

CARING FOR THE PERSON WITH MENTAL DISORDER ACCORDING TO THE FAMILY'S UNDERSTANDING

Cuidado à pessoa com transtorno mental na compreensão do familiar

Cuidado a la persona con trastorno mental en la comprensión del familiar

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ABSTRACT

Objective: To understand how the family cares for the person with mental disorder. **Methods:** Qualitative research, exploratory and descriptive, carried out in a Psychosocial Care Unit. The production of data occurred, from May to July, 2017, through semi-structured interviews with 20 relatives. **Results:** Based on the analyzes, the meanings in relation to the care provided were highlighted, being: care as a form of affection, love, compassion; care as a lookout, attention to something, or refer to care, how to administer medication, care for personal hygiene and food. There was evidence of an illness in the family that occurred from the symptoms of the disease, and also the lack of support and social support to caregivers. Yet, the issue of religion / faith / spirituality emerged as supportive devices. **Conclusion:** it was considered that the care provided by the relative to the person with mental disorder is unique, according to each reality.

Descriptors: Care, mental disorder, family.

RESUMO

Objetivo: Compreender como o familiar cuida da pessoa com transtorno mental. **Métodos:** Pesquisa de abordagem qualitativa, do tipo exploratória e descritiva, realizada em uma Unidade de Atenção Psicossocial. A produção de dados ocorreu, no período de maio a julho de 2017, por meio de entrevistas semiestruturadas com 20 familiares. **Resultados:** A partir das análises, destacaram-se os significados em relação ao cuidado prestado, sendo eles: cuidado como forma de carinho, amor, compaixão; cuidado como forma de vigia, estar atento a algo, ou ainda se referem ao cuidado, como administrar a medicação, cuidar da higiene pessoal e alimentação. Evidenciou-se

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um adoecimento dos familiares, que ocorreram a partir dos sintomas da doença e, também, a falta de apoio e suporte social aos cuidadores. Ainda, emergiu a questão da religião/fé/espiritualidade como dispositivos de suporte. **Conclusão:** Considerou-se que o cuidado prestado pelo familiar à pessoa com transtorno mental é singular, segundo cada realidade.

Descritores: Cuidado, transtorno mental, família.

RESUMÉN

Objetivo: comprender cómo el familiar cuida de la persona con trastorno mental. **Métodos:** investigación de abordaje cualitativa, tipo exploratoria y descriptiva, llevada a cabo en una Unidad de Atención Psicosocial. La producción de datos ocurrió en el periodo de mayo a julio de 2017, por medio de encuestas semiestructuradas, con 20 familiares. **Resultados:** a partir de los análisis, se destacan los significados en relación al cuidado prestado, siendo ellos: cuidado como forma de cariño, amor, compasión; cuidado como forma de vigilia, estar atento a algo, o aún se refieren al cuidado como administrar la medicación, cuidar de la higiene persona y alimentación. Se evidenció una enfermedad de los familiares, que ocurrieron a partir de los síntomas de la enfermedad y también la falta de apoyo y soporte social a los cuidadores. Aun, emergió la cuestión de la religión/fé/espiritualidad como dispositivos de soporte. **Conclusión:** se consideró que el cuidado prestado por el familiar a la persona con transtorno mental es singular, según cada realidad.

Descriptoros: Cuidado, transtorno mental, familia.

INTRODUCTION

In mental health care understood from the Brazilian Psychiatric Reform, Law No. 10.216²¹, the family is inserted as a possibility of support and welcome to the person with a mental disorder. The family has several configurations, in other words, in addition to its capacity to produce subjectivities, it is also a unit of care and internal redistribution of resources, moreover, it has been daily built and rebuilt within relationships and negotiations between itself, its members and society.¹

The family can be considered as a fundamental social actor for the effectiveness of psychiatric care, and also understood as a group with great potential for welcoming and socializing its members over again.² It is not only an indispensable actor in this context of welcoming and resocialization, but also configures itself, as a public construction and has an important role in structuring society in its social, political and economic aspects.¹

Historically, the family did not play the role of caregiver for two reasons. The first one is due to the distance in which the psychiatric hospitals were allocated, making it difficult to follow the treatment and, second, is that the family was considered the producer of disease, once the member became ill, it was responsible for all the problems of the family nucleus. The Psychiatric Reform allowed a new look at family members, and this segment gained responsibilities and came to occupy a relevant position in the context of mental health care because the person with the disorder is no longer seen in isolation.³

For the effective participation of the family in care, planning with the team is necessary to establish a relationship of trust, bond, and acceptance by both the user in adhering to treatment and the family to strengthen

co-responsible care.⁴ However, despite the changes in mental health policy, there is a distance from what is proposed and what family members experience in their daily lives.⁵

The return of the person in the family and social life after extended periods of institutionalization puts in question the difficulty of resuming care for family members.⁶ This model of caring represents a challenge for the family, as it involves feelings intrinsic to their reality.² These challenges meet the ability of family members to adapt to this new reality, in other words, when the responsibility for primary care is demanded, the family needs support and preparation.

The interest in the theme regarding the care of people with mental disorders emerged while working as residents in a Psychosocial Care Unit, and this experience allowed an approximation with the reality of the family's role in this framework. Hence, this study aims to understand how the family member cares for the person bearing a mental disorder.

METHODS

This is a descriptive-exploratory study with a qualitative approach. The qualitative approach meets the object of study, as it is conducive to investigations that highlight delimited groups and segments and enables an analysis of the relationships, beliefs, perceptions of the subjects involved about what they think, live or happen to them.⁷ Exploratory, because it comprises several phases of the construction of a research trajectory, as an example: the choice of the research topic, definition of the object and objectives, field exploration, among others. And, descriptive because it seeks the meanings in the enunciative sequences and actions to arrive at a perception and explanation of the study.⁷

The research was conducted in a Psychosocial Care Unit of a large teaching hospital in a city in the State of *Rio Grande do Sul*, Brazil. This unit serves people from the region that covers the 4th Regional Health Coordination, in situations of severe mental disorders, such as bipolar affective disorder, schizophrenia, depression, among others. It currently has a team of permanent professionals composed of a psychologist, an occupational therapist, a social worker, 2 doctors, 11 nurses, 15 nurse technicians, and 5 nurse assistants. Besides, it has the insertion of the Integrated Multi-professional Health Residency Program, with two resident nurses, two psychologists, a social worker, and two occupational therapists; and four medical residents.

The choice of this scenario is justified, because it is observed, in the daily work, the absence of studies and interventions concerning the relatives of people hospitalized in the reference hospital. Also, it is perceived in the place of work, numerous reports of family members regarding the difficulties faced by them regarding the care provided to people with mental disorders.

The study included 20 family members of hospitalized users during the data collection period, which was held

from May to July 2017. The following inclusion criteria were chosen: family members identified primarily by the medical record and most closely related to the user, in other words, those who were present in the hospital visits during and/or in family groups of the unit. And, as exclusion criteria: family members who did not respond to the contact of the researchers after three attempts; and family members of users who were discharged before the interview was scheduled. The choice of exclusion criteria was due to the nature of the service, as there is a rotation of hospitalizations, making it difficult to schedule and locate family members.

Family members who participated in the study answered a semi-structured interview consisting of questions about sociodemographic data (gender, age, occupation, education, family income, living conditions, religion, number of hospitalizations) and guiding questions regarding care provided by the relative to the person with a mental disorder: how is it for you to take care of your relative? What care is this?

The participants' speeches were recorded with the aid of a digital instrument and later transcribed for analysis and reading of the data. The speech fragments were identified in the results by the letter 'R' (Relative), followed by the number corresponding to the order of the interview (R1, R2 ... R20).

The data were analyzed by Minayo's Operative Proposal, which is characterized by two operational moments. The first included the fundamental determinations of the study, which is mapped in the exploratory phase of the investigation. The second was called interpretive, as it consisted of the starting point and the arrival point of the investigation, representing the encounter with the empirical facts.⁷

The study was conducted in accordance with the Resolution No. 466/2012 from the National Health Council, which deals with guidelines and regulatory standards for research with human beings²⁰ approved by the Research Ethics Committee of the institution according to the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 65186917.8.0000.5346 and Legal Opinion No. 2,009,636. The data production process was performed after the signing of the Informed Consent Form (ICF) by the family members who participated in the study, being signed in two copies, one made available to the participant and the other held by the researchers. The ICF was read aloud so that family members understood the content and decided whether or not to participate.

RESULTS AND DISCUSSION

Twenty family members have participated of this study. Most of them (70%) represented women as caregivers, and 30% were men. Concerning the hospitalized person, 40% referred as being mothers, 30% sister/brother, 20% husband/wife, 5% son/daughter and 5% father. Regarding the number of hospitalizations, 60% reported from 1 to

3 hospitalizations, 30% from 4 to 8 hospitalizations and 10% from 10 or more hospitalizations.

The age group was from 31 to 68 years old. Observing the education, 30% reported having incomplete elementary school, 10% had completed elementary school, 5% completed high school, 25% completed high school and 30% completed higher education. Concerning the income, 60% reported family income of up to three minimum wages, 20% reported income of up to one minimum wage, 5% reported less than one minimum wage and 15% more than four minimum wages. About housing conditions, 75% reported home ownership, 15% rented home and 10% ceded home. Regarding the religion, 45% reported being Catholic, 35% evangelical, 10% reported that they have no religion, 5% spiritualist and 5% could not answer.

After analyzing the data, three categories emerged: "I care because I love": fraternal feelings as a form of caring; "I also have my moments of weakness": the family member's health condition while facing the disease instability; "You must believe in a spiritual being": religion/faith/spirituality as a care support.

"I care because I love": fraternal feelings as a form of caring

Family members highlighted a set of situations regarding care and the understanding of this meaning concerning of the person with a mental disorder. They point out issues that involve feelings such as love, affection, affection, and compassion.

I "take care because I love", son for me is more than anything, if I could exchange life with her I would [...]. Caring is giving love, care, and attention. (R1)

I have a job, but I like to do, take care of her. (R5)

It is not easy, we do not have a training in this area, but it comes to bring the affection, the warmth that the person so much needs. (R14)

Caring for the other belongs to the structure of human life, it can be seen as attitudes of loving, harmonious and protective relationships.⁸ Caring causes emotions/feelings regarding the subjective dimension of people, encompassing emotional issues involved and developed in this process.⁹

The family's role concerning people with mental disorders can be understood through actions such as being present, being a provider of affection, companionship, and encouragement. Besides, the role may be linked to attitudes of zeal, protection, affection, and understanding.² Loving, protective, and caring care are existential, that is, objective data on the structure of time and their relationships. They are prior to any other act and submit to everything we undertake.⁸ Thus, the family's participation in care is

essential, because it is in this context that its members seek support and envision possibilities for interventions.²

It can be seen from the speech feeling of pleasure when the subject refers to the care provided. This feeling meets the availability of family time to give attention and support that both the person with mental disorder needs. The presence of this affection can contribute to an improvement in the quality of life of both the caregiver and the person who suffers through this process. This exchange of feelings favors the daily life of these people, minimizing the accumulation of demands that such situation reveals.

Another element present in the speech of family members is care as a form of vigilance, being aware of something, or even refer to care, such as administering medication, taking care of personal hygiene and food.

I do everything for her, if I need to bath, if I need to give medicine in the mouth. (R4)

When he was home it was all me [...] I gave food in the mouth. [...] The bath at home was me, the clothes I changed, everything was me. (R8)

She is not alone in the house for a second, so I have to be with her always. (R9)

This caution I say is about her avoiding foolishness. (R16)

I take care of him, give him the medicine, see if he swallowed it all. [...]. It's me who bathes him, because he doesn't know how to clean himself up. (R20)

It is identified by the statements that self-care activities, such as bathing, eating, and medication, are impaired, having to have daily intervention by caregivers. The continuous demand for the supervision of these activities requires responsibilities and, as a result, can cause overload to family members.

From the moment the family members face this daily situation, they undergo a significant change in their lives, having to constantly adapt to the new ways of conducting their daily lives.¹⁰ From this context, such overload emerges caused by the constant accountability of family members and the difficulties of performing their caregiving role.¹¹

There is a dependence of the person with mental disorders on the care provided by family members, and this requires the family a constant management of activities. In addition to this continuous management, there is a need to develop the exercise of tolerance and patience with these subjects.¹²

The family member who cares becomes perpetuated with a daily outlined by concerns, so mental disorders are experienced collectively. When a family member falls ill,

all of their webs of relationships change, with the family most often being an individual's primary insertion group.¹⁰

This daily configuration of care is associated with the daily effort of family members to provide assistance to their members, leading to an objective burden. The objective overload present in the reports meets the supervision of tasks that are performed by family members, such as bathing, eating, and medication. Continuous supervision interferes with the caregiver's social and professional life, such as the symptoms of the disease and the subject's lack of autonomy; however, if there is a good relationship between the user and the family member, the feeling of objective overload may alleviate.¹¹

"I also have my moments of weakness": the family member's health condition while facing the disease instability

In the findings of the research, it was present in the speeches of respondents a path of illness and an overload of family members who care for a person with a mental disorder. This disease presented after the symptoms of the disease and also due to the lack of family and social support of these caregivers.

I can't squat anymore, he pushes me, already knocked me down twice. When the disease started, I had no such problem. (R2)

It's hard because I'm getting older, I have little hearing. (R3)

I couldn't take care of him all the time alone, I was tired, I was already getting sick from my head. (R8)

I am still recovering; I am taking the medicines [...]. I'm afraid of falling again and she's like that and no one can help anybody [...] It's hard for me, because "I also have my moments of weakness", sometimes I don't have the strength to move on, and I still have to advise her. (R11)

I wanted to vent, talk, I cry a lot. When I go to the shower, I cry a lot, I talk to God. I wanted help [...]. I have depression [...]. I get sad. [...] I am glad that he is here, because at least I can get some rest [...]. I get exhausted. (R20)

Living with a person with mental disorders causes a strain on the family, especially when there are acute manifestations of the disease, which ends up generating a physical and emotional overload for the family member.¹³ Physical and emotional overload is characterized by subjective overload, because there is a feeling of weight and wear.¹¹ Physical and emotional wear has to do with the number of activities performed by caregivers, which consequently implies their self-care and self-esteem.⁶

In the statements, it is perceived feelings of helplessness of these family members. When they bring the difficulties of care and the accumulation of overload, often have insufficient family support to help and share this daily exhaustion. The State and the support network for these family members must be committed and have a more sensitive look for these caregivers, because care is the experience of the relationship between the predisposition of care and the need to be cared for.⁸

Considering the speeches and studies, it is possible to understand the daily exhaustion of these family members, suffering that depends not only on primary care but on the support and sharing of daily events. There is an intense workload that can cause physical and emotional distress, yet this responsibility directly implies the personal and professional lives of these caregivers. The care required for family members is not characterized as salaried work, but voluntary, implying time, resources, which is not explicit and not covered by public policies.

It is also noticed, as in R20 speech "I am glad that he is here" that hospitalization is sometimes the moment when the family member rests and renews themselves, thus bringing provisional support. The nature of hospitalization is to stabilize the acute conditions, but as can be seen in the speech, it has been characterized as another support for these family members. From this, we can analyze the fragility of the mental health network for these family members, because when they resort to hospitalization as a form of support and help, it does not meet some goals of the Psychiatric Reform, which brings the assistance and support to family members preferably in community mental health services.

The above demand is a picture of the lack of support for these family members, and also of the hegemonic model of capitalist society, which excludes less favorable segments due to social inequality. It can thus be reflected in Public Policies, causing, for example, low incentive and investment in mental health care services.¹

Furthermore, it was evidenced that the care provided is closely related to the figure of the woman, which 70% of respondents reported as mothers, wives, and sisters. This means an even greater burden, because besides having to perform the tasks of the home and constantly dedicate themselves to the role of caregiver, they end up compromising the care itself, causing physical and emotional distress. This configuration of care is expressed through the issue of gender present in society, which cultivates the superiority of male power, over the responsibility in the productive sphere, and the woman with the responsibility of the social reproduction of their individuals culminating in difficulties in everyday life, both professional and personal.

There are many judgments of these family members by some health professionals, which are sometimes identified within the daily hospitalization. These judgments permeate the discourse of lack of support and monitoring of users within the service, such as the appropriation of the benefit of Social Security, the convenience of leaving the person

hospitalized and the responsibility to take care of the family environment.

Mental health network services are of paramount importance because they can through partnerships reduce the burden felt by caregivers, this would have benefits to the treatment of the user.¹⁴ This partnership occurs through professional assistance to families with a more focused on the quality of life of those who practice this care.¹⁰ Besides, a shared process is needed between family members and health professionals, which takes place through democratic management spaces, with the effective participation of these subjects, encouraging autonomy and identifying the sources of difficulties and also the possibilities for change.¹

In addition, it is evident in the statements of family members the worsening of symptoms and behavioral changes that occur due to the instability of the disease, causing difficult understanding and management of the situation.

It's hard because just as she is in one way, she can be in another. [...]. According to even your words, which you use, you have to speak carefully. [...]. (R6)

It is very difficult to take care of him. [...] He is euphoric, agitated, does not sleep. He was in an outbreak, even attacked me. (R7)

He never stopped. Once he ran away at dawn, I couldn't find him [...]. (R8)

It is very difficult [...] because she is so aggressive, I am afraid of being alone with her. It's not even fear anymore, it's panic. I am not alone with her at home, because she comes and attacks you, and you have no defense, you cannot defend yourself [...]. So, I am always apprehensive. (R9)

She closes [...] shut up, lock herself indoors. (R11)

She gets nervous, irritated over little things. (R12)

It's hard [...] he had those impulses to break everything, so he broke... [...] he would just get up to the basics, not talk to anyone. (R19)

Not easy, he runs away. [...] for a while he was very aggressive, it hurts me, I have marks. [...] (R20)

The responsibility of caring for the family member with a mental disorder requires the family to know the episodes related to the behavior of the person with the disorder and, usually, they are not in a position to experience certain circumstances that are part of the symptoms of

the disorder, such as the change in way of behaving, being sometimes aggressive and sometimes violent, which causes in the family environment an apprehension and instability, generating feelings of anxiety and fear.¹⁰

The burden of care is caused by the difficulties of crisis management and the self-injurious behaviors of the affected family members. And, it can express anxiety because it does not know how to deal with some behaviors presented, such as excessive silence, unpredictability in their actions, supervision of problematic behaviors, leading to concrete negative consequences involved in the care process.^{10,12} These situations contribute to the family gives up on giving proper care to the patient, which is not characterized as rejection, but rather difficulty living with threatening and unstable behaviors, and thus causing insecurity and fear.¹⁵

Care for the person with mental disorders demands the family situations that are related to the symptoms of the disease, which often the caregivers themselves are not prepared to intervene. The impulsive, aggressive, and restless behaviors present in speech and literature cause a climate of insecurity that affects family dynamics.¹⁰

Within the scenario presented, caregivers may portray feelings of anguish and anxiety regarding the management of manifested behaviors, as an example in interview R11, bringing excessive silence. Many family members are not content to see the mentally ill person, who was once full of life projects and socially well-integrated, become a committed, dependent and limited person.¹⁰

“You must believe in a spiritual being”: religion/faith/spirituality as a care support

Considering the interviewees’ speeches, it is clear that religion and spirituality are configured as search mechanisms for support for family members. Support can be thought of as words of encouragement to the person with mental disorders, as for the protection of these family members.

I help with friendly words, give her the strength to move on [...] spiritual support, I am religious. (R11)

I think this spiritual issue we have to take a lot of care too, you seek God, no matter what your religion, “you have to believe in a spiritual being.” (R13)

He asks me a lot, he has needs, he has a very spiritual appearance [...] I try to bring all this presence of Christ with him because he asks me. (R14)

Religion and spirituality are present in people’s daily lives, and they carry countless meanings.¹⁶ These meanings are complex because they involve a very wide field, which makes it possible for each individual to give their own opinion about what each one is.¹⁷

Religion and spirituality are coping resources against stressful stimuli, and they also work as a way to improve

mental health through increased social support. For the authors, these mechanisms provide greater contact with the subjective reality of people and enable possible changes in attitudes and ideas regarding the current experiences of the reality of each individual.¹⁶

Historically, the issue of religion and spirituality had their implications present in psychiatry, being linked to negative attitudes that compromised the improvement of the clinical condition and the production of symptoms.¹⁸ The current scenario is in contrast, pointing to better results of the treatment of mental disorders if there is spiritual involvement.¹⁹

The influence of religion and spirituality in the interviewees’ statements is perceived, and how this changes the behaviors and lifestyles bringing the social support that the family member needs.¹⁶ It is necessary to understand that religious choices and expressions must be respected, respecting one’s desire and individual faith.¹⁸

Religion and spirituality sometimes become resources for these family members for support when there is a lack of access and support to health services absence or the presence of other family members to share the anxieties and challenges of everyday life. Religion and spirituality strengthen the bonds between the relative and the user, they are also tools for facing daily difficulties. The importance of these mechanisms amid process of illness is characterized as a perspective of improvement for these subjects, furthermore, emotional appeal and comfort for the family members.

CONCLUSION

Understanding how the family member cares for the person with a mental disorder, it was evidenced that fraternal feelings are expressed as a form of care. Nevertheless, there are moments of weakness when the family member’s health condition is weakened due to the instability of the disease. In this sense, family members seek the support of religion and spirituality as mechanisms that play a significant role in the care process.

The results of this study contributed to the elucidation of important elements that involve the care process, especially regarding the contexts of fragility and vulnerability of family members who have at their core a person with a mental disorder.

The statements of family members point to the fact that care is unique, that is, each person has an understanding of this meaning. For some, this becomes affectionate and pleasurable, but for most respondents, it is seen as an overload.

Support for family members is crucial, concerning the creation of support mechanisms, which is through a greater incentive to the mental health care network and also greater accountability on the part of the public authorities to guarantee and create public policies targeted at these segments. The network services can contribute to the exchange of knowledge with these family members,

to support them to fulfill their responsibilities, sensitively and especially without exhaustive overloads.

The study made it possible to reflect on how it still moves slowly with the Psychiatric Reform. As new care is required for family members, it is necessary to insert this core in mental health actions. Moreover, the theme with families is extremely relevant to the various professional areas that work in this context, such as nursing and social work. For nursing, the study contributed with teaching and practice as it allows understanding the context in which the family is inserted, its potentialities and its weaknesses, helping in the elaboration of strategies that help in the promotion and recovery of the user's health and their family members.

For the Social Work, the study made it possible to comprehend broadly the social, economic and political factors that involve the health/disease process, as well as to ensure through Public Policies the guarantee of social rights.

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