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Experiencing feelings and weaknesses of care in schizophrenia: family caregivers vision

Vivenciando sentimentos e fragilidades do cuidar em esquizofrenia: visão de familiares cuidadores

Experimentar sentimientos y debilidades de la atención en la esquizofrenia: los cuidadores familiares de visión

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ABSTRACT

Objective: To understand the burden of care in schizophrenia from the family caregivers' view and analyze the feelings involved in the care process. **Methods:** A qualitative, descriptive and exploratory study. It was held at CAPS II in Teresina, Piauí, with nine family caregivers in April 2011. A script of semi-structured interviews was used; the interviews were recorded and transcribed in full and analyzed according to Bardin. With a favorable opinion by the CAAE 0489.0.043.000-10 protocol CEP UNINOVAFAPI. **Results and Discussion:** The "Feelings and weaknesses involving the burden of care in schizophrenia," showed that there was loneliness, anguish and fear when the care responsibility was assigned to a unique family member. **Conclusion:** Professionals can better plan their therapeutic practice, with particular attention to the experiences of the caregiver, taking into consideration the feelings and weaknesses involving the burden of care.

Descriptors: Caregivers; Family; Schizophrenia.

RESUMO

Objetivo: Compreender como se dá a sobrecarga do cuidar em esquizofrenia na visão de familiares cuidadores e analisar os sentimentos envolvidos no processo de cuidar. Métodos: Estudo do tipo qualitativo, descritivo, exploratório. Realizado no Centro de Atenção Psicossocial (CAPS) II em Teresina, Piauí, com nove familiares cuidadores, no mês de abril de 2011. Foi utilizado um roteiro semiestruturado de entrevistas; os depoimentos foram gravados e transcritos na íntegra e analisados conforme Bardin, com parecer favorável por meio do protocolo CAAE 0489.0.043.000-10 do CEP do Centro Universitário Uninovafapi. Resultados e discussão: A categoria "Dos sentimentos às fragilidades que envolve a sobrecarga do cuidar em esquizofrenia" demonstrou haver solidão, angústia e medo em decorrência da responsabilização do cuidar ser atribuída a um familiar exclusivo. Conclusão: Os profissionais poderão planejar melhor sua prática terapêutica, dando relevância para a vivência do cuidador, levando em consideração os sentimentos e as fragilidades que envolvem a sobrecarga do cuidado.

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Descritores: Cuidadores, Família, Esquizofrenia.

RESUMEN

Objetivo: Comprender cómo es la carga de la atención en la esquizofrenia en la familia cuidadores ver y analizar los sentimientos involucrados en el proceso de atención. Métodos: Estudio de cualitativo, descriptivo, exploratorio. Celebrada en el CAPS II en Teresina, Piauí, con nueve cuidadores familiares, en abril de 2011 se utilizó una hoja de ruta de entrevistas semiestructuradas, las entrevistas fueron grabadas y transcritas en su totalidad y se analizaron según Bardin. Con un dictamen favorable por el protocolo CAAE 0489.0.043.000-10 CEP Uninovafapi. Resultados y discusión: Los "Sentimientos debilidades que implican la carga de la atención en la esquizofrenia", mostraron que no había soledad, la angustia y el miedo por la responsabilidad de cuidar a ser asignado a una familia única. Conclusión: Los profesionales pueden planificar mejor su práctica terapéutica, dando relevancia a las experiencias del médico, teniendo en cuenta los sentimientos y debilidades que implican la carga de la atención.

Descriptores: Los médicos, Familia, La esquizofrenia.

INTRODUCTION

With the logic of the deinstitutionalization of the mental practices of exclusion and stigma of madness, from the origin of the Brazilian Psychiatric Reform in the middle of the twentieth century, the families of the people living with mental problems began to stand out in the strategies of treatment and care.¹

Although a new network of mental health care, practices and policies focusing on the autonomy, freedom and socialization of the mentally ill has been constructed, with the return of this mental patient to the family and social environment, Almeida *et al.*² point out that the family was not prepared to return to its role of legal guardian in the face of the care needs of the subject living with mental disorders.

In this context, according to Teixeira³, schizophrenia presents itself as a serious public health problem due to the fragility and incapacity in face of its chronic character, which leads the subject to the disintegration of thoughts and consciousness, directly affecting their work and self-care functionality.

Therefore, schizophrenia is considered the most serious among mental illness, affecting around two million Brazilians, being surrounded by taboos, prejudices and judgments, due to the ignorance of the majority of the population about the disease.⁴

Because it is a health problem that tends to chronicity, it affects everyone around the mentally ill, such as family and society. In this context, the family plays a very important role in the caring process, due to its own social and civil value within the community.³

It is in the face of the family's role that the presence of the disorder causes rupture of the existential routine of the main family caregiver, through feelings of distress, depression, isolation, chronic sadness, guilt and anguish. The relative responsible for the integral care starts to stay in the background faced with its own fragility, generated by the overload of care, which is taken as a burden.⁵

Care overload is characterized by two dimensions: objective and subjective. Tessler and Gamache⁶ refer that the concrete and observable facts are linked to the negative consequences of the objective overload, inherent in the reintegration of the mentally ill in the family nucleus. When discussing the objective approach, one should consider the daily activities that need to be performed by the caregiver to meet the needs of the subject who bears mental problems. This phase is linked with financial losses, changes in the social, family and professional routine of the main family caregiver, as well as the support that the schizophrenic receives from his relatives. The subjective dimension is presented as the self-perception of the caregiver about the situation experienced, in the face of emotional reactions, such as the feeling of suffering from the care overload responsibility, the very internalization of these aspects that affect mental health.

In face of such perspectives that affect the life of the family caregiver, the following objectives emerged: to understand how the care overload in schizophrenia occurs in the view of family caregivers and analyze the feelings involved in the caring process.

METHODS

This is a qualitative, descriptive, exploratory study held at CAPSIILesteinTeresina, Piauí. Nine relatives (main caregivers) of people living with a medical diagnosis of schizophrenia in semi-intensive and intensive treatmentattended at this health facility, held in April 2011. A semi-structured interview script was used, divided into two phrases; the first phase sought to describe socio-demographic characteristics, such as: gender, age, marital status, relationship, schooling, family and personal income, get-together time and care, number of residents per household, and caregiver health problems. The second phase was built using the guiding question: talk about your experience as a caregiver of a family member who is schizophrenic.

The interviewees' speeches were heard, transcribed in their entirety and organized according to the similarity of content, so as to allow a better understanding of the meanings sought in the research objectives, and these testimonies were analyzed, interpreted and categorized according to Bardin.

The technique of content analysis of Bardin goes through three phases, namely: Pre-analysis; Material exploitation; Treatment of results, inference and interpretation. The Pre-analysis moment was developed before the organization of the material to be analyzed, from the systematization of the contents, where a floating reading was developed and the choice of the speeches was done. The phase of Material exploitation was developed through the analytical and in-depth description with respect to the content corpus, , guided by the object and theoretical foundation. The last step was done in the treatment of results, inference and interpretation, where the results were treated, condensed, codified and categorized, which made possible the interpretation, analysis and discussion of the findings.⁷

The study obeyed the norms of the National Council of Health, through Resolution 196/96 updated by 466/2012, which deals with research involving human beings.⁸ Research conducted after a favorable opinion of the Research Ethics Committee of the University Center UNINOVAFAPI, under the number of the CAAE protocol: 0489.0.043.000-10. The secrecy of the deponents was maintained, coded by numerical description in order of testimony and initials of the deponent's name.

RESULTS AND DISCUSSION

The data recorded in the script of semi-structured interview in the first phase allowed to characterize the subject of the study, in the second phase the statements derived from the guiding question gave rise to the following category: Feelings and weaknesses involving the burden of care in schizophrenia. In this way, the research managed to reach its objectives, in the face of the understanding and analysis of the family caregiver's view of the subject with schizophrenia on the care overload and the feelings involved in the caregiver relationship with the one that is being cared for.

CHARACTERIZATION OF CAREGIVERS

We interviewed nine family members (primary caregivers) of people living with schizophrenia. It should be considered that none of the caregivers invited refused to participate in the study, so all the testimonials were analyzed.

Thus, the study identified that all the deponents are female, as for the age group: three had age between 42 and 48 years, two between 54 and 59, three between 64 and 69 years and one with 70 years. As to the degree of kinship and marital status: six were married mothers, a divorced mother, a married daughter, a widowed grandmother. Two were illiterate, four had incomplete elementary education, two had incomplete secondary education and one with complete higher education.

These data are in agreement with the study developed by WEGNER and PEDRO⁹, which presents the female figure as the sole and main executor of the care in different environments: family, home, hospital, community and others, being the relation caring and woman related to the maternal instinct and the difficulties of man to perform care. Women are historically linked to the health and disease process in a natural movement, which leads and mobilizes women to perform the care of their family members.¹⁰

In addressing the care time and contact that the family caregiver has with the person living with schizophrenia, five said they cared for between one and ten years, two since birth, one thirty-nine years ago. All caregivers reported that they dedicate full time to their families, with an average of five people per family unit. The health problems most reported by the caregivers were: hypertension, high cholesterol, osteoporosis, nervous gastritis and depression.

The question of time of care and health problems present in the caregivers' lives is in agreement with the studies of Lima *et al.*,¹¹ which exposes that caring for people with mental disorders is built in the face of a constant vigil. On the other hand, the health problems presented by the caregivers may be related to the mental disorder that is inserted in the family nucleus by making the environment stressful due to the care overload, the disorder and family breakdown, or by the absence of the self-care of those who perform care.

OF THE FEELINGS AND FRAILTIES THAT SURROUND THE CARE OVERLOAD IN SCHIZOPHRENIA

The search for a new model of mental health care, built under policies linked to citizenship and the right to freedom and social inclusion, has placed on the family the responsibility of caring for their family members. The resumption of care of the person living with mental problems in the family context has raised the family caregivers, who are subjects that offer care to satisfy temporary or permanent functional disability of the individual.

This category will discuss the problem experienced by the caregiver of the person with schizophrenia, the person's incapacity in relation to their independence and autonomy generated by the illness itself that subjectively and objectively burdens the caregivers, compromising their quality of life and their families. This relationship of care causes dependence on the family member, with consequent breakdown of daily routine, appearance of emotional, physical problems, loss of social bond, professional and family breakdown.

The reintegration of the family member who lives with schizophrenia in the family nucleus tends to cause an objective overload to the main family caregiver, due to the breakdown of the caregiver's social and professional routine. The testimonies reveal a troubled context in the face of the caregiver's lack of time to exercise his or her previous leisure activities, self-care, professional activity, separation between the caregiver and other members of the family due to the excessive dependence that the schizophrenic requires, the members of this family place all the responsibility for caring for one person only, which makes them the main family caregiver.

Therefore, the social life of the caregiver changes because they do not have time for themselves and for daily leisure activities, where the routine is modified or ceases to exist. The family member gives him/herself completely to the ill person, failing to provide assistance to the other family members.

The stress generated by the subjective overload of comprehensive care causes a feeling of helplessness, making the caregiver a fragile subject in an activity that he/she does not know how to do, what to do, and who to ask for help. Caring becomes internalized for itself, as an exclusive and exhausting activity, commonly represented as: suffocating, lonely, distressing, discouraging, which can be understood as a depressing process, as seen in the testimonies.

[...] I stay with him all morning, my time is little for me, when I go to work, our son stays with him at home [...] (01 L)

[...] to tell you the truth, I do not have time for myself. I cannot go out, take a walk, nobody wants to be with her, everyone says that she likes her, yet nobody else wants to stay with her, I am the only one who stays with her, I think that's why I got that depression, because she keeps saying the same thing all the time. [...] (02 A)

[...] I spend most of the day with him, I have to order him to brush his teeth, take the medicine, if I do not do that, he does not take [the medicine] or bath, neither change clothes or he wears the same [...] (03 M)

[...] I take care of him all the time. Being at home does not give a break, he does not let you settle down, it's horrible, I always have a headache, he suffocates people like that, there's no rest, I do not trust leaving him alone, because he's disoriented, he does not 'go well' with things [...] (04 E)

[...] I abandoned my family, she did not sleep, I spent all night walking, even taking medicines, listening to voices [...] people calling her name. I wish I had time. As I am married I have to pay attention to her and a teenage daughter, which is at the stage of not wanting to study, there are clients of mine who do not abandon me, but I have lost many clients, it's difficult. People I've been washing for more than five years... [...] (05 Z)

The experimentation of the impotence feeling, revealed by the deponents, is directly associated with the momentary or permanent dependency relationship that the person with schizophrenia tends to cause to the main familiar caregiver because he needs to take the patient's domestic activities for himself, to assist them in the self-care tasks (hygiene and appearance), commonly provoked by the chronification of schizophrenia, where the subject tends to neglect his or her self-care. This excessive dependence is explained by the fact that the negative symptoms generate passivity to the people with schizophrenic disorder in the daily activities, leading to the necessity of execution by the relatives or the caregiver.¹²

The changes in the social routine of the caregiver are commonly modified, giving rise in his life attributions, rules and conditions that cause frailty and suffering to those who experience the caring process in schizophrenia. The daily coexistence with the individual with mental disorder generates physical, emotional and psychological wear on the caregiver.¹³

The lack of time, the overload generated by the care and the family disintegration due to the incomprehension of schizophrenia in the family environment are factors that directly impact the quality of life of the caregiver, as well as the whole family.³

Lima *et al.*¹¹ emphasize that the intra-family relationship becomes worn out when one has a family member with schizophrenia, due to the family's inability to deal with the situation, and care is characterized and experienced as

difficult and unilateral, in the face of the need for help and support of the other family companions. It is this excessive responsibility on the main family caregiver that makes caregiving expensive, compulsory, and exhausting.

It is because of this situation that the caregiver deprives himself of his life to provide a minimally adequate care. Thus, it is inevitable that this family members distance themselves from their social, professional and family activities. That causes the split of social and family relationships.¹³

The caregiver ends up giving up his/her own life, dedicating him/herself exclusively to this ill member. Although it is tiring, the caregiver feels in control for not ceasing to provide care to the person with schizophrenia, giving him/herself a responsibility and a duty to be fulfilled.³

In this way, the caregiver suffers with the person who bears schizophrenia for feeling abandoned as if he or she were the only family member who had the understanding necessary to adjust to the new way of life of this new family nucleus. It is precisely the difficulty of understanding on the part of the other members of the family that will tend to make the familiar environment more troubled, chaotic and disorganized.¹¹

This experience shows the invasive nature of the schizophrenic disorder in the life of the individual that performs the care by provoking the need to modify the life plans of the familiar caregiver.¹⁴

When realizing the difficulty in understanding and dealing with schizophrenia, it is important that the familiar caregiver is able to identify behavioral changes that lead to a crisis episode in the sense of providing better care. By being directly in contact with the person with schizophrenia, the caregiver allows himself to understand atypical episodes of schizophrenic behavior. It is this knowledge that becomes important, because it makes possible changes in the caring approach, according to the following reports:

[...] it's a lot of struggle, when she's in crisis, she only talks about suicide, there are people who persecute her, she already had 3 to 4 hospitalizations besides the crises she already had at home. I try to endure so that she will not be hospitalized, it is too much suffering, she does not care for anything, she does not take care of herself[...] (06 O)

[...] I know he's going to get into a crisis when he gets anxious, he spends the night walking indoors, isolates himself, he's afraid [...] people want to kill him [...] (03 M)

According Giacon and Galera¹⁵, there is no specific development course of schizophrenia because of the broad symptomatology presented that diverges from individual to individual. About 5% of people with schizophrenia have an outbreak during their lifetime, with most people experiencing multiple outbreaks in the course of chronicity of the psychopathology, especially at the onset of the illness.

According to Teixeira³, the family caregiver plays an increasingly important role in the recognition of the symptoms of this disease, since he/she is the one who is directly connected to the person with schizophrenia.

Even in view of the caregiver's relevance in knowing the disease that has as its object of care, Lima et al.16 infer that the knowledge of caregivers about schizophrenia is deficient before the superficial understanding they possess. This misunderstanding, in many cases, can be aggravated by the difficulty of communication between health professionals and family members, where the health guidelines in the consultations or therapeutic follow-up is based on the report of the disease diagnosis, on the medical prescription and on basic guidelines on self-care to be developed, and the family is relegated to the sidelines at the moment of the therapeutic consultation that could provide comprehensible information for the existence of the disease in their family environment, causing uncertainties on the way of dealing with and experiencing this new factor.

The characterization of schizophrenia should be clearly and simply addressed, from the reasons for mental disorganization until the "phases" that make up its positive symptoms: delusions, hallucinations, disorganization of thought and negative symptoms, such as lack of pleasure in activities (anhedonia),social isolation, depression, hopelessness, suicidal ideation. There is usually impairment in the development of work activity, causing dependence on the care of other people to perform activity previously performed by the subject itself.¹⁷

Fear is observed as a real factor, which tends to weaken the familiar caregiver, in the face of possible aggression, possibility of suicidal practice, homicide or the reoccurrence of new crises.

Crisis situations tend to cause a sense of anxiety and fear on the part of the caregiver due to the lack of control that the subject living with schizophrenia presents in moments of mental instability. At this moment, the caregiver feels that caring becomes a risky activity, because of the vulnerability that is exposed in the face of a possible aggression inherent in the reoccurrence of a new crisis, which can result in acts of violence against the caregiver, third parties.

Aggression and suicide are triggered in response to some stressor or to the disease itself. However, aggression to the caregiver or to other family member occurs in extreme situations. The caregiver, in this setting, reveals concern with the provision of objects that may help in the completion of a suicidal or homicidal act.

[...]I'm afraid of him too much. [...] afraid of him assaulting me, doing something [...] these people with these illnesses hurt the people they like the most [...] (01 L)

[...] afraid that he can become restless at any time, doing something with us at home [...] (03 M)

[...] sometimes I'm afraid. Such people are unreliable. When she goes into crisis, she can do us harm. She even said that if I did not shut my mouth, she would stick me with the knife until the handle. I get very scared [...] these people aren't normal [...] (07 S)

[...]I still have the concern of not leaving a sharp object near him. He already managed to pick one up and pointed to himself. That scares me [...] (09 U)

Aggression frequently occurs in response to a triggering factor, seen as threatening and often refers to a myriad of factors that are held responsible for the ultimate practice of violence. The caregiver, for not knowing how to act at this moment, ends up being afraid of the aggressiveness that the person with schizophrenia presents. With the lack of control, impulsivity and disinhibition of acts, there is a reduction of the feeling of fear and guilt. The imbalance can cause the person with schizophrenia to commit suicide.¹⁸

Even in the face of a life that has been described and felt as laborious, exhausting and risky inherent in care, the familiar caregiver demonstrates a feeling common to the familiar bond that binds the caregiver and the one who is cared for, which denies the possibility of death of the patient. The loss of the person living with schizophrenia is felt to be a failure of care, correlated with the error about the form of care, which led the schizophrenic subject to commit an act against his/her own life.

Emotion took over the caregiver as he talked about his fears, making it clear that they would like to be close to their sick relatives at all times and did not want to lose them. Even though the life of the caregiver is overloaded, he/she does not detach itself from this care, because there are bonds of affection and responsibility that unites them.

[...] the thing I am most afraid is that my mother has another crisis [...] she has children who do not thank God, but I thank God for having my mother, even with that problem. I do not want her to die. [...] (08 D)

Even with so many difficulties, family members know that the person with schizophrenia depends on their care; concern and fear arise from a feeling of overprotection and insecurity.³

The sadness and affection expressed by the relative arising from the fear of a possible crisis brings to the fore the feeling of sadness in the face of a possible absence of the schizophrenic familiar. Such sensitivity shows concern for the subject who lives with mental disorder. It is this sensitivity that causes the caregiver not to let go of this care, even though it is, in many cases, laborious and risky.¹³

CONCLUSIONS

When considering the new logic of caring inherent to the process of reconstruction of the mentally ill citizenship, we can consider that the family nucleus has become the main path of conviviality of the subject living with schizophrenia. In detriment of this, the new practices of mental health care and care must comprehend, care

for and instrumentalize the family caregiver in the main activity of care. So that this protagonism is not experienced as suffocating, lonely, distressing and discouraging, which causes changes in social, professional and family activities, generating overload to the main family caregiver, affecting his/her own self-care.

The caregiver feels fragile and powerless when experiencing schizophrenia, unaware of its origin, the reason for its presence in the family and how to deal with and understand it. By experiencing fear as the feeling of the death of the subject living with schizophrenia, the caregiver shows the strong bond of affection that unites them, not wishing that this fear materializes.

Given this context, it is fundamental that healthcare professionals who perform care orient in a clear way, freely exposing the characteristics and problems that the subject with schizophrenia experiences, aiming at a harmonious coexistence on the part of all the members of the family. This care can be shared by all family members. In this way, this family nucleus will be prepared to receive and care for its member, who lives in mental suffering.

It is from the explained above that professionals can better plan their therapeutic practice, giving relevance to the lived experiences, inherent to the care process of the main family caregiver, taking into consideration the feelings and fragilities that involves the care overload in treatment in a new model of mental health care, which aims to take care of the psychosocial aspect.

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