



MEANINGS OF BEING A FAMILY CAREGIVER IN A PSYCHIATRIC HOSPITALIZATION UNIT

SIGNIFICADOS DE SER FAMILIAR CUIDADOR NUMA UNIDADE DE INTERNAÇÃO PSIQUIÁTRICA SIGNIFICADOS DE SER UM FAMILIAR CUIDADOR EM UNA UNIDAD DE HOSPITALIZACIÓN PSIQUIÁTRICA

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ABSTRACT

Objectives: to understand the meanings and feelings of family caregivers of patients hospitalized at a psychiatric unit, and to know the relationship between family and caregivers. **Method:** descriptive study, with a qualitative approach, with 26 caregivers, performed at the Psychiatric Hospital Unit of Dr. Estevam Ponte Hospital, Sobral (CE), Brazil. The data were produced from a semi-structured interview. For the data analysis, there was the thematic analysis. **Results:** the relatives presented with a high level of overload, resulting from the care process. **Conclusion:** it is necessary to elaborate researches aimed at the development and analysis of strategies that will help reduce the daily difficulties of caregivers, promoting the reduction of mental distress in the care activity. **Descriptors:** Mental Health; Caregivers; Family Relationships.

RESUMO

Objetivos: compreender os significados e sentimentos de familiares cuidadores de pacientes internados em uma unidade psiquiátrica e conhecer essa relação de convívio entre familiares e cuidadores. **Método:** estudo descritivo, de abordagem qualitativa, com 26 acompanhantes, realizada na Unidade de Internação Psiquiátrica do Hospital Dr. Estevam Ponte, Sobral (CE), Brasil. Os dados foram produzidos a partir de uma entrevista semiestruturada. Para a análise de dados seguiu-se a análise temática. **Resultados:** foi encontrado um alto nível de sobrecarga pelos familiares, proveniente do cuidar. **Conclusão:** faz-se necessário a elaboração de pesquisas que se dirijam ao desenvolvimento e a análise de estratégias que venham ajudar a reduzir as dificuldades diárias dos cuidadores, promovendo a diminuição do desgaste mental na atividade do cuidado. **Descritores:** Saúde Mental; Cuidadores; Relações Familiares.

RESUMEN

Objetivos: conocer los significados y sentimientos de los cuidadores familiares de los pacientes ingresados en una unidad psiquiátrica y conocer la relación entre las familias y los cuidadores. **Método:** estudio descriptivo, de enfoque cualitativo, con 26 compañeros, conducido en la Unidad de Hospitalización Psiquiátrica del Hospital Dr. Puentes Estevam, Sobral (CE), Brasil. Los datos fueron producidos a partir de una entrevista semiestruturada. Para el análisis de datos, se utilizó el análisis temático. **Resultados:** fue encontrado un alto nivel de sobrecarga por miembros de la familia, de la atención. **Conclusión:** es necesario desarrollar investigaciones enfocadas en las estrategias de desarrollo y análisis que pueden ayudar a reducir las dificultades diarias de los cuidadores, promoviendo la reducción de la tensión mental de la actividad asistencial. **Descritores:** Salud Mental; Cuidadores; Relaciones Familiares.

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INTRODUCTION

Brazilian public mental health policies prioritize de-hospitalization and deinstitutionalization of care, making the family the patient's primary caregiver.¹ In those circumstances, the family can be defined as a society organization that has undergone changes throughout history and has several functions at the same time and place. Even presenting some disagreements, the family is unique in its predominant development of sociability, affectivity and physical well-being of its members, especially during childhood and adolescence.²

In that context, it is essential to identify the families' understanding of mental illness and possible forms of health care, knowing their meanings and experiences. It is also important to support the adaptation to a new lifestyle and the significant change that can occur in the whole family affected by some mental disorder.^{3,4}

In psychiatric care, it is fundamental that "the professional has an empathic capacity for the other's suffering, an internal willingness to listen, the flexibility to change his/her points of view", connecting the family in the search for the therapeutic process. In turn, Psychiatric Nursing can be defined as "an interpersonal process that promotes and maintains a patient's behavior (individual, family or community)".⁵

Clinical nursing care, as well as the new paradigms instituted by psychiatric reform and the concepts of psychic suffering, must permeate the conceptual sphere of what professional practice is. It is essential to recognize professionals, family members and service users as protagonists in the management of their autonomy and, therefore, attention receivers from a practice that provides interdisciplinarity, dignity, listening, creativity, dignity and sharing of knowledge.⁶

The hospitalization can be seen as a necessary attitude so that the relative realizes how the disease influences their daily life and their choices. There is a feeling of resistance in hospitalization, but in the face of the difficulties of the out-of-hospital network, the disorganization of the subject and the risks to his/her completeness and of others, the relatives end up accepting hospitalization.⁷

In that context, this study aims to:

- Understand the meanings and feelings of family caregivers of patients hospitalized at a psychiatric unit.

- Know the relationship between family and caregivers.

METHOD

Descriptive study, with qualitative approach⁹, carried out at a psychiatric inpatient unit of a general reference hospital located in the northern region of the State of Ceará and in the municipality of Sobral (CE), Brazil, which serves people with mental illnesses.

The subjects were the relatives who accompanied the patients hospitalized at a psychiatric hospitalization unit of a reference hospital in the city of Sobral (CE), Brazil. There was exclusion of family members whose relatives came from other municipalities or individuals who did not have the cognitive conditions to participate in the interview.

The interviews were carried out through a semi-structured script, which consisted of open questions. With that instrument, the researcher has a guide with guiding questions, has relative flexibility and does not have to follow the order foreseen in the guide and new questions can be formulated.¹⁰

In order to organize the information collected, a recorder was used as an aid tool for reliable transcription of the information. The interviews were individual according to the agreement of those subjects to participate in the study, expressing their authorization in writing through the Informed Consent Form (ICF). The interviews occurred between September and October 2012.

For the data analysis, there was the thematic analysis, divided into three stages. The pre-analysis is the choice of information, floating reading and intense contact with the material. The second stage is the exploration of the material, by gathering the data to understand the nature of the text; and the third step consists of the treatment of the data obtained and the interpretation based on personal understandings and on theoretical reference.¹¹

There was analysis of the obtained information through a textual description of the information and the construction of units of meaning, that is, analytical categories, through which they were interpreted, discussed and analyzed.

In consideration of the ethical and administrative aspects of scientific research, the work was approved by the Research Ethics Committee of the State University of Vale do Acaraú (UEVA), with protocol number 151,133, and, at all stages, it complied with the recommendations of Resolution 466/2012

referring to researches developed with humans.

RESULTS AND DISCUSSION

The results and discussion are subdivided by thematic axes and refer to data collected from 26 caregivers, six men and 20 women, aged 22 to 58 years (mean of 38.5 years). In relation to the degree of kinship with the patients under care, most of them were brothers (nine), followed by mothers (six) and daughters (three).

◆ The meanings of being a caregiver

Responses from caregivers included both positive as negative feelings about patient care. Among the positive feelings, there were zeal, affection and gratification, which revealed the willingness of the caregiver to be with his/her loved one for as long as possible. Even if the task is difficult, the relationship of affection between the caregiver and the patient becomes a factor that softens the difficulties that caring imposes, as we can observe:

Care is trying to put yourself in the place of the other person you are trying to help, is liking, loving your neighbor, is trying to help him in the best way (F6).

[...] it is important because you see there are people who have more problems than we do. You will see the others' problems, and that not only do we have problems (F7).

It is to be always present, and to help when he needs, is to listen to what he wants to speak, his relieves, it is [...] (F14).

Generally, in the family environment, there are people who are become responsible for certain roles, such as caregiver roles. However, for that choice, there is a hierarchy that depends on the following factors: affectivity between patient and caregiver, personality of the caregiver, generational factors, age, gender, relationship with the patient, financial situation of the caregiver, place of care caregiver's residence, among others.¹²

In that context, the family becomes the most direct source of social support to the individual. The family is the support and the most privileged place for the deprived person, with spouses and children in the first line of care, considered informal caregivers. Thus, any change in one of its members will affect the family as a whole. Hence, the disease process, besides affecting the individual in his/her holistic dimension, also causes instability to the family cell.¹³

In that way, the interviewees can perceive the importance of the act of caring that they provide, not only for the patient, but also for

themselves as people, as the following statements show:

Here I see several patients without a caregiver, which is dangerous for both the hospital as for the patient, what if he slips and something happens, because you know that here are several stubborn patients. Care is very important for both the person as the family (F1).

As I am taking care of my brother, I feel like I am his father, I am always guiding him to get out of this crisis he is going through. I feel happy, for nowadays I see that he is getting better [...] (F5).

Given the speeches, we perceive the emotional involvement of family members. In recent years, the family has been the subject of numerous debates involving questions about the new arrangements and the different forms of relationship and coexistence. In the last decade, the interventions of specialized professionals in the family have also intensified in the clinical and social context in situations of illness, risk and conflict.¹⁴

Pain, difficulty, caring concerns lead to the search for meaning for that act. It is important to give a meaning to suffering in order to learn and grow from the existential point of view. Growth, gratitude, giving, love, duty, reparation, obligation, conflict-making, redemption of omissions, exchange, needs for affection or love, mission, potential discovery, learning, God's will, are meanings that our interviewees gave to the care act:

Care is when you are with the person, it is like taking care of a baby, because when a person loses his/her mind, it is like a 3, 2-year-old child. (F15).

It feels good to be good to others, to be helping. I am happy because we can save many lives of the people who stay there (F18).

When assuming the role of caregivers, they become responsible for the well-being and care of the sick family member, which triggers feelings of satisfaction and well-being. Faced with the disease situation, the family directs its energy and does everything in its power to maintain or change as little as possible the family functioning. Thus, caregiver satisfaction represents the subjective perception of desirable gains and positive aspects associated with the informal care process.¹³

Care is a science practiced in health institutions by specialized professionals and lay people within the family and community context. The family member can help the person in psychological distress in the care aimed at objectifying his/her daily activities: self-care, work, leisure and extended socio-

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cultural participation in home and community contexts. In that sense, he/she develops a collaborative role in patient care among professionals of mental health equipment.⁷

Spirituality also gives the care act a meaning. We can reveal that fact in the following speech:

I do not feel sad, because thanks to GOD, I first trust GOD, I have a lot of faith that when I leave here I am going to leave, I will be more joyful, with health (F25).

In this category, specifically, our interviewees showed the strength of religious and moral precepts to signify caring. They confirmed the existing researches in the area, which see religion and spirituality as motivating and helpful elements in coping with the difficulties encountered in care, while both give meaning to life.¹³

Caregivers, when questioned about feelings from the moment they became responsible for the care, revealed an ambiguous sense of satisfaction from the fulfilled duty and, at the same time, perceived wear by the amount of tasks they need to perform. Therefore, innumerable feelings that permeate the care process influence the meaning of being a caregiver.¹⁶

◆ Main difficulties encountered in relation to care

The family caregivers revealed that the following difficulties in the care process: the family members' non-acceptance of the disease; abandonment of other family members, because they are in an inpatient setting; resistance to pharmacological treatment by patients; fear and stigma of being at a psychiatric sector, as caregiver. The following statements describe it:

I have never been here, it is the first time, we get a little scared too [...] People talking about having mental problem, I do not know, I am a bit scared too (laughs) [...] F11).

No, I feel good, and at the same time sad when seeing those people, because it is very strange to see this kind of people taking these medicines, but I feel happy because I am able to help her, the person I like (cry) [...] (F22).

The impotence to attend individuals in crises outside the hospital environment is clear and, at the same time, there is a feeling of resistance to hospitalization. The relatives end up accepting the hospitalization before the disintegration of the subject and the risks to his/her integrality, as well as of the others.

Being a caregiver of a person with mental disorder leaves the family member in situations associated with the symptoms of

the illness, in which he/she is often unprepared to cope. Those situations include uncontrolled behaviors of the sick family member, aggressiveness and restlessness, causing a climate of uneasiness that goes beyond the known patterns they were used to, thus affecting the entire family structure.¹⁷

Through such situations, the caregivers seek the psychiatric hospitalization service, where they express their feelings of sadness and anguish, when at the hospital, as in the following statements:

I think it is bad, really bad, I do not think it is good to be in a hospital, taking care of someone. I only come because she is my sister, otherwise, I would not come. It makes me sad, sad [...] (F16).

When I enter, I first pray, because I am sad, it is sad to see a person here in the hospital, it is a suffering, I think. The sick person suffers a lot, I think. I feel bad, to see the others' suffering (F21).

For me it is awful, because for me I have never seen a worse environment [...] I work all day trying to forget [...] (F24).

The participants reported that they have severe suffering with the hospitalization of the family member at a psychiatric institution, and that they only accept it for lacking options, such as in cases of crises when the family members cannot do anything at home.

At many times, feelings such as fear of the possibility of death of the other and even physical and subjective tiredness come. Nevertheless, close to patients, caregivers always try to demonstrate that things are okay even when they are not. Caregiver discourses are in line with the literature, which points out that the emotional state of caregivers affects the emotional state of the patients.¹⁵

With that, the treatment is a fundamental element in the patients' life. Being hospitalized, or not, completely changes the daily life of that population, especially for those who live the process of hospitalization and readmission. The hospitalization is not only a form of treatment for the patient, since the relatives consider the hospitalization a way to live with tranquility and rest.¹⁸

Therefore, it is important that nurses or other professional from the multidisciplinary team orientate, at the time of hospital discharge, the rights and safe trajectories to search for resources, either in the community or in the Health System, to facilitate care. It is necessary, then, to elaborate and implement a plan of orientations for the caregiver, aiming at the construction of a

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strategy of support and aid for him/her and the patient.¹⁵

The family member may also feel anxious for being unable to deal with some of the presented attitudes, such as continuous and disordered speech or the unpredictability of their actions, the perception of the patient's increasingly deteriorated life, and excessive silence. Many of them do not feel content to see their relative become a compromised, dependent, unprotected and constrained person of all nature, who was previously brilliant, full of life projects and well integrated into society. The following reports express that situation:

It is horrible, it is horrible to me, I have never been through it [crying] [...] I never imagined myself with my son in such a situation. I never thought I would be, one day, with him here. It makes me sad, because we see people there (patients), we wonder, will he be like that too?! The good thing is that he will be treated (F14).

When I see him like this, he gives makes me feel so sad, he only speaks like that, meaningless things. Everything he does there, I am very worried about him. (F17).

Given the speeches, we perceive the non-acceptance of the disease. Although, at the beginning, it is difficult to accept or even perceive the symptoms, with the evolution of the disease, people slowly begin to accept the condition, although most of interviewees do not completely accept that, especially those caregivers who are mothers and who do not conform over the years, believing in the healing possibilities.

The connection to dependent family member breaks out in the life trajectory demanding changes, adaptations with training and consolidation of knowledge to deal with the new imposing reality.¹⁵

The individual with mental disorder and his/her family should be oriented about the disease and its characteristics, about its prognosis and diagnosis, because accepting the disease is essential to a successful treatment, which, generally, lasts an indeterminate time, requiring knowledge. In order to establish a bond of trust and greater adherence to treatment, the health team must inform and guide the family in a clear and objective manner.⁷

The dependency of a family member represents a crisis that generates stress, which threatens the balance of the normal personal, family and social functioning. That situation can cause a psychosocial disorganization, often accompanied by

negative feelings such as fear, guilt and anxiety.¹⁵

Family members experience ambiguity regarding the relative staying at home or at the hospital. They would like him/her to remain at home to receive affection and care, while, at the same time, they think the hospital is an alternative to ensure control of the crisis and medication administration, following the treatment, as shown by these lines:

The doctor and the nurse help me. When I am alone with him at home, he does not accept the medication and he puts everything "into the bush" and he is very aggressive with me, he does not answer me, and, here, he is better because the doctor is taking care of him well (F3).

I feel happier because at home I do not have the medicine to give to him, because here thanks to God he is in the doctor's hands. I feel more confident, conformed and protected. (F10).

A significant part of the care that the dependents need, are assured by the family members, are of great complexity and intensity, thus pointing to the great relevance of support in nursing care, facilitators of the healthy transitions of that target population.¹⁸

In that context, many families seek, in the health system, qualified information and emotional support aimed at alleviating problems, which increase when the disease is unknown, and how it affect the person's life. Difficulties in daily living with caring may persist if coupled with the caregiver's perception that nothing can alleviate his/her suffering.⁷

Reflecting on treatment requires a committed relationship among the user, the family and the staff, the organization of a more human and singular connection, seeking a service that gets close to the needs of families and their users. Therefore, actions are necessary, in addition to a practical redirection, being the commitment and co-responsibility in the achievement of a collective care important.¹³

The composition of the partnership between the family members and their integration into the patient's treatment were punctuated as actions that the team must constantly discuss, so that dialogue and mutual understanding contribute to the division of tasks and responsibilities in mental health care among those involved in that relationship.¹⁹

In view of those changes reported by the family members, the interviews showed that the relatives developed resilience to deal with

the situation. In that way, the suffering and the challenges of caring for a person outside therapeutic possibilities have caused the relatives to develop self-knowledge and to find unknown potentialities to face the situation.²⁰

Therefore, there should be the implantation of mental health services increasingly closer to the social reality in which they are inserted, understanding the socioeconomic and cultural context of the families that need their action; and health professionals who are caregivers in a dynamic way, which provides measures that may improve the quality of life.²¹

◆ Changes in the caregiver's routine

When talking about personal life, most participants reported changes after assuming the role of caregiver. There were discordances in the speeches: for some interviewees, the change in personal life was negative; for others, it was positive.

The negative change associated with loss of employment, lack of freedom and reduction of social life. The interviewees neglected their life or part of it, which can generate sensations of sadness, isolation, loss of freedom and carelessness. Highlighting the positive aspects, we found the power of union in the delicate moments of crises, as in the following speech:

It is very important to take care of our family, right? Because he is my uncle, and I have never been to reach him and give him the blessing, now I have more access to him, and this access was very important because it is at the time that he needs it most. Modified for the better, because I feel better, we ended up creating a friendship we did not have, today we are closer (F1).

The family system can change as the patient develops the pathology, since there is a reversal of roles among the family, changing the dynamics of the group and its structure. In families that no longer work well, difficulties in relationships may persist or increase, although there are cases of family members who reconcile relationships after a period of crisis, and the disease, in those circumstances, has the function of uniting.²⁰

Patients remain at home for a longer period of time, becoming part of the family routine, where they started to guarantee their basic needs; monitor their daily activities; accompany them to health services; administer their medication; deal with their problematic behaviors and crisis episodes, offering social support; afford financially; and, finally, overcome the impact on the social and professional life of the family

member, besides the difficulties of those tasks with the individual with mental disorder.²¹

According to that referential, some of the interviewees showed negative points regarding the care commitment, without providing the time to organize their routine, as in those speeches:

Whether or not we leave our obligations, because he needs a caregiver. I do not feel good, because it catches us at once, it "deprograms" us (F12).

I left my son at home, the father has to go to work, I work too, but I am on vacation I can stay here taking care of him and if I had to work it would be worse. It takes my time, he has to be accompanied and I was not going to leave him alone! (F14).

The role of the patient's primary caregiver and support has been delegated to the family, exercising unpreparedly the help, knowledge and support for the task, resulting in great burden on caregivers by causing them frustration due to the non-compliance with the expected independence process for an adult.²²

Several changes in the physical, psychological and social dimensions of the caregiver come along with the care, at home, of a dependent family member. One of the most affected and highlighted points is the social support network due to the lack of opportunities for leisure activities, the impossibility of working outside the home and changes in family routines.²³

The following statements show the difficulties that the caregivers have to reconcile their daily activities, in moments of crisis of the individual with mental disorder, where some end up quitting the job, as the interviewees declared:

Great responsibility [...] I abandon everything to take care of her, my work [...] I am more her than the work, to take care of, right?! (F16).

I quitted the job to be here with him, but that is not all. It is all his health, his life. It is no use going being in a job, away, making a lot of money, if he is here, needing my love and affection, I would rather leave everything and pay attention to him (F17).

In addition to the learning demands for care, the noticeable change in the caregiver's life can be understood, in the conception of the study subjects, as the aspects that were modified in his/her lives, from the moment he/she became responsible for the care of the dependent family member. Among those changes, there were the work abandonment, generating economic restrictions, the reduction of social interaction with neighbors,

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friends and other relatives and, consequently, leisure moments.¹⁵

Recognizing oneself as responsible for care requires dedication and changes in the way of life. Thus, daily and necessary activities, including for survival, are compromised. Taking care of a dependent person changes the lifestyle according to the other's needs, the leisure activities and social life end up being altered or canceled, causing the feeling of not having autonomy to manage his/her own life and having to live in function of the other.¹⁸

The literature has often evaluated the overload in two dimensions: under the objective lens, characterizing it as the observable consequence of caring, due to the excess of patient care, changes in the family routine, coordination of problematic behaviors, financial expenses; and under the subjective range, in the aspects related to the degree of the perceived or detected discomfort by the family member, in the routine of patient care in the tasks, in dealing with problematic situations and in the concern with the patient; it involves the emotional reaction and the feeling of being subjected to an overload.²¹

Caregivers report fatigue, weariness, revolt, and depression. In addition to those triggers of overload, in the speech we can find complaints from the main caregivers because they do not have anyone to share responsibility for the care, and because they do not find support from other family members, as in the following statement:

I am so worried because I am the only one who goes after everything [...] I am very worried because I am the man and the woman to go after everything in life [...] (cry) (F10).

The change in daily activities, as already recognized by the Ministry of Health, ended up overwhelming those caregivers who suffered physical fatigue, depression, work abandonment, changes in marital and family life, hurting not only themselves but also the people cared for. Thus, the new assignments, often imposed without proper guidance, have generated negative impacts on the caregiver's quality of life.¹⁵

Overload (or family burden) can appear in its objective and subjective dimensions. The objective relates to the negative consequences of the presence of a person with mental disorder in the family, such as the accumulation of tasks, increase in financial costs, limiting daily activities and weakening relationships among family members, among others. Subjective overload

refers to the personal perception of the family member about the experience of living with the patient, their feelings about responsibility and the concerns that surround health care.²⁴

In their speeches, caregivers point out that, due to lack of time, among other factors, they move away from social interaction, or people move away from them, which makes them feel alone. Listening to them, offering them a moment to unburden their fears and anxieties, is important to assist in the adaptation and acceptance of their new existential project, through the re-signification of the experienced situation.¹⁸

The task of caring and being a family member at the same time requires a great deal of readiness and patience, for he/she is often the only family member who welcomes the patient. Caring for a patient in the family context requires a process of adaptation of all members, so the actions manifested by one member influence, and are influenced by the others, affecting the entire family system because the family members are interconnected and depend on each other.²⁰

Caregivers point out that they lose their freedom even in relation to other relatives, that is, the more the patient needs care or feels alone, more "isolated" they tend to be at home to take care of him/her and, consequently, more isolated they feel from other family members and the social context, changing leisure opportunities and daily habits.¹⁸

As a consequence of such responsibility, some of the interviewees affirmed a certain conflict, regarding personal life, for having assumed the role of caregiver. It directly interferes with the quality of life of the family caregiver, as in the speech described below:

I suffer from osteoporosis, and I do not even have time to go to the doctor, I feel a great responsibility to take care of a patient who has mental problems. My time is only for him, but I worry more about him than with others (F3).

In that context, the family member who plays the caregiver role of the sick person may be subject to illness because of his/her function. That fact shows us the importance and the need to receive appropriate and dignified emotional and psychological support so that the caregiver feels strengthened and prepared to act in that process.²⁴

According to the presented interviews, the difficulties and the overload imposed by the daily living with the individual with mental disorder at home and in the routine, as well as the suffering of that coexistence, are evident. Thus, health service professionals

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need to focus their attention also on the caregiver, aiming at establishing a service capable of meeting the real needs of the family, as the main care unit.²⁵

Although for many authors, deinstitutionalization and psychiatric reform are recent movements, we already know that family members need support. Family overload was present in the daily relations of caregivers who, often, through concern, social obligation, the affection, care for family members with mental disorder and are overloaded, forgetting to take care of themselves or not having future expectations of change.²¹

According to that fact, and with the interviewees, we realized that health professionals should be sensitive to the cause, should perceive in both the looks as the silence the search for help and have active methodologies that strengthen the spaces of mental health and the links, stimulating autonomy and sharing of care. Finally, we emphasize the importance of network assistance. Mental health professionals should use the health network of the municipality to ensure comprehensive care and allow people the possibilities to guide them to the mental health center.²⁶

CONCLUSION

Patients and families have become increasingly the main providers of mental health care, with judicious psychiatric hospitalizations and marked by their short period of duration.

Taking into account such values, we found a high level of overload by the relatives, from the caring act. In that way, there is need to develop researches directed to the development and the analysis of strategies that will help to reduce the daily difficulties of the caregivers, promoting the reduction of the mental exhaustion in the care activity, and consequently, the overload.

In psychiatric care, the role of nurses goes beyond their technical attributions, being a fundamental piece to maintain and create a therapeutic environment, establishing interpersonal relationships with family members, who need a different look, and also with patients.

The study worked with a small sample, in view of the large contingent that faces such reality in Brazil. For dealing with a problem of multicausal origin, within unequal contexts, it is not a situation of easy resolution. Thus, the research allowed moments of listening without pretensions of judgments, in order to

know the meanings of the family caregiver of a person with mental disorder, highlighting the difficulties and the routine of those caregivers in the permanent exercise of caring.

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