

# The care of people in mental suffering: from the perspective of family members

**RESUMO** | Objetivo: analisar a percepção do cuidado a pessoa com sofrimento mental sob a ótica dos familiares. Método: A pesquisa é exploratória-descritiva, com abordagem qualitativa. Para coleta, foi realizada a técnica de coleta de dados usando o grupo focal, utilizando questões norteadoras, no período de abril, ano de 2014. A amostra foi composta por 20 familiares/cuidadores de usuários do CAPS I, na capital Paraíba. Os dados qualitativos foram analisados, tendo-se como referência o método de análise de conteúdo, do tipo categorial temática. Resultados: Foram identificadas as seguintes categorias: Categoria I - Interferência e convivência com a doença mental e a Categoria II – A sobrecarga no cuidado ao doente mental. Conclusão: Considera-se, que ainda existam lacunas a serem preenchidas para se efetivar uma oferta qualificada a estes atores (usuários/cuidadores-familiares) que, de fato, possam empoderar estes sujeitos e minimizar seus sofrimentos.

**Palavras-chaves:** Sofrimento; Saúde Mental; Cuidado; Família.

**ABSTRACT** | Objective: to analyze a perception of caring for a person with mental distress and two family members sobbing. Method: The research is exploratory-descriptive, with a qualitative approach. For collection, the data collection technique was performed using the focus group, using guiding questions, in the period of April, 2014. It was shown to be composed by 20 family members / caregivers of CAPS I users. The qualitative data are analyzed, they are tended as a reference or method of content analysis, of thematic category type. Results: identified as following categories: Na Category I - Interference and coexistence with a mental education and a Category II - A overload not caring for the mental patient. Conclusion: It is considered that there are still lacunae to be pre-filled to make a qualified offer to these actors (users / caregivers-relatives) that, of course, will be able to empower these little subjects and minimize their.

**Keywords:** Hurt; Mental Health; Careful; Family.

**RESUMEN** | Objetivo: analizar la percepción del cuidado de las personas con sufrimiento mental desde la perspectiva de los familiares. Método: La investigación es exploratoria-descriptiva, con enfoque cualitativo. Para la recolección, la técnica de recolección de datos se realizó mediante el grupo focal, mediante preguntas orientadoras, en el período de abril de 2014. La muestra estuvo formada por 20 familiares / cuidadores de usuarios de CAPS I. Se analizaron datos cualitativos, teniendo como referencia el método de análisis de contenido, del tipo temático categorial. Resultados: Se identificaron las siguientes categorías: Categoría I - Interferencia y convivencia con enfermedad mental y Categoría II - Carga en el cuidado de los enfermos mentales. Conclusión: Se considera que aún quedan vacíos por llenar para poder realizar una oferta calificada a estos actores (usuarios / cuidadores-familia) que, de hecho, puedan empoderar a estos sujetos y minimizar su sufrimiento.

**Palabras claves:** Sufrimiento; Salud mental; Precaución; Familia.

## Aline Pereira da Silva

Enfermeira. Pós-graduada em obstetrícia e neonatologia. Universidade Federal de Campina Grande.

ORCID: 0000-0001-8185-9471

## Perla Figueiredo Carreiro Soares

Enfermeira. Mestre em Neurociência Cognitiva e Comportamento. Pós-graduada em enfermagem obstétrica. Chefe do Núcleo de Serviços Diagnósticos/SES/PB.

ORCID: 0000-0002-0407-685X

## Erlânia Souza Costa

Enfermeira. Pós-graduada em obstetrícia e neonatologia. Faculdade de Enfermagem Nova Esperança.

ORCID: 0000-0002-5018-0404

## Lúcia Gomes de Souza Silva

Enfermeira. Faculdade Maurício de Nassau. Pós-graduada em Urgência/Emergência e Unidade de Terapia Intensiva.

ORCID: 0000-0001-6998-435X

## Rogéria Gomes da Silva

Enfermeira. Pós-graduada em Gestão em Saúde, Gestão da Clínica nas regiões de Saúde e Docência do Ensino Superior. Chefe do Núcleo de Atenção Ambulatorial/SES/PB.

ORCID: 0000-0001-7075-1369

## Luanna Silva Braga

Enfermeira. Mestre em Enfermagem pelo Programa de Pós-Graduação em Enfermagem da Universidade Federal da Paraíba (PPGENF/UFPB).

ORCID: 0000-0002-0093-0406

## INTRODUCTION

The prevalence of individuals suffering from psychological distress in the general population is quite significant, according to data from the Ministry of Health (MH) 3% of the general population suffers from persistent severe mental disorder; more than 6% of the population has a severe psychiatric disorder resulting from the use of alcohol and drugs; 12% of the population needs some mental health care, whether continuous or occasional, and only 2,3% of the annual SUS budget is allocated to mental health. <sup>(1)</sup>

The Brazilian Psychiatric Reform is based on Law 10,216 created by Deputy Paulo Delgado, enacted in 2001, which redirects mental health care, prioritizing the provision of treatment in communi-

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ty-based services on the protection and rights of people in psychological distress, but it does not establish clear mechanisms for the reduction of asylums. Although the promulgation of this document imposes a new impulse and a new pace for the deinstitutionalization process. <sup>(2)</sup>

Currently, the Brazilian national mental health policy is based on the principles of the Unified Health System (SUS) and the guidelines of the psychiatric reform, which advocates the rescue of citizenship from psychic suffering. In this sense, the presence and support of the family is essential for effective care for mental disorders, considering that the first manifestations of behavioral changes are perceived in the family environment. <sup>(2)</sup>

Based on these new paradigms arising from the Psychiatric Reform, the Psychosocial Care Centers (CAPS) emerged. The creation of these centers enabled the organization of a network to replace the Psychiatric Hospital in the country. CAPS are municipal, open and community health services that offer daily care. These services have the function of replacing and not complementing the psychiatric hospital. In fact, the CAPS is the nucleus of a new clinic, producing autonomy, which invites the user to take responsibility and take a leading role throughout the course of their treatment. <sup>(1)</sup>

The projects of these services often go beyond the physical structure itself, in search of the social support network, which enhances their actions, concerned with the subject and the singularity, their history, culture and daily life. Other mental health care devices such as the homecoming program, therapeutic residences are of strategic importance for the Brazilian Psychiatric Reform and the reintegration of people with psychological distress into society. <sup>(1)</sup>

At this moment of social inclusion, in the context of psychosocial monitoring and treatment, it is of paramount importance to offer support to the family in extra-hospital services, which are able to meet the needs of the person with psycho-

logical distress and their family, so that this process takes place as close as possible to the community, valuing the maintenance of social and family ties. <sup>(3)</sup>

The family, in particular, the family member/caregiver is subjected to constant stressful events during the course of this disease, which can affect, in addition to family relationships, the health of the family member/caregiver, always bringing some degree of overload and causing constant need for adaptation. <sup>(4)</sup> In this sense, accountability turned more to the heart of the family, which, when faced with this role, has the need to find new care strategies. In this perspective, it is worth emphasizing the guiding question of the research: What are the coping strategies that the mentally ill caregiver develops to better care for their family member? Its objective is: to analyze the perception of care for people with mental suffering from the perspective of family members.

#### METHOD

This study is an exploratory-descriptive research with a qualitative approach. The exploratory method was selected because it presents greater analogy with the study discussed, according to Gil, <sup>(5)</sup> exploratory research aims to develop, elucidate and transform concepts and ideas, with a view to formulating more precise problems or hypotheses. In this context, the use of descriptive research allowed the researcher to expand his experience about a group already defined by the researcher, focusing on practical performance.

With regard to the qualitative approach, according to Richardson, <sup>(6)</sup> it is characterized by being a detailed research on a given theme and constituted by the situations presented by the interviewees. The study was developed in a Psychosocial Care Center (CAPS I), in April, 2014.

In the year of the survey, the population at CAPS I, which is located in a municipality in Paraíba, in the northeast region, was composed of 78 users monitored by the team, of which 30 to 40 are active and

about 20 users attend the service daily. In 2021, the mental health care network increased, and services were expanded, having: 68 CAPS I (service for 15 thousand inhabitants); nine CAPS II (70 thousand inhabitants); 05 CAPS III 24 hours (150 thousand); six CAPS AD for 70 thousand inhabitants; 09 CAPS AD III 24h (150 thousand); 12 CAPS Children and Youth (70 thousand); 14 Therapeutic Residences; five Street Clinics; four Reception Units; 20 Mental Health beds in a General Hospital and 65 beneficiaries of the Volta Pra Casa Program (PVC - Programa de Volta Pra Casa). <sup>(7)</sup> The service in which the research was carried out underwent changes, and in 2021 it has: 95 users monitored by the team, and of this group, 40 are active, however, 25 are daily coming to the service, due to the pandemic moment experienced in Brazil and in the world.

Continuously, the study sample consisted of about 20 family members/caregivers with psychological distress. This sample was built for accessibility. To be included in the research, participants had the following requirements: to be a family member or caregiver of the Psychosocial Care Center (CAPS) user, the user must be actively participating in the CAPS, the family member or caregiver of individuals in psychological distress must be willing to voluntarily participate in the research, as well as sign the free and informed consent form (ICF). Therefore, all those who did not meet these criteria were excluded from the survey.

As a technique for data collection and analysis, an approach was carried out with the participants through the focus group, which aimed at the interaction of family members/caregivers with psychological distress in order to promote a broad problematization of coping strategies for mental health care: family perception. According to Backes et al, <sup>(7)</sup> the focus group is configured as a group interview, in which interaction is an integral part of the method. In the process, the group meetings allowed the participants to explore their points of view, based on reflections on a

certain theme.

Empirical material was collected through a focus group with family members and/or caregivers of CAPS users. This technique enabled a broad problematization of the problem addressed, for the realization of this focus group, we developed guiding questions and subjective questions, in order to achieve the proposed objectives with regard to family members or caregivers with psychological distress with the use of a recorder (MP3), where we had the possibility to listen and at the same time record what was said in the group.

The empirical material was discussed using the Content Analysis technique proposed by Bardin.<sup>(8)</sup> Thus, we use the categorical-thematic content analysis. This research followed the resolution 466/12 of the National Health Council, under the CAAE number: 22372113.0.0000.5182, in March 2014.

## RESULTS

The sample consisted of 20 family members/caregivers, about fifteen participants aged 40 to 60 years and mother. Five participants aged between 25 and 40, sister and aunt. The content of the research participants' speeches was analyzed and after repeated readings of the transcribed material, a global apprehension of the contents was carried out and, later, the themes that emerged in the interviews were identified. Below, the designated thematic categories.

### Thematic Category I - Interference and living with mental illness

In the research, we observed through the reports that interference and changes are present in the family context, but in different ways. For some participants, the early diagnosis of mental disorder in the family environment generates an adaptation with the limitations and requirements imposed, that is, there was interference, but as the family spends a lot of time in care, changes and interference end up being part of the family routine. The re-

ports that follow emphasize this issue:

"It doesn't interfere, because we get used to the situation, he presented this problem when he was still a child". (Participant 2)

"It doesn't interfere, because we learn from an early age to live with the problem". (Participant 4)

Other participants report that this interference is perceived drastically. The following participants spoke of this interference as follows:

"It interferes with my routine, because almost all my hours are geared towards him, whether here at CAPS or on a daily basis". (Participant 9)

"It does interfere, especially with me who work, I have to be constantly participating in the meetings here at CAPS, because I need to know how he's doing." (Participant 12)

The meetings to which participant 9 and 12 refer are meetings that the CAPS promotes every fortnight with family groups, thus enabling an interaction and sharing of experiences between the participants, constituting a space for the exchange of knowledge and experiences. Professionals have the opportunity to guide and clarify the family about everyday life situations.

Thus, the Psychosocial Care Center (CAPS - Centro de Atenção Psicossocial) has a fundamental role in supporting the family and the user. In the CAPS, the reception, home visits, individual and group care to family members are configured as family care activities, thus seeking to implement this partnership and the interaction between the actors in this process. Some interviewees reported the CAPS in their speeches as a coping strategy for the daily tribulations and in the effectiveness

of the treatment offered to their families:

"Today it interferes less, in the past we suffered a lot, he was aggressive, he was constantly leaving the house, he was hospitalized directly, after he started coming to the CAPS he started taking the medicine and the girls here at the CAPS help a lot". (Participant 19)

"After he started coming to the CAPS, he changed a lot, he started taking the medicine, the people here help a lot, so there's a psychologist here, there's a doctor". (Participant 15)

Interferences caused in the family's daily life differ in circumstances between family members, although some participants reported that living with the person with psychological distress in the family context does not interfere in the family's daily life, we can see in the following category that all participants refer to overload in relation to care. Thus, it is understood that there is interference, but not perceived by the participants.

### Category II - Overload in the care of the mentally ill

Although some family caregivers deny interference in the family context, all research participants affirmed the existence of overload and stress, arising from the care of psychological distress. Overwork is attributed to excessive work and stress resulting from the difficult coexistence with psychological distress, especially in situations of great dependence on the individual who receives care. The following testimonies show the overload and stress in the family's daily life:

"There is stress and overload, but the overload is even greater. I have to bathe him myself, I have to give him the medication and wait for him to take it, I have to put him to sleep and I still have

to go to work, that's why I end up overloaded". (Participant 10).

"They both exist, because I'm overloaded with the amount of daily tasks and sometimes I don't have time to resolve other issues". (Participant 13)

"Stress and overload is part of the day, since everything is with me, I have to stay on top so he can eat, make him take a shower and so many other things, then we end up stressing and losing patience." (Participant 14)

Family burden is understood as objective and subjective, the first refers to the concrete and observable negative consequences resulting from the role of caregiver, such as financial losses, disturbances in the routine of family life, excess of tasks that the family member must perform in daily care with the patient and supervision of the patient's problematic behaviors, these aspects being considered as stressful stimuli for family members.

## DISCUSSION

Since, according to Grandi and Waidman<sup>(10)</sup> living with psychological distress in the family environment is difficult, as it involves many issues, such as prejudice not only with the family member, but with the whole family, the exclusion of the family member affected by psychological distress, fear and shame due to the symptoms of the disease, in addition to the fact that family members are not always able to deal with all the diversity and complexity that involves the mental disorder, such as, for example, changes in the household routine that include changes in meal times, in washing the clothing, shopping, recreation and leisure activities, among others.

The Psychosocial Care Centers (CAPS) are a strategy to deal not only with people

with mental illness, including in their actions the participation and collaboration of family members, friends and caregivers of users who attend them as part of the process by offering a range of activities aimed at users and their families, guarantee care, treatment and follow-up with a view to social inclusion and the recovery of citizenship.<sup>(11)</sup>

The family is the fundamental institution for the user's rehabilitation in the community, in which he is inserted. The involvement of the family in the treatment of users contributes to reducing relapses and the number of psychiatric hospitalizations for patients with severe mental disorders. It is essential to work with the users' families, in order to rescue the importance of not excluding the person in psychological distress from family life. In this sense, the participation of the family in the context of psychosocial care offered by the Psychosocial Care Center (CAPS) is essential, from its inclusion in the preparation of the therapeutic plan, in family groups, in meetings and assemblies, even the therapeutic support that is necessary.<sup>(11)</sup>

To Cardoso; Galera; Vieira,<sup>(4)</sup> the adverse consequences of a family member's mental illness for families have been systematically documented and point to the fact that all areas of family functioning are affected by the presence of mental illness. It is important to note that the burden related to mental health care is an easily noticeable phenomenon and that it persists even when the patient responds positively to innovative and effective treatments.

The aforementioned authors also emphasized that this burden can be attributed to the accumulation of tasks, increased financial costs, limitation of daily activities, weakening of relationships between family members, the family member's personal perception of the experience of living with the patient, their feelings as for the responsibility and concerns that involve caring for their health, the lack of autonomy of the individual in psychological distress is seen as a negative aspect that generates tension and concern, emotionally

affecting the caregiver.

The family suffers intensely from the ill person's situation, experiencing feelings of distress, depression, isolation, chronic sadness, guilt and anguish. The presence of psychological distress provokes a rupture in the family's existential routine, in which the main caregiver starts to put their own needs and desires in the background, becoming overwhelmed by bearing the burden generated by the disease. In view of this, the current model of the Psychosocial Care Network aims to re-include people with psychological distress, in the community and in the family, through the recovery of self-esteem and restructuring of bonds, offering support to the family in order to alleviate the suffering of both the user and the caregiver.<sup>(11)</sup>

Subjective burden refers to the perception or personal assessment of family members about the situation, involving their emotional reaction and their feeling of being burdened, attributed by them to the role of caregiver. It refers to the degree to which family members perceive the behavior or dependence of patients as a source of concern or psychological tension.<sup>(10)</sup>

The new model of assistance to patients with psychological distress promoted the deinstitutionalization and the reintegration of the individual in psychological distress in the family and community, however there are differences regarding the coexistence of psychological distress in the family environment. Mental illness represents an impact on the family, causing disorganization in the usual ways of dealing with everyday situations, as the family faces the family's behavioral changes and starts to assume the role of caregiver, responding to the demands of this role.<sup>(10)</sup>

All areas of family functioning are affected by the presence of psychological distress to the point of creating coping strategies to alleviate the stress and burden attributed to the care offered to the family member in psychological distress. In this scenario, extra-hospital services must provide families with information relevant to

the pathology, symptomatology of the disease, know their history, culture, beliefs, values, habits and customs so that they can alleviate the burden of family members and rescue their dignity and autonomy of the individual in psychological distress.<sup>(11)</sup>

The mental health care network has been working in new ways, with strategies considered to be more effective. Over the years, the progress of deinstitutionalization has become significant and there has been a reduction in psychiatric beds from 53.962 in 2001 to 25.988 in 2014.<sup>(12-13)</sup> This process started in 2001 with the implementation of the law that defended the rights of people in mental suffering, but it took 13 years to start having apparent results.<sup>(12-13)</sup>

In 2015, after conducting the survey, a study showed that Brazil has representatives from various sectors of mental health, and that scientific production on the subject grew, and brought greater quality to care. However, it was evident that there are still insufficiencies in the health system, and that the needs of patients and their families are sometimes not met, as in the case of emergency care. In 2016, government officials rethought their strategies, there was an expansion of some services,<sup>(12-13)</sup> for example, the CAPS, in which we realized that this service is now available in other municipalities in Paraíba, serving more users. It is noticed that the hospital-

-centric model needs to be overcome, and that new services are constantly emerging to replace this process, with Primary Health Care being one of the sectors that can also provide quality mental health care.<sup>(14)</sup>

## CONCLUSION

When analyzing the perceptions of family members about the care for psychological distress and the likely repercussions of this care in their lives, we realize the importance of the family in the treatment, monitoring and development of individuals in psychological distress in the family context and in social reintegration. The family is the main communication link in the social context.

The deinstitutionalization process included the family as an integral part of the treatment of psychological distress, however it demanded greater responsibility from family members regarding the care offered in psychological distress, thus causing sudden changes in the daily life of the family, generating overload and stress in the family context.

Mental health care has gone through advances, as seen in the discussion of this research, and had an impact on the daily lives of families, with regard to the adaptations resulting from the coexistence of mental suffering with other family members. This, in turn, starts to guarantee the

basic needs of the sick family member, these attributions generate feelings of anguish and distress in the caregiver.

With regard to the strategies developed by these family members to help alleviate the burden and, consequently, promote better assistance in the care of patients with psychological distress, it was identified in the analyzes that caregivers/family members do not plan or are unable to identify the strategies used to carry out care for the suffering person. However, in the absence of planning, organizing ideas and coping with daily difficulties, most participants reported that faith and CAPS are the main strength to overcome daily tribulations.

For all these aspects, it is worth emphasizing the importance of the Psychosocial Care Center (CAPS) with regard to support and care for families and users of these services, it is imperative that these services should accommodate the suffering of families and minimize their emotional burden through offering welcoming spaces that facilitate actions and exchange of experiences among the caregivers themselves, to share doubts, anxieties and joys in a movement of proximity to the treatment and towards the autonomy of patients and the reduction of the suffering of families. 🐦

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