

Perception of caregivers of persons with schizophrenia about a health education program

Summary

The mental health policy of Brazil has been guided by the search for citizenship, social equality and autonomy of the individuals with mental disorders and it started with the deinstitutionalization process. On the other hand, this paradigm shift contributed to making the patients stay in the family environment and thus the need for family members to play the role of caregivers. The attributions of these care functions have contributed to a physical and emotional overload. Using a psychoeducational approach focused on the family member/caregiver of people with schizophrenia, this study proposed to check the caregivers' perception about the importance of the practice of relaxation activities for the promotion of self-care. The intervention was performed during a six-month period. Participants were 31 family caregivers of mental health cohabitation centers in the city of Belo Horizonte, Brazil. Using the relatives' reports about the perception of the intervention, categories were listed and treated with the support of the software webQDA. The results revealed through the family members' perception, that the intervention program provided them with contributions such as wellbeing, self-control over impulses, increased self-esteem, and encouragement for self-care. The literature reinforces that the educational practice in health is composed of educational activities aimed at the development of individual and collective capacities aimed at improving the health and quality of life of people. The intervention program with relaxation exercises contributed to an improved physical and mental health for family caregivers, awakening them to self-care.

KEYWORDS: FAMILY CAREGIVER; SCHIZOPHRENIA; HEALTH EDUCATION.

Introduction

The new model of mental health care and psychiatry is the result of a paradigm shift that occurred through national and international movements involved in psychiatric reform in the mid-twentieth century and spread throughout the world resulting in the deinstitutionalization of people with mental disorders. The closure of psychiatric hospitals required the creation of substitutive services for mental health care through a political com-

Authors

ROSELANE LOMELO (corresponding author): Universidade de Aveiro (Aveiro University) – Departamento de Educação, Aveiro, Portugal. Address: Rua Dr. José Azerdo Perdigão, 6, Res Chão Esq., Aveiro, Portugal

E-mail: lomeoroselane@ua.pt

NILZA COSTA: Universidade de Aveiro (Aveiro University) – Departamento de Educação, Aveiro, Portugal.

E-mail: nilzacosta@ua.pt

WILSON ABREU: Escola Superior de Enfermagem do Porto (Nursing School of Porto).

CINTESIS – Center for Health Technology and Services Research, Porto, Portugal.

E-mail: wjabreu@esenf.pt

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mitment that involves strategies in this new model, in which the direct protagonists are health professionals, people with mental disorders and their families¹.

In Brazil the reform movement was intensified after the Caracas Congress in 1990. Deinstitutionalization took place with the implementation of services, the involvement of professionals and institutions, and the creation of laws to ensure their effectiveness. In this process, the family members occupy the important roles of informal caregivers, to share the care of their sick family members with health professionals. However, attributing care inherently to family caregivers requires knowledge about the disease and skills to deal with the characteristics of mental disorders².

The lack of knowledge about the characteristics of the mental illness causes in the family carers feelings of anguish, stress and suffering, since they are not properly prepared to deal with the disease and its evolution. Due to this aspect, it is common the development of overload in caregivers^{3,4}. In this sense, the problematic behavior of the person with schizophrenia is a strong determinant of overload in family caregivers with low self-control⁵.

There is consensus among several studies regarding the need for psychoeducational intervention for family caregivers in the expectation of making them more able to perform their role and ensure their physical and mental health^{6,7,5,8}. In this sense, attention is paid to psychoeducational interventions with relaxation exercises so that individuals are able to develop aptitudes to deal with anxiety emerging from the stress situations in everyday life⁹.

Attention is also paid to practices in health education, which, in order to be effective, must be developed in a dialogic, emancipatory, participative and creative perspective. These practices should provide the subjects with information about health education, autonomy, understanding their rights and all the attitudes essential to maintenance of their good health condition¹⁰.

Regarding training and information, it should focus on promoting health and valuing education in the life of the individual, the family and the community, considering the coexistence in all aspects of social life. In this way, the sum of the knowledge and experiences lived in the daily life of the individual should be considered in order to direct the actions developed by health professionals. In this context, health education is considered an important tool for health promotion because through educational and environmental support it can produce actions intervening in the conditions of life that lead to the health of the individuals and populations¹⁰.

The implications of the caregiver's responsibilities related to the tasks of caring for the persons with schizophrenia in the daily life result in the unleashing of serious consequences, such as the impairment of physical and mental health. In this sense, it is essential to use resources through support interventions focused on the specific needs of family caregivers to promote functional adjustment both to the disease and the demands of care tasks.

Therefore, and due to high levels of overload in family caregivers of people with mental disorders as verified in the results of studies on the subject, the authors suggest the application of psychoeducational interventions in order to reduce the overload and to improve the health of the caregivers and the people with mental disorder^{7,5,8}.

The psychoeducation emerged in the mid-1980s in Germany through the working group called Psychoeducation of Patients with Schizophrenia, and began to be understood as a didactic intervention of a psychotherapeutic nature. This intervention is supported by experimental and scientific methods and is based on the fact that cognition generates emotions and behaviors. The authors state that the cognitive component precedes the affective, considering the transfer of information an emotional response. The actions developed in psychoeducation should not only be informative about the disease, but should also aim at improving the psychological and emotional state of the caregivers in a way that they are able to recognize and establish in their social environment a social support network¹¹.

Several scientific studies present the contribution of psychoeducational intervention as an effective alternative, because this intervention model comes along with significant results of improvement in the quality of life of the family caregiver^{12,13,14}.

Authors found marked improvements in family caregivers of people with schizophrenia who underwent psychoeducational intervention with an approach related to awareness of the disease, improvement in problem solving skills of communication, the daily life among those involved and the daily tasks performed by the family member caregiver. The authors warn that the intervention should be part of the therapy of mental health services and should be integrated into the routine of patients and family caregivers¹².

Further in this direction it was found in study, significant improvements in

decreasing the overall level of family burden impact on daily activities and social relationships, improvement in family cohesion and depressive symptoms in family members who cared for patients with schizophrenia for more than 10 years¹³.

Among the diverse psychoeducational practices, physical activity is seen as an important resource that allows the individuals to experience corporal practices performed according to their possibilities, limits and potentialities. It favors social bonds and resuming social roles, enriches the relationship with the environment, and assists in the gain and maintenance of health and psychic, affective and relational development.

Specifically, mental health relaxation exercises offer several benefits that positively influence the routine behavior of the individual¹⁵, as well as provide improvements in physical and mental health¹⁶.

Relaxation is defined as a state of consciousness described by feelings of peace, relief from tension, anxiety and fear, favors emotional balance, improved mood, gaining self-esteem, improved memory, reduced risk of depression, improved immune system, reducing muscle tension and improving sleep⁹. It is also understood as a moment of muscular relaxation that requires voluntary rest and provides the pertinent use of the individuals' physical and mental resources, contributing to protect the body from stress-related illnesses and psychopathologies¹⁷.

In order to better understand the contribution of relaxation activities for reducing burden over family caregivers, this study seeks to verify the perception of family caregivers of people with schizophrenia on the importance of practicing relaxation in order to promote self-care related to the development of caregiver tasks.

Methods

The present study has a qualitative

nature, whose approach is characterized as an investigation oriented to the analysis of concrete cases in its temporality and location, through expressions and meanings that people attribute to their thoughts, attitudes, behaviors and practices¹⁸.

In order to use the psychoeducational intervention to intervene on the overload in 31 family caregivers of people with schizophrenia and awaken them to self-care, it was necessary to know better the behavior and the human experiences, in order to use an educational intervention through the practice of systematic physical relaxation activity. Using this intervention as a starting point the research recorded the perception of the participants as a function of the experience of the practice. This approach applies to the study of relationships, representations, beliefs, perceptions and opinions, which are products of people's interpretations of how they live, feel, and think¹⁹.

The study was carried out in the year 2015, in the period of six months, with a weekly session lasting 30 minutes. Each session was operationalized following the structure: 15 minutes of relaxation and 15 minutes for the reports of the familiar caregivers, recorded in audio. For this study it was selected the family member considered to be the main caregiver of the person with schizophrenia enrolled in the CCC.

After transcribing the reports, we used the Bardin content analysis technique with the support of the software WebQDA.

The study was evaluated and approved by the Research Ethics Committee of the Municipal Health Secretariat of Belo Horizonte via Plataforma Brasil, registry CAAE n° 41787015.6.3001.5140.

Findings

Characteristics of family caregivers and people with schizophrenia

The sociodemographic characteristics of the family members show that the average age of the 31 family caregivers is 67 years, (80.6%) female, and of these (54.9%) are mothers. As for marital status, 41.9% are married, 64.5% of the caregivers are retired, 58.1% have low level of education, 87.1% live in the same household with the subject with schizophrenia, and (41.9%) have been caring that person for more than 11 years.

Categories featured in content analysis

The analysis was performed in two stages, namely: 1st) Pre-analysis, 2st) Exploration of data.

1st) **Pre-analysis:** in this phase the material to be analyzed was organized, making it operational, through the contents of the transcription of the reports, and followed by the identification of subcategories;

2nd) **Exploration:** In a second reading, the subcategories were grouped and distributed into two categories (Relaxation Activities, Meaning of Health Education Intervention Program) (table 1).

For each subcategory of the Relaxation Activities Category, excerpts from relatives will be presented:

Feeling of well-being

FC28 – *You can see that it relaxes, it calms me, it makes me feel more calm, so I have always been ready too, with both physical and mental well-being.*

FC5 – *After I started to participate in this relaxation, I'm feeling very well on the physical ... the pain I felt behind my legs and that bothered me so much, is over.*

Sensation of relaxation

FC7 – *It was great for me, I got to relax, I rested, I'm feeling very good. Relaxed, it was very good.*

FC16 – *Every day I'm getting disconnected. ... when I realize, I was already somewhere else, on a beautiful mountain and I went away.*

Strengthening self-esteem

FC29 – *I feel like a courageous person, after I started doing this gymnastics I have valued myself more, I am feeling very well and I want to continue.*

FC7 – *I'm feeling lucky to be here. Happy to take care of me...*

Positive perception of self in the other's vision

FC29 – *My son said that he thinks I'm very willing, more cheerful. I am like this because I am participating of these*

CATEGORY RELAXATION ACTIVITY AND SUBCATEGORIES

1

| Relaxation Activity | Number of References |
|--|----------------------|
| Subcategories: | |
| <i>Feeling of Well-being</i> | 421 |
| <i>Sensation of Relaxation</i> | 145 |
| <i>Strengthening Self-Esteem</i> | 101 |
| <i>Positive perception of self in the other's vision</i> | 13 |
| <i>Self-control of impulses</i> | 85 |
| Social support among Group members | 10 |

MEANING OF THE HEALTH EDUCATION PROGRAM AND ITS SUBCATEGORIES

2

| Category | Number of references |
|---|----------------------|
| Meaning of the Health Education Program | |
| <i>Learning with the intervention program</i> | 143 |
| <i>Appreciation of the intervention program</i> | 201 |

classes. I'm getting more cheerful, doing something that makes me feel better. I want to proceed. I even think about going into the gym.

FC13 – *This exercise is really good. My son-in-law said that he thinks I'm more relaxed with people and JB, because I was very agitated with him. I'm calmer now.*

Self-control of impulses

FC4 – “I'm much calmer. Today G. made me very angry, ... but I did not pay attention to her. And that's a sign that I can control myself. It's difficult, but I'm having more patience with her. “

FC21 – “... I improved the care with my wife, I have more calm, more patience. “

Learning with the intervention program

FC6 – *I'm feeling good, I think it's good to be here. We only take care of our children and we do not take care of ourselves ... I have to take better care of myself.*

FC5 – *I'm doing the exercises at home and my girl is doing it together. I want to continue. “*

Appreciation of the intervention program

FC5 – *I'm going to miss it, I learned a lot from these classes. My blood pressure is better controlled after I started to participate in this activity. I improved a lot, it was very good.*

FC13 – *... this activity revived me. If I could I would not let it end. Seriously, for me it was very good. It helped me a lot...*

Discussion

The change, reported by family caregivers, caused by Relaxation Activities (Feeling of well-being, Sensation of Relaxation, Strengthening Self-Esteem, Positive perception of self in the other's vision, Self-control of impulse, Social support among Group members) is confirmed by Roeder¹⁵, who states that physical exercises, specifically, relaxation exercises promote the reduction of anxiety and stress, increase the sense of self-esteem and improve the capacity to manage psychosocial stress, leading the individual to perceive physical and mental well-being. In this sense, it is verified through the results of the present study that the intervention program with the relaxation activity provided the physical and mental well-being in the family caregivers, in concurrence with the studies of Hansen¹², which stresses that a psychoeducational intervention can provide well-being to the family caregivers, since it protects them from physical and mental impact caused on personal, social

and work life by care tasks. Family caregivers reported issues such as physical and mental fatigue and lack of sleep. However, during the development of the program with relaxation exercises, the family perceived a sense of tranquility and well-being attributed to the exercises. This result is in agreement with Vancampfort¹⁶. According to this author, relaxation exercises promote improvements in the physical health and mental health of the individual.

The improvements triggered by the relaxation exercises were described by Payne⁹ such as perceiving feelings of peace, tension relief, anxiety relief, which favors the practitioner's emotional balance, improved mood, reduction of muscle tension, improved sleep and as an important means of improving self-esteem. Increased self-esteem involves a positive change in various aspects of the caregiver's life, which interferes with one's own health and care of the sick person¹⁷. In the results of this study it was observed that the family members obtained improvements in their self-esteem, self-esteem awareness, adherence to healthy habits, and feelings of happiness, recognition of changes arising from a new behavior towards the caregiver task and in social life.

According to Salci¹⁰, self-esteem is the value that each individual has about him/herself, which involves physical and emotional factors and feelings that the person faces throughout life.

It was observed in the reports of family members that participation in the intervention provided them with improvements in self-esteem, awareness of self-worth, adherence to healthy habits, feelings of happiness, recognition of changes arising from a new behavior towards the task of caregiver, as well as in social life.

Being involved in the care of people with schizophrenia has been highlighted in the literature as an experience that generates stress, overload, physical and mental ex-

haustion, and interferes with the quality of life of caregivers. One of the tools that may contribute to the reduction of these symptoms is psychoeducational intervention. This type of sustained intervention in the practice of relaxation exercises can contribute to the increase of the self-control of these relatives⁵. In the present study, the family caregivers in their reports confirm the positive influence that the intervention provided in the emotional state regarding the control of emotions. It was verified that in the course of the development of the relaxation sessions, the relatives showed greater sensitivity in relation to the need to self-control in the face of stress situations.

The Meaning of the Health Education Program at family caregiver has two subcategories, as shown in table 2: Learning with the intervention program and Appreciation of the intervention program, that pointed out psychoeducational intervention as an important support tool in terms of training / informing caregivers by enabling them to increase their problem-solving capacity, which will lead to better management of the disease by reducing levels of stress in the family^{12,14}. In this sense, the family caregivers participating in this study, through their reports, confirmed that they improved their learning regarding how to deal with the problematic behaviors of the persons with schizophrenia, greater control over stress, perception of physical and mental improvements, and perception about the need for self-care.

Conclusion

The innovations in the mental health policy launched by the paradigm shift in psychiatric care attributed to the family the role of caregivers. The fact that they are unprepared for this new responsibility may result in consequences for the physical and mental health of the caregiver and affect family functioning.

It is evidenced through studies in the literature review the need for mental health services to develop psychoeducational intervention, aimed at guiding the family on how to deal with the problematic behaviors characteristic of mental disorders.

In another dimension, and geared towards providing the family caregiver with improvements regarding their physical and mental health and stimulating their self-care, this study proposed the application of a program of relaxation activities.

The results from the program demonstrated that the objective of the study was reached, evidenced by the fact that it was possible to promote in the caregivers a greater awareness about the importance and the valorization that they should have with their self-care.

Therefore, it is proposed that this type of intervention in health education may be incorporated within the activities of mental health services, as a way of appreciating the well-being of the family caregiver.

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