

## MENTAL HEALTH CARE AT THE PSYCHOSOCIAL CARE CENTER FROM THE FAMILY'S PERSPECTIVE

Cuidado em saúde mental no centro de atenção psicossocial sob o olhar da família

Cuidado en salud mental en el centro de atención psicosocial bajo la mirada de la familia

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### ABSTRACT

**Objective:** To discuss the mental health care provided by the Psychosocial Care Center team from family discourses, describing the experienced transformations with the change occurred in the model of mental health care. **Methods:** It is an exploratory and descriptive research with a qualitative approach. For data collection, semi-structured interviews were conducted with the relatives of the service. Data analysis was done using the Thematic Content Analysis technique. **Results:** Family members feel supported and welcomed at CAPS and they are recognized by professionals as a strong therapeutic resource. During the study, it was observed that the service in which the research was developed is facing difficulties in carrying out specific activities for caregivers. **Conclusion:** In view of this scenario, it is presented, as a challenge, to develop practical methods and techniques capable of qualifying assistance to the families.

**Descriptors:** Caregivers; Mental health services; User embracement; Qualitative research; Delivery of health care.

### RESUMO

**Objetivo:** Discutir o cuidado em saúde mental prestado pela equipe do Centro de Atenção Psicossocial geral a partir dos discursos de familiares, descrevendo as transformações vivenciadas com a mudança ocorrida no modelo de atenção em saúde mental. **Métodos:**

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Trata-se de uma investigação descritiva com abordagem qualitativa. Para a coleta de dados, foram realizadas entrevistas semiestruturadas com os familiares que desempenham papel de cuidadores de usuários do serviço. Utilizou-se o genograma e o ecomapa para caracterização da família e suas redes de apoio. A análise dos dados deu-se por meio da Análise de Conteúdo Temática. **Resultados:** Os familiares se sentem apoiados e acolhidos no serviço e o reconhecem como forte recurso terapêutico. No entanto, ainda existem muitos limites nos serviços de atenção psicossocial. **Conclusão:** Diante desse cenário, apresenta-se, como desafio, desenvolver métodos e técnicas práticas capazes de qualificar a assistência aos familiares.

**Descritores:** Cuidador de família; Serviços de saúde mental; Acolhimento; Pesquisa qualitativa; Assistência à saúde.

## RESUMÉN

**Objetivo:** Discutir el cuidado en salud mental prestado por el equipo del Centro de Atención Psiosocial general a partir de los discursos de familiares, describiendo las transformaciones vivenciadas con el cambio ocurrido en el modelo de atención en salud mental. **Métodos:** Se trata de una investigación descriptiva con abordaje cualitativo. Para la recolección de datos, se realizaron entrevistas semiestruturadas con los familiares que desempeñan papel de cuidadores de usuarios del servicio. Se utilizaron recursos como el genograma y ecomapa para caracterización de la familia y sus redes de apoyo. El análisis de los datos se dio a través del Análisis de Contenido Temático. **Resultados:** Los familiares se sienten apoyados y acogidos en el servicio y lo reconocen como un fuerte recurso terapéutico. Sin embargo, todavía hay muchos límites servicio de atención psicossocial. **Conclusión:** Ante este escenario, se presenta, como desafío, desarrollar métodos y técnicas prácticas capaces de calificar la asistencia a los familiares.

**Descriptores:** Cuidadores; Servicios de salud mental; Acogida; Investigación cualitativa; Prestación de atención de salud.

## INTRODUCTION

The discussion about family and mental health care comes from authors who assume the need for family care, since it has a positive impact on the psychosocial rehabilitation of people with mental disorders or in psychological distress. However, they add that the family, as a partner in this care, deserves special attention from all health professionals and services.<sup>1-5</sup>

The option to include families in mental health care was made possible by the Psychiatric Reform Movement, considered a complex process, still under development, of changes in knowledge and practices, which seeks to displace the center of care from the hospital to the community, making room for the family that is now considered a partner in the new mental health care environments.<sup>3</sup>

Considering changes in mental healthcare, Psychosocial Care Centers (CAPS) emerge as institutions, available in the community, making it possible to reorganize care services for the patients with severe and persistent mental illness, in order to recognize them as a citizens who, as such, have the right and access to care services at the various levels of complexity. Based on this logic of care the person with mental disorder returns to their condition as a human and political subject,

belonging to the territory and the community, through actions that promote their psychosocial rehabilitation of without breaking social ties among them, their families and the community.<sup>6</sup>

The complex demand for mental health care is not restricted to symptom control or decreased hospitalization risks, but also involves aspects of access to services, overcoming resource scarcity, inadequate professional care, and stigmatization, among others.<sup>7</sup> To this end, the investments were made in training of all the subjects who are involved in this process (patients, family, professionals and society), improving mental health care and restoring, according to available resources, the potential of families and their loved ones in psychic suffering for autonomous life in society.<sup>9</sup>

Given this scenario, the question is: How do family members classify mental health care provided by the CAPS team? What are the transformations experienced by the family due to the change in the mental health care model? How do CAPS organize themselves to meet the needs of the mentally ill person's family?

This research is justified because, in the last two decades, the family approach has been adopted as a basis of Brazilian public health policies and programs. In the field of mental health, the debate about family and care based on policy changes, especially due to the reorientation of the care model, has become a relevant object in the articles on psychosocial care. Nevertheless, in practice there are gaps in the reception of families of the patients. Thus, it is an opportune scenario for conducting studies in the field of psychosocial care, exploring the singularities and experiences of families in health care reserach and practices in search for solutions to their health problems.

This research seeks to contribute to the production of knowledge on family care and health professionals' practices, seeking a more detailed analysis of the issues surrounding the context of care, in this case, the care provided to the person's with mental disorder family.

Thus, this study aimed to understand mental health care provided by the CAPS team based on the reports by family members, describing the transformations experienced once the changes were introduced in mental health care system.

## METHODOLOGY

This article is a part of a larger project entitled: Family and Chronic Conditions: Therapeutic Guidelines, Social Assistance Networks and Accessibility. This is a descriptive and exploratory research with a qualitative approach, seeking to understand the relationship between CAPS professionals and the family of patients in psychological distress. We considered a qualitative approach as the most suitable method for this study, as it provides understanding and interpretation of the meanings that a person relates to the phenomena.<sup>10</sup>

The present study was carried out in a General type II CAPS, located in Fortaleza, Ceará. This service receives people of all age groups with severe mental disorders and is a part of the Municipality Mental Health Assistance Network, which currently includes 14 CAPS, in addition to other specific mental health care centers.<sup>11</sup>

This research included five relatives of people with mental disorders who undergo treatment in the referred CAPS. The sampling was defined by the criteria of convenience, as described by Polit and Beck.<sup>12</sup> For the inclusion criteria, we considered family members who identified themselves as the main caregiver at home, being in care center for at least one year, being over 18 years old. Family members under the influence of medications that prevented comprehension of the research were excluded, as well as those with cognitive deficits and who attended the service only to receive the medication. Eight family members did not want to participate, justifying the refusal by shame or fear of not knowing how to answer the questions.

The information was obtained through a semi-structured interview, collected from April to May 2016, in a single take. The interviews were recorded on audio equipment and later transcribed in full for qualitative data analysis. The collection of empirical material followed the ethical principles that guide the scientific work, keeping anonymity and confidentiality of the respondents' answers, which were identified by E1 (interviewee 1), E2, etc., according to the order of the interview.

After transcribing the interviews, exhaustive readings of the transcribed material were performed using the Thematic Content Analysis technique, following the pre-analysis steps: exploration of the material with identification of central ideas and treatment of the results, inference and interpretation.<sup>13</sup>

For characterization of families, we used the genogram and the ecomap.<sup>14</sup> Both are diagrams that serve to graphically represent family information, highlighting family dynamics and the relationships among their members. The genogram is considered a standardized instrument in which symbols and codes are used to view and track family history as well as internal relationships. The ecomap presents the relationships between family and community, helping to evaluate the support system.

In this article, we chose to discuss only one genogram to illustrate the family relationships of subjects in psychological distress as well as the changes experienced by family members and the process of care for the sick person.

The present study complied with the bioethics guidelines for research with human beings according to Resolution No. 466/2012 of the National Health Council. We obtained a favorable opinion after analysis by the Ethics Committee on Human Research (CEP) with protocol number 501.422. and date of approval 19/08/2013. A checklist based on the international guide COREQ was prepared for the preparation of this article, in order to elucidate the research path and the methodological rigor used.

## RESULTS AND DISCUSSION

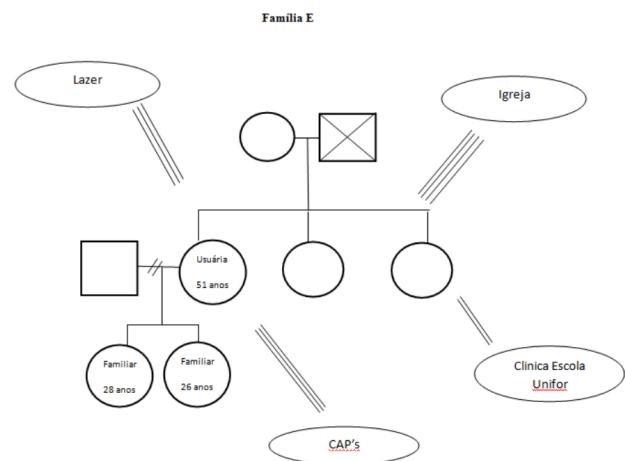
### Families and their supportive relationships

The families were interviewed and their testimonies allowed the elaboration of five genograms connected to ecomaps, highlighting strong bonds, conflicts, fragile relationships and dependence, and characterizing family support networks in the studied territory.

However, formal health services often disregard the informal care provided at the family level. According to Gutierrez and Minayo<sup>15</sup>, this indifference to the importance of the family in mental health is related to a reductionist concept of health, still in force, understood as "absence disease", making medical actions and procedures the only ones that can "cure". On the other hand, starting from a broader conception of health, the authors consider family-produced care more important than formal care, therefore, it should be added to the care offered by the health services.<sup>15</sup>

The genogram and ecomap represent the bonds of the family and their support networks. The family named E (figure 1) illustrates an extended family arrangement of a psychologically suffering CAPS user, consisting of three generations living in the same household: grandmother (head of household), mother (patient), daughters (main caregivers) and aunts.

**Figura 1 -** Genograma e Ecomapa da família E. Fortaleza, CE, Brasil, 2011



In family E, chosen to illustrate the genogram (figure 1), we observed that the 51-year-old CAPS patient lives with two daughters and her mother. Although they claim to maintain good relationship, care is mainly offered by daughters. In addition to the mother in psychic distress, they also take care of the elderly grandmother, who is often shaken because of her daughter's aggressive behavior towards her family. The figure expresses the strong bond of the patient with the family, with the CAPS and with the church.

The mother goes to CAPS, but the daughters and grandmother do not attend the service very often, but all agree that the place is an important support in the treatment

of the mother, since all trust the professionals who work there and seek to follow their guidance. The family also finds support in the church, all attending it weekly looking for comfort and faith. Another place of care is the UNIFOR school clinic in case of other health problems.

Therefore, we observed that the family maintains social bonds that can function as an informal support network, but the main support for mental health is provided by CAPS, accessed much more often by the family members.

Indeed, social support is scarce and the demands related to mental health are met almost exclusively by the CAPS. In this scenario, a “familist” social assistance policy prevails, whereby the responsibility for meeting social demands is centered mainly on the family, while the role of the state is diminished, representing the remnants of neoliberalist economic policies of the 1990s reflecting a fragile social context, where community resources do not exist or are invisible to the mental health network that does not activate them.

### CAPS mental health care

CAPS in their different modalities emerge as a paradigmatic change in the ethical horizon of mental health care, full of changes in the form of care delivery and with an innovative perspective towards the subject in psychological distress and their family, which is now considered a strong therapeutic resource, that helps promote autonomy and co-responsibility within the psychosocial rehabilitation process.<sup>17</sup>

Family members generally described mental health care provided by CAPS as welcoming, caring, attentive and providing equal treatment to all patients. In addition, the feeling of support and recognition of the work done by service professionals reflects feelings of gratitude. Family members consider this support necessary to help them face daily challenges.

The reports collected demonstrate satisfaction with the service and care offered by the professionals, emphasizing principles such as comprehensiveness, care with resolve and equality to all. This justifies the fact that care is not restricted only to family groups or therapeutic workshops, but also considers subjectivities of each patient and offers a pleasant and comfortable environment to everyone.

CAPS users report that welcoming as a dimension of humanization is manifested through the attitude of respect, listening and attention by the professional who receives and tends to them. CAPS patients reiterate the importance of humanization as a requirement to ensure the quality of care.<sup>18</sup>

The host seeks to promote adjustments in the work process so as to meet all who seek health services, thus acting as an agent of transformation by proposing a redirection of actions, making them the responsibility of the entire team, promoting the integration of knowledge and practices, increasing the likelihood of positive solution.<sup>19</sup>

Through the reception, the treatment and support in mental health offered by professionals are seen by family members as a chance to establish partnership which helps share responsibility for the solution of the problem to be faced.

It is also characterized as a space of trust and hope, in which one is sure to be understood and accepted, hence serving as an excellent therapeutic resource, improving service users self-esteem and self-confidence, helping them to live with problems and managing them in a healthier manner.<sup>20</sup>

A powerful strategy for bringing families closer to services is recognizing the importance of their role in user care. Professionals signal this recognition by offering support and listening, and by inviting them to take part in the activities of mental health network.<sup>3,21</sup> Thus, it is clear that the best care options for family members involve the use of light technologies, i.e., those that rely on interpersonal relationships.

However a study on family participation in the care of patients in psychological distress carried in Santos-SP<sup>1</sup> with five family members and seven users contradicts these findings finding that most family members evaluate CAPS negatively. In this study, the participants report that, due to the lack of specific reception for family members, they do not like to attend the service. They also add that, when they needed it, they were not heard and / or did not appreciate the activities recommended.<sup>1</sup>

A recent integrative review<sup>22</sup> selected 20 articles on the quality of service provided at CAPS as seen by the families, revealing the appreciation of activities undertaken while in care, for example workshops, groups, home visits, and highlighted care and guidance for families as important actions implemented by the CAPS teams, which were perceived as welcoming and careful in the exercise of their responsibilities. The articles of this research<sup>22</sup> pointed out that families were satisfied with CAPS due to the activities offered to the user (visits, group sessions, individual therapy, workshops); due to team availability for meetings with family members that allow dialogue and reduce the burden; due to differences between CAPS and the psychiatric hospital, as well as the teams of welcoming professionals.

It is evident that family members need to be seen as subjects of action, and receive the attention of professionals in order to become supporters in providing care. In this sense, family should be included in care actions offered by the CAPS team, since adequate reception requires attention and dedication, identification of the health needs and peculiarities of each service user, recognition of their subjectivities, and certainty that care is built through commitment and involvement with others.<sup>1,3,16,22</sup>

### “CAPS has changed our lives, but it still needs improvement”

In this study, the transformations experienced by family members due to CAPS action were also assessed, demonstrating that, in the opinion of family members, CAPS are increasingly effective as a substitute model for mental health care.

*[...] here (CAPS) you follow the patient, are treating at home, very normal, you start to get more attention, it is better, I think one hundred percent. (E1)*



*When we discovered CAPS for me it was a light that God put in my way, because besides having professional psychiatrists, psychologists, its wonderful to have the whole team as well as therapists. I thank God every day for this opportunity, because it only changed [life] for the better (E2).*

Under the Psychiatric Reform (PR), psychosocial care attributed greater value replacing the classic asylum treatment, therefore reinstating family ties and the possibility of the family being closer to the person with mental disorder, becoming an active participant in their care and treatment. The PR demystified the institutional image created by the Psychiatric Hospitals, traditionally perceived as locations where the patient was ignored, abandoned by the society and destined to inevitably break his/her ties with the family.<sup>23</sup>

For Bernardi and Kanan<sup>24</sup>, there is a strong relationship between ambience and care, which can be a factor of increase or reduction of care, as suggested by the statement E1, where the caregiver expresses his contentment in receiving the care at home, either because this allows for more time and attention for others, or because of the comfort that home environment provides.

Moreover, unlike the care model that prevailed in asylums with punishment for acts, constant control and monitoring of inmates and the inexistent communication, and absence of affection and receptiveness among family and professionals as well as professionals and their patients, the new knowledge and practices used in psychosocial care require a multidisciplinary team, capable of transforming the dynamics of the care process, previously performed in the asylum, infusing mental health care with attention and responsiveness.<sup>19</sup> This can be clearly observed in the statements of family members:

*“But Ave Maria, there it was [...] (referring to the CAPS) I think I entered heaven and I’m still in it [...] and I was devastated, I entered crying in the CAPS and I left smiling. Because a lot of people helped me a lot [...].” (E3)*

*“As a companion we are treated with respect, because nobody abuses us [...] To me as a companion, we suffer as much as the patient, so I felt that a companion is welcome here.”(E2)*

Upon perceiving that their suffering is recognized, family members link the work with families carried out by the CAPS team as part of this team’s focus on mental health care, as it involves meeting the needs of both service users and their family.<sup>25</sup>

Composed of professionals of different specialties the multidisciplinary team should focus its attention on the user and the family, understanding them as biopsychosocial individuals in a broad and complex context of social factors.

However, family members perceive CAPS as the only mental health service capable of offering a complete and qualified service, attributing an overvaluation of the

service. They appear to not perceive that CAPS is part of a Psychosocial Care Network (RAS), therefore not the only service capable of providing care to users.

The RAS, still unknown to many users and family members, is composed of various services including Therapeutic Residences, Living and Culture Centers, Reception Units, beds in General Hospitals when hospitalization is needed and, finally, CAPS in their different modalities. The purpose of RAS is to link the units of mental health care, as defined by the Ordinance No. 3.088 of the Ministry of Health.<sup>26</sup> However, unaware of this network, the subjects perceive CAPS as a stand alone service de-linked from the other components of RAS, perceiving it as the solution of their problems, as demonstrated by the empirical studies.

Thus, we perceive that family members face difficulties, because they are unaware of the existence of other services besides CAPS, leading to overcrowding in psychosocial care units and excessive workload for the health care teams. Thus, it is up to each professional to put these individuals in contact with the different units of the mental health network, demonstrating them the various options offered by the RAS, so that they are not restricted to a single service.

When asked to reflect on the services offered to them in CAPS, we observed discrepancies in the statements. Some family members reported not knowing the existence of groups dedicated to families, while others had high satisfaction with the service, suggesting that the inclusion of the family members in CAPS activities still seems to be superficial, as shown by the testimonials:

*“I do not participate in any service, because here there is nothing... for the companion, everything is for the patient [...] But this is, it is at your discretion, if you want to participate with the patient you participate or not [...].” (E1)*

*“When we discovered Caps for me it was a light that God put in my way, because besides having professional psychiatrists, psychologists, having the whole team, therapists is wonderful. They are wonderful.” (E2)*

Study recognizes the progress in current mental health care model, but reinforces that CAPS may be closer to families, their homes, get to know the family dynamics in order to intervene more efficiently. They also require better physical structure and more appropriate CAPS environment.<sup>22</sup>

The satisfaction of the family members with the substitutive services is linked to the integral care, the welcoming attitude, the break with the social isolation, the establishment of bonds and the improvement of the user’s quality of life, different from the situation seen and experienced under the previous hospital-centric model. They also note that, for the family members, the notion of treatment only acquired meaning due to the contact with these services.<sup>27</sup>

However, there are contradictions regarding the inclusion of the family in substitute services, as they are seen as an aid to treatment and shared care, rather than being recognized as subjects who need attention and care. This is evidenced

by the dissatisfaction in the speech of the family member expressed the need for support, for someone to listen to him, provide guidance. If such support is not provided, feelings of helplessness and discomfort due to the lack of attention they need so much increase even if the family member is received at the unit. Thus the need for specific moments for the professional-caregiver contact is clear.

This invisibility of family in care has been justified by the high demand for service and excessive workload of the team, scarcity of human resources, inadequate infrastructure and insufficient training for professionals. Hence the importance of organizing the work process better by defining the roles of each professional, avoiding excessive responsibility and professional overload.<sup>21</sup>

The need for more information for users about the mental health services network is evident, as well as the need for continuing education strategies to broaden the professionals' understanding of the importance of including the family in mental health care. Care actions should be reorganized to include the family members, who share lives with the person with mental disorder, suffering personal deprivation and overload, and are in need of support and attention continuously.

Based on what has been discussed, it is necessary to involve all those who integrate substitutive services, so that they come to understand that welcoming does not only mean receiving the user and his or her family in the service, but also creating a space for care, listening and fostering future partnership.

## FINAL CONSIDERATIONS

CAPS mental health care is generally described by family members as welcoming, caring, attentive and providing equal treatment to everyone. It is perceived as the only service capable of offering a complete and qualified care, without considering the possibilities of the psychosocial care network, which in turn tends towards institutionalization.

On the other hand, we highlight the difficulties of CAPS in performing activities that are specific to family members / caregivers/ companions. As a result, the inclusion of these family members in CAPS activities is superficial. This indicates that mental health services have been dealing with caregivers in an inefficient manner, as high demand for care cannot limit the provision of care to/ inclusion of family members.

In this context, development of practical methods and techniques capable of improving care for family members of CAPS is a challenge. The multidisciplinary team can not be restricted to family groups in their care, but rather undertake other activities that benefit all, such as community-based mental health promotion activities, contacts with primary health care units and the informal network of support to users and their families, attentive listening and guidance in order to strengthen the links between the CAPS and the family, fundamental for the rehabilitation of the users.

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