ORIGINAL ARTICLE

Relatives of patients with mental disorders: experiencing care at a Psychosocial Care Center

FAMILIARES DE PORTADORES DE TRANSTORNO MENTAL: VIVENCIANDO O CUIDADO EM UM CENTRO DE ATENÇÃO PSICOSSOCIAL

FAMILIARES DE PORTADORES DE TRASTORNO MENTAL: EXPERIMENTANDO EL CUIDADO EN UN CENTRO DE ATENCIÓN PSICOSOCIAL

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ABSTRACT

This study aimed at learning how relatives of patients with mental disorders have experienced dealing with a mental health care service. The exploratory and descriptive method was used with a qualitative approach. Data collection was performed using semi-structured interviews. Subjects were six family members who had been living for over three years with the process of having a mentally ill relative. Data analysis allowed us to infer that relatives who closely follow the patient had to deal with the knowledge acquired from their day-today experience and were subject to rejection by other family and community members. As regards the psychosocial care center, the relatives felt welcomed in their complaints, receiving a unique treatment; however, they did not know the mechanisms for social participation, which points to a deficiency in the service as it should stimulate forms of insertion into the community and the strengthening of the patients' rights as citizens.

KEY WORDS

Mental health. Family. Mental Health Services.

RESUMO

Esta investigação teve por objetivo apreender como os familiares de portadores de transtorno mental têm convivido com um serviço de saúde mental. Foi utilizado o método exploratório/descritivo, de natureza qualitativa. Como instrumento de coleta de dados, utilizou-se uma entrevista semiestruturada, sendo sujeitos dessa pesquisa seis familiares que já conviviam há mais de três anos com o adoecimento psíguico. A análise dos dados permitiu inferir que os familiares que acompanham o usuário têm de lidar com um aprendizado que adquiriram na vivência cotidiana e são sujeitos à rejeição de membros da família e da comunidade; com relação ao centro de atenção psicossocial, os familiares se sentem acolhidos em suas queixas, recebendo um atendimento singular; porém, desconhecem os mecanismos para a sua participação social, o que aponta para uma deficiência do serviço, à medida que este deve estimular formas de inserção na comunidade, e da ampliação dos direitos de cidadania dos usuários.

DESCRITORES

Saúde mental. Família. Serviços de Saúde Mental.

RESUMEN

Esta investigación tuvo por objetivo aprender como los familiares de portadores de trastorno mental han convivido con un servicio de salud mental. Fue utilizado el método exploratorio/descriptivo, de naturaleza cualitativa. Como instrumento de recolección de datos se utilizó la entrevista semiestructurada, siendo sujetos de esta investigación seis familiares que ya convivían hace más de tres años con la enfermedad psíquica. El análisis de los datos permitió inferir que los familiares que acompañan al usuario tienen que lidiar con un aprendizaje que adquirieron en la vivencia cotidiana y están sujetos al rechazo de los miembros de la familia y de la comunidad; con relación al centro de atención psicosocial, los familiares se sienten acogidos en sus quejas, recibiendo una atención singular, sin embargo, desconocen los mecanismos que permiten su participación social. Lo que apunta para una deficiencia del servicio en la medida que este debe estimular formas de inserción en la comunidad y de ampliación de los derechos de ciudadanía de los usuarios.

DESCRIPTORES

Salud mental. Familia. Servicios de Salud Mental.

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INTRODUCTION

Recent changes in mental healthcare have established people with mental disorders and their relatives as the protagonists in a process that seeks to innovate the forms of care, and are also supported by the mental healthcare professionals working in many different scenarios, aiming at helping this population to be welcomed, to bond, and to become responsible members of society, within the boundaries of healthcare ethics.

Psychiatric care in the past was characterized by excluding families from supporting their relatives during psychiatric treatment. One of the causes thought to be responsible for the development of mental disorders was the negligence of the family regarding moral issues and lack of education. Therefore, the proposed treatment for those who suffered from mental illness included social isolation, vigilance and time spent in psychiatric institutions that sought to provide reeducation to mental patients through rigid routines and inflexible regulations; the hospital institution was tasked with guaranteeing an environment ruled by discipline⁽¹⁾.

The family was excluded from visiting their loved ones at the psychiatric hospital whenever the patients experienced a remission in their psychic disorders, in order to avoid episodes that could hamper the treatment plan proposed by the physicians. Therefore, the family was not a part of the care provided to the mental patient.

Therefore, the family was stigmatized and, as a consequence, there were a large number of people living in psychiatric institutions due to the rupture of these family bonds; some of these people suffered due to decreased communication between its members and the institution, in addition to the sparse knowledge regarding psychiatric disorders. However, following the transformations in the mental healthcare field after the 1970s, the family was invited to play an active role in supporting and treating the person and lack of education.

Regulation SNAS 224/92, which outlines the rules that govern the substitutive services in relation to psychiatric hospitals, covers issues such as universality, hierarchy, regionalization and integrality of actions. It also indicates that the services must offer alternative methods and techniques aimed at providing healthcare, as well as multiprofessional aspects and social participation emphasizing the importance of elaborating mental healthcare policies and social control. It states that the local regulatory agencies are responsible for complementing the current regulation and evaluating the service providers⁽²⁾.

The Psychosocial Healthcare Centers – Núcleos e Centros de Atenção Psicossocial (NAPS/CAPS) were designed to provide family activities aimed at integrating the mental pa-

tient into the community, as well as encouraging their social insertion $^{(2)}$.

After ten years, with the implementation of the daily services, Regulation GM 336/02 replaced Regulation 224 and established the modalities of psychosocial healthcare centers (CAPS) according to their characteristics and the followings attributes: organizing the demand for services and the mental healthcare network within its territory; regulating the healthcare network at its entry point; coordinating supervisory activities in psychiatric hospitals according to the local regulations, and overseeing and qualifying the basic healthcare teams, among others⁽²⁾.

The activities proposed by Regulation 336, designed to include the family, are the same that were dictated by Regulation 224/92⁽²⁾. These activities were proposed to enlist the family group, aiming at creating common bonds among the participants, in order to discuss common problems, learn how to cope with difficult situations and to receive education regarding the diagnosis affecting their loved one and their participation in the therapeutic plan⁽³⁾.

As such, according to Regulation 336, the role of the

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CAPS team was broadened, since these professionals are understood to have the technical capacity to work with other mental and basic healthcare services; however, it does not regard the political-legal difficulties in enacting social participation and formulating mental healthcare and social control policies, as stated in Regulation 224.

It is worth noting that the CAPS have retained their technical/care-providing function, improving their role as innovators in the mental healthcare model. Some weaknesses

can be observed, especially in regards to the diversity of actions required for the qualification of care and changes in social acceptance related to the issues of rejection related to mental illness⁽⁴⁾.

Also, although the psychosocial healthcare centers have made advances in relation to the implementation of the services, they cannot be considered as an endpoint for psychiatric reform, which is an ongoing process and must evaluated within the mental healthcare field and psychosocial care in its four dimensions: the first dimension is theoretical-conceptual, which examines the epistemological context, i.e. how mental disorders are understood, using the positivist paradigm or understanding it as a process of experiencing suffering. This understanding supports the technical/care-providing dimension, as this is how the services are built and how they deal with people and spaces for subjectivity and socialization⁽⁵⁾.

The political-legal dimension regards the construction of citizenship by approving laws and decrees, but it also implies changing mindsets, attitudes, beliefs and social relations. In the socio-cultural dimension, we invite the civil-

undergoing psychic suffering.



ian society to discuss mental illness, and the role of the psychiatric hospital through artistic, cultural and sport activities, among others, in order to reach the social conscience. The participation of the subjects involved is paramount – users, relatives, associations engaged in the protection of people with psychic disorders and their relatives, professionals and the community⁽⁵⁾.

To execute this study, *family* was referred to an indispensable environment to guarantee the survival and protection of its members, regardless of how they are structured. It provides the emotional support and the necessary materials to the development of its components. It has a decisive role in the informal and formal education that provides ethical and humanitarian values, as well as solidarity bonds. The family is inserted in a socio-cultural context, which includes the professional and informal systems of healthcare. These systems influence the exchanges and the family relationships^(G-7).

As such, the goal of the present investigation is to understand how the relatives of users of a psychosocial healthcare center see their role in the treatment of the mental patient and how they visualize their social participation as subjects.

METHOD

This is a qualitative, descriptive-exploratory investigation, which allowed us to broaden the knowledge related to the family and its experience in a territorial mental healthcare service⁽⁸⁾.

To begin with, a questionnaire was used to obtain the following personal data: age, gender, education and type of relative. An interview was used to collect data, which included the following questions: how the relative sees the role of the family in the care provided to the user; the easy and difficult aspects of relating to the healthcare service; and how the family views their effective participation in the healthcare services and their contribution to improving healthcare for the user.

The interviews were held after the project was approved by the Review Board of the Faculdade de Medicina de Botucatu - UNESP, file #575/2004. The interviewees were informed about the study before deciding whether they would take part in it.

The interviews took place at the CAPS, from October to November of 2005. For this study, the relatives chosen to participate were those who had been assisting the user for more than three years in navigating the mental healthcare services and who were considered to be references by the healthcare team in providing information regarding the daily events of the users or for orientations about their treatment. The interviews were recorded on cassettes.

The empiric field in this investigation, the CAPS, started functioning in October of 1999, associated with a state-owned

psychiatric hospital, and is responsible for the population of 38 cities that are part of the Regional Health Division.

Data analysis was performed according to the thematic analysis technique, which is one of the modalities of content analysis (9). Initially, the tapes were transcribed, with the material being read several times in the first stage to sort the elements, ideas or expressions contained in the testimonies of the interviewees, which allowed for the organization of the material according to the theoretical guiding questions. In the second stage, it was possible to elaborate the meaning cores and their approximation with the available bibliography and the researcher's experience, which made the analysis of information possible (9).

RESULTS AND DISCUSSION

Six relatives were the subjects in this study: two brothers, two parents, one wife and one daughter, aged 20-71. Regarding education, the eldest relatives had not completed elementary education. Among young adults, there were variations of incomplete elementary education, high school and university level education. All of them lived in Botucatu.

Data analysis allowed for the construction of the following themes: the role of the family in the care of the mentally disordered patient; the family and its relationship with the psychosocial healthcare center; and the social participation of the family of the mental patient. They are presented next.

The role of the family in the care of the mentally ill patient

The relatives point to the importance of monitoring the mental patient, providing support, showing patience and learning how to deal with their behaviors.

F3 – the role of the family, especially at home, we try to encourage them very, very much, because we've been living with this situation for almost 11 years [...] there's that saying, *living and learning* [...] the way we seek help, and how we live with people with this problem, you have to be patient, have a lot of patience.

F5 – The family is the patient's structure; you have to be patient in the first place. I believe that care, protection, showing that you care -it's hard. And there comes a time when it affects the relatives themselves, more than the patient himself. You have to pay attention, give care and protect.

The family tries to see to the needs of the patient by providing care and, especially, patience within the relationship, in learning to cope with the situation. In this case, the bonds of solidarity are predominant, since all the family members have to organize themselves to face the process of caring for a loved one with a psychiatric disorder⁽⁶⁻⁷⁾.

In the testimonies, however, there is the issue of family overload, as the relatives still see the patient as a person



with decreased capability to perform activities in his or her life, needing to be monitored or protected⁽¹⁰⁾.

F4 – I think it's important for the family to help, because, to start with, they can't take care of themselves. Someone needs to be around to take care of them. It's really demanding for us, there are times when we think about giving it all up because it won't change anything.

The testimony of this relative shows that the patient is considered incapable by the family, who does not understand the mental illness and the patient's way of experiencing it. Therefore, care becomes a burden, as the patient is considered to lack autonomy, or as someone who will not exert autonomy without changes in attitude. All of this makes everyday relationships more difficult to sustain. This form of misunderstanding stems from the lack of knowledge about the process of the illness and the possibilities for social reinsertion, based on a treatment supported by lifelong projects.

Two relatives show the fragility of the affective bonds with other family members, or even the possibility of rejection.

F1 – If she weren't rejected by other family members, she could be much better. She's been sick since she was 18. She completed the eighth grade, she had a job. So, I think she misses a lot of people in the family.

F2 – I see that D... such as, when she's worried about something... with the other people in the family. She tends to improve, but when there's a period of abandonment, she goes down. If the families could change this way of seeing her... I used to see her as a burden, a thing, but that's not the way it is, you can live with it.

According to these brothers, the higher levels of overburdening are found in those who provide care for the patient, as the other relatives keep away and do not relate with the user as often.

The relatives acknowledge that this distancing is not good for the patients, as they feel abandoned and rejected. What happens in the community is often repeated in the family.

The testimonies of the relatives show the importance of the substitutive services in supporting the families, providing a sympathetic ear to their difficulties and doubts regarding how to cope with the disease of their relative, and the necessary changes that must be undertaken in order to live well within the community where they are inserted⁽⁷⁾.

In the relatives' testimonies, we also find markers of the epistemological dimension, where the knowledge is supported by behaviors that demand protection of the mentally handicapped, indicating the danger posed by the mental patients and their lack of coping skills. The task placed on the healthcare sector is to dispel this way of conceiving psychic suffering⁽⁵⁾.

The family and its relationship with the psychosocial healthcare center

The interviewed relatives pointed out the importance of the treatment at the substitutive service, where the

working process is focused on welcoming. They say that each relative receives individual attention.

F2 – It's easy, because... they're willing to take your calls anytime you need, and also to provide clarifications, help you and support you; it's important. However, the most important thing at CAPS, I think, is that the CAPS staff taught me how to understand D, so it's easier to deal with her. With the contact we have with them, we learned a little more.

F4 – Dealing with them is as easy as it gets, they talk to me anytime I need them; I call them, they're always ready to answer, and I've never had any problem. It was always great to use the service here. When he has a problem, they try to help, they're always ready.

F6 – I found it really easy, it was good for A. He was admitted to hospital C. (a psychiatric hospital) several times; he had several crises there, every week he had to be admitted there. Then he started going to the CAPS, and after that he was admitted into the C only one more time. Then, he didn't have to go to the hospital anymore, it was a big improvement.

The relatives talk about being welcomed by the CAPS team no matter what their requirements were, either for clarification, orientation or to receive support whenever they needed it, which allows the relative to feel cared for. They also learn how to deal with situations that could have led to psychiatric hospitalizations before the involvement with CAPS.

Welcoming was a strategy used to see to the needs of the users and relatives, focused on establishing a working relationship. The meeting is initiated by a complaint; however, the service provides room for listening. It is a place for meetings, interventions and negotiations among workers, users and relatives, being a part of the working process as a possibility of establishing a conversational network (11).

There is also an open-door policy with the users and relatives, so as to provide care for everyone who comes to the service to validate their concerns, demonstrating the availability and ability to understand the reality of the experience of psychic suffering, emphasizing the quick provision of care for pain and the willingness to listen to the many forms of expression of the demand⁽¹²⁾.

When the testimonies are validated, the family is also taught to validate the testimony of the mental patient:

F2 – Now I respect D's individuality much more than before; that's what I had to learn and start from scratch. You learn to do this or you abandon the person, either you welcome too much or end up cutting it off. So, that's the midpoint, you have to reach a midpoint and know exactly when you have to act, you have to let her do it. This is something that is very difficult, the relative has to learn and receive support from the CAPS.

The innovations in the mental healthcare field enhance the possibility of listening to each other, either as a user, relative or healthcare professional. In this situation, everyone who is involved learns new forms of living collectively.



The service must provide the relatives with a mutual space for sharing:

F2 – I think that the family must participate anyway; they shouldn't leave the whole problem for the CAPS to solve. They have to be partners. And the communication between the family and the CAPS is important. Not only the CAPS, but all services.

Unlike during psychiatric hospitalizations, where relatives do not play a significant role in the patient's therapeutic plan in relation to the CAPS, there is a need for partnership, since the service and the family are in contact with the patient every day.

Regarding the family, CAPS also offers groups of relatives the opportunity to take part in the treatment:

F2 – A meeting would be a good way... the weekly meeting that they hold, it would be a way of expressing what you're feeling and also to receive information.

F6 – I think that these occasions when we participate, when we support him, by going to the meetings held by the CAPS, we're always up-to-date with whatever the CAPS is doing.

The family group is a space for exchanging experiences, where the participants identify with the problems of the others, becoming more able to reflect on their own reality. The opportunity to listen to the difficulties that emerge from daily life makes it possible to identify with others and brings relief from the feeling of isolation, which is often present in families, with the construction of a group creating a space for reference, experimentation and friendly exchanges⁽¹³⁾.

When the family feels that it is a participant in the treatment at the psychosocial healthcare center, they even feel capable of taking on the role of volunteer:

F1 – I could even be a volunteer. I've always liked it, I've always applied for it and they never called me until now. I dream about volunteering at a place like this to help out, to work with people.

F6 – I think that it could even happen just by talking, as I said. My mother has had this depression for a long time; I think that even if I could talk with relatives of other patients who are beginning their treatment to offer clarifications... sometimes the person says, *that's not relevant*, but everything is part of the disease. It's hard to live with that in the beginning, because, at that moment, arriving, talking to new relatives, users, even with the patient, is a part that I think I could collaborate with: as a volunteer, talking to the relatives.

This is one of the proposals elaborated for the family, which becomes a transforming agent and participates in the activities proposed by the service, both internal (such as in the working projects) and external (such as community actions of social integration). The relatives should be considered partners in a new model of mental healthcare by the CAPS⁽¹²⁾.

When the relatives show their desire to become volunteers, they share life experiences with those who still do not understand the process of the psychiatric disease completely.

Considering the technical/care-providing dimension, it is possible to see that the service is focused on welcoming, which allows the family members to be heard individually, based on the dialogue and the necessary information exchanges⁽⁵⁾. In addition, the relatives are willing to contribute to the improvement of the service.

The mental patient's family and the social participation

When we investigated the relatives in relation to the healthcare service, we realized that the families feel isolated when they are not included in a mental healthcare service that welcomes them.

When they involve themselves with the CAPS, we could see that the service becomes the social network of the families that, prior to their involvement with the CAPS, did not have such an outlet for their necessities⁽¹⁴⁾.

However, we also try to understand what the relatives acknowledge as participation in the community, considered to be a place for negotiation and struggle for the rights of the mental patient. They were asked who they should consult in case of problems that were beyond the competence of the CAPS. Lack of knowledge was the norm:

F1 – I think that the families of people undergoing treatment, the government, I don't know, CAPS and the government? The government, also, the family of those who attend the CAPS, that's what I think.

F2-I wouldn't know where... maybe in the Municipal, or the State Secretary of Health? I don't think so. I've sought out the State service, it's located by the P. I think it would be there; if there were complaints, I think that it wouldn't be accessible for most of the population. For example, if I had a complaint or suggestion and couldn't bring it here to the CAPS, about D, I'd go there, but I wouldn't know who I should talk to there, you know? And there's no way of knowing.

The relatives do not know which government sphere is responsible for managing the psychosocial center in question. However, they mention that this lack of knowledge is common for all the healthcare services.

This weak spot of the CAPS proposal is evident, as its projects involve working with other services to organize the demands for care and creating a mental healthcare network. In addition, part of their role is to work with the community to improve the understanding of mental diseases and to increase the sensitivity towards new healthcare practices.

It should be noted that, according to regulation #336, the CAPS is configured as the articulator of actions that aim to organize the demand for care and the mental healthcare network within the territory, from the basic healthcare units up to the hospitals⁽²⁾.



When performing these roles, the CAPS must also plan social support activities focused on exercising civil rights through the formation of patient or family member associations⁽¹⁵⁾. Through these societies, the relatives can make themselves heard in the many institutions that promote social participation, such as the Municipal Health Council.

There is an association of patients, relatives and mental care professionals that has existed for 13 years in the city where this investigation was performed. Its goal is to promote actions that improve the citizenship of the patients and their relatives through social inclusion⁽¹⁴⁾.

A relative proposes a clarification campaign as a way to approach the community:

F2 – Today, maybe a health campaign, or a clarification campaign such as those about cigarettes could help people, but the difficulty is the prejudice that exists and this idea that people have, that even I had, that D is a bad person, that the mental patient is dangerous, an extremely dangerous person. It's not always like that. You can be rich, but they can be richer than you, it's sort of like that. I believe that the way in which the person sees the relative changes, people who don't have this problem end up having a biased image. It's not just a family problem, it's everyone's problem.

By suggesting a clarification campaign, this relative highlights the importance of communication whenever forms of conceiving and treating the mental patients are sought, as well as the problems caused when these patients are subjected to rejection.

Regarding psychosocial care, its legal-political dimension and the construction of citizenship, it is necessary to consider that, along with the current laws, we also need to change mentalities, attitudes, beliefs and social relations. If they're articulated with the socio-cultural dimension, they will move the discussion to civil society, focusing on the social concepts of mental disease. The mental healthcare services must use artistic, cultural and sport-related manifestations, among others, including the involved subjects themselves: users, relatives, associations involved in the defense of mental patients and their families and healthcare

professionals in order to make the community more aware of the scope of mental illness⁽⁵⁾.

Broadening these dimensions is a challenge given to the CAPS, the empirical field of this investigation. However, we must consider the reality of this service, which is still based in the State. This means providing service to a population that is heterogeneous in its place of residence, making it difficult to bring the precepts of territoriality and daily living into practice, since the realities of the cities that make up the region are different.

FINAL CONSIDERATIONS

When we tried to understand the reality of relatives of mental patients, we could detect the importance of the family in the monitoring of the patient, and the ways of dealing with the disease and the rejection that they are faced with within the family and society, which still cannot accept a person who behaves differently than the societal norm.

For these relatives, the CAPS is a welcoming space, which offers a new way to live collectively, allowing for affective exchanges, extending its social network and making it possible to experience the care that should be provided to the user, collectively.

In our investigation, the relatives mentioned the need for increasing the resources that challenge the way in which the mental patient is viewed by the community. They also lack knowledge regarding the mechanisms of participation in order to claim their rights, as well as those of their relatives. The service needs to be articulated with a healthcare network in which the relatives can be actor-subjects, which is fundamental for the implementation of new routes in healthcare.

We also recommend that the service seek out methods of making its visibility more effective in the community, as a way of guaranteeing the necessary advances towards the implementation of a new way of seeing and giving care to the mental patient, with the resources and services that already exist in the city.

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