

Experiences of relatives of schizophrenic people

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The purpose of this study was to describe the experiences of family members of the person with schizophrenia. Descriptive-qualitative study conducted at a Psychosocial Care Center in Teresina - Piauí. A semi-structured interview script was used and content analysis was carried out in the light of Bardin's theoretical framework. The results revealed that the family members suffer profound physical and emotional exhaustion resulting from the exercise of the care of the person with schizophrenia and experience significant conflicts in the daily living, compromising the quality of life and the social and psychic functioning of those who exercise the role of caregiver. The study points to the need to develop care strategies for the client-caregiver binomial.

Descriptors: Schizophrenia; Family; Nursing.

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Vivências de familiares da pessoa com esquizofrenia

Objetivou-se descrever as vivências de familiares da pessoa com esquizofrenia. Estudo descritivo-qualitativo realizado em um Centro de Atenção Psicossocial de Teresina – Piauí. Utilizou-se roteiro de entrevista semiestruturada e procedeu-se a análise de conteúdo à luz do referencial teórico de Bardin. Os resultados revelaram que os familiares sofrem profundos desgastes físicos e emocionais decorrentes do exercício do cuidar da pessoa com esquizofrenia e vivenciam significativos conflitos no convívio diário, comprometendo a qualidade de vida e o funcionamento social e psíquico daqueles que exercem o papel de cuidador. O estudo aponta para a necessidade de elaboração de estratégias de cuidado ao binômio cliente-cuidador.

Descritores: Esquizofrenia; Família; Enfermagem.

Experiencias de los familiares de la persona con esquizofrenia

Este estudio tuvo como objetivo describir la familia de las experiencias de las personas con esquizofrenia. estudio cualitativo descriptivo en un Centro de Atención Psicossocial de Teresina - Piauí. Se utilizó entrevistas semiestructuradas y se procedió a un análisis de contenidos basado en la marco teórico de Bardin. Los resultados revelaron que los miembros de la familia sufren agotamiento físico y emocional profunda que resulte del ejercicio de la atención de personas con esquizofrenia y la experiencia de los conflictos significativos sobre base diaria, poniendo en peligro la calidad de vida y el funcionamiento social y psicológico de los que ejercen el papel de cuidador. El estudio apunta a la necesidad de elaborar estrategias de atención al binomio cliente-cuidador.

Descriptores: Esquizofrenia; Familia; Enfermería.

Introduction

Schizophrenia represents a serious health problem that implies significant impairment in personal, social and family functioning, characterized by social withdrawal and limitations to play roles and maintain relationships. Family life with people affected by schizophrenia is considered a daily struggle with suffering which is aggravated in times of crisis and loss of abilities⁽¹⁾.

The main clinical symptoms of the disease are characterized as belonging to two types, positive and negative. Positive symptoms correspond to delusions and hallucinations, and negative symptoms to blunted affect, cognitive impairment and memory deficit. Both types of symptoms are responsible for the image of

madness in society, portraying the affected person as being aggressive, introspective and socially isolated^(2,3).

There is a time lag between the onset of symptoms and the search for treatment, which may influence a poor prognosis as symptoms become more intense, requiring longer psychopharmacological treatment and higher doses of medication. Appropriate intervention involves pharmacological and psychosocial treatment and family involvement⁽⁴⁾.

Schizophrenic disorder is equally prevalent among men and women; however, the problem starts earlier in man, between the ages 10 and 25 years, with the first hospitalization usually before the age 25. Among women, the age at which the illness mostly appears is between 25 and 30 years, leading to a more favorable prognosis in comparison to men, due to the

later onset⁽⁴⁾. Schizophrenia can be manifested in an insidious or acute way, but there is a prodromal phase characterized by social isolation and experiences of absence of emotional response⁽⁵⁾.

With respect to crisis episodes experienced by schizophrenic people, a study revealed that only 5% of the patients present a single outbreak during the whole life; most schizophrenic people have recurrent episodes or relapses, mainly in the early years of the disease. This shows that the evolution of the disease demands the involvement of family members in the care or monitoring of the person affected by the disorder and this may cause a physical and emotional overload of caregivers, considering that schizophrenia is a type of disorder with high potential for chronicity⁽¹⁾.

When family members discover schizophrenia in their home, they experience a new phase in which a variety of feelings emerge. The impact generated in the family entails situations of stress, fatigue and hopelessness because the family often does not understand what is actually happening to their relative. Living with a person with schizophrenia can be a harrowing experience insofar as feelings of uncertainty about the present and the future of the family member and that surround their own life prospects emerge⁽⁶⁾.

A study carried out with relatives of people with schizophrenia pointed out that the caregivers suffer physical and emotional overload caused by the wear and tear that results from the behavior of the patients, because they have to dedicate time and take on task of daily care. This happens because, besides the functional limitations that schizophrenic disorder triggers in the life of the sick person, the disease also arouses much prejudice in society and this situation demands further protection and care for the person suffering with schizophrenia⁽¹⁾.

Caring for persons with schizophrenia requires that family members change their daily social activities and tasks, which are then exercised by other people because they need time to dedicate to the care of the patient. This places the family in a condition of personal loss and suffering caused by the stress load generated by daily care, since the family represents a key element in the treatment and recovery of the schizophrenic person⁽⁷⁾.

Thus, considering that the family represents an important resource in the care and rehabilitation of people with schizophrenia, we understand that knowing the experiences reported by relatives of people with schizophrenia may support the creation of strategies of care for people with this mental disorder, as well as the development of measures to promote the health of family members and caregivers.

For this, we share here the understanding of experiences based on a study developed by Barretta⁽⁸⁾ grounded on the conceptions of Freud and Husserl. The author says that the term experience is used to encompass both the senses of experiencing and of living. It is an experience immediately lived, that is, not presumed, nor merely heard, but directly and personally realized and at the same time, it is a lasting and significant experience, although generally in the pathological sense. In short, the same author emphasizes that the term "living" is used to refer to a direct and personal experience of something, but also a decisive and significant in a person's life.

In this context, this study aims to describe the experiences of relatives of people with schizophrenia.

Materials and methods

Social research can be understood as a set of types of research that deal with human beings in society, their relations and institutions, their history and their symbolic production. This type of method seeks to "unravel" social processes that are still little known and belong to particular groups, and its objective and final indication is to provide the construction and/or revision of new approaches, concepts and categories related to the phenomenon studied⁽⁹⁾.

In this perspective, this research adopted the precepts of a qualitative-descriptive research, aiming to analyze the experience of relatives of schizophrenic people. To this end, the research scenario was a Psychosocial Care Center (PSCC), located in the city of Teresina (PI).

The study participants were relatives of people with schizophrenia, followed up in the PSCC selected for the study. The number of participants was 12 (twelve) family members; however, as this is a qualitative study, the number of participants involved in the study was defined based on speech saturation criteria applied in research of this nature.

The inclusion criteria for participation in the study were: family member of a person with schizophrenia regardless of the degree of kinship, over 18 years of age, of both sexes, and living in the same household with the patient. As for the exclusion criteria, these were: family member of the person with schizophrenia but who does not live with the patient or family member living in the same household, but aged less than 18 years.

Data collection took place in November 2015. A semi-structured interview script was used, including closed questions to characterize the profile of the

study participants and open questions related to their experiences with the person with schizophrenia.

Meetings of interviewer and interviewees occurred at the Psychosocial Care Center where they are assisted, in an atmosphere that ensured the respect, comfort, safety and privacy to participants. All the procedures recommended by Resolution 466/12 were applied to guarantee the detailed clarification of the research to the participants through the reading and signing of the Informed Consent Term (ICT)⁽¹⁰⁾. Also, in order to comply with the aforementioned Resolution, the participants were identified by flower names to guarantee their anonymity.

Before starting the study, the research project was sent to the Municipal Health Foundation (MHF) of Teresina, an institution that participated in the research, and was then referred to the Research Ethics Committee (REC) of the UNINOVAFAPI University Center under CAAE 49462715.3.0000.5210.

Data analysis followed the assumptions of the content analysis technique in the light of the theoretical reference of Bardin⁽¹¹⁾, which allowed the creation of thematic categories.

Results and Discussion

The instrument used in the interviews was answered by 12 people with ages varying 22 to 76 years. Among these, the age group above 60 years (4 participants) and female individuals predominated, totaling 11 participants. The most commonly found kinship among respondents was first-degree relative (mothers). The majority of the participants (5) were married, had completed primary school, were unemployed and of practiced the Catholic religion (8 participants in each variable).

The research aimed at obtaining information that allowed describing the experiences of relatives of people with schizophrenia, in accordance with the objectives of this study. The results were grouped into the following categories which will be discussed below:

Fear experienced by relatives of people with schizophrenia and difficult family life

Among the psychic alterations present in schizophrenia are hallucinations that produce significant behavioral changes, leading to manifestations of unstable and often aggressive behavior. In more severe cases, schizophrenic patients reveal an extreme disorganization of thoughts and this makes family relationships or the relationship with the caregiver

deeply impaired, often marked by fear and insecurity of aggression. These experiences were mentioned by the participants of this study.

Some days he is well, and others not. Some days he keeps cursing and I am like enduring all the time, some days I have no patience, I even want to go out, because a person who struggles with these people ends up, too, having problems. [...] At first I used to cry so much because he would keep talking to people who had already died, and I'm afraid he does something to me when I'm asleep. (Rose)

Another participant adds that [...] *it is very difficult, he is a person who, because you know that these people always choose one person in the family, in our family there are twelve people, but the only ones who solve the things are me and my sister, we are the ones who struggle with him. He has already attempted a rape, he is very aggressive in that moment when he is in crisis you have to give in to his will, otherwise he may even kill you; so, it is very difficult! (Tulip)*

As reported in the above statements, living with a schizophrenic person is an exhaustive task due to the behavioral changes that disorganize the individual, producing symptoms that include aggression and thinking that is incompatible with reality⁽¹²⁾.

Prolonged interaction with a relative who have schizophrenia, often involving full-time care and daily exposure to an excessive amount of time devoted to caring for the sick person, produces in the caregiver significant health problems, both of physical as well as psychic order. Heart problems, stress, tension, fear, nervousness, isolation, discouragement, anxiety and psychosomatic symptoms are common, in addition to the possible development of a mental disorder.

My interaction with him is very suffered, because he is very aggressive. He even hits me! Once he was hospitalized, then he took a bag of clothes [...] and left. It was still dark, five o'clock in the morning, when I went after him to look for the bag, the answer he gave me was a slap in the face, he punched me in my face, I got lots of bruises because he punched me. So, it's very difficult. (Gardenia)

This points to the need to provide more support, information and clarification about mental disorders and ways of dealing with them and living with persons who suffer from schizophrenia⁽⁸⁾.

A study carried out with caregivers of schizophrenic people showed that the caregivers suffer physical and emotional overload caused by the distress of having to deal with the behavior of the patients, that makes family interaction extremely difficult⁽¹³⁾.

Investing in drug and psychosocial treatments represents important measures of care for people with schizophrenic disorder and facilitators of family interaction⁽¹²⁾.

Another issue revealed by the testimonies in this study is related to the need for greater attention on the part of professionals in providing care and clarification to the family and caregivers about the mental disorder and its management in moments of crises. On this, the following testimony highlights that:

It's complicated because you have to understand some things right? Because, sometimes, things change a lot. Periods when he does not have the medication, things get difficult. He needs constant medication, only thank to this he is here, but in the rest he is a cheerful person, very playful, he has several friends and the illness has not prevented this much, and he is like this only thank to the controlled medication. (Jasmine)

It is necessary to consider that the coexistence of family members with a person with mental disorder is not always harmonious. The interaction is commonly permeated by tension and conflicts, because this is in this space where emotions are more easily expressed⁽¹²⁻¹³⁾. Furthermore, the family also experiences a high concern about the safety and protection of the person with schizophrenic disorder, as episodes of self-aggressiveness may be manifested with suicidal behavior.

He has already tried to kill himself with a garbage bag; he wrapped around his neck and got breathless. When he is not taking the medicine he becomes aggressive, but when he takes it, he is quite normal. Those who see him can't tell that he is under medication. It is very difficult to live with him, but he is my son, I have to endure, I love him with all my heart. (Carnation)

She is aggressive [...] she, she is stubborn; she punched there with her hand. She is aggressive even with her mother. Her mother does not like to be with her, because she does not get along with her. This woman is a serious case, some days she receives me, sometimes she receives me. In the house she does her things very well, but she is very aggressive. (Sunflower)

Manifestations of aggression, present in the majority of reports in this study, are one of the greatest obstacles to good interaction between the sick person and the family members. Generally, relatives do not adequately manage this health condition to keep it controlled. There is also a difficulty in ensuring adherence to drug treatment. Insertion in rehabilitation devices contributes to further aggravate the patient's condition, leading to more frequent crises.

Psychological overload experienced by the caregiver and the adaptation of the family to the problem

When family members discover schizophrenia in their home, they experience a new phase in which

diverse feelings emerge. The impact generated by the illness in the family causes situations of stress, fatigue and hopelessness. is the family does not always understand what is actually happening to their sick relative. Living with a person with schizophrenia can be a harrowing experience because of feelings of uncertainty about the present and the future of the affected person and about the relatives' own prospects in life⁽⁶⁾.

In this sense, participants in this study say that: *it is difficult to see the way she is, her situation, we can't do anything about it, she has to be numb under medication all the time, twenty-four hours a day. It is difficult! She is not aggressive, she is always doing her own stuff, quiet, all time doped and it is difficult because I cannot do anything to help. (Orchid)*

We've been married for twenty years. It was wonderful at first! But then she started to have these crises. It was awful at first! But then I adapted because I am responsible for her; I have already got used to it; I have more patience, but my son, sometimes he does not understand, when she is in days of crisis speaking nonsense, he does not understand, he thinks it is her fault. (Lily)

The family is considered indispensable for the effectiveness of psychiatric care and it is understood as a group with great potential for embracement and re-socialization of the family members⁽⁹⁾. However, for this to occur, it is necessary that health professionals guarantee support to caregivers in order to prepare them to manage even situations of crises.

My interaction with him is good, because he is not aggressive; he is aggressive like in household affairs, sometimes he gets aggressive. He throws things in the woods, turns down the refrigerator, turns down the stove, but that is not every day. With me, thank God, he is not aggressive. My interaction with him is good. The only thing is that he talks too much. He says the men are after him; he throws the food on the wall. (Violet)

It's good; at first, it was bad because it has been nine months since my brother died, and she got worse, so that the doctor prescribed her another medication, and she has improved a lot. She causes no problem, no. She's just aggressive when she speaks. (Daisy)

Despite the physical and emotional exhaustion experienced by family members and caregivers, it is evident that in many cases the family seeks and attempts to maintain a state of balance before the problem. It is as if the relative who gets responsible for the care of the schizophrenic person finds personal protection and help to cope with the suffering they experience, revealing a kind of acceptance of the sick person and skills in the task of caring, as reported below:

We see many families that suffer because the patient is very aggressive, this is not his case, he does not offend anyone, he is not aggressive with anyone, but when he is feeling a pain, he pulls his hair off his head. In this period, of the second semester, he gets much more agitated; and that is bad for us and for him. When it is raining and it is not so hot, he is quieter. He has the phase that he is super in peace, but has also the phase that he is aggressive, he rips everything. (Hydrangea)

My living with him is not bad; I am the only woman, and three men at home, and when he's not under medication he gets very aggressive, but now he's taking the injection, and that helps, he only offends me with bad words. (Chamomile)

In order to share the care of people with mental disorders among mental health professionals and families, the current national mental health policy encourages the development of activities that promote the embracement and guidance of families and patients to prepare them for the development of care. Thus, the services offered by Psychosocial Care Centers (PSCC) include therapeutic groups with family members of the ill person. In this action, besides being educated about the management and care of the sick person, family members receive care to soften stress and prevent illnesses.

Final considerations

The present study made it possible to know the experiences of family members of people with a mental disorder and the impact generated in the life of the caregivers. Thus, the participants of this study revealed that they experience situations of fear, aggression, fatigue, worry and stress that result in conditions of physical and emotional exhaustion of relatives/caregivers. In addition, the study revealed the burden in terms of social and psychic impairments that make it difficult to live with people with schizophrenic disorder.

However, it is worth noting that, despite the difficulties described by the study participants, they seek to adapt and accept their schizophrenic relative.

Thus, we can point to the need to devote more attention and guidance to family caregivers of people with mental disorders, in this study portrayed by people with schizophrenia, in order to prepare family members for the mission of care and, in this way, strengthen the care network for the people with mental disorders.

We conclude that the family represents support, embracement and love for those who are mentally ill. Families need to understand that their role may be essential for the evolution of the treatment, as well as to promote health and prevent illnesses of other family members.

We hope that this study, based on the reports of relatives of schizophrenic people may help students and professionals in the health area to know the real suffering caused by this difficult interaction. We also expect that, from this knowledge, they may reflect on their daily practices, since, regardless of the area in which the health professional chooses to act, there will always be an opportunity to welcome people with mental disorder with dignity and respect for their citizenship.

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