no societies capable of thinking wisely without the communication between them⁽²⁰⁾.

"The worst thing in the world is to get stuck in time, but this does not happen here. You are always updated; you look like butterflies coming out of the cocoon searching for fresh air. You are ethical, have an ethical attitude, treat us nicely, your ethics here is excellent, you treat everybody in the same way, be it a man or a woman, black or white, it's the same for everybody." (P3)

The patient care requires an attitude of sensitivity. The patient has the right to decide about his well-being, and the physiotherapist needs to understand patient's feelings and respect them without imposing his will or being paternalist. The physiotherapist needs to be open-minded regarding what patients desire in terms of rehabilitation. Thus, the patients become the subject of the process rather than the object⁽²¹⁾.

"We receive much love and care and a lot of information on how to cope with the disease, we have to learn how to live and cope with it. When we get here, we already feel like we're a different person. Being home bored, and feeling pain won't solve the problem. [...]The physiotherapists are great, we are not afraid because I find myself in the arms of reliable people, I feel safe." (P7)

The aspects involved in the relationship between the person who treats and the person being treated show that the quality of the relationship between them is the key to the process of adherence to physiotherapy treatment. This process should not only be based on the number of sessions, but on the quality of each one of them⁽²²⁾.

The main tools of a physiotherapist are the hands, whose touch can care, rehabilitate, ease and cure. The hands of physiotherapists who operate modern equipment are also those that touch and massage users. Rescuing the use of the hands in the direct contact between the professional and the patient is contributing to the humanization of care and the valuation of the touch, which is contrary to the overvaluation of machines at the expense of a humanized care⁽²³⁾.

FINAL CONSIDERATIONS

Most of the patients assessed defined themselves as tired and stressed because of constant pain, which is their main complaint and the main factor causing decreased functional and working activities. Since the pain is directly

related to their emotional state, they recognize they must be mentally healthy in order to improve physical conditions.

Although patients know that fibromyalgia is a chronic disease that has no cure, they have good expectations regarding the improvement of their physical condition; however, they are uncertain of the maintenance of this improvement. They also understand the importance and the role of the physical therapies proposed by the physiotherapist in the process of adapting their physical limitations and living with pain.

Patients see the physiotherapist as a permanent ally in this process, and their relationship makes affectional bonds – ruled by ethical principles – that make treatment welcoming, individualized, reliable and satisfactory.

The reports show that patients undergoing physiotherapy treatment assume they are sick and know the importance of the physiotherapist for their functional condition. The present narrative provides a feedback to the professional, identifying the objectives and factors interfering with the treatment and maybe suggesting the need for interventions by professionals from different areas.

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