Interdisciplinary care praxis in groups of people living with fibromyalgia

Práxis interdisciplinar de cuidado em grupo de pessoas que vivem com fibromialgia

Praxis interdisciplinaria del cuidado en grupo de personas que viven con fibromialgia


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ABSTRACT

Objectives: to analyze the integrated community therapy model for the empowerment of people living with fibromyalgia and discuss the impact of this interdisciplinary intervention in the health-disease process and self-care. Method: a participatory-approach qualitative study, developed in 2015 with 11 participants at the Laboratory of Physiology Applied to Physical Education of the Rio de Janeiro State University, RJ. Data production comprised World Café, participant observation and semi-structured interview. The analysis was performed according to Bardin, through data triangulation in dialogue with the relevant literature. Results: the integrated community therapy group is a driving force in building and expanding knowledge about fibromyalgia and in self-care empowerment. Conclusion: this group strategy proved to be an interdisciplinary praxis tool that enables the development of solidary care networks. Thus, shared knowledge was generated, transformed into a listening and reflection environment to manage personal and family obstacles.

Descriptors: Nursing; Chronic Diseases; Group Therapy; Fibromyalgia; Qualitative Analysis.
aplicada a la Educación Física de la Universidad do Estado do Rio de Janeiro, RJ. La producción de datos incluyó el World Café, la observación participante y la entrevista semi-estructurada. El análisis se realizó de acuerdo con Bardin por la triangulación de los datos en diálogo con la literatura relevante. **Resultados:** el grupo de terapia comunitaria integradora es una fuerza impulsora en la construcción y ampliación de conocimientos sobre la fibromialgia y el empoderamiento para el autocuidado. **Conclusión:** esta estrategia de grupo ha demostrado ser una herramienta de praxis interdisciplinaria que permite la construcción de redes de solidaridad de la atención. Así, se ha generado conocimiento compartido, transformado en un ambiente de escucha y reflexión para manejar los obstáculos personales y familiares. **Descriptores:** Enfermería; Enfermedades Crónicas; Terapia de Grupo; Fibromialgia; Análisis Cualitativo.

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**INTRODUCTION**

The characteristic of Noncommunicable Diseases (NCDs) has required changes in care practice in order to surpass the Cartesian model and develop an interdisciplinary care praxis that addresses the physical body in its somatic, psychic and spiritual dimensions, involving different views, interdisciplinary knowledge, and liberating teaching practices for life. The context of NCDs has drawn attention, especially those that cause chronic pain and subject people to different degrees of disability, as is the case of people experiencing fibromyalgia syndrome (FMS). Such patients have arrived at health care centers complaining of aches, discouraged, sad, suffering, with persistent chronic pain and no diagnosis to begin treatment. Clinical observation associated with reports has expanded to physical limitations, different levels of anxiety disorders, and insomnia, which end up affecting their daily routine and quality of life. Fibromyalgia syndrome (FMS) is a rheumatic condition characterized by musculoskeletal complaints of diffuse pain and the presence of tender points in anatomically well-defined regions. Added to these symptoms are fatigue, sleeping disorders, morning stiffness, limb paresthesia, subjective feelings of swelling and cognitive disorders. Studies have pointed to depression, anxiety, chronic fatigue syndrome, myofascial pain syndrome, irritable bowel syndrome, and nonspecific urethral syndrome as the most frequent symptoms.

The literature reveals that international epidemiological indicators on the prevalence of FMS are variable depending on the type of study, method, and tested population, ranging from 0.7% to 5% in the population at large. According to a Brazilian study, the prevalence of FMS is 2.5% of the population, mostly female, in a ratio of 8:1, with 40.8% in the age group of 35-44 years; however, it can affect children, adolescents and the elderly. In some European countries, FMS rates reach 10.5% of the adult population. This condition is commonly seen in daily clinical practice and is one of the leading causes of visits related to the musculoskeletal system.

In this perspective, the nurse, as a point of reference and a professional who is in closest and most constant contact with patients, is able to identify health needs and intervene effectively to improve the quality of life of these people. In this sense, he or she should be alert to changes in care paradigms, interventions of the Health Promotion Model, strategies of participatory and educational action required in care services, in which all participants are called on to become involved, and the needs of population groups as the starting point for the establishment of common goals and interests.

In this sense, care focused on discussion groups favors the creation of an interactive space that enables professionals to reflect and debate with people their health problems, and identify deficits and failures in self-care in order to guide their correction. Nurses can add other professionals to the group, or take part in groups that develop care praxis from the perspective of interdisciplinary, gathering people with different views and knowledge.

Prominent in this approach is the use of Integrated Community Therapy (ICT) as a guideline for health practices. ICT is a therapeutic model that emerged after World War II, when an American social psychologist, Kurt Lewin, worked with a group of people for therapeutic purposes. He affirms that individuals feel therapeutic action when listening to people contextualize their problems and discuss how they can be solved.

In Brazil, ICT was developed with the intention of building solidary social networks to promote life and mobilize resources and skills of individuals, families and communities, promoting empowerment. This practice is beneficial for promoting welfare, health and social rights, seeking to arouse the therapeutic dimension of the actual group and enhance the cultural heritage and knowledge produced by the life experience of each person.

The state of the art on the subject, expressed in the national and international literature following the online search criteria of the last 10 years, showed that studies based on the concept of empowerment, associated with NCDs, despite being developed with different objectives and methodologies, reveal the need for interdisciplinary teams to devote quality time to monitoring, encouraging and supporting self-care. Next, other results show that the empowerment process can break down barriers that hinder the teaching-learning process and create opportunities to expand self-care, skills and knowledge. Two subsequent studies, for example, pointed out that the empowerment process helped to improve the quality of life of families of children with kidney disease and of elderly patients with chronic diseases.

The search revealed that there is scant research in the nursing literature related to NCDs and empowerment at national and international levels. It was also noticed that the most...
studied age group was the elderly, followed by studies with families of children with NCDs. However, it was observed that no paper emphatically addressed fibromyalgia, and only two articles used the group technique for empowerment.

Therefore, this study raises two questions: Can ICT aid the self-care process of its participants? Is it possible to affirm that the participants, after experiencing the stages of the health education process through ICT, have been empowered?

This study aimed to analyze the integrated community therapy model for the empowerment of people living with fibromyalgia and discuss the impact of this interdisciplinary intervention in the health-disease process and self-care.

THEORETICAL FRAMEWORK

As a care strategy, the ICT model is based on five basic schools of thought. Paulo Freire’s educational theory states that all people have content and experiences to exchange, learning and teaching in constant synergy. This idea is based on the perspective that education acts as a liberating practice and also that it starts out from the life experience of each individual, and not from content determined by an institution. In this regard, education must be a continuous process of awareness raising and transformation of the individual and the world.

Systems Thinking, described as a new way of viewing reality, abandons the linear model of cause and effect of scientific thought and aims to perceive the world through the circular model, from a relationship-integration perspective that seeks the perception of the whole and of the parts that compose it. This line tries to understand how the parts and the whole are interrelated, i.e., it favors the understanding of the individual in his relationship with the family, society, his values and beliefs, contributing to his understanding and transformation. In other words, the problems and crises can only really be solved when viewed as a complex network full of ramifications that compose the individual as a whole with the biological (body), the psychological (mind and emotions) and society.

Communication Theory is emphasized as a linking element between individuals, where all behavior is determined by communication, which can be verbal or nonverbal. The communication process is a means of transmitting ideas, emotions and values via a system of produced symbols, and functions as a vehicle to transmit culture or a cultural motivator of each individual, because without it human culture would be absolutely impossible. It can be established through verbal and non-verbal language, which includes body language and images.

In Anthropology, cultural values are estimated as important factors in forming individual and group identity, an area that supports the building of social networks, which include intersectoral and interinstitutional action, appreciation of local resources, strengthening of ties, and support to family dynamics. Thus, Community Therapy seeks to understand the meanings that individuals themselves attach to their behavior, being of great interest to everyday life, its challenges, joys and habits, being a science that investigates the origins, culture, development and similarities of human societies, as well as the differences between them.

Finally, Resilience, as the ability of individuals, families and communities to overcome difficulties, produces knowledge with the possibility of change. The primary purpose of ICT is to strengthen the internal dynamics of each individual. Thus, each one discovers their own values and potential and becomes more secure, which increases individual self-esteem, enhances the family and its role, and encourages community development and the formation of bonds of trust within the community. Strengthening such dynamics also creates safety nets, enhances cultural practices, promotes dialogue between popular and scientific knowledge, and encourages participation, dialogue and reflection for participants to take initiatives to be the agents of their transformation.

This study is justified for having a proposal aligned with the guidelines of the Ministry of Health and the Unified Health System (SUS) Policies, the World Health Organization and the Guidelines for monitoring and care of people with chronic health problems.

Its scientific relevance derives from the inadequate nursing literature and reduced number of papers on the subject. From the social point of view, it is important since, if the intervention is effective, it will enhance the quality of life of a population group, potentially extending to other groups. Also relevant is the study’s contribution to the production of nursing knowledge related to the interdisciplinary care of people who experience FMS, to nursing education, and to the improvement of nursing practice.

METHOD

Ethical aspects

This research was carried out in accordance with the provisions of Resolution No. 466/12 of the National Health Council/MS, which provides Guidelines and Regulatory Standards for Research in Human Beings, and was approved by the Research Ethics Committee, no. 455,395, and CAAE registration number 164 13013100052559.

Type of study

The study is a cross-section of a research paper entitled “Empowerment and Interdisciplinary Care Praxis of People with Fibromyalgia: challenges for nursing.”

The research is qualitative, with a participatory approach. This approach is characterized by a collaborative process involving community members, representatives of governmental and nongovernmental organizations and institutions, and researchers on the knowledge production process. Participants contribute unique and shared resources to understand the phenomenon of the study, its socio-cultural dynamics and the co-creation of knowledge. The aim is to give voice to and recognize the credibility of those involved, implementing interventions to improve the health and welfare conditions of groups and communities, besides allowing the expression of their needs.

Research site and participants

The survey was carried out between February and July 2015, in the Laboratory of Physiology Applied to Physical Education and Health Promotion of the Institute of Physical
Education and Sports of the Rio de Janeiro State University (LAFISAEF/IEDE/UERJ), where several projects are developed, including Health Promotion for People with Fibromyalgia.

The group consisted of 11 participants selected according to the following inclusion criteria: people with a diagnosis of fibromyalgia; participants of the interdisciplinary group of LAFISAEF/IEDE/UERJ, regardless of gender, ethnicity and religion; validated registration; confirmed diagnosis; stress test results; medical fitness certificate. Those who agreed to participate (called Participant Group – PG) in the study signed a formal Free and Informed Consent (FIC). People with severe heart disease associated with fibromyalgia were excluded.

The Interdisciplinary Group of Integrated Community Therapy (IGICT), so named to differentiate it from the PG, was composed of professionals from the fields of Physical Education, Psychology, Nutrition, Nursing, Speech Therapy and Medicine, and a student from the Master’s Degree Course in Nursing. This group was responsible for devising strategies, planning and joint decisions of all activities.

Data collection and analysis

The activities with the PG at LAFISAEF-EDFI/UERJ were carried out in 20 weekly meetings lasting 60 minutes each, from February to June 2015. The freely chosen themes of discussion were: FMS and its manifestations, healthy diets, stress, anxiety, safe use of medication, depression, somatization, violence, menstrual cycle, menopause and health changes, memory, self-awareness, self-image and family. The strategies used were group dynamics and interactive games, chosen in order to enhance the development of skills and abilities, besides the use of audiovisual materials to aid the explanation of the issues and make the discussions more enjoyable, relaxing and motivating.

Over the nine-month period, participants went through three stages: adaptation, which integrates health education activities with the interdisciplinary group, once a week; transition, which relates to group therapy with the support of psychology, once a week; and coexistence, a phase that offers group therapy every 15 days. Each phase lasted three months, all of them associated with the physical activities of weight training, stretching and relaxation, as well as nutritional counseling and nursing care. At the end, a meeting was held with the participants’ families to coordinate self-care with potential strategies of mutual aid and improve relations within the family group to achieve healthy living conditions.

Data were produced through group dynamics, World Café techniques, semi-structured interviews and participant observation. World Café is a technique whose creative process aims to generate and encourage dialogue between individuals, creating a living network of collaborative dialogue that accesses and taps the collective intelligence to respond to major concerns of organizations and communities.

The study employed a tool to assess knowledge of the health-disease process and self-care, with previously validated open and closed questions, addressing topics related to the subject, administered at two different moments: before the beginning of the adaptation group activities and at end of the 20th meeting, to compare responses. Following the intervention group activities, in addition to the assessment tool, audio recorded interviews were conducted and then transcribed. Respecting the confidentiality and anonymity of respondents, interviews excerpts were identified by the letter E, associated with the sequential number of participation, according to the example: E1, E2, E3.

Content analysis was used for data organization, identification and categorization, in the following order: pre-analysis, exploration and organization of material, treatment of results, actual inference analysis, with encoding, breakdown, enumeration and interpretation.

RESULTS

Three main categories emerged in the data analysis: the ICT group as a driving force in building knowledge for self-care; feelings and sensations of empowerment; changes in family relationships.

The ICT group as a driving force in building knowledge for self-care

This category reflects the contribution of the ICT group to building knowledge for self-care, demonstrating that learning environments contain a host of objective, subjective and intersubjective relations. Within such activity, it is important to give meaning to the relationships that are established.

All topics interested me, I think everything was just right [...]. The presentation on compassion, that we must be compassionate towards ourselves. The nurse’s lecture about sexuality. (E9)

I gained more information about the whole process of the disease, I had such great support! [...]. The part about psychology, nutrition, everything. The group gave me the support and knowledge I didn’t have before. (E10)

The meetings really helped [...]. I didn’t have much knowledge [...]. I really liked it when the rheumatologist came and addressed the issue of treatment, the medications that are used along with the others. (E3)

It brought knowledge, I learnt with the discussions on fibromyalgia and other things that this disease favors [...]. The subject of depression marked me most, memory was also very good. I didn’t know how to handle those things. It was very important to acquire such knowledge. (E4)

It is understood that in collective participation, particularly in conversation circles, the more dialogue there is, the more participants are encouraged to reflect, to have contact with themselves, with their doubts, with the others, realizing how each one reacts to daily situations regarding self-care. In this sense, the repercussions were continuous and expressed as follows:

The topics were good, relevant, everything was just right [...]. The themes on sexuality the nurse brought, her experience, the part about compassion, and what the psychologist says, we must learn to listen to ourselves, listen to the
The community therapy circles afforded an opportunity to speak, offering people a welcoming environment, of active listening and respect for each other. Thus, people felt comfortable to discuss their life situations.

[... ] In the group I certainly had room to speak and I said a lot about my life, I revealed many things I had never said in public and learned a lot about everything. (E1)

I enjoyed the group, I didn’t feel anything was missing [...]. I found it quite complete. Having several people with other views, and from different areas, was very good. (E3)

Moreover, people with common problems and similar interests came together, seeking to support each other.

Being with other people helped me a lot, it gave me a lot of insight and here I met people where we talked and felt the same things. (E4)

It added a lot, for example, I sometimes want to do certain things that I used to do some time ago, and then I remember what people said in the group, and I realize it can wait, or I can get around it or do it later. I keep remembering and storing everything that was said during the group. (E9)

Getting together with people with the same life situations retrieves past experiences, values, knowledge and enables reorientation to improve self-care. As attested by the statements, other experiences are revealed, affording continuity and promoting the understanding of the ICT group.

Feelings and sensations of empowerment
This category covers the main benefits and contributions perceived and experienced by the participants throughout the intervention process.

I became a little more aware of the things I would do to get better, and also of what I used to do that made it worse. I’m respecting my body more, especially in relation to excess [...]. I have realized how caring for myself makes me feel good and eases the pain. (E3)

The activities helped me feel much better and taught me control in relation to food, to stressful situations, to weight, to establishing some limits in my life. (E4)

Some statements reveal changes and coping strategies adopted.

My self-esteem has improved, I feel more pleasure in waking up early and coming, and I have been coming to the activity in a more positive mood. (E7)

I live on a hillside street and I used to climb it two, three times a day, no matter how tired. Not now; now I first rest my body and then decide [...]. I have to take care of myself, love my body. (E9)

Below are positive statements regarding learning and improved health.

The group helped me think a lot, the pain has eased so much I no longer need to take so many drugs, at my last visit to the doctor all of them were reduced, I am satisfied with the result and don’t intend to stop. (E1)

I’d like to say that I can bear it, I do the walking exercise and feel really good. I have also improved my behavior, I am not so stressed out. I think I’m changing, I can feel it in myself. (E2)

Before I did no physical activity at all, nothing. Today I make a point of coming and I like to exercise [...]. I love the group discussions, I like everything, but I focus on the exercise, that’s where I really let go. (E5)

Other statements reveal self-care strategies in daily life situations.

At first, if I had to do five things in the day, I wanted to do everything. Not now, if it’s possible to do one in the day I do it, and the other four I leave for another day. And I do things slowly, and whenever I’m going to do something I remember what someone said in the group. Because we also have to help each other. (E8)

I’m feeling much better and calmer. Because when I was unable to solve everything I got stressed out with everybody [...]. I really don’t feel so much pain anymore, I’m more motivated to do things. This is what I do: if I can do it that day, I do it, if my arms start to hurt I stop immediately and leave it for tomorrow [...]. I stop because from now on I want to get even better. (E9)

Today I have compassion for myself, I have lost weight, improved my diet a lot, reduced the eating binges, cut out the bad things I used to eat, the nutrition gave me a good diet. I think I’m improving with myself, I’m looking at myself more closely in the mirror, viewing myself differently. (E11)

Changes in family relationships
This final category features situations related to changes in family relationships. After the ICT group meetings, participants showed they were more competent to deal with their health condition, more confident and empowered to interact better with the family, as shown in the following statements:

The relationship with my family has improved. Before, when someone talked about problems, I would fly off the handle, get really angry. I was still bossy. I wanted things done immediately, and got mad if they were not done correctly [...]. Not now, if they help me, they do it their own way, I don’t pick on them anymore, I am happy and family life has improved. (E9)

Life at home with my husband and son is calmer, because I’m less stressed out [...]. I also try to understand their side, because everyone has their problems. (E10)

In explaining their feelings, they report their limits and the search for personal development in their own daily life.
A lot has changed for the better at home, because I understand it’s not their fault and they don’t know what I’m feeling. I have to know my limits, value myself and say no when I cannot do something. Before I would do everything I thought I had to. (E2)

The other day my son wanted me to look after his daughter, [...] I said couldn’t, that it was impossible that day, I managed to say no. They looked at me sideways, but then understood. I learnt in the group, talking to colleagues, exchanging messages on Whatsapp and supporting each other. (E11)

The satisfaction and communication of all participants in this group process was evident, including through the creation of a Whatsapp (virtual messaging app) group that favored communication among participants in addition to the physical meetings.

DISCUSSION

This study aimed to investigate the integrated therapy model to empower people living with fibromyalgia and discuss the impact of this interdisciplinary intervention in the health-disease process and self-care.

Early in the ICT process with the group of people with FMS, it was observed through the knowledge assessment tool that the participants made mistakes in the responses, showed little knowledge about the health-disease process, risk factors for FMS, self-care, physical activity, nutrition, sport, leisure, and other necessary strategies for living with FMS. At the end of the group therapy, after three months, the same tool was administered, this time with more assertive and consistent answers. With these results, a change in the level of knowledge was noticed.

In the first category, it was observed that the ICT group is a driving force in building knowledge and self-care improvement. Learning was positive for each one of the participants, who demonstrated joy and interest in learning from other experiences. The process was understood and symbolically related with a bridge between people and care, indicating that care practices needed to be revisited, repeated and understood so they could apply and store them to memory, and review other ways of keeping healthy.

The data indicated that the participants referred to the ICT group in a positive way, providing conditions that contributed to the construction of new knowledge, not only on fibromyalgia, but also on issues they brought up for discussion at meetings, such as depression, sexuality, memory loss, nutrition and self-image.

In this context, ICT proved to be an interdisciplinary praxis tool that enables the construction of solidarity care networks and the mobilization of individual and collective resources and skills, involving families and communities. This tool generated feelings of empowerment demonstrated by the participants, who demonstrated joy and interest in learning from other people and interacting with others. Their speech also expressed affection, sensitivity and a lot of emotion. The participants told their stories and discovered themselves by revealing their problems: these experiences sometimes reminded them of their past, other times of their current daily reality. Thus, other participants felt comfortable discussing the issues and also reporting their experiences.

It can be said that empowerment enables individuals to unite in support of a single cause, overcome adversity, build knowledge, and enhance their skills and resources. Such capability gives people the power to decide what is best for their life. The empowered person is an individual with sufficient knowledge and ability to carry out action resulting in health improvement(23). The interdisciplinary group’s dialogue and position cooperated in the search for alternatives to cope with barriers and difficulties in achieving goals, that is, the realization of self-care practices. It was observed that the more timid participants were also motivated, showing interest in expressing themselves and interacting with others.

The literature confirms that group dynamics focused on assisting the monitoring of a chronic condition, which affects self-care and the daily life of people, is more effective than individual monitoring without the help of social support groups. That is, the individual who connects with social support groups achieves healing/disease control in less time, and the incidence of complications caused by chronic diseases is lower than in individuals who take no part in support networks(24,25).

In this perspective, a similar situation was presented in the third category, which expressed changes in family relationships. The participants evaluated to what extent they were able to review certain positions with their family members, avoiding stressful situations.

Through dialogue, they sought to understand, appreciating the family, trying to deal with their physical bodies in a milder way and assume a more proactive approach by reviewing their behavior, because they understood that their family members are also affected by the changes that occur with them.

It is noteworthy that the topic of “family,” spontaneously chosen by the participants, was discussed in the first stage
and during all conversation circles. In these activities, they cited examples of family relations and, at the same time, listened to reports of how other families behaved. Thus, each one of them reflected, sought to adapt to circumstances, and empowered themselves to deal with the problems. These data are similar to results from other studies that point to the empowerment of people, whether in psychosocial rehabilitation centers, whether in families with technology-dependent children, or even in family strategies. That happened because they assigned new meaning to knowledge and their worldview and fostered positive change. Thus, it is clear that these experiences promoted empowerment by improving self-care, emphasizing that the problem is not how people control their own disease, but how they are able to manage their life, despite the disease. Empowerment of patients for self-care is an effective way to deal with chronic diseases, helping patients develop critical awareness regarding their health problems and create solidary networks.

**FINAL CONSIDERATIONS**

Given the main findings, one can say that this kind of strategy, based on ICT, proves to be an alternative for the promotion of health care, being at the same time suitable for the participatory research approach due to its dialogical and interdisciplinary nature, enabling an integrating space that seeks to enhance self-care, to discover potentials as an alternative to discuss health problems and reorient positions, reducing intra- and interpersonal conflicts.

In addition to the benefits associated with improved quality of life, it is noteworthy that the use of this type of group strategy affords a low-cost option for public health, since it requires few resources to be implemented, making use of existing spaces for the activities and the experiences of participants as a form of learning.

The people involved, both the study participants and the interdisciplinary group, are no longer the same people from the beginning. The participants acquired skills and attributes compatible with empowerment, such as flexibility to review their positions and accept change, and the development of reflective and critical thinking. They developed personal skills, self-care, expanded their worldview and felt confident enough to manage their own lives. They felt they were cooperating agents of their objectives, rather than mere spectators; they engaged in self-care, demonstrating courage and strength to face change in everyday life; they boosted their self-esteem, becoming stronger in situations of fragility.

It can be argued that ICT is an important and efficient strategic model for the empowerment of people experiencing fibromyalgia, promoting a greater understanding of the health-disease process, of actions and attitudes that can benefit its control, besides preventing the emergence of associated comorbidities, enabling people to take action to benefit their health.

Similarly, participatory proposals such as those presented, besides contributing to the production and dissemination of scientific knowledge, provide changes and improvement in health education, as well as improvement of professionals who work based on that proposal. These activities aim at overall health and the reduction of health inequalities, according to the strategies defined by the WHO.

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