# Mental health care: meanings and strategies for **families**

Cuidado em saúde mental: significados e estratégias para os familiares Atención de salud mental: significados y estrategias para las familias

#### **RESUMO**

Objetivo: Compreender os significados e as estratégias elaboradas pelos familiares de pacientes em acompanhamento de saúde mental. Método: A pesquisa é do tipo exploratório-descritiva, com abordagem qualitativa, que ocorreu em um Centro de Atenção Psicossocial (CAPS I), no Nordeste. A pesquisa foi composta por 20 familiares de pacientes em sofrimento psíquico, mediante acessibilidade e conveniência. A técnica de coleta de dados foi a de Grupo Focal (GF), mediante questões norteadoras do roteiro, com perguntas reflexivas, o GF foi guiado. Fez-se o uso da Análise de Bardin. A pesquisa seguiu os preceitos éticos, sob o CAAE: 22372113.0.0000.5182. Resultados: Foram construídas duas categorias: I- Significado do Cuidado e II - Estratégias de enfrentamento para as adversidades. Conclusão: O estudo alcançou o seu objetivo inicial e em suas categorias, percebeu-se a complexidade do cuidado em saúde mental e a necessidade de novas estratégias junto à família dos pacientes.

DESCRITORES: Cuidado; Sobrecarga; Saúde mental; Estratégias de Saúde

#### **ABSTRACT**

Objective: To understand the meanings and strategies developed by the families of patients in mental health monitoring. Method: The research is exploratory-descriptive, with a qualitative approach, which took place in a Psychosocial Care Center (CAPS I), in the Northeast. The research consisted of 20 family members of patients in psychological distress, through accessibility and convenience. The data collection technique was the Focus Group (FG), through guiding questions of the script, with reflective questions, the FG was guided. The Bardin Analysis was used. The research followed the ethical precepts, under the CAAE: 22372113.0.0000.5182. Results: Two categories were built: I- Meaning of Care and II - Coping strategies for adversities. Conclusion: The study reached its initial objective and in its categories, the complexity of mental health care and the need for new strategies with the patients' families were perceived.

**DESCRIPTORS:** Care; Overload; Mental health; Health Strategies.

# RESUMEN

Objetivo: Comprender los significados y estrategias que desarrollan las familias de los pacientes en el seguimiento de la salud mental. Método: La investigación es exploratoria-descriptiva, con abordaje cualitativo, que se llevó a cabo en un Centro de Atención Psicosocial (CAPS I), en el Nordeste. La investigación consistió en 20 familiares de pacientes en distrés psicológico, a través de accesibilidad y conveniencia. La técnica de recolección de datos fue el Focus Group (FG), a través de preguntas orientadoras del guión, con preguntas reflexivas, se guió el FG. Se utilizó el análisis de Bardina. La investigación siguió los preceptos éticos, bajo el CAAE: 22372113.0.0000.5182. Resultados: Se construyeron dos categorías: I- Significado del cuidado y II - Estrategias de afrontamiento de las adversidades. Conclusión: El estudio alcanzó su objetivo inicial y en sus categorías se percibió la complejidad de la atención en salud mental y la necesidad de nuevas estrategias con las familias de los pacientes. DESCRIPTORES: Atención; Sobrecarga; Salud mental; Estrategias de salud

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# Aline Pereira da Silva

Nurse. Postgraduate in obstetrics and neonatology. Federal University of Campina Grande. ORCID: 0000-0001-8185-9471.

### Perla Figueredo Carreiro Soares

Nurse. Master in Cognitive Neuroscience and Behavior. Postgraduate in obstetric nursing. Head of the Diagnostic Services Nucleus/SES/PB.

ORCID: 0000-0002-0407-685X

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# Erlania Souza Costa

Nurse. Postgraduate in obstetrics and neonatology. Nova Esperança College of Nursing. ORCID: 0000-0002-5018-0404.

# Lucia Gomes de Souza Silva

Nurse. Mauritius College of Nassau. Postgraduate in Urgency/Emergency and Intensive Care Unit. ORCID: 0000-0001-6998-435X.

# Rogeria Gomes da Silva

Nurse. Postgraduate in Health Management, Clinical Management in the Health and Teaching regions of Higher Education. Head of the Outpatient Care Center/SES/PB.

ORCID: 0000-0001-7075-1369.

# Luanna Silva Braga

Nurse. Master in Nursing by the Graduate Program in Nursing at the Federal University of Paraíba (PPGENF/UFPB). ORCID: 0000-0002-0093-0406.

# INTRODUCTION

he Psychiatric Reform is characterized as a historical movement of political, social and economic character, which developed parallel to the Health Reform and aims at the progressive replacement of asylums by other services in the community, shifting the therapeutic intervention to the social context of people, triggering a process of transformation in the organization of mental health systems. (1)

For the effectiveness of this process, it is essential that strategies be developed so that one can work with people in psychological distress who have been discharged from long-term hospitalizations, so that they can be inserted and integrated in their own family and community, considering that the very condition of "mental patient" by itself, causes the individual affected by psychological distress and their families some limitations, impediments and situations that can change the person's relationship with work, with other family members, friends and partners, as well as shake their identity. (1)

On April 6th, 2001, the Federal Government enacted Law No. 10,216, which provides for the protection and rights of people in psychological distress and redirects the mental health care model. The law redirects the psychiatric care model, regulates special care for the clientele hospitalized for long years and provides for the possibility of punishment for arbitrary or unnecessary voluntary hospitalization. (2)

The Brazilian psychiatric reform is supported by Law No. 10.216 and by numerous ordinances introduced by the Ministry of Health (MH) with the aim of providing quality care to patients with psychological distress and their families. The extension project is constituted by the community model with its various institutional devices: the Psychosocial Care Centers (CAPS - Centros de Atenção Psicossocial) as network organizers; the "De Volta para Casa" (Back Home) program, which reinserts long-term users hospitalized in psychiatric hospitals into society; psychiatric beds in a general hospital; the construction of an intersectoral public policy for alcohol and drugs, as well as for children and adolescents; articulation with the basic health network; and the consequent reduction of beds in psychiatric hospitals. (3)

The previous paragraph precisely reflects the strategies currently used in the face of mental health policy, which has among its objectives, to enable care with different ways of providing health care for the patient and his family. The new model of assistance to mental suffering is centered on the reintegration of these people into the family and community, these are tasks to which the SUS has been dedicating itself with special effort.

Therefore, it was questioned: How is mental health care from the perspective of meanings and strategies developed by family members. Its objective is: to understand the meanings and strategies elaborated by the relatives of patients in mental health monitoring.

#### **METHOD**

The research is exploratory-descriptive, with a qualitative approach. This study took place in a Psychosocial Care Center (CAPS I), in the city of a northeastern state, in 2014, in the first quarter. The total population of CAPS is 78 users, however, only 40 are active in the health unit. Of these 78 users, only 20 attend the service every day. Thus, the sample of this research was composed of 20 family members of patients in psychological distress, through accessibility and convenience.

Continuously, the research had as inclusion criteria: being a family member, and the user needs to be active in the CAPS health service, accepting to participate in the research and signing the free and informed consent form (FICF). Therefore, those who did not meet the inclusion criteria were excluded. The data collection technique was the Focus Group (FG), providing interaction, construction of problems and transformation of the participants' reality. (4) In the FG, there are some group meetings, in which the participants leave their opinions and reflections on the topic under study. (4) The FG lasted 90 minutes, so that the lines were explored in the best possible way. Four open questions were asked, guided by a script, in addition to an initial questionnaire, which outlined the profile of the participants, in this questionnaire, the questions were open and closed, dealing with questions to characterize the research participants, such as: gender, age, length of experience in the research sector, among other questions.

Through guiding questions of the script, with reflective questions, the FG was guided. All content was recorded by an electronic device in MP3 mode, in addition, Bardin's Thematic Content Analysis (5) was used. The research followed the ethical precepts, under the CAAE: 22372113.0.0000.5182, in March, 2014.

#### **RESULTS**

In view of the analysis steps, the sample was characterized as follows: from a total of 20 participants, 15 were aged between 40 and 60 years, and the others between 25 and 40 years. Family members were: aunts, mothers and sisters of patients in psychological distress. Two categories were constructed: I- Meaning of Care and II -Coping strategies for adversity.

# Category I - Meaning of Care

When taking care, it is supposed to generate in the person being cared for a feeling of retribution, affection, understanding, that is, a feeling to be offered in search of several hidden ones. Therefore, when a feeling is offered, the feeling of others is rescued and improved, with the mutual purpose that it perpetuates for a long time between one and the other.

The interviewed participants describe through their speeches a perfect understanding of care in its conception:

> "Caring is taking an interest in the other's life, worrying, giving affection, attention is knowing how to support in difficult times as well as teaching right and wrong, because taking care is also educating". (Participant 7)

"Care is straightforward! Sometimes I'm sleeping and I wake up to find out how he's doing, because I get worried, keep wondering if he is okay, then I'm going to check on him. When he doesn't come home from school for five or ten minutes, I get already worried that he was run over and then I end up leaving my duties and I go after him". (Participant 12)

"Care is that you do good, because we only take care of and worry about those we love". (Participant 13)

The development of the ability to care is essential for the development of the being. The basic care behaviors are: compassion, competence, trust, awareness and commit-

According to the reports of research participants, family caregivers consume most of their time dedicating themselves to meeting the needs of the family member in psychological distress in order to put their needs and desires in the background. Participants address the following information about what it means to take care of a family member in mental distress:

> "Caring for a special child is a double job." (Participant 1)

> "Taking care of a special child requires more dedication. " (Participant 7)

> "Care is straightforward! Sometimes I'm sleeping and I wake up to find out how he's doing, because I get worried, keep wondering if he is okay, then I'm going to check on him. When he doesn't come home from school for five or ten minutes, I get already worried that he was run over and then I end up leaving my duties and I go after him". (Participant 12)

In these reports, it is evident that taking care of a family member who is mentally suffering requires greater responsibility. By assuming this role, the family caregiver starts to play directly the role of observer, evaluator, determining the actions and decisions to be taken, thus giving rise to stress and anxiety due to the transformation of the situations experienced. This family member starts to live a daily life full of concern. In this sense, mental disorders are experienced collectively, by the family group as a whole. When a family member falls ill, their entire

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network of relationships is altered, with the family, in most cases, being the primary insertion group of an individual.

# Category II - Coping Strategies for Adversity

When analyzing the collected material, the difficulty that family members/caregivers encounter in devising strategies in the face of daily adversities is noticeable. All participants referred to faith as a strong ally to overcome daily difficulties. The following lines emphasize this issue:

> [...] everyone has difficulties, regardless of whether they have a special

When confronting the disease, people are emotionally fragile, they often turn to spiritual help, whether in times of pain or hopelessness, or in the search for meanings for the events in their lives relative or not, but when we believe in God, all the problems and difficulties go away. (Participant 6)

When I have a lot of problems I go to church, God is so wonderful that when we see it, there is no difficulty. (Participant 7)

Only God can help us in times of difficulty. (Participant 19)

When confronting the disease, people are emotionally fragile, they often turn to spiritual help, whether in times of pain or hopelessness, or in the search for meanings for the events in their lives. Illness can become a situation of approaching the divine in an attempt to save or solve problems. The more attached to the spiritual aspects, the more the family identifies resources and maintains its energy to take the stressful situation forward. Religion or religiosity does not have the power to resolve the situation instantly, but to renew energies so that the family can identify resources and learn to deal with situations.

The family uses religious resources to understand the disease and deal with it. Thus, religious beliefs and values are used by the family to help make sense of the illness event of the family member in psychological distress.

#### DISCUSSION

The results reveal several strategies and substitute services for patients and family members to be included. Therapeutic residences, or simply dwellings, are places destined to attend to mental disorders, they are urban located houses, with the purpose of meeting the housing needs of people with severe and persistent mental suffering, discharged from psychiatric hospitals or not. Although therapeutic residences are configured as a health facility, they must be able to guarantee the right to housing for individuals with mental disorders as well as assist the resident in their process of reintegration into the community. (6)

The Back to Home Program is confi-

gured as an empowering strategy for the emancipation of people with psychological distress. Created by federal law 10.708 and sanctioned in 2003, this program is a partnership between the Ministry of Health and Caixa Econômica Federal with the partner municipalities, and aims to promote and facilitate the process of rehabilitation and social inclusion of people suffering from mental disorders, who have a life history with 02 (two) or more years of admissions to psychiatric hospitals. (7)

The Psychosocial Care Center (CAPS) is presented by the Ministry of Health as a priority device for mental health care. With its implementation and operation, the aim is to innovate care from the perspective of health promotion and a break with the hegemonic care model. CAPS, as the organizer of the mental health care system, has the social responsibility not only to take care of replacing the asylum model, but also to provide health promotion strategies and programs. Starting with its articulation with the community, aiming at its effective and concrete participation in the selection of priorities, in decision-making and in the elaboration and development of strategies to achieve a better level of health. (6)

Ordinance 3.088, of 2011, of the Ministry of Health, defines the following types of CAPS: CAPS I, CAPS II, CAPS III, CAPS Ad, CAPS AD, CAPS AD III and CAPS i, in ascending order of size, complexity and populational scope. They fulfill the same function in public mental health care. It is responsible, under the coordination of the local manager, for the organization of demand and the mental health care network within its territory. The environment must be able to provide care to clients with severe and persistent mental disorders, in intensive, semi-intensive and non-intensive treatment regimens. The ordinance also determines that the CAPS supervise and train primary care teams, services and mental health programs within its scope. (8)

The CAPS are configured as outpatient and regionalized community services, in which patients must receive medical consultations, individual and/or group therapeutic care, and may participate in open workshops, playful and recreational activities promoted by the service professionals, more or less intense and articulated around an individualized therapeutic project aimed at psychosocial treatment and rehabilitation, and there should also be extensive initiatives for family members and social issues present in the daily lives of users. (9)

This new model, which goes beyond the idea of simply promoting dehospitalization, caused numerous problems in everyday life. In the temporary trajectory towards a new care organization, the first visible actions were characterized by the decrease in admissions to psychiatric hospitals and the creation of extra-hospital care resources. (10)

The professionals of extra-hospital services, such as CAPS and therapeutic residences follow the principles of integrality, helping the user in all areas of the human being: biopsychosocial and spiritual, not fragmenting care. Making the care humanized, existing links between the team and the user and having the responsibility of both for the care offered. During the activities, the service professionals seek to open spaces for individual conversations, or even with the group, in order to alleviate anxieties, fears and discuss specific situations that are experienced by users. (11)

To work with families with psychological distress, it is important for nurses to know the daily life and the family structure, their beliefs, values and knowledge about the disease, so that, from there, they can plan their necessary care, according to the needs of these family members. (12)

This bond established between the professional and the user is seen as a facilitator in the treatment, with loyalty between both parties. Thus, mental health care gains materiality in the attitude of CAPS professionals, in their relationship with users, with integrality as the focus of intervention, that is, it is a meeting place, dialogue between people with needs, desires, stories and specific knowledge. The care proposed by these professionals is beyond the users, offering the family support, considering that the family is a fundamental part for the satisfactory evolution of the user. (11)

However, these measures implied an intensification of the commitment requirements of the families of individuals with psychological distress. Significantly transformed the trajectory of their participation in the care process. As a whole, new demands were imposed, without being instrumentalized to meet them, causing them a feeling of helplessness. (10)

The family becomes responsible for meeting their basic needs, such as coordinating their daily activities; administer your medication; accompany them to health services; deal with their problematic behaviors and crisis episodes; provide them with social support; pay your expenses; and overcoming the difficulties of these tasks and their impact on the family member's social and professional life. (10)

Severe mental disorder, in addition to causing physical and psychological harm to the patient, causes changes in the daily lives of people around them. It is observed that the participation of the family in mental health care has shown convergence. There is a need to provide the family of the individual affected by psychological distress with information and guidance so that, in this way, the family can collaborate as a resocializing agent and facilitator of the patient in the family and community. (14)

Taking care of a family member with psychological distress imposes on family members situations associated with the symptoms of the disease, which they are not always willing to bear. These situations include uncontrolled behavior by the sick family member, who becomes more aggressive and restless, causing a climate of unrest that goes beyond the standards previously known by those who live with him and that affect the entire family structure. (12)

The family caregiver may develop anxiety for not knowing how to deal with some behaviors presented by psychological distress, such as exaggerated silence, continuous and disordered speech or with the unpredictability of their actions, and the perception of an increasingly "impoverished" life of the patient. Many are not satisfied with seeing a family member, who until then was brilliant, full of life projects Taking care of a family member with psychological distress imposes on family members situations associated with the symptoms of the disease. which they are not always willing to bear. These situations include uncontrolled behavior by the sick family member, who becomes more aggressive and restless, causing a climate of unrest that goes beyond the standards previously known by those who live with him and that affect the entire family structure

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and socially well integrated, transform into a committed, dependent, unprotected person and taken by limitations of all kinds. (12)

Faced with this new mode of care, the family is seen as an ally with regard to the process of caring for the person with psychological distress, but these families need health professionals to offer support so that they can keep the family core healthy, since the living with a family member in psychological distress imposes changes in the family's daily life, such as changes in the sleep routine, damage to work and the financial situation, the need to take care of the family member regarding the administration of medication and body hygiene, and physical and psychological overload. (14) Thus, Primary Health Care (PHC) also has its responsibility, seeking longitudinal care, as it is a tool to expand the care offered to patients in mental suffering, breaking challenges and enhancing health. (15)

# CONCLUSION

The study reached its initial objective and in its categories, the meaning of care was perceived within the FG, which referred to dedicating part of her life to the other, promoting physical, emotional and psychological well-being when being cared for. In another category of this research, new specific strategies for the care of the family member in psychological distress were pointed out. However, given the problems faced daily, the FG demonstrated that faith has been the main strategy to win with the patient in mental health care.

Therefore, it is essential to recognize the type of existing families, strengthen the psychosocial care network in the region, and that the bonds between family members and users are based on a relationship of respect, where the uniqueness and individuality of all are preserved, so that family members/caregivers do not feel overburdened, and people with psychological distress can regain their citizenship and autonomy.

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