

ORIGINAL ARTICLE

HISTORY OF FAMILY MEMBERS WHO ARE HAVING THE EXPERIENCE OF CARING FOR SOMEONE WITH DEPRESSION*

Naiane Ribeiro Prandini¹, Miriam Aparecida Nimtz², Marcio Roberto Paes³, Monica Macedo⁴, Rita de Cassia Nascimento Lages⁵

ABSTRACT

Objective: To know the experience of family members in the care of people with depression.

Method: Thematic Oral History that uses a hybrid methodology performed in a CAPS III (Psychosocial Care Center) in the capital of a state in southern Brazil, with data collected between January and July 2019. Family members of individuals undergoing treatment for depression in the CAPS III were included in the study and those family members who had no time to participate in the study and those who were underage were excluded. Four collaborators participated in the study.

Results: Four themes were revealed: Understanding the disease and the historical path in health services; the impact of depression on the physical health and on the financial situation of family members; the emotional impact of depression on family relationships; Religiosity and spirituality as elements for coping with the disease.


Conclusion: Depression makes patients' families vulnerable and affects their lives. The study suggests foci for interventions by health professionals with family members, adds knowledge on depression and collaborates with further studies.


DESCRIPTORS: Depression; Nursing; Family; Health professionals; Family relationships.


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¹Nurse. PhD Student in Nursing. Universidade Federal do Paraná. São José dos Pinhais, PR, Brazil. 

²Nurse. PhD, Nursing. Nursing Professor at Universidade Federal do Paraná. Curitiba, PR, Brazil. 

³Nurse. PhD, Nursing. Nursing Professor at Universidade Federal do Paraná. Curitiba, PR, Brazil. 

⁴Occupational Therapist. PhD, Psychology. Professor at Universidade Federal do Paraná. Curitiba, PR, Brazil. 

⁵Nurse. Master degree in Nursing. Nurse at the Hematopoietic Stem Cell Transplant Service of Hospital de Clínicas, Universidade Federal do Paraná. Curitiba, PR, Brazil. 

HISTÓRIA DE FAMILIARES QUE VIVENCIAM O CUIDADO DA PESSOA COM DEPRESSÃO

RESUMO

Objetivo: conhecer a vivência dos familiares no cuidado da pessoa com depressão.

Método: História Oral Temática Híbrida, tendo como local um CAPS III de uma capital do sul do Brasil, com coleta de dados entre janeiro e julho de 2019. Incluiu-se o familiar da pessoa em tratamento para depressão no CAPS III e excluídos os que tinham indisponibilidade de tempo, e familiar menor de idade. Participaram quatro colaboradores.

Resultados: revelaram-se quatro temas: O entendimento sobre a doença e a trajetória nos serviços de saúde; O impacto da depressão na saúde física e na questão financeira dos familiares; O impacto emocional da depressão nas relações familiares; A religiosidade e a espiritualidade como elementos para o enfrentamento da doença.

Conclusão: a depressão vulnerabiliza e afeta a vida do familiar. A pesquisa sugere focos de intervenção dos profissionais de saúde com os familiares, agrega conhecimento sobre a depressão e colabora para novas pesquisas.

DESCRITORES: Depressão; Enfermagem; Família; Profissionais de saúde; Relações Familiares.

HISTORIA DE FAMILIARES QUE VIVEN EL CUIDADO DE LA PERSONA CON DEPRESIÓN

RESUMEN:

Objetivo: conocer la vivencia de los familiares en el cuidado de la persona con depresión.

Método: Historia Oral Temática Híbrida, cuyo sitio fue un Centro de Atención Psicosocial III de una capital del sur de Brasil, con obtención de datos entre enero y julio de 2019. Se añadió el familiar de la persona en tratamiento para depresión en el CAPS III y se excluyeron los que tenían indisponibilidad de tiempo, además de familiar menor de edad. Participaron cuatro empleados.

Resultados: emergieron cuatro temas: El entendimiento acerca de la enfermedad y la trayectoria en los servicios de salud; El impacto de la depresión en la salud física y en la cuestión financiera de los familiares; El impacto emocional de la depresión en las relaciones familiares; La religiosidad y la espiritualidad como elementos para el afrontamiento de la enfermedad.

Conclusión: la depresión vuelve vulnerable y afecta la vida del familiar. La investigación sugiere focos de intervención de los profesionales de salud con los familiares, añade conocimiento sobre la depresión y colabora para nuevas investigaciones.

DESCRIPTORES: Depresión; Enfermería; Familia; Profesionales de salud; Relaciones Familiares.

INTRODUCTION

The global transformations in mental health, which pervaded full-time hospitalizations, preventive mental care, colonies, among others, led to changes in the forms of care and treatment in the mental area⁽¹⁾. In Brazil, Regulation No. 3,088⁽²⁾, of December 23, 2011, established the Psychosocial Care Network (RAPS), which consisted of various municipal services such as *Consultórios na Rua* (Outdoor clinics), Residential Therapeutic Services, emergency services and comprehensive care beds. Psychosocial Care Centers (CAPS) are among these services. Established in 2002, the CAPS are open community services, with a multidisciplinary team that replace full hospitalization⁽²⁾.

Treatment of depression, among others, is offered in CAPS III. Depression is currently one of the most prevalent psychiatric diseases⁽³⁾, affecting about 322 million people worldwide, and is expected to continue to rise. Its prevalence is 2.5% higher among women than men, usually at the age range of 55-74 years, and also affects children and adolescents under 15 years old⁽⁴⁾. The causes of depression are biopsychosocial and, therefore, it is considered a multifactor disease. Symptoms include intense emotional and mood changes, difficulty thinking and sleeping, and poor concentration, which may include suicidal ideation, attempted suicide and psychotic symptoms⁽⁴⁾.

Due to the impact of these symptoms on people's lives, social support related to the functional or qualitative dimension of a social network is important. It is a reciprocal process among people who have frequent contact, which benefits everyone involved⁽⁵⁾, and is usually provided by family members. Difficulties may arise in the provision of this support, as family members may feel frustrated, emotionally and financially overburdened, and even unable to provide care⁽⁶⁾. A diagnosis of depression requires dealing with the unknown and the unexpected; in addition to feeling fragile, the family often needs to reorganize itself in the face of this situation. Thus, professional care must be offered to family members, through individual assistance, home visits, group activities at the CAPS, as this allows them to talk about their experiences, re-signify the experience of getting sick and prepare for home care⁽⁶⁾.

Analyzing the changes in mental health policy, the prevalence of depression today, the impact of the disease on patients and families, the present study aimed to gain insight on the experiences of family members in the care of people with depression.

METHOD

Thematic Oral History that uses a hybrid methodology, which considers the oral histories of collaborators related to a certain theme, to elucidate circumstances connected with the theme. After the final version of the text formed by the statements of the collaborators was obtained, the findings were related to other sources so that the singularities of the study were highlighted in this comparison. This method centralizes and highlights the narratives, revealing the experience of family members of individuals who suffer from depression, in which the collaborators, in particular, are key actors, as they experienced what we intend to know.

The study was carried out in a CAPS III in the city of Curitiba, Paraná, which assists, under the Unified Health System (SUS), people who suffer from mental disorders. The CAPS is managed by a state foundation in partnership with the city hall, and has night-care beds and 185 users. The inclusion criteria were as follows: be a family member of someone being treated for depression in that service. (the collaborator who provided home care to a sick family member was cited as the "person who cared for", and "companion" was considered the individual who attended the treatment of a family member at the CAPS, for an indefinite

period of time, regardless of whether or not they were related by consanguinity, and the family member having been diagnosed with depression that falls under CID codes F32 and F33. The individual should be available to participate in the study. Family members who had no time to participate in the study and those who were underage were excluded from the study.

The recruitment of participants was done by an invitation containing information about the research and the contact of the researcher displayed on the walls of the site of the research, as well as by direct approach by the researcher in CAPS spaces. The diagnosis of depression was verified in an official document (registry of patients). However, the diagnosis was confirmed by a professional of the CAPS, by consulting the patient's medical record. In the first contact, an interview was scheduled with the approached individuals who agreed to participate in the research.

Four Collaborators participated in this study. In Oral History research, participants are called Collaborators, given the collaboration established between the researcher and the researched⁽⁷⁾. Data were collected between February and June 2019, during the day, in a private room prepared for the interviews. The interviews were scheduled with each collaborator, depending on their availability.

The interviews began with the presentation of the researcher and the reading of the Free Informed Consent Form (ICF), which was subsequently signed. Two recording devices were used simultaneously to ensure an excellent result in the recording of all the interviews. They were semi-structured interviews, as questionnaires are allowed in this method. Field diaries were used. When emotional demonstrations occurred during the interview, assistance was provided to the individual, and the process was resumed, if that was the collaborator's desire. At the end of each interview, a new individual meeting was scheduled, on a date convenient for the collaborator, for the return of the text.

Data analysis in Oral History followed. Each interview was transcribed in full in the stage of full transcription. The second step was textualization: the text was read and re-read many times, words that lacked semantic content were revised, punctuation was adapted and questions were subtracted to allow a more fluid reading. In textualization, the "vital tone" is selected. It is a phrase that guided the collaborator's narrative, i.e., everything that was said by the collaborator is related to the vital tone. The final text was then obtained and returned to the collaborator, to express their agreement with the use of the text, signing a letter in which they transfer their rights over the text⁽⁷⁾. During the reading of the statements, points of intersection were assimilated. These are central ideas that culminated in the list of four Relevant Themes, based on which the discussion was developed.

In compliance with ethical aspects, the names of the collaborators were replaced by fictitious names, maintaining their confidentiality. In the reports, the initials of the persons mentioned have been replaced by other letters. The study observed the ethical principles of research involving human beings. The research began after the issuance of a favorable opinion from the Ethics Committee of the Municipal Health Department of Curitiba, under no 3,000,661 and from the Research Ethics Committee of the Health Sciences Sector of Universidade Federal do Paraná, opinion no 2,898,381, and with the agreement of the CAPS management in Curitiba, through the state foundation and submission to the coordination of the referred CAPS III.

RESULTS

In Chart 1, we present the characterization of the collaborators, as well as the vital tone of each interview.

Chart 1 – Characterization of the Collaborators, Curitiba, PR, Brazil, 2019

Collaborator	Vital Tone	Degree of Kinship	Gender	Age	Marital Status	Education	Work Activity	Number of people in the house	Religion
Vitória, 1	<i>Resilience and spirituality to face the challenges of the disease</i>	Mother	F	60	Divorced	Complete primary education	Senior Caregiver	3	Evangelical
Eloísa, 2	<i>Learn to deal with and get used to the nuances of the disease</i>	Wife	F	58	Married	Incomplete secondary education	Caregiver	3	Evangelical
Antonia, 3	<i>Despair in the face of tiredness and impotence to deal with the disease</i>	Sister	F	58	Stable Union	Incomplete elementary school	Day laborer	4	Catholic
Augusto, 4	<i>The understanding of illness and the concern with treatment</i>	Brother	M	42	Single	Complete vocational secondary education	Delivery person	3	Has no religion

After careful reading of the texts and assimilation of the points of intersection, the following Relevant Themes were listed: Understanding the disease and the trajectory in health care services, The impact of depression on the physical health and financial issues of family members, The emotional impact of depression on family relationships and Religiosity and spirituality as elements in coping with the disease.

Understanding the disease and the trajectory in health care services

The collaborators were found to perceive the diagnosis of depression in different ways.

[...] Panic Disorder? It looks like that ... Depression? This sort of things [...]. look, I don't know what kind of illness this is, what kind of depression this is. She had a CT scan, because the symptoms can be caused by frustrating experiences [...].She has endometriosis. She has had an injection every 90 days for many years. We thought that this could have been caused by blood problems. (Collaborator 1, Vitória)

He was admitted to a hospital that was not suitable. Hospital for crazy people, as he says. He had a terrible nervous breakdown, and this had never happened before. (Collaborator 3, Antonia)

[referring to his sister's diagnosis of depression] No, for me it was like reading the diagnosis in a book. They saw the person crying and said: you have depression. They heard the person say she did not want to live: you have depression. [referring to his sister] - Oh, I'm sad, I

still can't get over my parents' death. So you have depression. So take this antidepressant here. That's it. It was no surprise to me. It was blindingly obvious to me. (Collaborator 4, Augusto)

In this Relevant Theme, the trajectory experienced by collaborators and their families to obtain care at CAPS III was assimilated. In most cases, initial support was provided by urgency and emergency services and the Basic Health Unit (UBS).

He came here [CAPS] because he was found in the woods, lost. He was taken by SAMU to UPA P. [name of UPA]. As there was no vacancy, I took care of him at home until I got a permanent vacancy here for him. (Collaborator 2, Eloísa)

Collaborator 3, Antonia, said that her family member was assisted by the urgency and emergency network, then he was referred for admission to a hospital psychiatric unit and later for treatment in Curitiba.

[...] When he was in PG, I talked to the social worker by phone and asked her to refer him for treatment here. I didn't know the CAPS. It was this social worker who told me that he needed treatment at the CAPS, with a psychologist, etc. With the referral, everything became easier: I went to the health care center, then they called me and set a date for me to come here at the CAPS as soon as possible. (Collaborator 3, Antonia).

The collaborators demonstrated favorable perceptions, ignorance and also criticism about the role of CAPS III in the treatment of their family members.

[...] She thanks God for this little place that welcomed her [tearful], they treat her and us so well [...] here[at the CAPS] she can at least walk a little, see other people, and is beginning to understand that she needs care and someone to care for her [pause] So I thank God for having this opportunity to be here and at least understand what this is. Or else try to understand. (Collaborator 1, Vitória)

[...] Yes. I don't know how to explain it to you. This has been good for him [referring to treatment at the CAPS], he is participating in the meetings here. (Collaborator 3, Antonia)

There is none [referring to treatment at CAPS]. There is none. It is sad, but unfortunately it was expected. And it was expected because our cultural, social, South American, Latin context, I don't know exactly what it is, makes me avoid seeking care at a public health service, whenever possible. I will not use public health services, because I know that in Brazil they are usually inefficient. I didn't have much hope that something different would happen here [...] Her supposed reference therapist is kind of a dictator. So, she only comes here two to three times a week. If she were allowed, she would come here every day of the week, but now, according to this supposed therapist, she shouldn't be coming every day. She can only come here on the days when activities that are part of her personalized therapy plan are carried out, as if such a plan really existed. (Collaborator 4, Augusto).

The impact of depression on the physical health and the financial situation of family members

When someone suffers from depression, it impacts the physical health of family members. In this regard, as it can be seen in the note in the field diary, collaborator 3, Antonia, reported being hypertensive and having stopped her treatment because of her new routine and the responsibilities of caring for her brother; she said she was tired and worried and that she had reduced her leisure activities.

The collaborators reported the financial impact suffered, as some of the individuals diagnosed with depression do not receive financial assistance and had to move to the homes of their family members.

[...] She has been like this for 5 months. I am still working. But what if I lose my job? If

necessary, I'm sure I can do anything else, but if I'm working elsewhere, it can get worse, because she needs someone around. (Collaborator 1, Vitória)

[...] he said that if he gets his retirement benefits again, he will be quieter, calmer. I agree. He needs this because he can't work. (Collaborator 3, Antonia)

[...] And they tell me that she can't undergo a Social Security's medical examination to get sick aid? So she is sick, unemployed, she has already contributed to social security... where else will she get the money to buy her medicines? The drugs prescribed here are not found at the health center. [...] And I realized that here they think "that this is inevitable and there is nothing to do". So, patience. As I do not receive any assistance, I have been earning money as an informal worker, making deliveries. [...] The lack of money taught me a lot about reinventing myself. (Collaborator 4, Augusto)

The emotional impact of depression on family relationships

The interference caused by the disease in interpersonal relationships is assimilated, especially the one generated by symptoms related to affection and emotions faced by those who have depression.

[...] Her behavior has completely changed: she speaks softly, almost no longer talks to us [emotionally], and when she is at home she spends most of her time lying down, avoiding contact with us [...] It is not easy [emotional] I feel sorry for her [...]. I have managed to deal with it. But this is killing me [crying]. It's too difficult for me [...] and we need to bathe her and put food in her mouth [...]. This is so painful! [crying, she wipes her tears with a paper towel, touches the paper towel, looks down and speaks, expresses pain and regret] (Collaborator 1, Vitória)

[...] You know, I ask God to give me strength, because there are times when I feel like giving up myself. My God, I need to work, I have a family, I have a husband, I have a son too. All of this happened suddenly at the end of the year. (Collaborator 3, Antonia)

[...] the words sad and frustrating, in particular, are among the first words that come to mind when dealing with this situation, because you see someone at home, who has no motivation, no incentive to do anything, and you realize that this person is completely passive and negative [...]. No, I don't suffer. It hurts. That's what I said. It's sad. You asked me about this situation, but it is a situation and I am not part of it. I do not internalize this situation. So, no, I don't suffer [...] I don't see it as a burden, I see it as something I had to do. I had to do it, but I wanted to, I see no problem in doing this [...] (Collaborator 4, Augusto)

Religiosity and spirituality as elements for coping with the disease.

The narratives showed religiosity and spirituality as positive factors in facing the difficulties experienced. The collaborators used their beliefs as a support to face this process in the search for understanding what has happened.

[...] Now, we must ask God to have the strength and faith to succeed. She needs to have an active life again. I don't know what can happen. Only God can help her. And I have faith in God that she will get better. With God's protection and monitoring of doctors, and with God giving me strength and the ability to understand her too, because otherwise it is difficult. [pause]. (Collaborator 1, Vitória)

[...] Oh my God! I only ask God to give me strength [...] I tell him to have faith, to go to church more often, that God will help and it will work. (Collaborator 3, Antonia)

[...] I believe the Lord will never give you a burden greater than you can bear... to everything there is a season (slowly), I think God gave him some time to get away from his family, away from everything and everyone. (Collaborator 2, Eloísa)

DISCUSSION

In this study, three of the four collaborators are female, a finding common to other studies^(8,9) that showed that women provide most of the care for people with mental disorders, and the demands associated with care produce major changes in their lives⁽¹⁰⁾.

The causes of depression may be related to biopsychosocial factors, such as monoamine neurotransmitters, hormones, genetic, social, environmental factors, life experiences and events⁽¹¹⁾. Regardless of the cause, the disease causes the family to become disoriented, as the expected course of life has weakened, expectations related to the family member who fell ill are left aside; the family members need to reorganize themselves in the face of this new reality imposed on them^(10,12), even though they feel fragile, incapable, guilty or deny the diagnosis⁽¹³⁾. In addition to the socio-cultural context and the interpretations of each family member about what they experienced, these issues can clarify differences in the understanding about depression⁽¹⁰⁾.

The collaborators revealed their trajectory in the health services where their family members were assisted. Overall, the individuals were initially assisted at the Emergency Care Units (UPA) 24 h and at the BHU (Basic Health Units). This corroborates the objective of the emergency services, which provide emergency assistance with subsequent coordination with specialized services and with the care offered at UBS, a health service closer to the user, which includes actions for promotion, prevention, protection, diagnosis, rehabilitation, health maintenance and harm reduction that can be coordinated with other services of the mental health care network⁽²⁾. This was reported by a study carried out in Sobral-CE, in which referral to specialized mental health services was made through the UBS, social units and private units⁽¹⁴⁾.

The perceptions about the treatment received at CAPS III were revealed in the interviews and in the field diary. For some collaborators, the actions promoted by this health service were not clear; there were criticisms related to the Personalized Therapy Plan, the turnover of professionals, the attitude of the Reference Professional in Mental Health. When families are not involved in the treatment, it is still a vertical treatment that disregards what people living with the problem have to say⁽¹⁵⁾. Some studies suggest that the CAPS helps the families to better understand the disease and, sometimes, it is the only support available to them^(8,16,17).

The impact on physical health addressed in this study did not concern deeper issues such as those reported in other studies, like the development of chronic diseases, sleep disorders and physical injuries⁽¹⁰⁾. However, it warns health professionals on the collaborator health issue. A study with caregivers of people with mental disorders revealed that 52.5% of the respondents were undergoing treatment for clinical and mental problems⁽¹⁸⁾.

In addition to the physical burden caused by factors such as difficulty of living with a sick person and loss of individuality⁽¹⁵⁾, family members also face a financial burden, as they must bear domestic costs and those associated with the needs of the sick person. This is because chronic mental illness can lead to disability, affecting work activity due to the symptoms, interfering with productivity and resulting in sick leaves, which generates social costs and impairs the quality of life⁽¹⁹⁾. In this study, all family members had flexible jobs, which facilitates the care and monitoring of the patient, also described by other authors⁽⁹⁾.

The act of caring and its impacts may differ for each family member^(9,20), and this was found in the present study, as half of the collaborators had suffered emotional impact, because of the difficulty in maintaining an adequate dialogue and daily coexistence, also reported in another study⁽¹⁰⁾. The notes in the field diary also reveal the collaborators' tiredness and sadness, expressed in crying and a choked voice. The emotional burden of family members of individuals with mental disorders is manifested in feelings of fear, shame, distress, fragility⁽¹⁶⁾, sadness⁽⁶⁾, tiredness, worry and suffering⁽¹⁰⁾. Caring for people with mental distress requires considerable efforts of the family members who often do not

know how to help⁽¹⁰⁾, which can contribute to emotional distress.

Depression, lack of information, family members' difficulty in dealing with their emotions may result in a breakdown in family relationships. This contributes to inflexibility in family relationships and coexistence^(9,21) and causes family overload⁽²⁰⁾. When family members are not heard and do not participate in care, affective relationships tend to become inflexible, because of the experiences lived by the family and the understanding that there will be no cure for the disease⁽⁹⁾.

The spiritual well-being of the collaborators must be considered, as it has a positive impact on mental health. Belief in something superior helps people define a life purpose, maintain hope and resilience, and encourages healthy habits of life. Religiosity contributes to mental stability, helps to explain mental disorders⁽²²⁾, interpersonal relationships, physical and mental health, and can be a protective factor against suicide and improve quality of life⁽²²⁾.

The narratives about religiosity and spirituality suggest a professional approach, as they were revealed as a positive factor and require further investigation in the academic area. Health professionals cogitate on the importance of this theme. However, limitations in academic training, work demands and the absence of models to introduce the topic in clinical practice generate discomfort and insecurity in addressing the support of religiosity and spirituality with patients and family members⁽²³⁾.

Focus on depression can be pointed out as a limitation of this study, since relevant publications depict the experiences of mental disorders in general, and there is discrepancy between the symptoms generated, which highlights the importance of studies focused on depression.

FINAL CONSIDERATIONS

The present study revealed different understandings about the onset of depression, its causes, symptoms, evolution of the disease and recovery of depressive persons. Some collaborators were unaware of the role of CAPS III in the recovery of their family members, and criticized the attitude of the Reference Professional in Mental Care, the preparation of the Personalized Therapy Plan and the turnover of health professionals. They said that the sick persons were first assisted in emergency services and later in specialized services. However, other health services such as emergency care units (UPAs) and BHU were also used.

The study showed the experiences of family members in the care for people with depression. The disease has a negative impact on physical health, financial issues, emotional health and interpersonal relationships. Each family member suffers and experiences this situation in their own way: some more intensely, others with greater resilience.

The experience of family members who care for someone with depression can be perceived as difficult, frustrating, mainly because of the symptoms of depression that affect all those around the individual. Knowledge of these experiences and dissemination of the findings of this study among mental health services will demonstrate that family members are suffering and also need care.

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Corresponding author:

Naiane Ribeiro Prandini

Universidade Federal do Paraná

Al. Bom Pastor, 715 – 83015-140 – São José dos Pinhais, PR, Brasil

E-mail: naiane.prandini@gmail.com

Role of Authors:

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - MRP

Drafting the work or revising it critically for important intellectual content - MRP, MMMI, RCNL

Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - NRP, MAN



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