Article

Mental health care: narratives of family members of voice hearers

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Abstract: Considering the challenges of social reintegration and the composition of care strategies in a context of liberty, this study aims to analyze the narratives of family members of voice hearers regarding their experiences as caregivers from a psychosocial perspective. Narrative interviews were conducted with family members of individuals attending a group of voice hearers at a Psychosocial Care Center in the city of Pelotas, Rio Grande do Sul, Brazil. Three thematic axes were obtained from the thematic analysis of interview data: (1) experience of hearing voices and the need for care; (2) family: care practices; and (3) therapeutic strategies: weaving care networks in mental health. Caregivers report difficulties in living with family members who hear voices, care-related work overload, and challenges faced in daily life. In this context, the results stress the importance of mutual aid groups in supporting caregivers.

Keywords: family, caregivers, voice hearers, mental health.

Introduction

The Brazilian Psychiatric Reform brought new perspectives to mental health care, with more humanized treatments and reorientation of the mental health care model by means of the implementation of Law No. 10.216 (2001). The Psychosocial Care Centers (CAPS), regulated by Ordinance No. 336 (2002), start to work serving people suffering from severe and persistent mental disorders with a focus on psychosocial rehabilitation (Mota & Costa, 2017), and are responsible for promoting a social and intersectoral articulation, expanding their actions beyond the institution (Delfini, Sato, Antoneli, & Guimarães, 2009).

CAPS work with a multidisciplinary team that provides group and individual care, as well as proposals for diverse interventions, such as therapeutic workshops, physical education practices, and art therapy, among others (Mielke, 2009). The provision of care starts involving participation of the suffering individuals themselves, their families and the community. These strategies are important to break the hospitalocentric model paradigm (Kantorski & Andrade, 2017). However, Pereira, Reinaldo and Andrade (2015) present a discussion about professional training aimed at this model of care. The authors state that this process, which began with the Psychiatric Reform, is still under construction within educational institutions,

in which actors remain divided between biological and psychosocial issues of mental disorders, which characterizes the professionals' training in the area of mental health (Pereira et al., 2015). Therefore, it becomes increasingly necessary to think and discuss about new approaches to mental health within health courses.

The International Hearing Voices Movement is among the new approaches to mental health; it was founded in 1987 in the Netherlands by Patsy Hage, a voice hearer, and her psychiatrist Marius Romme. The voices that Patsy heard were of a negative nature and the drugs prescribed did not provide beneficial results, which led her to look for other ways to deal with this experience (Escher & Romme, 2012).

After some interventions, Marius Romme and Sandra Escher set up the first groups of voice hearers in the Netherlands, with the objective of providing a place where they could share their experiences (Escher & Romme, 2012). From the perspective of the Movement, hearing voices that others do not hear is taken as a human experience that, by itself, cannot be considered a symptom of psychiatric disorder. The Hearing Voices Movement is another strategy to be used in the treatment of people who do not respond well to prescribed treatments. In this sense, the objective is to produce coping strategies to deal with voices in everyday life, rather than seeking to annihilate them (Egyto & Silva, 2019).

However, the biomedical model categorizes the presence of voices as signs and symptoms related to



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schizophrenia, major depression, substance use, among other conditions. In this perspective, voices are related to a pathological condition that needs to be resolved, and not to a human experience, as pointed out by the approach to voice hearers (Corradi-Webster, Leão, & Rufato, 2018).

Mental health care takes into account the subject in their entirety, their families and community context, bringing together "the care one provides and the care one aims to provide in mental health" (Santin & Klafke, 2011, p. 147). In this approach, the family is seen as "the support base and has a therapeutic role, which implies help, emotional support and generation of affection, safety, promotion of development, stability and comfort" (Silva, Quadros, Laroque, Lima, & Coimbra, 2010, p. 247).

Before the Psychiatric Reform, there were different forms of understanding in relation to the family, which somehow contributed to its blaming and its distancing from the subject with psychological distress during mental health care (Rosa, 2005). With the reform, the family started to play a fundamental role in this treatment, becoming responsible for their family member's full-time care, in addition to being important in the process of resuming life in society and a link with life in community.

Studies show that there are a number of benefits to the treatment when the individual with psychological distress is closer to their family; however, it is necessary to pay attention to the fact that the care of a person with psychological distress can generate an overload for family members, which makes a specialized support to these caregivers indispensable (Costa, Pessôa, Soares, & Rocha, 2014).

In Brazilian literature, the theme of voice hearers has been developed in studies related to contents, meanings and relationships of hearers with voices, in addition to identifying the possible traumas that led to hearing voices and the recommended treatments. However, research related to voice hearers' family caregivers are still scarce. In this sense, this study takes into account the importance of looking at the voice hearers' interpersonal relationships, especially at the relationships that occur in the family context, understanding this support as a differential in treatment (Baker, 2016). Anchored in a psychosocial perspective, considering the challenges of social reintegration and the composition of care strategies

in a context of liberty, this article aims to analyze the narratives of voice hearers' family members about their experiences as caregivers.

Method

The methodological path included listening, recording and analysis of the narratives about the effects of family members' experiences in taking care of voice hearers. Data production took place through narrative interviews (Jovchelovitch & Bauer, 2008) with family members/caregivers of a group of voice hearers attending a CAPS in the city of Pelotas.

First, there was the insertion of the researcher in the group of voice hearers, which met every 15 days and was accompanied by the professional for four consecutive months. To carry out the study, 10 assiduous group members were identified, who were presented with the research objectives and asked to point out caregivers who could participate in the study. Three participants did not feel comfortable to nominate a family member for the research. After the others' consent, the caregivers were contacted by telephone to schedule the interview.

Six women and one man were interviewed, and all had blood relation with the patients. To participate in the study, it was necessary to be a family member/caregiver of a participant of the "Hearing Voices" group of a CAPS in the city of Pelotas and have been indicated by the patient.

The interviews were recorded and transcribed, and the material produced was analyzed based on thematic analysis (Braun & Clarke, 2006). However, two participants did not feel comfortable recording the interviews and their narratives were written in a field diary. From this analysis proposal, it was sought to identify the generating and representative themes of the family members' narratives.

This research was approved by the Research Ethics Committee in the area of Health (Cepas) under opinion no 3.936.821.

Results/discussion

From the analysis of the interviews, three thematic axes were produced: (1) experience of hearing voices and need for care; (2) family: care practices, and (3) therapeutic strategies: weaving of care networks in mental health.

Table 1. Sociodemographic data of voice hearers' family members/caregivers

Name	Age	Marital status	Degree of kinship	Currently working
Ana	63 years old	Divorced	Mother	Retired
Beatriz	49 years old	Widow	Mother	Unemployed
Carmen	56 years old	Married	Mother	Retired
Daniela	20 years old	Single	Daughter	Employed
Eduardo	37 years old	Married	Son	Employed
Fernanda	34 years old	Divorced	Daughter	Employed
Gabriela	25 years old	Single	Niece	Unemployed

Source: Authors' elaboration

Experience of hearing voices and need for care

Many of the caregivers reported that the onset of psychological distress occurred "as a depression" and that, little by little, other diagnoses were established, such as schizophrenia, which raised concern, as this pathology carries a strong social stigma. This diagnosis triggered, in the caregiver's perception, a greater difficulty in accepting the change and, later, in organizing strategies for living with the family member at home.

Changes in behavior, caused by auditory and visual hallucinations, often generate suffering and concerns for caregivers (Carvalho, Sousa, Pinho, Fernandes, & Oliveira, 2017), as evidenced by the statements of Carmen, a patient's mother, and Fernanda's, a patient's daughter:

It was found to be schizophrenia, but the onset was depression. And that was scaring for me, I didn't know it, I didn't know the illness. It was horrible. (Carmen)

It started with a depression. But over time, she started to hear voices that said she should do things. She had breaks at night, during the day. She was aggressive, didn't recognize us, especially at night. She hid the medication and didn't take it, and then it got worse. (Fernanda)

Similarly, schizophrenia diagnosis can also be associated with feelings of guilt (Giacon & Galera, 2013), as shown in Ana's speech about her experience with her daughter:

Ah, from the first time she tried to commit suicide it was very difficult. What happened, where did I go wrong? She is so different, because the other [sister] is easy going, very different, she's normal, and she [the patient] always in trouble. She had no dialogue, [was] very introspective. (Ana)

The caregivers in this study went through a period filled with anguish, fear and new adaptations due to

their family members' illness. Simultaneously, they often sought explanations for the situation they were experiencing. Therefore, it is important to bear in mind that caregivers also need care so that they do not got sick due to feelings such as guilt, tiredness, and loneliness (Ferreira, Sampaio, Oliveira, & Gomes, 2019).

In many cases, the auditory experience is transient and can disappear over time (van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009), which is supported by a study that followed, for five years, 337 children who heard voices, aged between 7 and 8 years, with the aim of measuring possible risk factors, noting in their results that the majority (76%) of them stopped hearing voices when they reached the age of 12-13 years (Bartels- Velthuis, Willige, Jenner, van Os, & Wiersma, 2011). But what to do when family members still hear voices after years, even with a history of regular use of psychotropic drugs?

Among the orientations of the International Hearing Voices Movement, there are the following: engage in a dialogue with the voices heard; try to make a selection of positive voices and only hear and talk to those voices; try to arrange meetings with the voices so that they do not appear at any time of the day; when hearing something that they cannot differentiate whether it is reality or not, the suggestion is that the patient should ask a person close to them if this person heard the voice as well (Baker, 2016). These coping strategies are important in order for the voice hearer to find meaning for the voices, in addition to helping accept this experience.

Caregivers' contact with these strategies makes it possible to understand their family members' experience in another way. Beatriz, a patient's mother, said to be the first person to whom her daughter said was hearing voices. In addition, she stated that she knows voices are concrete, because since her daughter started treatment at CAPS, she began to notice the amount of people who hear voices, but the caregiver recognizes that there is still strong prejudice.

The prejudice against voice hearers is very present and may be linked to the stereotype of hearing voices as synonymous with madness. Many voice hearers are afraid to talk openly about it, as they fear being referred to a psychiatrist and/or hospitalized, in addition to receiving increased doses in drug treatment (Kantorski, Andrade, & Cardano, 2017).

The proximity of relatives with the content of the patients' voices is not always an easy task, especially when they are negative. Fernanda commented that the voices her mother heard told her to hurt herself and others: "it was complicated, strange, because she had never said anything, and especially when she said should kill her granddaughter, who is a little baby."

The Movement recognizes that sensory experiences can appear in auditory (voices, sounds, noise and music), visual and other perceptions (smelling something, for instance). In addition, they can have positive, negative or neutral content, such as calling voices (Couto & Kantorski, 2020). A study carried out with eight voice hearers in Brazil showed that those who performed some type of monitoring in mental health services demonstrated more negative than positive relationships with voices (Kantorski, Souza, Farias, Santos, & Couto, 2018), which is in line with the statements of the participants in this study about the voices of their relatives.

Eduardo, in turn, revealed tranquility when dealing with his mother's voices, even though he has some concerns:

I don't get scared that much because I read a lot, so it's not a nonsense when a person says that is hearing voices. I think that it's not normal, but there's some conflict in the brain, I don't know the right word, but you have to adjust it, this being there is not normal, you have to treat it. (Eduardo)

During the study, the caregivers' narratives brought experiences associated with suffering, since they were often unable to conduct a dialogue with their relatives about the voices. Health services are responsible for listening and welcoming all these difficulties presented by caregivers, so that is possible to think of intervention strategies that help them during their relatives' treatment.

Family: care practices

The narratives express physical and emotional overload associated with the close contact with the person in psychological distress, as can be seen in Daniela's speech: "I have three children: my son, my mother and my brother." In her routine, Daniela takes care of her home and helps in her mother's home. She recalls that her mother helped her taking care of her three-year-old son; however, when the illness worsened, she was no longer able to continue in this activity, causing Daniela to change her work schedule and adapt to the new routine.

Just like Daniela, Fernanda also reports being the main responsible for the mother: "I am the main [caregiver].

I take her everywhere. It's very difficult for my sister to do this. But I take her everywhere, to the doctor... I do whatever I have to do for her".

As evidenced in other studies, women have been responsible for taking care of people in psychological distress in the family throughout history (Nolasco, Bandeira, Oliveira, & Vidal, 2014; Reis, Dahl, Barbosa, Teixeira, & Delgado, 2016). The care of children, older people and the disabled is delegated to women, so that, in addition to work activities outside the home, there is an accumulation of tasks and, consequently, physical and psychological overload (Meira, Reis, Gonçalves, Rodrigues, & Philipp, 2017).

In addition, living with the person in psychological distress can trigger health problems for caregivers and cause feelings such as stress, discouragement and fear, as well as more serious conditions, such as heart disease and mental disorders (Carvalho et al., 2017). Two interviewees reported undergoing some type of follow-up due to the overload of care they provide to their relatives. Beatriz says that she decided to seek care and started attending CAPS. Ana already reported adhering to sporadic treatments: "when she is very sick, I get very angry and depressed. Then I undergo treatment for three months and stop. During the whole last year I took Fluoxetine, but I've stopped."

Gabriela reports that her aunt is quite independent and looks for her whenever she needs some help: "She looks for me a lot, she says: there's a lecture in a place; there will be a vacancy for an internship. She always tries to help." On the other hand, Daniela said that her mother is quite dependent, "whether to choose a nail polish color, an outfit or even more important decisions; I have to give my opinion to everything."

From the narratives, it was evident that mental health care can change family dynamics, as they include in daily life visits to CAPS, to the doctor, to the basic health unit, and other activities necessary for the treatment of the person in psychological distress.

Two research participants reported that their relatives are independent, so they can perform these activities without help from a caregiver. However, other caregivers commented on the need to carry out a closer monitoring in order to protect the relative, as it is the case of Beatriz, who said she does not feel comfortable leaving her daughter alone at home, as she hears voices who order her to attempt against her own life. For Fernanda, care has also to be taken more closely:

I have to take care of everything, right, because she doesn't do anything by herself. She's tried to commit suicide several times; I'm the one who gives her medication... Take care of doctor matters, take care of everything, whether she eats or not; I have to be always attentive. (Fernanda)

According to a study by SantAna, Pereira, Borenstein and Silva (2011), being responsible for caring, added to the fact of treating a close family member, tends to demand availability and patience from this caregiver, as sometimes the person is the only one who is willing to carry out this activity. One of the challenges is to balance the exercise of care so that it does not translate into guardianship, compromising the process of autonomy and participation in the treatment (Ramos, Calais, & Zotesso, 2019).

During the interviews, the caregivers' lack of time to dedicate themselves to activities other than taking care of their relatives was evident, often because they are the only people to assume this responsibility. In this study, five of the respondents stated that they have no other person to help them to take care of their relatives. Carmen has recently retired and has been at home with her son and husband ever since. Regarding leisure time, she reported: "None." On the other hand, Fernanda said that she currently seeks to organize herself to have time for doing her things and recalls that there was a time when she stopped doing several activities because was taking care of her mother: Now I allow myself more [time]; before everything was for her... I've already stopped doing things, but now I don't anymore".

Among the seven caregivers interviewed, the three who lived in the same house with the family member in psychological distress reported not having much time for themselves or for leisure. It is noticed that the fact of dealing more closely with the family member in psychological distress demands a greater responsibility from the caregiver, who often neglects their personal care due to the family member's demands. In contrast to this, other participants said that they can reconcile this care and the time dedicated to themselves. This fact may result from the situation of a greater dependence or independence on the part of the patient, or also from the way it is perceived by family members.

Throughout the research, the participants reported that they took care of their relatives in different ways, such as: accompanying them to medical appointments and to CAPS, helping them in their home routine, and encouraging them to carry out other activities that are outside the context of the "illness." Sometimes, "excessive" care generated a state of overload on some of the interviewees, who, in addition to dealing with their tasks and commitments, were responsible for the fulfillment of other tasks of the family member in psychological distress, which causes suffering and illness to these caregivers. It is understood that the balance between the tasks performed is not simple, but when they find support to share their anxieties, fears and concerns, the relatives are more able to look at themselves and seek to perform self-care practices, besides activities that are pleasurable to them and that promote mental health.

Therapeutic strategies: weaving care networks in mental health

In this thematic axis, reflections on the sharing of care, which occurs at CAPS, will be addressed, as well as the provision of care provided by the "Voice hearers – new approaches in mental health" project, developed by the *Universidade Federal de Pelotas* (UFPel). CAPS offers, among its activities, the group of voice hearers, organized in partnership with UFPel. The group has been meeting at this location since 2017 and all voice hearers attending CAPS are invited to participate.

It is noteworthy that CAPS have an important role in the mental health care network, as they are a space for the development of autonomy, care and social inclusion. However, it is necessary to ensure that these services do not carry out practices associated with the users' guardianship, besides not to making their status chronic (Costa, Figueiró, & Freire, 2014), thus reiterating asylum practices that limit and stigmatize the person's performance in the city's daily life.

Thus, CAPS work proposal aims at the psychosocial rehabilitation of its users, and it is important that caregivers participate in the process. In this sense, respondents were asked about the treatment of their family member in CAPS and their relationship with the professionals at the place.

Ana said that whenever she has any doubts or notices something she thinks is wrong, she goes to CAPS and talks to a professional. She stated that feels very good with regard to welcoming:

They helped whenever I had more serious problems with my daughter. My difficulties, my daughter's health issues, they always helped me, there is no complaint. They are always available, always open to conversation and dialogue. (Ana)

In this context, it is understood that family groups are essential for a greater contact between the caregiver and the health service, as the meetings contribute to the exchange of experiences, in which caregivers can listen to life stories similar to or different from theirs; they can expose their difficulties, feelings and anxieties, besides receiving support from both the other participants and the professional team (Machado & Rodrigues, 2017).

Fernanda said that her mother went through several hospitalizations, suicide attempts and depression. After entering CAPS and starting therapeutic follow-up, she noticed an improvement in the mother's health status, who began to have greater participation in the activities offered: "She hasn't been hospitalized since she started assisting CAPS, I think it's been a year or so". In relation to this issue, Duarte and Ferreira Neto (2016) carried out a study aimed at investigating the changes in

life experienced by caregivers of people in psychological distress, and have found that "new modalities of treatment to replace psychiatric hospitalization were well accepted by the family members responsible for the care" (p. 483).

However, some caregivers reported dissatisfaction with CAPS. Daniela commented that she didn't like the service provided at the place, because every time when she went there to talk about her mother, she felt not being understood by the professionals. In addition, she expressed that the service should include a more sensitive treatment for people in psychological distress, without judgment and with more welcoming listening spaces.

For Beatriz, her daughter's treatment at CAPS is not working, since she takes a lot of medication and continues to hear voices. About his mother's treatment at CAPS, Eduardo said he noticed a gradual improvement, because, at first, the treatment seemed to be very stagnant and not having "effect", but it evolved slowly.

[She] only said good things about the staff here. I think she feels that the people are here to help, you see, and there's a lot of pressure, there's no money, they have to do magic, so she recognizes the effort the professionals who work here make to see her wellbeing, even a little bit. (Eduardo)

Also in relation to CAPS, it is important to highlight the history and participation of Gabriela's aunt in the mental health network. The voice hearer has a suitcase, in which she kept several materials she collected related to facts, news, photos and events in the city's mental health network and, based on this, a book was produced, in which she told her life story:

I learned a lot about my aunt through college... About the suitcase... I knew she had a suitcase with pictures, but I've never known what she had. We, the relatives, we didn't know it. Once I met her at college and she was going to present her suitcase for a course and then I found out what was in it. (Gabriela)

According to the Hearing Voices Movement, the fact of hearing voices alone would not be a reason for a diagnosis of schizophrenia. Besides, it emphasizes that the choice of undergoing drug treatment or not should be made in conjunction with the patient (Romme & Escher, 2000), since a study shows that there is a significant proportion (30%) of voice hearers who continued to hear voices despite taking high doses of antipsychotics (Curson et al., 1985). Similarly, the majority of caregivers reported that their family members take antipsychotics as a result of the voices and continue to hear them.

From the perspective of the Hearing Voices Movement, an "improvement" is not expected from the

patient, since voices are not understood as a disease, and, consequently, instead of a "cure," helping the patient live with them is sought. On the other hand, CAPS work with diagnoses, as they understand voices as a symptom that needs to be eliminated. The Hearing Voices Movement's proposal is supported by statistical data that show that the experience of hearing voices is not shared only by people who use mental health services, as there are individuals who hear voices, do not have any psychiatric diagnosis and are not undergoing any medical treatment because of them (Eaton, Romanoski, Anthony, & Nestadt, 1991; Johns & van Os, 2001).

This finding is corroborated by the study by Romme and Escher (1989), in which interviews were conducted with 350 voice hearers in the Netherlands, and a third of them declared had never resorted psychiatric care (Romme & Escher, 1989), as well as by the a study by Tien (1991), in which 18,572 interviews with people from the general population were analyzed and it was found that 10% of men and 15% of women heard or had already heard voices at some time in their lives, also showing that the proportions of voices that do not cause suffering or other impairments were much higher than those associated with impairment of daily activities.

The UFPel Nursing course has carried out several activities in favor of mental health in the city of Pelotas, and one of them is the group of voice hearers, organized in partnership with a CAPS in the city. This group aims to offer a safe space for exchanging experiences about voices, in addition to promoting the self-empowerment and independence of these patients.

However, in the caregivers' narratives, it was possible to notice that the voice hearers did not comment on the group with their families. Daniela reported that she knew little about the approach to voice hearers: "I think they try to help". According to the participant, her mother does not talk to her about the groups.

Beatriz reported that her daughter never commented on what happens at the meetings. The mother mentioned that the group's professionals encouraged her daughter to write about voices in a diary, however, the girl never wanted to share the content of this material with her. Writing a diary about voices is one of the coping strategies used by voice hearers, as, through writing, they can find meanings and learn more about this experience (Kantorski et al., 2017). Therefore, when family members have more support and clarification regarding voices, in addition to the biomedical model, they can become closer to listen and help voice hearers.

Voice hearers report that the support network is important for their treatment. Nevertheless, there is little material and information about new approaches to dealing with voices available to family members. It is essential, for these voice hearers, that their friends and family should be aware of the possible causes

and meanings of hearing voices to help them in their treatment (Baker, 2016).

In this study, some caregivers reported that they got to know more about the approach to voice hearers in the group that their relative participates at CAPS. Fernanda commented that she knew about voice hearers, however she did not have much knowledge:

It's really good for her to see that it's not just her, right. Mainly because people think they are freaks... Here there are a lot of people of different ages, there are very young people. Seeing that it's not just her is good. That helps her, helps understand what to do when she hears voices. (Fernanda)

The group is a support and reflection space that provides voice hearers with the development of a more critical sense of their experience. Furthermore, it becomes a powerful support network tool so that people feel welcomed and understood.

About this, Carmen said that her son is very reserved and does not like to talk either about the activities he participates at CAPS or about the voices he hears. But she believes that the group has helped him through advice and welcoming:

I think they advise him, I don't know. They try to know what's going on in his mind in order to help. To get him out of this outbreak. We have to listen to someone to change, right. And coming here to listen is good for him. (Carmen)

Gabriela says that she learned about the approach to voice hearers at a lecture on mental health in her city, even before she knew that her aunt heard voices:

When I first met [it], I was kind of amazed, because it's really new to me. Because when we usually think we hear voices, we think about naming it, think about a diagnosis... If the person is seeing things, is schizophrenic; if hears voices, take this person to a Spiritist center because there's a spirit talking to the person... I think it had to be something much more discussed, because people suffer from it, because they don't open up to people, feel afraid or self-medicate. (Gabriela)

As a result, groups are encouraged to be held outside health services, so that they are not associated with ideas of illness or treatment, encouraging a greater number of people to participate (Fernandes & Zanello, 2018). One emphasizes the need to offer spaces, debates and structures regarding the approach to voice hearers within the mental health network, so that, with this, both the users and their families and the population in general can acquire tools to deconstruct the stereotypes that permeate the experience of hearing voices.

Final considerations

This study sought to understand the narratives of voice hearers' family members about their experiences as caregivers. After the psychiatric reform, full-time care for people in psychological distress was delegated to family members, who often need to reorganize their daily lives in light of this care. As this is a new theme in the Brazilian scenario, there are still few studies on voice hearers, mainly in the family environment.

In everyday life, interaction and care practices are not always easy tasks. Both negligence and excessive care can generate complications for family caregivers, as well as for people in psychological distress, as excess can bring an overload of care for the family member – who assumes a position of direct responsibility for the voice hearer and leaves his/her self-care in the background – and loss of autonomy on the part of the patient due to the dependence on care provided by others. Therefore, it is essential to seek a balance between the importance of the follow-up by the family caregiver and the autonomy of the person with psychological distress, so that monitoring does not become harmful for both. This help can be provided through the mental health network services.

The Hearing Voices Movement emphasizes that hearing voices needs to be seen as a human being's experience and bases its intervention through the demystification of this experience, promoting opportunities for hearers to mean the voices and gain control of their experience. However, it is important to remember that hearing voices, from a biomedical point of view, is still treated as a synonym for madness, linked to signs and symptoms of diseases, especially schizophrenia. During the interviews, it was noticed that the caregivers presented their speeches guided by a more biomedical bias, expressing a distinction between what would be "normal" or not when referring to the behavior of their family member in psychological distress. In addition, it is possible to observe the caregivers' lack of information on the topic of voice hearers and their consequent lack of knowledge of the main strategies for coping with them. This may be a result of the fact that the voice hearer group is linked to CAPS and the way its professionals act with regard to hearing voices.

Although CAPS is a service with the objective of psychosocial rehabilitation of people in psychological distress, it is still closely linked to the biomedical model, as it offers the use of medication as the main form of treatment, which is why it is seen by society as a continuation from the old psychiatric hospitals, in which the focus was the disease, not the subject. This type of view contributes to the perpetuation of prejudices and stigmas associated with people who use the service. Thus, CAPS, together with the group of voice hearers, should establish strategies for the

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dissemination of knowledge on the subject. In order to strengthen strategies for these voice hearers to be reinserted in city's life, not only family members, but society as a whole, have to become aware and collaborate so that care in a context of liberty becomes an increasingly daily reality.

O cuidado em saúde mental: narrativas de familiares de ouvidores de vozes

Resumo: Ancorado numa perspectiva psicossocial, frente aos desafios da reinserção social e da composição de estratégias de cuidado em liberdade, este estudo tem por objetivo analisar as narrativas dos familiares de ouvidores de vozes sobre suas experiências como cuidadores. Foram realizadas entrevistas narrativas com familiares de participantes de um grupo de ouvidores de vozes em um Centro de Atenção Psicossocial (Caps) da cidade de Pelotas, no Rio Grande do Sul, Brasil. A partir da análise temática, produziram-se três eixos temáticos: (1) experiência de ouvir vozes e necessidade de cuidado; (1) família: práticas de cuidado; e (3) estratégias terapêuticas: tecendo redes de cuidado compartilhadas em saúde mental. As narrativas dos cuidadores reportam dificuldades na convivência com familiares que ouvem vozes, sobrecarga de trabalho relacionada ao cuidado e desafios enfrentados no cotidiano. Destaca-se a importância de espaços grupais de ajuda mútua que possam auxiliar os cuidadores.

Palavras-chave: família, cuidadores, ouvidores de vozes, saúde mental.

Soins de santé mentale : récits des familles des entendeurs de voix

Résumé: Face aux défis de la réinsertion sociale et de la constitution des stratégies de soins dans un contexte de liberté, cette étude analyse les récits des familles des entendeurs sur leurs expériences en tant que soignants de la perspective psychosociale. On a mené des entretiens narratifs avec des membres de la famille de participants à un groupe d'entendeurs de voix dans un Centre de soins psychosociaux de la ville de Pelotas, Rio Grande do Sul, au Brésil. De l'analyse thématique se sont issues trois axes thématiques: (1) l'expérience de l'entente des voix et le besoin de soins; (2) la famille: pratiques de soins; et (3) les stratégies thérapeutiques: tisser de réseaux de soins partagés en santé mentale. Les récits des soignants signalent de difficultés à vivre avec des membres de la famille qui entendent des voix, de la surcharge de travail liée aux soins et des défis à relever dans la vie quotidienne. L'article souligne l'importance des espaces de groupes d'entraide qui peuvent aider les soignants.

Mots-clés: famille, soignants, entendeurs de voix, santé mentale.

Cuidado en salud mental: relatos de familiares de oyentes de voces

Resumen: A partir de una perspectiva psicosocial y teniendo en cuenta los desafíos de la reinserción social y la composición de las estrategias de cuidado en libertad, este estudio tiene como objetivo analizar los relatos de familiares de los oyentes de voces sobre sus vivencias como cuidadores. Se realizaron entrevistas a familiares de oyentes de voces de un Centro de Atención Psicosocial de la ciudad de Pelotas, en Rio Grande do Sul, Brasil. A partir del análisis temático se produjeron tres ejes temáticos: (1) experiencia de escuchar voces y necesidad de cuidado; (2) familia: prácticas de cuidado; y (3) estrategias terapéuticas: tejiendo redes de cuidado compartidas en salud mental. Los cuidadores relatan las dificultades para convivir con familiares que escuchan voces, la sobrecarga laboral relacionada con el cuidado y los desafíos que enfrentan en la vida diaria. Se destaca la importancia de los espacios grupales de ayuda mutua que pueden ayudar a los cuidadores.

Palabras clave: familia, cuidadores, oyentes de voz, salud mental.

References

Baker, P. (2016). Abordagem de ouvir vozes: treinamento Brasil (L. F. Lansky, Trans.). São Paulo, SP: Cenat.
Bartels-Velthuis, A. A., Willige, G., Jenner, J. A., van Os, J., & Wiersma, D. (2011). Course of auditory vocal hallucinations in childhood: 5-year follow-up

study. *The British Journal of Psychiatry*, 199(4), 296-302. doi: 10.1192/bjp.bp.110.086918

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa

- Carvalho, C. M. S., Sousa, D. M. G., Pinho, R. I. A., Fernandes, M. A., & Oliveira, A. D. S. (2017). Vivências de familiares da pessoa com esquizofrenia. SMAD: Revista Eletrônica Saúde Mental Álcool e Drogas, 13(3), 125-131. doi: 10.11606/issn.1806-6976.v13i3p125-131
- Corradi-Webster, C. M., Leão, E. A., & Rufato, L. S. (2019).
 Colaborando na trajetória de superação em saúde mental:
 Grupo de Ouvidores de Vozes. Nova Perspectiva Sistêmica, 27(61), 22-34. doi: 10.38034/nps.v27i61.411
- Costa, G. M., Pessôa, C. K. L., Soares, C. A., & Rocha, S. A. M. (2014). A importância da família nas práticas de cuidado no campo da Saúde Mental. *Cadernos ESP*, 8(1), 41-57.
- Costa, M. G. S. G., Figueiró, R. A., & Freire, F. H. M. A. (2014). O fenômeno da cronificação nos Centros de Atenção Psicossocial: um estudo de caso. *Temas em Psicologia*, 22(4), 839-851. doi: 10.9788/TP2014.4-13
- Couto, M. L. O., & Kantorski, L. P. (2020). Ouvidores de vozes de um serviço de saúde mental: Características das vozes e estratégias de enfrentamento. *Psicologia & Sociedade*, 32, e219779. doi: 10.1590/1807-0310/2020v32219779
- Curson, D. A., Barnes, T. R., Bamber, R. W., Platt, S. D., Hirsch, S. R., & Duffy, J. C. (1985). Long-term depot maintenance of chronic schizophrenic out-patients: the seven year follow-up of the Medical Research Council fluphenazine/placebo trial. III. Relapse postponement or relapse prevention? The implications for long-term outcome. *The British Journal of Psychiatry*, 146(5), 474-480. doi: 10.1192/bjp.146.5.474
- Delfini, P. S. S., Sato, M. T., Antoneli, P. P., & Guimarães, P. O. S. (2009). Parceria entre CAPS e PSF: o desafio da construção de um novo saber. *Ciência & Saúde Coletiva*, 14(Suppl. 1), 1483-1492. doi: 10.1590/S1413-81232009000800021
- Duarte, L. G. M. F., & Ferreira Neto, J. L. (2016). Familiares responsáveis pelo cuidado de pessoa com transtorno mental em um município de pequeno porte. *Pesquisas e Práticas Psicossociais*, 11(2), 473-488.
- Eaton, W., Romanoski, A., Anthony, J., & Nestadt, G. (1991). Screening for psychosis in the general population with a self-report interview. *The Journal of Nervous and Mental Disease*, *179*(11), 689-693. doi: 10.1097/00005053-199111000-00007
- Egito, M. A. T., & Silva, E. A. (2019). Grupo de ouvidores de vozes no enfretamento de estigmas e preconceitos. *Revista do NUFEN*, 11(2), 60-76. doi: 10.26823/RevistadoNUFEN.vol11.n02artigo53
- Escher S., & Romme M. (2012). The hearing voices movement. In J. D. Blom, & I. E. C. Sommer (Eds.), *Hallucinations research and practice* (pp. 385-393). New York: Springer.
- Fernandes, H. C. D., & Zanello, V. (2018). O grupo de ouvidores de vozes: dispositivo de cuidado em saúde mental. *Psicologia em Estudo*, 23. doi: 10.4025/psicolestud.v23.e39076
- Ferreira, T. P. S., Sampaio, J., Oliveira, I. L., & Gomes, L. B. (2019). A família no cuidado em saúde mental:

- desafios para a produção de vidas. Saúde em Debate, 43(121), 441-449. doi: 10.1590/0103-1104201912112
- Giacon, B. C. C., & Galera, S. A. F. (2013). Ajustamento familiar após o surgimento da esquizofrenia. *Revista Brasileira de Enfermagem*, 66(3), 321-326. doi: 10.1590/ S0034-71672013000300003
- Johns, L. C., & van Os, J. (2001). The continuity of psychotic experiences in the general population. *Clinical Psychology Review*, 21(8), 1125-1141. doi: 10.1016/ s0272-7358(01)00103-9
- Jovchelovitch, S., & Bauer, M. W. (2008). Entrevista narrativa. In M. W. Bauer, & Gaskell, G. (Orgs.), Pesquisa qualitativa com texto: imagem e som: um manual prático (7a ed., pp. 90-113). Petrópolis, RJ: Vozes.
- Kantorski, L. P., & Andrade, A. P. M. (2017). Assistência psiquiátrica mundo afora: práticas de resistência e garantia de direitos. Cadernos Brasileiros de Saúde Mental, 9(24), 50-72.
- Kantorski, L. P., Andrade, A. P. M., & Cardano, M. (2017). Estratégias, expertise e experiências de ouvir vozes: entrevista com Cristina Contini. *Interface – Comunicação, Saúde, Educação, 21*(63), 1039-1048. doi: 10.1590/1807-57622017.0031
- Kantorski, L. P., Souza, T. T., Farias, T. A., Santos, L. H., & Couto, M. L. O. (2018). Ouvidores de vozes: relações com as vozes e estratégias de enfrentamento [número especial]. *Journal of Nursing and Health*, 8, 1-8. doi: 10.15210/jonah.v8i0.14121
- Lei n. 10.216, de 6 de abril de 2001. (2001). Dispõe sobre a proteção e os direitos das pessoas portadoras de transtornos mentais e redireciona o modelo assistencial em saúde mental. *Diário Oficial da União*. Retrieved from https://bit.ly/3lsIwOd
- Machado, B. R., & Rodrigues, T. (2017). Grupos de familiares em caps II: Gerando reflexões acerca da participação da família no tratamento dos usuários. *Disciplinarum Scientia. Série: Ciências Humanas*, 18(1), 171-180.
- Meira, E. C., Reis, L. A., Gonçalves, L. H. T., Rodrigues, V. P., & Philipp, R. R. (2017). Vivências de mulheres cuidadoras de pessoas idosas dependentes: orientação de gênero para o cuidado. *Escola Anna Nery*, 21(2), 1-8. doi: 10.5935/1414-8145.20170046
- Mielke, F. B. (2009). O cuidado em saúde mental no Caps no entendimento dos profissionais. *Ciência & Saúde Coletiva*, *14*(1), 159-164. doi: 10.1590/S1413-81232009000100021
- Mota, V. A., & Costa, I. M. G. (2017). Relato de experiência de uma psicóloga em um Caps, Mato Grosso, Brasil. *Psicologia: Ciência e Profissão*, 37(3), 831-841. doi: 10.1590/1982-3703004292016
- Nolasco, M., Bandeira, M., Oliveira, M. S., & Vidal, C. E. L. (2014). Sobrecarga de familiares cuidadores em relação ao diagnóstico de pacientes psiquiátricos. *Jornal Brasileiro de Psiquiatria*, 63(2), 89-97. doi: 10.1590/0047-2085000000011
- Pereira, A. A., Reinaldo, A. M. S., & Andrade, D. C. L. (2015). Formação dos enfermeiros em saúde mental

- que atuam na Atenção Primária à Saúde: contribuições teóricas. SANARE, 14(1), 8-14.
- Portaria nº 336, de 19 de fevereiro de 2002. (2002, 20 de fevereiro). Estabelece que os Centros de Atenção Psicossocial poderão constituir-se nas seguintes modalidades de serviços: CAPS I, CAPS II e CAPS III, definidos por ordem crescente de porte/complexidade e abrangência populacional. *Diário Oficial da União*.
- Ramos, A. C., Calais, S. L., & Zotesso, M. C. (2019). Convivência do familiar cuidador junto a pessoa com transtorno mental. *Contextos Clínicos*, 12(1), 282-302. doi: 10.4013/ctc.2019.121.12
- Reis, T. L., Dahl, C. M., Barbosa, S. M., Teixeira, M. R., & Delgado, P. G. G. (2016). Sobrecarga e participação de familiares no cuidado de usuários de Centros de Atenção Psicossocial. *Saúde em Debate*, 40(109), 70-85. doi: 10.1590/0103-1104201610906
- Romme, M., & Escher, A. (1989). Hearing voices. *Schizophrenia Bulletin*, *15*, 209-216. doi: 10.1093/schbul/15.2.209
- Romme, M., & Escher, S. (2000). Making sense of voices: a guide for mental health professionals working with voice-hearers. London: Mind.
- Rosa, L. C. S. (2005). A inclusão da família nos projetos terapêuticos dos serviços de saúde mental. *Psicologia em Revista*, 11(18), 205-218.

- Sant'Ana, M. M., Pereira, V. P., Borenstein, M. S., & Silva, A. L. (2011). O significado de ser familiar cuidador do portador de transtorno mental. *Texto & Contexto Enfermagem*, 20(1), 50-58. doi: 10.1590/S0104-07072011000100006
- Santin, G., & Klafke, T. E. (2011). A família e o cuidado em saúde mental. *Barbaroi*, (34), 146-160.
- Silva, E. C., Quadros, L. C. M., Laroque, M. F., Lima, Z. G., & Coimbra, V. C. C. (2010). Inserção da família no cuidado ao portador de transtorno mental. In V. C. C. Coimbra & L. P. Kantorski (Orgs.), Atenção psicossocial no Sistema Único de Saúde (pp. 245-255). Pelotas, RS: Editora PREC-UFPEL.
- Tien, A. Y. (1991). Distribution of hallucinations in the population. *Social Psychiatry and Psychiatric Epidemiology*, 26(6), 287-292. doi: 10.1007/BF00789221
- van Os, J., Linscott, R. J., Myin-Germeys, I., Delespaul, P., & Krabbendam, L. (2009). A systematic review and meta-analysis of the psychosis continuum: evidence for a psychosis proneness-persistence-impairment model of psychotic disorder. *Psychological Medicine*, 39(2), 179-195. doi: 10.1017/S0033291708003814

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