The Center for Psychosocial Care according to family members of users: a study from the therapeutic itineraries

Objective: this article investigated, from the therapeutic itinerary of the user, the family members’ perception about the treatment in the Psychosocial Care Centers. Method: ten family members of people undergoing treatment at a Psychosocial Care Center with, at least, one psychiatric hospitalization were interviewed. Results: psychiatric hospitalization was the first service used in psychosocial care. The Psychosocial Care Center was understood as a service with a welcoming staff that, using different care tools, helped stabilize the patient’s condition. The drug treatment was emphasized as being able to eliminate undesirable behavior in the family. Conclusion: the family was satisfied with the care provided by the service. Some points would still need to be improved to offer more effective care.

Descriptors: Family; Mental Health Services; Qualitative Research; Psychiatric Hospitalization.
O Centro de Atenção Psicosocial segundo familiares de usuários: um estudo a partir dos itinerários terapêuticos

Objetivo: este artigo investigou, a partir do itinerário terapêutico do usuário, a percepção dos familiares sobre o tratamento nos Centros de Atenção Psicosocial. Método: foram entrevistados dez familiares de pessoas em tratamento em Centro de Atenção Psicosocial com ao menos uma internação psiquiátrica. Resultados: a internação psiquiátrica foi o primeiro serviço utilizado na atenção psicosocial. O Centro de Atenção Psicosocial foi compreendido como um serviço com equipe acolhedora que, utilizando de diferentes ferramentas de cuidado, auxiliou a estabilização do quadro do usuário. Enfatizou-se o tratamento medicamentoso, visto como capaz de eliminar comportamentos indesejáveis à família. Conclusão: houve satisfação da família ao cuidado prestado pelo serviço. Alguns pontos ainda precisariam ser aprimorados para o oferecimento de cuidado mais efetivo.

Descritores: Família; Serviços de Saúde Mental; Pesquisa Qualitativa; Internação Psiquiátrica.

El Centro de Atención Psicosocial según familiares de usuarios
un estudio a partir de los itinerarios terapéuticos

Objetivo: este artículo investigó, a partir del itinerario terapéutico del usuario, la percepción de los familiares sobre el tratamiento en los Centros de Atención Psicosocial. Método: se han entrevistado a diez familiares de personas en tratamiento en el Centros de Atención Psicosocial y con al menos una internación psiquiátrica previa con ayuda de un itinerario semiestructurado. Resultados: la internación psiquiátrica precedió al uso de servicio de atención psicosocial. El Centros de Atención Psicosocial fue comprendido como un servicio que ayudó a estabilizar el cuadro del usuario por el empleo de diferentes herramientas de cuidado por parte de su equipo y postura acogida dirigida a usuarios y familiares. Hay énfasis en el tratamiento medicamentoso, visto como capaz de eliminar comportamientos indeseables a la familia. Conclusión: hubo satisfacción de la familia al cuidado dado por el servicio, en su mayoría. Diferentes puntos todavía necesitarían ser perfeccionados para el ofrecimiento de cuidado más efectivo.

Descriptores: Familia; Servicios de Salud Mental; Investigación Cualitativa; Internación Psiquiátrica.
Introduction

In Brazil, the asylum / psychiatric service was almost the only treatment option until the 1970s. Law 10216, published in 2001, guarantees the right to treatment for people suffering from psychic suffering as a priority in community-based health equipment (extra-hospital services) and organized in the form of a network, as reaffirmed by Portaria/GM N. 3,088, which regulates the Psychosocial Care Network (PCN). This network articulates different points of care for this public, considering the services of basic, specialized and urgent/emergency services that allow care from the perspective of deinstitutionalization and insertion through work (PCN).

Long-term hospitalizations cannot occur in Brazil since the enactment of Law 10216, but the short-term hospitalization resource exists and is triggered, when necessary, at the time of the crisis. In addition to this resource, the CAPS - Center for Psychosocial Care - is an important equipment in the care of the person in severe psychic suffering. According to Portaria 3088/2011, the CAPS is a service formed by a multi-professional team, which carries out, primarily, activities in collective spaces and in articulation with other points of care, involving its staff, families and users in the construction of unique therapeutic projects for performing longitudinal care of the person in psychological distress.

At the time when psychiatric hospitalizations were the predominant treatment resource in Brazil, the relationship between families and services was established by placing the family as a mere informant of the health status of the user. The growth in the supply of out-of-hospital services in Brazil since the 1990s has caused changes in the service-family relationship. This became a protagonist in the treatment of the user and partner in the attempt to social (re)insertion of the same. The presence of the relative is gradually being seen as essential for the support and assistance of professionals in the care of the person suffering from psychic suffering in the territory. When looking for the family, the team places itself closer to what is demanded by the user, and the family, by agreeing to work with the service, can facilitate the actions of insertion of the user in the community and generate a greater bond between the family in the support person in psychological distress within the family nucleus.

In addition, the family is also perceived as a target of care services. In this sense, it is the role of mental health teams to also think about the families, responsible for the development and growth of that user, as well as daily care. Such attention can be given through meetings with family members, home visits or phone calls, which can assist the family in their care difficulties, but also add to the capacity to take care of the team, in order to allow the elaboration of more complete therapeutic projects that include the family.

It is emphasized that a more humanized care and which better contemplates the needs of the person in psychological distress should consider the participation of the families in the constitution of the unique therapeutic projects of the users. In addition, the family is often responsible for the choices of the services to be accessed for the care of the user.

Choices about the ways of caring for a sick person or maintaining their health are termed Therapeutic Itinerary (T.I.). The T. I. is a concept derived from the Anthropology of Health and refers to the path that a person makes in the intention of self-promotion or improvement of health. Therapeutic itineraries indicate how choices, evaluation and adherence to treatment or health care take place. In the case of users of mental health services, the family has a relevant role in the choice of these resources, since in many cases it is responsible for identifying the need to seek support to face the crisis situation and psychological suffering. Based on the above considerations, the research problems that guided this study were delineated, namely: what do families think about the CAPS service?; how did users start service in this service?; how do families perceive care actions for families and users offered by CAPS? Based on these research problems, the objective of this study was to investigate the evaluation of relatives in situations of severe psychic suffering on the Psychosocial Care Center (CAPS) from the therapeutic itineraries of the users. To do this, through interviews with family members, one sought to know when the psychosocial care service was accessed along the therapeutic itinerary of users with at least one psychiatric hospitalization and the caregiver’s perception about the treatment performed at CAPS.

Method

This is a qualitative study and developed from the “Data Based Theory” (DBT), which aims to understand how the human being, as a social being, thinks, feels and interacts, investigating the significance/meanings attributed to people, facts, phenomena and lived situations. The participants interviewed were ten family members of users of one of the Psychosocial Care Centers (CAPS) of the city of Uberlândia-MG. This service was a Type II CAPS, which ran from 8 am to 6 pm, from Monday to Friday, consisting of a multi-professional team (doctors, nurses and nursing technicians, psychologists, social workers), as well as support professionals and kitchen) and administrative staff. This CAPS served adult public with serious mental disorders, offering group activities, consultations, foster
care, family group, householder, home visits and outside activities. It consisted of a reception room, in which were the files with the users’ medical records, coordination room, nursing room, rooms for multi-professional service and team meeting, as well as a larger room for holding groups and workshops of 30 people, kitchen and a covered area in which it was also possible to carry out group activities.

The sample size was defined by the concept of theoretical sampling, that is, the number of interviews was closed when the new themes explored by the participants ceased to appear\(^{(13)}\). Participants interviewed were over 18 years of age, their family members had at least one psychiatric hospitalization and permission to record audio interviews. In addition, the participants had no history of psychiatric hospitalization or had follow-up in mental health services.

Two instruments were used to perform the data collection. The first was a semi-structured interview script for family members who initially investigated characterization data (age, occupation, schooling, for example) and then guiding questions about the families’ understanding of the treatment received in CAPS by the users and the inclusion the family in these / by these services. As for the second instrument used, a questionnaire\(^{(12)}\) was used to extract data from users’ records (age, diagnosis, number of hospitalizations and time of treatment in CAPS), with author’s authorization. It is worth mentioning that this article is the result of a larger study that investigated not only the families’ understanding of the treatment in CAPS, but also the access to other PCN care points and popular and religious resources in mental health care.

To start the research, after approval by the Ethics Committee (Opinion 1,007,528/ 2015), a meeting was held at the CAPS to discuss the project with the team, organize the researchers’ entry into the field and identify the moments with the greatest possibility of family. Relatives of users who were waiting in the waiting room for the service were contacted. In this first moment, the family member received verbal explanations about the research and, when he agreed to participate, the interview was scheduled and performed at the family member’s home, using the Free and Informed Consent Term (FICT). At the request of one participant, a single interview was scheduled and performed at the family member’s home, using the Free and Informed Consent Term (FICT). At the request of one participant, a single interview was scheduled and performed at the family member’s home, using the Free and Informed Consent Term (FICT).

As ethical care, due to the need to preserve the identity of the deponent, in transcripts, the acronym E1 for the first interviewee, E2 for the second and so on were adopted. The names of the services and persons mentioned in the interviews, such as family members and health professionals, were also omitted.

The first step for analysis was the full reading of the literal transcriptions, and for each one, there was the organization of ideas from the association tree technique\(^{(13)}\). In this technique, it is sought, through a clipping of the material, to understand the argument that was exposed, through the identification of flags that illustrate the phenomenon investigated. This technique, by the literature\(^{(13)}\), from the point of view of the production of meanings, it was adopted in this study to facilitate the encoding of the interviews, based on Data Based Theory\(^{(10)}\), in the stages of: open, axial and selective coding, allowing the identification of the properties of the categories of analysis and the establishment of relations between categories. In the open coding stage, the researchers read the whole set of transcripts in search of sentences, words or paragraphs that could constitute preliminary codes of analysis. Then, in the axial coding stage, the researchers sought to identify characteristics related to the highlights made in the initial stage, considering the relationships between phenomena, explanations for them and their consequences. Finally, in the selective coding, the main topics discussed in the interviews were systematized, contributing to the formation of the categories of analysis that, in this research, are: (1) The CAPS in the therapeutic itinerary of the user; (2) The role of CAPS in stabilizing the crisis; (3) CAPS care tools; (4) CAPS support and the fragile social support network; (5) Problems: what should improve in CAPS.

Results and Discussion

(A) Characterization of interviewees and users

The majority of the interviewees were women (F=7), with a minimum age of 32 and a maximum of 67, of whom four had a partner, most of them had incomplete Primary Education, occupation/profession related to the household (domestic or (slave, mother, daughter or spouse), with a family member who has Higher Education, characteristics similar to those indicated in the literature\(^{(14)}\). Users whose family members were interviewed were mostly women (with a minimum age of 19 years and a maximum of 55), most of them without a partner, with no information about schooling in most records, and most he was not currently employed. Regarding the diagnosis, the majority of the users had been classified with schizophrenic spectrum disorders and had the minimum of one hospitalization and a maximum of six.
(B) The CAPS in the therapeutic itinerary of the user

The therapeutic itineraries informed by the families indicated that, in eight of the ten interviews, the CAPS was not the first service used for the treatment of the user. In general, another service referred to the CAPS, namely: psychiatric emergency / emergency service (E5), basic care (E7), education field equipment indicated service (E8) and, five interviews (E1, E2, E3, E6, E10), at the end of the period of psychiatric hospitalization, the team referred the user to CAPS. Thus, in seven cases, hospital admission or specialized psychiatric emergency service preceded care in the CAPS (E1, E2, E3, E4, E5, E6, E10), which is contrary to the provisions of Administrative Rule MS 4279 / 2010[15], which defined primary care as a gateway to public health in Brazil. In addition, Portaria MS 3088/2011, which deals with the creation of the Psychosocial Care Network[16], proposed the articulation of all PCN care points (from primary care to hospital, including transitional and residential units), and, in its Article 8 § 2, emphasizes that the CAPS are responsible for the reception and care of the person suffering from psychic suffering during the acute phase, that is, in crisis, in order to “continue the process of replacing the beds in psychiatric hospitals”[17] the expansion of the possibilities of care in the territory, with the smallest number of hospitalizations possible. It was noticed through the therapeutic itineraries that hospital care and emergency services were the gateway to treatment in PCN, without to exhaust the alternatives for care in a community context.

In two cases, the user’s therapeutic itinerary revealed that CAPS was triggered by spontaneous demand as the first service in PCN. In one of these cases, the interviewee had professional training in the health area.

I already knew that it was the CAPS that was going to give the support that we needed! (E9).

In another interview (E4), the demand also occurred at the initiative of the family.

A year and a half ago we discovered CAPS. We did not know either [what CAPS was], [family members] passed the street and saw the plaque (E4), entering the service and, then, taking the family to the welcoming. These two cases characterize the open CAPS model[18], that is, without the need for routing. After the reception by the team, configured the crisis situation, these two users were integrated into the CAPS service routine.

(C) The role of CAPS in stabilizing the crisis

It is important to note that the interviews were not restricted to the CAPS assessment in which the collection occurred, since some users had already attended other services. The CAPS equipment was perceived, by the interviewees, as a service with the ability to assist the user, because attending it regularly implied having medical supervision and prescription of drugs, essential points to overcome the crisis or prevent it/avoid it, the opinion of the family members.

He had this crisis because he stopped going to CAPS and stopped taking medicine now at the end of the year. [...] If he has been attending CAPS regularly, he will not go into crisis. (E9)

Another testimony reinforces this idea:

That’s where it all came back. The crises ... went without the medicines, went without, without accompaniment, right? (E10)

The medication had a fundamental role in stabilizing the situation when the behavior of the family was disturbed and the behaviors that facilitated the family life were reduced, besides requiring less daily care with the user[16,17]. The family perceived, through the user’s adherence to the CAPS and the use of prescription medication, changes in behavior, such as talking more, understanding what was said, being more sociable and helping in the organization of the home.

She already talks with us, she already participates ... before she did not like to sit down to watch television, today she already sits ... [...] I think she had a very good evolution. (E7); Getting a bed, he knows that when he gets up he has to clean his bed, if he is in a crisis, he will not get it, right? (E2)

These behavioral changes signaled, for most of the family members, the central need for the use of medication, obtained through the continuity of care in CAPS. Being without the medication, ingesting it irregularly or changes in medication were perceived as potential events for the onset of a new crisis. The literature points out[19] that the Psychiatrist Reform attempts to deconstruct medication logic as the path of treatment excellence and, therefore, it is important to create spaces for families to reflect on the use of medication. According to the authors, if the family summarizes the services to medical-medical support and hygiene care to the user, it runs counter to the biomedical and asylum logic that is intended to overcome.

(D) The CAPS Care Tools

According to the interviewees, the service-family approach took care of several tools, such as: family groups, home visits, telephone calls, guidelines for families, as foreseen in legislation[20], and reflected satisfaction and the confidence of the participants, who perceived CAPS as a point of support. Home visits and telephone calls were highlighted as tools that indicated not only the interest of the team by the users, but, also, the families, who evaluated as a space where it was possible to talk about the difficulties in the care of the user and to question the or its evolution.
This meeting is family oriented, just as we are talking here. The psychologists sit with us, and ask the patient’s behavior, how he is, how he is with the family (E10).

In the specific case of mental health services, some studies have focused on understanding whether or not family members feel they are included\(^{(19-20)}\), which shows the importance of discussing this inclusion in today’s world and understanding that family is not just the escort who informs about the status of the user to the services. The family members interviewed, when declaring the importance of listening spaces for themselves in the routine of the CAPS, separate from the users, reaffirmed themselves as subjects who also needed the care of the team.

Do you know when you feel that the person is valued? Who has consideration and is welcomed? And I feel that way too. (E9) or I called the girls [psychologists] of the CAPS. Then we would talk to the [psychologist], she would guide us what to do, another time they would go there ... they gave me a lot of attention [...] (E7).

In this sense, it is worth emphasizing\(^{(21)}\) that care to the user and his / her family can broaden the condition of this group to be managed and strengthened, when the family is understood as part of the health promotion, which must be welcomed and taken care of in its entirety and potentiality. Since CAPS is a place of care for the person in crisis, and not equipment for longitudinal care, the strengthening of families becomes even more relevant because of the more fragile moment they face.

**E) CAPS support and the fragile social support network**

The CAPS-family relationship gained another dimension when contrasted with the restricted social support network with which participants could count.

*It’s really the CAPS, the CAPS and the [psychiatric clinic] ... it’s the health services, there’s no one there, nobody helps* (E3).

In different testimonies, it was possible to perceive that the caregiver felt overwhelmed by the responsibility of caring for the user, and the only source of support and assistance to this family member became the service.

*Because I know that in the period that she was all day [in the CAPS], I know that I’m quiet there, because there [CAPS] the girls so there.* (E10)

In some cases, the relative left his or her own problems in the background for the care of the user.

*So that means I’m going to have another six months until he gets used to going by bus [to CAPS]. Then until he gets used to it, I’m going to delay a little more [the treatment] of my deafness problem.* (E1)

The same situation was discussed in the literature\(^{(22)}\), which emphasizes that the lack of a support/support network in the care of the family member in crisis implies the need for the caregiver to place one’s life in the background. According to the authors, when the caregiver takes responsibility for the life and behaviors of his family member in crisis, he assumes a very heavy role, characterizing the overload.

The assistance of neighbors, other relatives, a religion and friends allow them to live in a healthier and calmer way.

**F) Problems: what should improve in CAPS**

Although most of the speeches indicated that the family members felt welcomed by the service, some interviewees brought shortcomings of the service’s support in care and guidance to the family.

*They [CAPS] call here to ask him, but they never call here, for example, at least for me, for me (sic) to go there and talk to me to find out how he is.* (E4)

The family could, therefore, feel excluded from the decisions for the treatment, for the lack of space so that it could expose its perception on the user. In addition, the lack of a conversation with the family about the processes of discharge of the user or follow-up in another point of care of the network was remembered by two interviewees.

*For example, the day I went there, they were almost discharging him because he goes there, he’s calm [...] He arrives here and starts cursing, that is, they had to have called here and looked for information! [...] his prediction of his release was already almost predicted and until then he had not called here to know how he was [...] then I found it disjointed.* (E4)

The exclusion of the family member from the CAPS discharge process articulated by the teams refers us to the idea of shared custody\(^{(23)}\), that is, the need to build care strategies for the user-family-services set, through sharing, co-responsibility. In addition, there is a need to provide new ways of involving the family in a shared care as one of the challenges of CAPS. This is an important aspect, since co-responsibility is understood in the care of the user, which should involve the family, the psychosocial care network and the user itself, without one of these actors being seen as solely responsible\(^{(24)}\).

Another issue pointed out as negative by the participants was the first impression of a relative when visiting the CAPS and finding there people / users lying on the floor. This led him to question the quality of the institution and the care taken by the team.

*I questioned why people lay on the floor. Here [CAPS] is not a place for them to lie down. One that if they put bed, many want to go there to sleep, right? It’s not their goal ...* (E4)

Care transposes the barrier of asylum treatment\(^{(25)}\) insofar as the user and his / her family are not perceived as objects to be analyzed, but as acting subjects, allowing the construction of the singular meaning of health for that local community and family. Therefore, one can perceive how the possibilities of looks and care
expand when expressed through the junction of the informal network and health services.

Conclusion

The purpose of this study was reached because it was possible to investigate the evaluation of family members about the care offered by the CAPS through the investigation of the therapeutic itineraries of the users. The main results of this research are the satisfaction with the care offered by the CAPS, the approach of the team with the families and the emphasis on medication treatment, as it is able to eliminate undesirable behaviors to the family. One limit of this study was its realization from a single CAPS, from which the participants were invited. Another limit of the research refers to the focus given to the family members who were in the CAPS, which allows the suggestion for future studies with families less present in the services in order to understand how they perceive the service. One contribution of this study was to highlight the fragile support network of family members of CAPS users. It is understood that for the continuity of the care in extra-hospital service, the creation of mechanisms for the expansion of this support network for the caregiver is necessary and urgent. Another contribution concerns the invisibility of the CAPS as a point of care for the Psychosocial Care Network, and has been sought, often, only after hospitalization. The positive evaluation that the relatives did about the way care is carried out in the CAPS contrasts with the fact that it is a service little known to them. It is important to emphasize the need for a greater dialogue between the health network services and also in inter-sectoral contexts so that the existence of this care equipment, which privileges the maintenance of the person in their socio-family environment, can be more widely disseminated and known.

References

14. Nolasco M, Bandeira M, Oliveira MS, Vidal CEL. Family caregivers? burden as a function of psychiatric patients
Corresponding Author:
Renata Fabiana Pegoraro
E-mail: rfpegoraro@yahoo.com.br
https://orcid.org/0000-0001-6052-5763


Authors’ contributions

All authors approved the final version of the text.

Conflict of interest: The authors have stated that there are no conflicts of interest.