



## CARE FOR PEOPLE WITH PSYCHOLOGICAL DISTRESS AND ITS REPERCUSSIONS ON THE FAMILY<sup>1</sup>

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### ABSTRACT

**Objective:** to understand how the daily care of people in psychological distress affects the life of the family caregiver and to measure the level of caregiver burden. **Method:** this is an exploratory and descriptive study with a mixed approach. Data was collected using a semistructured interview and the Zarit Burden Interview with 15 family members of people in psychological distress who were followed up at a CAPS III unit in a city in the metropolitan region of Salvador. Data were collected between February and August 2021, organized and analyzed using the Thematic Content Analysis technique and discussed based on existing literature. **Results:** the correlation of the variables revealed the level of objective and subjective burden, in addition to the feelings expressed by these family members. Six family members had moderate to severe burden according to the ZBI scale, with scores ranging from 43 to 54. The units of meaning gave rise to three thematic categories, which were presented in the infographic and illustrate how the daily care of people with psychological distress affects the lives of family caregivers. **Final considerations:** the study revealed that care for people in psychological distress has been carried out mainly by black women, reflecting gender and race inequalities, and that this care involves ambivalent feelings and expectations, varying levels of burden, and the need for social and state support.

**Keywords:** Caregivers. Deinstitutionalization. Family. Mental Health Assistance. Social Support.

### INTRODUCTION

For long periods of history, the family has been responsible for caring for people experiencing psychological distress. However, with the emergence of psychiatry as a medical specialization focused on mental illness, the family was excluded from the care of their sick loved one, as asylums became a place of “treatment” where visits were prohibited, which led to feelings of guilt among family members<sup>(1,2)</sup>.

The asylum model persisted for a long period of time, during which individuals with psychological distress had their fundamental rights violated, including their right to health. Complaints revealed that these individuals were living in degrading conditions, and there were various cases of deaths that occurred in asylums,

such as those exposed by journalist Daniele Arbex in the book “*Holocausto Brasileiro*” (Brazilian Holocaust), which describes the terrible conditions experienced by patients at the *Hospício de Barbacena*, later renamed *Hospital Colônia de Barbacena*<sup>(3)</sup>.

In the early 1970s, the Brazilian Mental Health Workers Movement was created with the purpose of reforming psychiatric care, and led to valuable reflections on psychiatric knowledge and deinstitutionalization of care<sup>(4)</sup>. This culminated in the passing of Federal Law no. 10.216/2001 and in the III National Conference on Mental Health, which promoted the Brazilian psychiatric reform and the consolidation of services in mental health outside of hospitals<sup>(4-5)</sup>.

Among mental health services, Psychosocial Care Centers (CAPS) stand out. These health

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devices are designed to assist people in severe psychological distress within their respective territories on a daily basis. CAPS offers clinical and psychosocial care, avoiding hospitalizations and helping to reintegrate patients into community and family life through strategies that enable access to work and leisure and the exercise of their rights<sup>(5)</sup>. In this scenario, family members once again play a crucial role as partners in care, welcoming and including the individual in community life and ensuring continuity and progress in treatment.

The lack of understanding about behavioral and mood changes of individuals experiencing psychological distress can generate conflicting feelings in family members, who often struggle to cope with crises or increased stress, considering that there is still prejudice and stigma surrounding mental illness. In this context, it is observed that living with a person with psychological distress has repercussions for family members, among which we highlight overburden<sup>(6)</sup>.

Overburden can be experienced in two dimensions, objective and subjective. The objective dimension is related to the consequences of the nature of care, the interaction of the family member with the psychological and organic signs and symptoms presented by the patient and the changes in daily life, leisure activities, domestic and financial life, and the physical and mental health of the family member, among others. The subjective dimension is related to the family member's personal perception of the consequences of providing care, including their feelings and discomfort, such as guilt, shame, anger and sadness, among others<sup>(7)</sup>.

It is important to emphasize that the burden and negative feelings associated with caring for people in psychological distress may be more closely associated with the process of exclusion, stigmatization and prejudice experienced by mental health services users and their families than with the illness itself. The lack of understanding about the illness can lead individuals with psychological distress and their families to social isolation, reducing or extinguishing their social bonds<sup>(8)</sup>.

Social bond refers to the connections between individuals, whether through people, institutions or healthcare services. Individuals experiencing psychological distress who have had their social

bonds weakened or even destroyed by isolation must be able to strengthen and rebuild them using the extra-hospital network tools consolidated by the psychiatric reform. This can help minimize the burden on caregivers in their daily lives<sup>(9)</sup>. In this study, the concept of daily life encompasses all the actions done on a daily basis, as well as the pressures of the present and the burdens and difficulties related to the individual's experience<sup>(10)</sup>.

It is also worth noting that the absence of support from the State, whether in terms of economic assistance or implementation of measures to access healthcare services, can contribute to increased stress and conflicts within the family environment.

Based on this issue, it is necessary to understand how family members perceive the impact of this care on their lives and to assess the level of burden they experience in order to improve the care provided for family members and analyze possible strategies that can minimize the impacts resulting from the caregiving process.

This study aims to provide reflections for mental health professionals and managers, with the objective of promoting care that improves the quality of life, social reintegration, and autonomy of individuals with psychological distress. This, in turn, can have a positive impact on the lives of their relatives.

In view of the above, the objective of this study is to understand how the daily care of people in psychological distress affects the life of the family caregiver and to measure the level of caregiver burden.

## METHOD

This is an exploratory and descriptive study with a mixed approach, involving concurrent collection of qualitative and quantitative data to determine convergences and differences. However, greater priority was given to the qualitative approach, which involved listening to the experiences, values, beliefs, and motivations of the participating family members<sup>(11)</sup>.

The manuscript was elaborated according to the recommendations of COREQ (Consolidated Criteria for Reporting Qualitative Research), meeting the scientific requirements for the development of studies with a qualitative

approach<sup>(12)</sup>.

Fifteen family members of people in psychological distress who were followed up at a CAPS III unit in a city in the metropolitan region of Salvador participated in the research. Inclusion criteria were: being a caregiver of the person in psychological distress and being over 18 years old. The exclusion criterion was family caregivers who received some remuneration for the care provided.

Data were collected between February and August 2021, and the participants were identified according to the patient records at the health unit. For this purpose, a semi-structured interview was conducted, which consisted of questions about the participants' characterization and their experiences in caring for their loved one with psychological distress.

The interviews were conducted by the lead researcher in a private setting, with a mean duration of 20 minutes, and were audio recorded and later transcribed and processed. A pilot test was carried out with a family member. Interviews were ended when content saturation was reached and no new elements related to the researched phenomenon could be observed<sup>(13)</sup>. Additionally, the Zarit Burden Interview (ZBI) scale was applied simultaneously with the interviews. The scale is composed of four dimensions: "Impact of care provision" "Interpersonal relationship" "Expectations with care" and "Perceived self-efficacy"<sup>(7)</sup>. The first two dimensions, "Impact of care provision" and "Interpersonal relationship", include the variables related to objective burden, and the latter two dimensions, "Expectations with the care" and "Perceived self-efficacy", are related to subjective burden.

Finally, the data from the interviews were organized using the Thematic Content Analysis technique, which was proposed in previous studies<sup>(14)</sup>. The Recording Units (RU) were organized in a table and separated by color to facilitate identification and visualization. Using this table, coding and subsequent categorization into units of meaning were carried out, allowing the treatment of the results. Then, an infographic was elaborated to better visualize the information obtained, and the data was analyzed and discussed based on existing literature.

The quantitative analysis of the Zarit Burden Interview Scale (ZBI) involved summing the

responses to the 22 items and identifying the level of perceived burden through a score ranging from 0 to 88. A higher score indicates a greater level of perceived burden. The data was categorized as follows: no burden (0 to 20), mild to moderate burden (21 to 40), moderate to severe burden (41 to 60), and severe burden (61 to 88)<sup>7</sup>.

The study was appreciated and approved by the Ethics and Research Committee of the State University of Bahia under opinion no. 4,427,991, and all participants signed the Informed Consent Form (ICF). To maintain their anonymity, each family member was identified by the letter "F" followed by a number corresponding to the order of their interview (F1, F2... F15).

## RESULTS

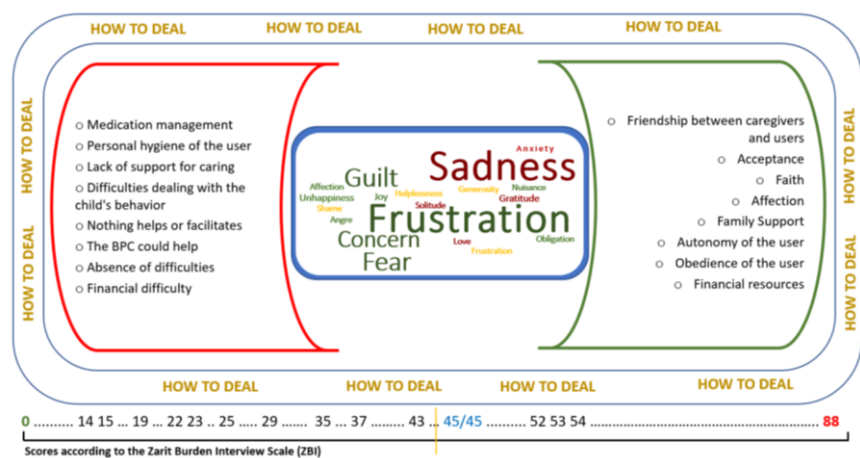
The study involved 15 family members, of which 12 were women and three were men. Age ranged from 20 to 75 years. Eleven of the participants self-identified as black. The mean time of education was nine years. Six family members identified as Evangelical, which was the predominant religion. Nine of them had a steady partner, and eight had formal employment. As for the ZBI scale, participants' scores ranged from 14, which indicates no burden, to 54, which indicates moderate to high burden.

Regarding the kinship of the family members, most were mothers, with a total of 8 participants. Thirteen participants were the main caregiver and 11 lived in the same house as the CAPS III user. Nine family members reported receiving additional support for caregiving, and the duration of their caregiving ranged from 15 days to 30 years.

The study included 16 mental health service users, consisting of eight men and eight women, all cisgender, with ages ranging from 21 to 68 years. "Schizophrenia" was the predominant diagnosis in the users' medical records and most patients did not receive the government benefit, *Benefício de prestação continuada* (BPC).

The infographic below (Figure 1) represents how the daily care of people in psychological distress affects the life of the family member. The units of meaning are based on the understanding of how family members deal with this care and their recognition of both facilitators and barriers to care.

**Figure 1.** Representation of how the daily care of people in psychological distress affects the life of the family caregiver.



The data collected revealed the level of objective and subjective overload, as well as the feelings expressed by these family members. The variables are presented in correlation with the profile of the study participants, including the socio-demographic profile of the caregiver (gender, age, marital status, profession, education, religion and race), the caregiving context (kinship, living in the same household, being the main caregiver, receiving support from other people, time spent as a caregiver) and the context of the person in psychological distress (gender, age, clinical diagnosis, and access to the BPC). Furthermore, the result of the ZBI Scale and its correlation with the factors described above were analyzed.

Six family members had moderate to severe burden according to the ZBI scale, with scores ranging from 43 to 54.

The units of meaning gave rise to three thematic categories, which were presented in the infographic and illustrate how the daily care of people with psychological distress affects the lives of family caregivers.

### Category 1: Facilities and difficulties in care

The recording units of the participating family members revealed that religiosity has been a resource used to deal with the psychic suffering of their mentally ill loved one:

I also ask God for wisdom to know how to deal with these types of situations. (F7)

I wish he was different... (cries), but it wasn't the Lord's will and we have to conform. (F8)

All family members who had a moderate to high level of burden reported that the mental health service user did not receive the BPC, which may have some impact on the objective burden.

The only difficulty I have with her is financial. (F4)

The benefit could help me a little, provide some relief. (F8)

A family member mentioned the autonomy of their loved one as the main facilitating factor in daily care:

She does things, she knows how to do everything, she washes the dishes, helps me, cleans the house. (F12)

### Category 2: Feelings related to caring

Sadness and frustration were the most cited feelings, regardless of the level of burden. On the other hand, joy also appeared in the reports:

It's a feeling of frustration with life, with your children, because you have that problem. It's a really deep sadness because they have not yet found a cure for schizophrenia. (F4)

After I accepted it, I got happier, I even love him more. (F6)

A family member presented that their biggest concern is the fear of their own death and the future, questioning how their mentally ill loved one will cope and survive without them and their care,

as shown in the UR below:

We're here to spend a few days, you know, and I'm like "Oh God, how can I do it?", if one day I close my eyes and die, which is everyone's fate, nobody is here forever, how will my son survive if I am the only one that takes care of him? (F10)

While not a common finding in the interviews, the fear of dying and leaving the loved one behind is associated with subjective burden and appears in the responses to the ZBI scale, where 12 family members expressed fear for the future of their loved one after their own passing.

The feeling of shame was reported by only one mother and was found to be associated with stigma and prejudice, and not necessarily with the behavior of the child in psychological distress.

Sometimes, society doesn't accept it and we may even feel... how do you say... shame, you know what I mean? But as parents, we must overcome these things. (F8)

### **Category 3:** Expectations of family members in relation to healthcare teams

Participants mentioned the support of the health team, which includes the availability of professionals for visits, their flexibility in relation to the limitations of users and the activities offered at the CAPS:

I think it would be great to have more support, like the home visits. If he refuses to come here (to the CAPS), a home visit might make him feel welcomed. (F1)

If he could participate in something else to fill his time. (F4)

One interviewee expressed a need for better access to specialized services, while another demonstrated satisfaction with the easy access to the family and community doctor who works in the neighborhood:

We could take care of him, do some tests, you know? Check his head and make sure we really know what's going on. These medical exams are very expensive. Then it would be better! (F9)

No, for now I think it's fine because there's a doctor coming here, I have an appointment with her tomorrow at the [PCC in the area] clinic. (F13)

Another interviewee suggested hospitalization

as a form of care for their family member, associating it with a chance of rest for the caregiver:

I pray to God that we get a place here than can admit him, because I had to take him to another city. Even if you do a good job like this, if you do not hospitalize him, the problem just keeps going on and on in your life. So I'm totally against this idea of not hospitalizing him, because it would not be for his whole life. (F1)

## **DISCUSSION**

The analysis of the socio-demographic context of family caregivers in this research revealed that women, primarily mothers, and black individuals are the predominant caregivers. This finding is consistent with a study conducted in Portugal<sup>(8)</sup> that explored gender as a factor in family caregiving, and highlighted the challenges associated with deinstitutionalization and the experiences of people with severe mental disorders, their families and their burden. It is clear, therefore, that the act of caring is closely related to the issue of gender, with a predominantly female role, even in situations where there is no type of illness<sup>(1)</sup>.

It was found that the mean level education decreased as the level of burden increase, which is in line with previous studies on caregivers and their relationship to diagnoses<sup>(15)</sup>. This indicates that individuals with lower levels of education may have more difficulty managing stressful situations. Moreover, family members who had paying jobs experienced even greater levels of burden, as they had to balance caregiving responsibilities with their personal and professional lives.

The role of religiosity in the lives of these family caregivers is noteworthy, as they report that their beliefs aid in coping with the challenges they face. In this regard, religion can have a significant impact on maintaining hope for both family members and mental health service users, reducing the distress associated with the caregiving process.

An important aspect to be discussed is the prevalence of self-declared black individuals among the participants. This reflects the Brazilian socio-demographic profile, as those who access public health services, including the CAPS, are primarily individuals with low income or who are socially vulnerable. This trend can be traced back to the country's history of colonization, with a

notable presence of black populations and a development system that has produced and perpetuated social segregations over time<sup>(16)</sup>.

It is important to emphasize that most of the caregivers who had a moderate to severe level of burden reside in the same household as the person with psychological distress and are their main caregiver. Five of these caregivers do not have support from others in providing care. It should be noted that a lack of or a limited support network can lead to increased physical and mental exhaustion for family members, as they are responsible for meeting the various material and emotional needs of the person under their care. It was observed that, although most family members report having a partner, the care burden tends to fall on a single individual, usually a woman. This situation can happen for two reasons: the family member chooses to not “bother” the rest of the family or the other family members show unavailability or unwillingness to provide care<sup>(8)</sup>.

Family members with a moderate to severe level of burden spent a diverse amount of time providing care to people in psychological distress, which suggests that prolonged care can lead to a higher level of burden, as shown in a study on the evaluation of the burden of family caregivers being followed up at a CAPS in a city in the interior of the state of São Paulo<sup>(17)</sup>.

No relationship was observed between the age and gender of the person in psychological distress and the level of burden reported by their family members. Those who had no burden and those who had moderate to severe burden provided care for individuals of various ages and with an equivalent proportion of men and women, which does not allow any inference to be made about the impact of these variables.

The study's findings indicate a high prevalence of schizophrenia diagnoses among the participants, as evidenced by their medical records. Caring for people with schizophrenia can be quite complex, both for the person with the disease and for their family, as the symptoms can be intense and the condition is often stigmatized as “crazy”<sup>(1)</sup>. In this context, stigma seems to play a crucial role in how family caregivers perceive their burden and in the feelings reported by the interviewees, such as shame.

Stigma is a negative label given to individuals who possess traits or characteristics that are

different or not accepted by most people, leading to prejudice and social exclusion<sup>(18)</sup>. In this context, people experiencing psychological distress have been stigmatized for a long time for being considered deviant from the societal norm, which has led to their exclusion from various aspects of society<sup>(6)</sup>.

In addition to or precisely due to social exclusion and stigma, financial barriers can also appear and hinder the care process for individuals experiencing psychological distress, as many of them are unable to enter the labor market or lose their capacity to work<sup>(8)</sup>. In this context, many family members need to reduce their work hours or leave their jobs to provide care, which can lead to or exacerbate poverty.

In Brazil, there is legal provision for guaranteeing security and income for individuals experiencing social vulnerability and those with certain mental disorders, in the form of the *Benefício de Prestação Continuada* (BPC). This benefit provides a transfer of one minimum wage to low-income individuals, people with disabilities or those over 65 years old, and is guaranteed by the Federal Constitution of 1988 and regulated by Law No. 8,742 of 1993<sup>(19)</sup>. The family members' reports indicate that the BPC is seen as a resource that can facilitate the care process.

One caregiver's speech was particularly relevant to the discussion of autonomy. They noted that the autonomy developed by individuals experiencing psychological distress is an important factor in alleviating the caregiver's burden, as the caregiver must attend to daily tasks such as hygiene and medication management. Furthermore, a decrease in autonomy can negatively impact the quality of life of the person experiencing psychological distress.

The recording units revealed that the feelings towards those who experience psychological distress can be contradictory. The most commonly reported emotions were sadness and frustration, especially during the phase of searching for a diagnosis. However, there were also reports of feelings of joy upon reaching a state of acceptance of the person's condition.

In general, family members expressed experiencing, concomitantly, sadness and happiness, hopefulness and discouragement, fear, shame and love, a mix of ambivalent but interconnected feelings that demonstrate their

humanity. These feelings can be considered as relatively stable affective states when compared to emotions, as they are less intense and less reactive to momentary stimuli<sup>(20)</sup>.

Overburden is a psychological indicator that is reflected in the attitudes and emotional responses of family members towards the care process. Its intensity can be amplified or minimized by the subjective perception of the family member, as well as by various factors, such as changes in routines, care needs, financial issues, and social support<sup>(21)</sup>.

It is also worth emphasizing that, in the ZBI scale, concern for the future of the mental health service user was the second item with the highest score, particularly when considering the death of the parents or guardians. The uncertainty about what will happen and the absence of options to ensure proper care and affection for the person causes great distress to family members. Therefore it can be observed that the fragility of the social connections of individuals who experience psychological distress may be the main factor associated with this fear.

In this context, the family member responsible for care becomes the only connection between the suffering person and the outside world. The uncertainty about the future and the lack of alternatives that ensure proper care and affection for these individuals can lead to significant distress for family members.

Substitute mental health services must pay close attention to the reconstruction and strengthening of these social bonds, through initiatives that promote greater autonomy for the user and encourage the use of public spaces such as parks, markets and residents' associations, so that the individual can feel a sense of belonging within their social environment<sup>(12)</sup>.

In terms of the expectations that family members have for health services, two specific points stood out: hospitalization still being considered as a care option, and the desire for comprehensive care.

For many families, hospitalization is still seen as the only or final resort during moments of desperation and when they are experiencing high physical and emotional burden, leading them to choose contentious care strategies<sup>(8)</sup>. As for comprehensive care, some family members expressed their hopes for an expansion of care

services with easier access to basic and specialized health services, and highlighted the importance of welcoming in mental health services, as it enables more effective care for its users. Therefore, these families advocate for comprehensive assistance for individuals in psychological distress, recognizing that they are members of the community and require care that extends beyond the scope of CAPS.

The study has limitations that should be taken into consideration, such as being conducted in only one CAPS and taking place during the SARS-CoV-2 pandemic, which hindered closer engagement with the participants.

## FINAL CONSIDERATIONS

The study's findings allowed understanding how the daily care of individuals in psychological distress affects the lives of their family caregivers, while also measuring the objective and subjective burden experienced by them. The socio-demographic and circumstantial contexts and the profile of mental health service users found in this study align with previous research in the field, with emphasis on gender and race inequalities and the predominance of black women as the main caregivers.

The study revealed that caring for individuals with psychological distress is characterized by ambivalent feelings and the need for comprehensive care. The approaches taken in caring for these individuals are varied and depend on the context and reality of each family.

The study found that caring for individuals with psychological distress involves affection and friendship, and that acceptance is perceived as a facilitating factor, as are the support of other family members and the intersectoral assistance provided by the State. Therefore, it is important for mental health professionals to understand the social network of individuals with psychological distress and their families to identify sources of support and conflict, which can allow the expansion of community resources and improve the mental health of everyone involved.

Another important aspect to highlight is the necessity for public policies aimed at individuals with severe psychological distress who are unable to work, which must include access to housing, considering that caregiver's fear of their own death

is often related to the concern for the survival of their loved one. Therefore, mental health professionals must promote the autonomy and empowerment of these individuals so that they can fully exercise their rights as citizens.

Therefore, the present study can contribute to the training of mental health professionals in

relation to the possibilities of psychosocial care aimed at family caregivers of those with psychological distress, as current actions do not always reach these caregivers, who are fundamental workforce in the process of psychosocial rehabilitation of those in psychological distress.

## O CUIDADO ÀS PESSOAS EM SOFRIMENTO PSÍQUICO E SUAS REPERCUSSÕES NA FAMÍLIA

### RESUMO

**Objetivo:** compreender como o cuidado cotidiano das pessoas em sofrimento psíquico repercute na vida do familiar cuidador e mensurar o seu nível de sobrecarga. **Método:** trata-se de um estudo exploratório e descritivo, de abordagem mista. A coleta de dados foi realizada utilizando-se entrevista semiestruturada e aplicação da escala *Zarit Burden Interview* com quinze familiares de pessoas em sofrimento psíquico que são acompanhadas numa unidade do Centro de Atenção Psicossocial III de um município da Região Metropolitana de Salvador. Os dados foram coletados entre os meses de fevereiro e agosto de 2021 e organizados e analisados segundo a Técnica de Análise de Conteúdo Temática e discutidos com base na literatura. **Resultados:** com a correlação das variáveis foi possível inferir o nível de sobrecarga objetiva e subjetiva, além dos sentimentos expressos por esses familiares. Seis familiares tiveram avaliação, a partir da escala ZBI, de sobrecarga moderada a severa, com pontuações variando entre 43 e 54. A partir das unidades de significado emergiram três categorias temáticas que permitiram ilustrar, conforme o infográfico, a representação de como o cuidado cotidiano das pessoas em sofrimento psíquico repercute na vida do familiar cuidador. **Considerações finais:** apreendeu-se que o cuidado às pessoas em sofrimento psíquico tem sido realizado predominantemente por mulheres negras, refletindo as desigualdades de gênero e raça, envolve sentimentos e expectativas ambivalentes, níveis diferenciados de sobrecarga e necessidade de suporte social e do Estado.

**Palavras-chave:** Apoio social. Assistência à Saúde Mental. Cuidadores. Desinstitucionalização. Família.

## EL CUIDADO A LAS PERSONAS EN SUFRIMIENTO PSÍQUICO Y SUS REPERCUSIONES EN LA FAMILIA

### RESUMEN

**Objetivo:** comprender cómo el cuidado cotidiano de las personas en sufrimiento psíquico repercute en la vida del familiar cuidador y medir su nivel de sobrecarga. **Método:** se trata de un estudio exploratorio y descriptivo, de abordaje mixto. La recolección de los datos fue realizada utilizando entrevista semiestructurada y aplicación de la escala *Zarit Burden Interview* con quince familiares de personas en sufrimiento psíquico que son acompañadas en una unidad del Centro de Atención Psicossocial III de un municipio de la Región Metropolitana de Salvador/Brasil. Los datos fueron recogidos entre los meses de febrero y agosto de 2021. Organizados y analizados según la Técnica de Análisis de Contenido Temático y discutidos con base en la literatura. **Resultados:** con la correlación de las variables fue posible inferir el nivel de sobrecarga objetiva y subjetiva, además de los sentimientos expresados por esos familiares. Seis familiares tuvieron evaluación, a partir de la escala ZBI, de sobrecarga moderada a severa, con puntuaciones variando entre 43 y 54. A partir de las unidades de significado surgieron tres categorías temáticas que permitieron ilustrar, conforme el infográfico, la representación de cómo el cuidado cotidiano a las personas en sufrimiento psíquico repercute en la vida del familiar cuidador. **Consideraciones finales:** se comprendió que el cuidado a las personas en sufrimiento psíquico se ha realizado predominantemente por las mujeres negras, reflejando las desigualdades de género y raza; implica sentimientos y expectativas ambivalentes; niveles diferenciados de sobrecarga y necesidad de apoyo social y del Estado.

**Palabras clave:** Apoyo social. Atención a la Salud Mental. Cuidadores. Desinstitucionalización. Familia.

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