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Being family of mental health consumers: experiences and feelings

Ser familiar de usuários de saúde mental: vivências e sentimentos

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ABSTRACT

To know the experiences of care of family members of mental health users who are accompanied in a Psychosocial Care Center II in the southern region of the country. This is an exploratory and descriptive research with a qualitative approach carried out with seven family members included in the group of family members of the service. They were classified in three themes: Experience regarding the care given by the family caregiver to the mental health user; Support network available to the family caregiver; Strategies used by the family caregiver to promote self-care. The study reveals the impact of the overload of the family caregiver when performing this function with family members who demand a high degree of dependence. As the dependence of the person who demands care increases, the family caregiver notices an increase in the overload, which interferes with their physical and psychological health. Becoming the primary caregiver entailed the abandonment of some activities at some point in life due to the user's dependence; including activities to promote self-care. By assuming this role, the participants reported the fragility of the intrafamily support network, and PSCC was mentioned as the main support network. In this study, it was possible to perceive the overload of the family caregiver from all the demands generated by this process that, when shared in the group, makes it possible to relieve the anguish and create care strategies that promote an improved interaction with the family member who is a PSCC user, and may stimulate this person to have more autonomy over their life.

Keywords: Care. Family. Mental health services.

RESUMO

Conhecer as vivências de cuidados dos familiares de usuários de saúde mental que são acompanhados em um Centro de Atenção Psicossocial II na região sul do país. Trata-se de uma pesquisa exploratória e descritiva, de abordagem qualitativa realizada com sete familiares inseridos no grupo de familiares do serviço. Foram classificados em três temáticas: Vivência acercados cuidados prestados pelo cuidador familiar ao usuário de saúde mental; Rede de apoio disponível ao familiar cuidador; Estratégias utilizadas pelo familiar para a promoção do cuidado de si. O estudo revela o impacto da sobrecarga do cuidador familiar ao desempenhar essa função com familiares que demandam um alto grau de dependência. À medida que aumenta a dependência da pessoa que demanda de cuidados, o familiar cuidador percebe o aumento da sobrecarga, que interferem na saúde física e psicológica dos mesmos. Tornar-se o cuidador principal acarretou o abandono de algumas atividades em algum momento da vida, devido à dependência do usuário. Incluindo atividades de promoção do cuidado de si. Ao assumir esse papel, foi relatado pelos participantes a fragilidade da rede de apoio intrafamiliar, sendo o CAPS citado como a principal rede de apoio. Neste estudo foi possível perceber a sobrecarga do familiar cuidador a partir de todas as demandas geradas por esse processo que ao ser compartilhado no grupo possibilita aliviar as angústias e criar estratégias de cuidado que promovam uma melhora interação com o seu familiar que é usuário do CAPS, podendo estimular que esta pessoa possa ter mais autonomia sobre sua vida.

Palavras-chave: Cuidado. Família. Serviços de saúde mental.

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INTRODUCTION

The Psychiatric Reform changed the mental health care through the deinstitutionalization process where, with the emergence of the Psychosocial Care Centers (PSCC), the family started to be considered as an important part in the process of caring at home for that member who lives with psychic suffering. The family member who now plays the role of caregiver begins to assume diverse and challenging functions, in which many are not prepared, which can lead to a low evaluation in the quality of life of these subjects and an overload to the family caregivers themselves (Kantorski et al., 2017).

It is common that in the process of some family member's illness, family members, especially the family caregiver, present a high physical, mental, emotional, social and financial overload, whose predictors come from the continuous care provided to the family member (Gomes, Silva & Batista, 2018).

The position of family caregiver of a relative with mental disorders is often a lonely task, because there is resistance from the other family members regarding the division of care. However, some caregivers can count on the sporadic help of the extra-family support network, such as friends and neighbors. However, by assuming the total responsibility for the care, the family caregiver has his/her daily activities compromised, and this included the self-care activities (Kebbe, Rôse, Fiorati & Carretta, 2014).

A study conducted with 537 family members of users of 16 PSCC I and II in the 21st Health Region of the State of Rio Grande do Sul, identified that the feeling of overload was strongly associated with a higher prevalence of the use of psychotropic drugs, and the most used class was antidepressants (47.20%), followed by anxiolytics (33.54%), antiepileptics (24.22%), antipsychotics (6.21%) and lastly, hypnotics and sedatives (1.86%), moreover, it was found that the division of care was associated with less use of psychotropic substances (Treichel et al., 2021).

Aiming to mitigate the burden faced by family caregivers, there are in PSCC groups directed to this public as a support space, where family members can clarify doubts regarding the care provided to their family member, as well as a space where he/she can talk about him/herself as a person, and not only as a caregiver (Santi & Kalafke, 2011).

The creation of these groups can also be seen as a care strategy, because it allows for the creation of bonds and the reception of the demand and anguish when one of the family members is ill. It is an environment that allows the exchange of experiences among the group members, who are often blamed and isolated when faced with the experience of mental illness (Neves & Omena, 2016). Health professionals should consider family members as key players during the construction of mental health care, so it is of utmost importance to value and listen to what they have to say (Martins & Guanaes-Lorenzi, 2016).

In light of this, the present research was developed with the objective of understanding the caregiving experiences of family members of mental health users monitored at a PSCC II in the southern region of Brazil.

MATERIAL AND METHODS

This is qualitative descriptive research, carried out in a type II PSCC located in the southern region of the country, with seven family members of active users in the service. For participation in the study, the following inclusion criteria were defined: being part of the group of family members of the service; being 18 years of age or older; and being identified as the main caregiver of the family member. Family members who refused the invitation were excluded. Of the seven participants interviewed the female gender prevailed (four), age ranging from 48 to 72 years old. Six of the seven interviewees were first degree relatives of the users attended in the service.

Data collection occurred in the second semester of 2019; the interviews were conducted individually in a reserved room of the service, in order to ensure the participant's privacy. A semistructured script with guiding questions was used to guide the interview. Each interview lasted about 30 minutes and were audio recorded, being later transcribed.

The data obtained in the research was analyzed according to Minayo's thematic analysis (Minayo, 2014). This study followed Resolution 466/2012 of the National Health Council of the Ministry of Health, which regulates research involving human beings (Resolution No. 466, 2012). The research was approved by the Research Ethics Committee of the Medical School of the Federal University of Pelotas, under opinion number 3.591414.

RESULTS AND DISCUSSION

From the analysis of the records obtained, three themes emerged: Experience with the care provided by the family caregiver to the mental health user; Support network available to the family caregiver and Strategies used by the family caregiver to promote self-care.

Theme 1 - Experience with illness and the care provided by the family caregiver to the mental health user.

The mental illness of a family member causes important changes within the family. The initial care provided to the ill family member is a remarkable experience, since the family caregiver is often not prepared to perform this function. In this study, participants described how they perceived the mental illness of their family members, through the following narratives:

> My daughter started having problems at the age of 19 and to this day we don't know if anything happened, she never said anything about it happening. (N2)

> This condition of hers has been going on for many years, she has already been admitted to hospital X when she was 21 years old, she says it was because she attacked her nerves. (N3)

> Before starting treatment here he had already been hospitalized twice. In 2004 he started to present these pictures, before that he worked, he was a machine operator. (N4)

The affliction of a mental disorder in adult life in general causes ruptures in the subjectivity of the subject, which has repercussions in his daily life, making the individual who was active until then have to give up social, work and leisure relationships (Kantorski, Cardano, Machado & Borges, 2019).

A study carried out through an international consortium in five European countries - England, France, Holland, Spain, Italy and Brazil - found that the incidence of first episodes of mental illness varies between regions and population groups, and that young men aged 18 to 24 are more vulnerable than women in the same age group, while the incidence of first episodes of mental illness in women occurs between 45 and 54 years of age (Jongsma et al., 2018).

Another study conducted in Italy with mental health users showed that the stigma internalized by the users themselves, due to the negative stereotype related to mental illness and hospitalization, generated in some the feeling of guilt (Kantorski et al., 2019). Two relatives related the loss of a family member as a possible determinant in the worsening of the user's mental illness:

> After my wife passed away, five years ago, my daughter got worse, she was very attached to her mother [...] Before that my daughter led a normal life, you know? She worked in a finance company, was independent and after she lost her mother her admission in hospital X happened. (N1)

> After my wife passed away my daughter took a turn for the worse, just like me she felt it too. (N2)

After the loss of the mother, in both cases it was the fathers who assumed the care of the service user. In the literature, there are few studies on men assuming the role of caregiver for people with mental disorders. The existence of few qualitative studies about the experience of male caregivers points out that they experience continuous changes in their lives, such as the sense of loss, decreased social activity, increased responsibility for the absence of sharing, and that they care with a sense of reciprocity (Melo, 2009).

Until the end of the 20th century, genetic factors were attributed as etiological factors of mental disorders; however, a study carried out in Europe and Brazil pointed out that environmental factors play a relevant role in the onset of mental illness. The researchers of this study intend to analyze the life histories of the subjects that present mental disorders, together with the socioeconomic conditions and compare them with the population that does not present this picture, in order to verify the possible risk factors for the development of the onset of mental illness (Jongsma et al., 2018). Traumatic experiences in childhood can trigger the onset of mental disorders, however, the experience of a childhood trauma alone cannot explain all the complexity that involves the process of mental illness (Nunes, Rezende, Silva & Alves, 2015; Schaefer, Lobo, Brunnet & Kristensen, 2016).

During the interviews, only one interviewee reported that his family member was born with a mental disorder, as in the following narrative:

> I believe that he was born with this disorder, as he was developing, I started to notice that there was something different, but my mother-in-law would not allow us to say that he had something or that we thought he had something, so many times I kept quiet, if I spoke, he would fight [...] Today I understand that this may have hindered the treatment of my son because if I had sought him earlier, he could be better. (N5)

When mental illness is established during the user's childhood it has a strong impact on the family, as well as in all areas of development, especially on the child's school life (Daltro, Moraes & Marsiglia, 2018). Regardless of the stage of the onset of the mental illness, the family, in general the family caregiver, mobilizes itself in search of treatment for the ill person, and emotional support for their doubts and anguishes.

In this sense, PSCC has a primordial role in the welcoming of family caregivers for the maintenance of physical and mental health of these subjects, as well as to work on the co-responsibility of care regarding the family member that is being monitored in the service. The insertion of the user in the service was referred to by the interviewees as an important event for the promotion of the quality of life of their families.

> Now she is taking injectable medication here at PSCC because her disease makes her aggressive and the injection prevents this. (N1)

> Here at PSCC she has been in treatment for a year and a half after I came to treat her here she got better. (N3)

> [...] but thank God, after he joined PSCC in 2005, he never disappeared again. (N4)

> That's when we brought him to PSCC, which wasn't here yet, it was in the X neighborhood. Then he began his treatment... It was very difficult at the beginning, yes, but afterwards with the medication, the treatment he was getting better. (N5)

> After he came to PSCC he got better because he really likes being here. He likes his colleagues, the workshops, the music teacher, he likes everyone here. (N7)

When the service team establishes a bond with users and their families, it facilitates their adherence to the treatments provided by the service. A closer service to the needs of the user affected by mental illness uses, on the part of the team, sensitivity to listening, understanding, and building individual therapeutic interventions, respecting the specificity of each user (Schrank & Olschowsky, 2008; Nagaoka, Furegato & Santos, 2011).

The development of activities such as workshops, home visits, events and commemorative parties also aim to improve the relationship between users and the service in which they are inserted, in addition to enabling the exchange of experiences and help (Nagaoka, Furegato & Santos, 2011). The interviewees in this study brought in their narratives the impact of caring for family members with a high degree of dependence. As the dependence of the person who demands care increases, the family caregiver notices the increase of the overload, which interferes with their physical and psychological health. When questioned about the care given to the mental health user, the family members focused on the dependency relationship established with the user:

> I am the one who makes the food, I am her father and mother. In the old days she would go out to the street and didn't have time to come back and I, as her father and mother, would be worried and would have to follow her. (N1)

> My care with my wife is like taking care of a small child, constant care and always keeping an eye on her, this is my responsibility with her. (N3)

> [...]I do everything for him, make his coffee, make his bed, serve his lunch myself. He is totally dependent on me, I always talk to him about having autonomy because I won't be here forever, he needs to be independent, but he doesn't feel any desire to do things for himself. (N7)

> I used to go to church, we were in the choir, but since she had a stroke, I had to stop going, so it's like this, whenever she doesn't want to go somewhere I don't go either. (N3)

> I would like to work and I miss doing some activity that is not focused on my son. I can't work or leave him alone at home [...] Then I can't work because I have to be controlling him. (N7)

Becoming the primary caregiver led to the abandonment of some activities at some point in life due to the user's dependence. By assuming this role, the caregiver becomes directly responsible for monitoring and administering medications, providing care, and treatment effectiveness in the home environment.

Thus, mental health services should organize themselves so that they can include them in the care plans, taking into account that the caregiver also needs to be cared for (Oliveira & Mendonça, 2011). The recognition of the difficulties faced by the family caregiver during the care process gives the health team the opportunity to create care strategies aimed at preventing the physical and mental illness of this subject, considering that the responsibility for home care usually falls on a single family member.

The services must also invest in care strategies that stimulate the users' autonomy, contributing to the psychosocial rehabilitation of these subjects, who will increase their capacity to understand and act by themselves, which will consequently have repercussions in the reduction of the family caregiver's burden.

The interviewees still reported some difficulties they faced, especially at the beginning of the process of caring for the family member. However, they do not perceive difficulties at the present time. These reports can be verified in the following narratives:

> Currently I don't see any difficulties, but before it bothered me a lot... Besides the disappearances that she used to give us to worry about. I had to hide the keys for her not to leave sometimes. (N1)

> In the past I felt overloaded because I worked, took care of my wife in the hospital and still took care of my daughter when I got home. Now I don't because my job is only to take care of my daughter. (N2)

> I think it has been worse, even though my son has the most agitated periods. After the treatment that he started doing here at PSCC, it became better to deal with him. (N5)

> I wish he would be more independent, that he would try to do something that would give him pleasure, that would occupy his mind, his head, you know? I would really like this to happen [...] With me it is only when he gets angry that he wants to punch me in the arms, I have to tell him not to do it. (N7)

The narratives of interviewees N1, N2, N5, and N7 refer to the difficulties that the activity of being a solo caregiver entails in their daily lives. Thus, it is essential to seek strategies with the caregiver's support network. To do so, the team's first step is to know this network, since in some cases there are caregivers with no support network beyond the health services.

Theme 2 - Support network available to the family caregiver.

The support network refers to a qualitative and functional characteristic of the subjects' social network, which can be understood as the sum of all the relationships that individuals perceive as significant for them (Faquinello, 2011; Aragão, 2018). Thus, the support network can be the family itself, but when this is inefficient, friends, neighbors, and health services can play this role by offering physical and mental support to caregivers.

In this study, the interviewees indicated PSCC as the main support network, highlighting the role of the family group as a space for welcoming and providing technical and emotional support, since most of them are in the role of primary caregiver solo.

> The support that the PSCC team gives us is positive, both for me and for my wife. Here I learn how to better deal with her illness. (N3)

> [...] I always talk to the people here at PSCC, they also help me a lot in the care of my son, and the acceptance of my family is also important for him to improve. (N4)

> Here at PSCC I talk a lot with the social worker and the family group is very good for me, besides me talking, putting what I feel out there I have the support of other family members who help me, in the group they help each other... I think that if it wasn't for PSCC I don't know what would become of it and of me. (N7)

A study conducted with family caregivers of people with mental illness in southern Brazil found that participation in groups promotes the reduction of the family members' burden, as they find in these spaces a possibility to get more information about the health-illness-care process of their family member, and can even discuss together about their doubts and the difficulties faced, feeling stronger and safer due to the environment of trust and belonging that happens in these groups, which reflects positively on their self-esteem (Duarte, Carvalho & Brentano, 2018).

Theme 3 - Strategies used by family members to promote self-care.

Becoming the primary caregiver for a family member takes time, and this often makes them forget that they are also a being that demands care. For some people, self-care is related to biological issues, so the resources they will seek will be heavily focused on biomedical care. However, we are complex human beings affected by emotional, social, and economic issues, which reflect in our health-disease-care process. In this sense, the ideal care for oneself and for the other would be the one that aims at the integrality of people as social subjects.

> I always go to the doctor to see how my health is, I don't take a medicine I hope to continue like this for a long time. (N1)
>
> Ah, I go to the doctor to consult and do exams, I take care of my health, right? Because if I don't have it my daughter will be abandoned by her brothers, so in this part I try to take care of myself. (N2)
>
> I joined these senior citizen groups; I go to these groups and I go out. I do weight training, weight lifting [...] I always find something, I don't stand still. (N4)
>
> When I can, I go to a hairdresser, I do a progressive, a semi-progressive, I moisturize, I apply creams, I do my eyebrows. (N5)

In the narratives of interviewees N1 and N2, self-care is linked to going "to the doctor", they do not realize that self-care is also related to means of health promotion such as leisure, physical activities, listening to music, among others. Respondents N4 and N5 have a broader view of self-care, bringing as forms of self-care activities that give them pleasure.

It is through the exchange of experiences in the group environment that they can stimulate other members to promote new forms of self-care, such as taking care of the appearance and having leisure time. Family groups can contribute to those who still have difficulty in practicing self-care. Hearing from other family members that it is possible to take care of oneself, to organize some time to take care of oneself, to do activities that are pleasurable to them, can be a stimulant for the change in attitude of these subjects that still can't prioritize themselves.

> I don't go out anywhere, I honestly don't go to a movie, a soccer game, I don't go anywhere. I don't feel like it anymore, I don't feel like doing those things anymore [...] Maybe one day

> someone here at PSCC can change my mind, maybe a psychologist can make me feel like it again. (N2)

> I don't have confidence to leave her in the care of others, and this hinders me a little to do things [...] I always have my heart in my hand, I am always afraid that something will happen when I am not with her. (N3)

> I can't do any because I am always involved with my son's care. If I need to go to the doctor's or something that has to be done alone, my husband takes him to work, but this happens rarely. (N7)

The narrative of N2 brings the hope that this subject places in the service so that one day he can learn to take care of himself. N3, on the other hand, sees himself as the only person capable of taking good care of his family member. This question could serve as a theme for discussion in the group, as an opportune moment to demystify the idea that only he is the ideal person to provide care and how this thought limits him to a behavior of self-sabotage. Not providing the opportunity to share caregiving can produce in other people the idea that the main caregiver doesn't need help, that he doesn't feel overburdened. Sharing care with other people from the support network can be an important device for creating empathy and tightening the network.

The family groups enable the contact with people who go through similar situations, the exchange among them can produce support, counseling, encouragement as to the change of harmful behaviors related to the care they provide to their family member and to self-care. Thus, this space can be an important device for the caregiver to reevaluate the way he/she conducts his/her role as primary caregiver, making him/her see him/herself as a subject who also requires care.

CONCLUSION

The process of mental illness of a family member is a complex moment that causes anguish and anxiety in the family that has difficulty understanding this moment. In the past, care for people in mental distress was delegated to the Psychiatric Hospital, based on a tutelary treatment, responsible for controlling the manifestation of madness. Currently, mental health care is based on the territory, in services that substitute Psychiatric Hospitals. Thus, the person in mental distress, as a priority, remains in his or her family environment and, therefore, the family needs to learn to deal with the mental illness and, from that, to restructure its family environment that, generally, will have a main caregiver.

In this study it was possible to realize the family caregiver's overload from all the demands generated by this process that, when shared in the group, makes it possible to relieve the anguish and create care strategies that promote an improved interaction with the family member who is a PSCC user, and may stimulate this person to have more autonomy over his life.

In addition, one can see the fragile support network in which PSCC is the main support of the caregiver. This makes it important to reflect on the need for the service to work on the support networks in the community and the use of the family group as a powerful moment to stimulate and weave these networks.

As for self-care, family members associate it with their physical health so that they do not get sick and can take care of their family member who is a PSCC user. Others report moments of leisure and care with their appearance, showing that they are able to have quality of life. The family group enables its participants to have a look at themselves and from this they can think strategies for self-care.

Thus, the family group becomes an important tool in psychosocial care, because it allows an expanded care to family members and users of the service that awakens the protagonism of these subjects, not only regarding the treatment performed in PSCC, but also in their lives.

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