



The family in the context of mental health and the challenges faced with psychiatric readmissions of the sick family member

A família no contexto da saúde mental e os desafios frente às reinternações psiquiátricas do familiar adoecido

La familia en el contexto de la salud mental y los retos que plantean los reingresos psiquiátricos del familiar enfermo

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Objective: to understand how families of people with mental disorders perceive their family member's frequent hospitalizations. **Methods:** qualitative study carried out in 2022, with data referring to 2019 and based on symbolic interactionism. Family members of people with more than two hospitalizations in a psychiatric hospital in the interior of the state of São Paulo, Brazil, were interviewed. The interviews were subjected to content analysis using the Iramuteq software. **Results:** 18 family members and 18 patients participated, and, from the thematic analysis, six classes of words were created that describe the family's coexistence with the person with a mental disorder and the frequent hospitalizations in two different moments called: *critical daily life (Non-adherence of the patient to the medication and psychosocial treatment; Understanding of the patient's non-adherence to medication; Vulnerability in the practice of care)* and *stable daily life (Family and the use of social and health equipment; The family and the search for hospitalization; The family: mental illness and other comorbidities)*. This coexistence is marked by overload of care, disbelief in the improvement of the ill family member and the care they receive from the health system. **Conclusion:** families face several difficulties in the care provided to family members with mental disorders, notably medication adherence and ambiguity of feelings regulating relationships; Therefore, they assume all care if they feel weakened by the lack of support from the Psychosocial Care Network, other services in the intersectoral network and health professionals.

Descriptors: Hospitalization; Mental disorders; Family health.

Objetivo: compreender como as famílias de portadores de transtornos mentais percebem as internações frequentes de seu familiar. **Método:** estudo qualitativo realizado em 2022, com dados referentes a 2019 e fundamentado no interacionismo simbólico. Entrevistou-se familiares de pessoas com mais de duas internações em um hospital psiquiátrico do interior paulista. As entrevistas foram submetidas a análise de conteúdo com auxílio do *software* Iramuteq. **Resultados:** participaram 18 familiares e 18 pacientes, e, da análise temática, resultaram seis classes de palavras que descrevem a convivência da família com o portador de transtorno mental e as frequentes internações em dois momentos distintos denominados: *cotidiano crítico (Não adesão do paciente ao tratamento medicamentoso e psicossocial; Entendimento da não adesão do paciente a medicação; A vulnerabilidade na prática do cuidado)* e *cotidiano estável (Família e o uso dos equipamentos sociais e de saúde; A família e a busca pelo recurso da internação; A família: doença mental e outras comorbidades)*. Esta convivência é marcada pela sobrecarga de cuidados, descrença na melhora do familiar doente e do atendimento que ele recebe do sistema de saúde. **Conclusão:** as famílias enfrentam diversas dificuldades no cuidado prestado ao familiar com transtorno mental, notadamente a adesão medicamentosa e a ambiguidade de sentimentos regulam as relações; Portanto, assumem todo cuidado se sentem fragilizadas pela falta de suporte da Rede de Atenção Psicossocial, dos demais serviços da rede intersectorial e dos profissionais de saúde.

Descritores: Hospitalização; Transtornos mentais; Saúde da família.

Objetivo: comprender cómo las familias de personas con trastornos mentales perciben las hospitalizaciones frecuentes de su pariente. **Método:** estudio cualitativo realizado en 2022, con datos referentes a 2019 y basado en el interaccionismo simbólico. Fueron entrevistados familiares de personas con más de dos internaciones en un hospital psiquiátrico del interior de São Paulo. Las entrevistas fueron sometidas a análisis de contenido utilizando el *software* Iramuteq. **Resultados:** participaron 18 familiares y 18 pacientes y el análisis temático resultó en seis clases de palabras que describen la convivencia de la familia con la persona con trastorno mental y las frecuentes hospitalizaciones en dos momentos distintos denominados: *cotidiano crítico (No adherencia del paciente a la medicación y al tratamiento psicossocial; Comprensión de la no adherencia del paciente a la medicación; Vulnerabilidad en la práctica del cuidado)* y *cotidiano estable (La familia y el uso de los dispositivos sociales y de salud; La familia y la búsqueda de recursos de hospitalización; La familia: enfermedad mental y otras comorbilidades)*. Esta convivencia está marcada por la sobrecarga de cuidados, la incredulidad en la mejoría del familiar enfermo y la atención que reciben del sistema sanitario. **Conclusión:** las familias se enfrentan a diversas dificultades en el cuidado de un familiar con trastorno mental, destacando la adherencia a la medicación y la ambigüedad de sentimientos que regulan las relaciones; por ello, asumen todos los cuidados si se sienten debilitadas por la falta de apoyo de la Red de Atención Psicossocial, de otros servicios de la red intersectorial y de los profesionales sanitarios.

Descriptores: Hospitalización; Trastornos mentales; Salud de la familia.

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INTRODUCTION

In Brazil, the organization of psychiatric care was based on the French model and, in this country too, the family was banned from participating in the treatment of the mentally ill. The family has historically been excluded from the treatment provided to people with mental disorders, as psychiatric hospitals were built far from large city centers, which made it difficult for family members to access these institutions.

Also, the family of a mentally ill person was considered the cause of the disease and the member who fell ill was its scapegoat, the one who carried all the ills of the family nucleus and should be removed from those considered responsible for their illness. In this way, the family was left with the role of referring their family member to the psychiatric institution, so that educated technicians could take charge of the treatment and cure¹.

This family distance was present in the subject-madness relationship until approximately the 1980s¹, when new possibilities emerged regarding the role and relationship of the family with the person with a mental disorder. These perspectives occur in the face of new policies in the area of mental health, a consequence of the psychiatric reform movement that is taking place in Brazil, and guides the transition of treatment spaces from the coercive and restrictive institution to community health care services.

The assistance offered in mental health today is the result of many social and political transformations, which resulted in the deinstitutionalization of the mentally ill and the creation of a community-based psychosocial care network²⁻⁴.

However, the absence of an extra-hospital network that accommodates the demand and guarantees quality and efficient care has been identified as a factor for the frequent hospitalizations of people diagnosed with serious disorders, in situations of social vulnerability, which exposes the difficulty in guaranteeing the continuity of care for the subject inserted in the social and family environment⁵⁻⁶.

Frequent hospitalizations can be disruptive for the sick person and their families, and place a strain on limited healthcare resources⁷. Most studies adopt a quantitative approach⁹ and few include the family as a factor to be investigated. Works that include the family generally describe it as overwhelmed, a closed system, with dysfunctions in different aspects of family life and high expressed emotion⁹⁻¹⁰. Therefore, this research aimed to understand how families of people with mental disorders perceive their family member's frequent hospitalizations.

METHODS

Qualitative study based on the theoretical framework of symbolic interactionism, which values the meaning that human beings attribute to their experiences in interactions with the world. In this interaction, it is understood that actions are based on the meaning that things have for the person; thus, the meaning of things derives from the person's social interaction with others, and these meanings can be altered by the interpretative process that the person adopts when dealing with the things or situations in which they find themselves¹¹.

The study participants are family members of people with mental disorders with a history of two or more hospitalizations in 2019, selected through a survey of hospitalizations that occurred in a psychiatric hospital in the interior of the state of São Paulo, and identified patients who met the criteria of having two or more hospitalizations during the year. After identifying eligible patients and excluding deaths, there were several attempts of contact, via telephone.

Data collection was carried out from May to October 2022. At the beginning of the interview, the participant was invited to answer a questionnaire on their personal characteristics (sex, age, education, family relationship and whether they lived with the family member), of the family (internal structure, income) and information about the sick family member (age, sex, diagnosis and education). The family member then participated in an in-depth interview, which consisted of a triggering question inviting them to reflect on the sick family member's frequent hospitalizations.

The data collection instrument was constructed and validated after carrying out a pilot test applied to three volunteers, consisting of a sociodemographic questionnaire and an individual interview with family members using the in-depth interview technique, which included a triggering question: "(Name of the patient) *had several hospitalizations in 2019. How do you perceive these frequent hospital readmissions?*"

The interviews took place in different locations (home, town square, cafeteria) according to the participant's availability. A researcher conducted all contacts and conducted the interviews, which were recorded and lasted from 30 minutes to up to an hour.

The data obtained from the in-depth interviews were organized into a single text after reading, as well as placed in the Iramuteq software. This tool extracts the frequency of words by calculating their regularity and classifying them into different contexts or different classes, which are articulated. A researcher searched for all excerpts from the interviews included in each category and then, together with another researcher, carefully read each category, wrote

about each one, chose a term to name it and built an understanding of the meaning of living with a family member with a serious mental illness and frequent hospitalizations.

The project was submitted to the Ethics Committee of the Escola de Enfermagem de Ribeirão Preto – USP, under CAAE protocol: 54180521.0.0000.5393 and approval under Opinion No. 5,386,774. It also had the consent and authorization of the hospital as a co-participating institution. All participating family members signed and received a copy of the Free and Informed Consent Form (FICF).

RESULTS

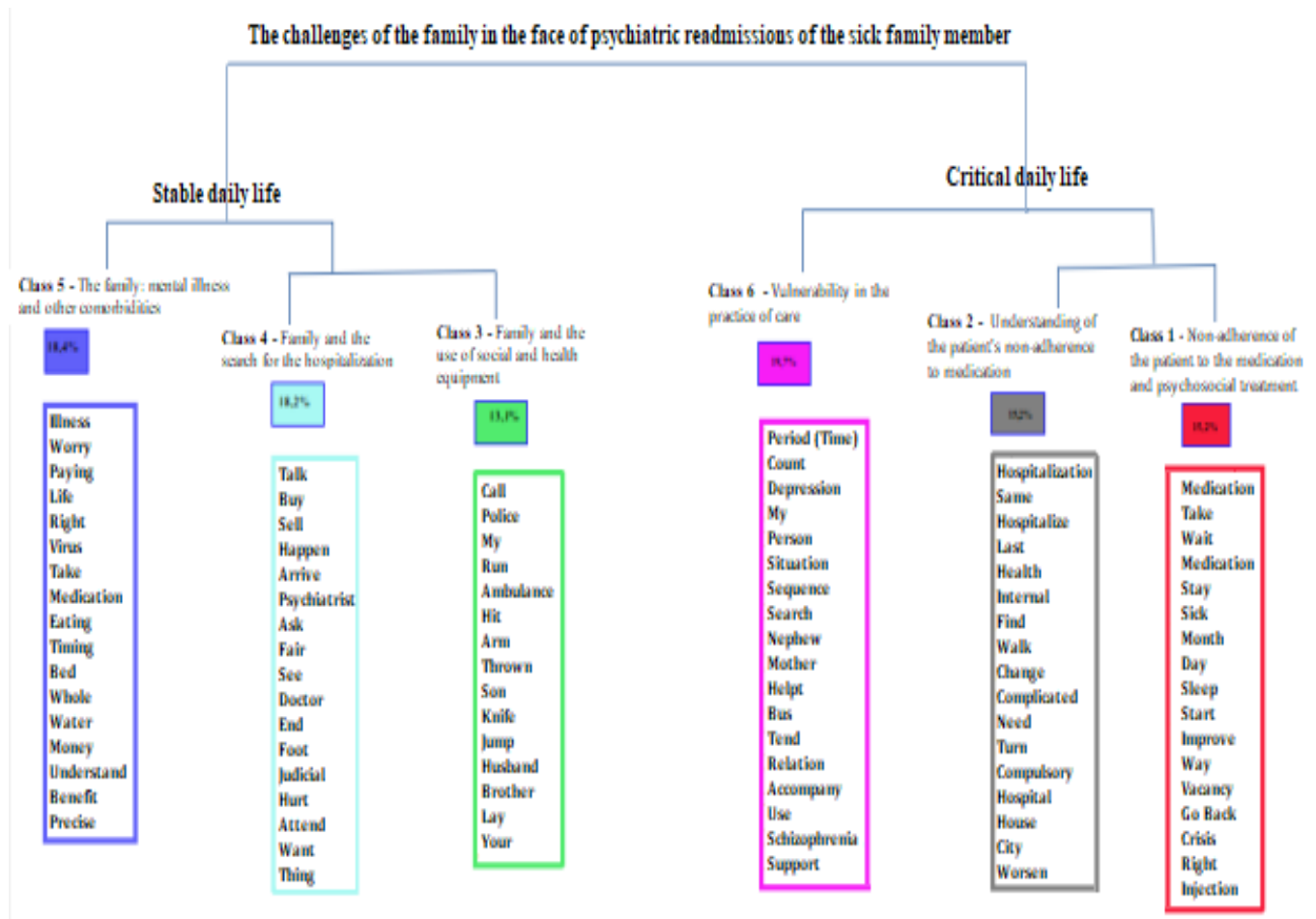
50 patients were identified, of which four died. In 26 cases, there was no response. In one case, the family member did not agree to participate in the research, citing unavailability of time. And another situation, the family member did not accept due to moving to another city.

18 family members of 18 patients with frequent hospitalizations participated, 16 of whom were female, with an average age of 45 years, with a minimum of 30 years and a maximum of 82 years. The degree of kinship of these family members with the sick person was: eight mothers, six sisters, two children, a father and an aunt. Sixteen family members lived with the patients in the same house. Nine family members reported that only one person contributed to the family income, which was above two minimum wages, seven received up to two minimum wages, eight reported receiving up to one minimum wage. Regarding care time, the average number of years dedicated to patients was 13.6 years and the average daily time was 11.2 hours a day.

Of the total 18 sick people, 10 were male, average age 38 years, with a minimum of 22 years and a maximum of 60 years. As for education, 07 had incomplete primary education; 04 complete primary education; 06 incomplete secondary education and 01 complete secondary education. The most frequent diagnoses were in the groups: F20-F29 (Schizophrenia, schizotypal disorders and delusional disorders, with 44.4%); F10-F19 (Substance use disorders, with 38.9%); F00-F09 (Organic mental disorders, including symptomatic ones, with 5.55%); F60-F69 (Adult personality and behavior disorders, with 5.55%) and F30-F39 (Mood/affective disorders, with 5.55%).

The organization of the *corpus* of interviews resulted in six classes of words. These classes were divided into two large blocks, one formed by categories or classes 1 and 2; both linked to class 6, this block describes the hospitalization routine. The other block is formed by classes 3 and 4; both linked to class 5, which involves the routine of staying at home after hospitalization; as can be seen in Figure 1.

Figure 1. Dendrogram regarding the family's challenges in the face of psychiatric readmissions of the sick family member, Ribeirão Preto/SP - Brazil, 2022.



First Block – Critical daily life

The period of critical daily life describes the family's journey in search of hospitalization, the pre-hospitalization of the sick family member, SAMU trajectory, Emergency Care Units (*Unidade de Pronto Atendimento - UPA*) and Hospitalization. This period can last days or weeks, and the family caregiver becomes very tired. Furthermore, staying in UPAs does not always result in hospitalization.

Class 1: Non-adherence of the patient to the medication and psychosocial treatment

Non-adherence to the proposed medication and psychosocial treatment has multiple causes, including characteristics of the patient themselves, often refusing medication because they do not accept that they are sick, resulting in the interruption of treatment:

[...] but our biggest challenge is to make him return to CAPS and make sure he takes the right medication; We can't do it and he always gets aggressive. If we try to make him take it by force, he won't take it. (E-09)

Combined with the patient's own difficulties, another factor that contributes to compromising adherence is the difficulty in supporting families who often find themselves alone and devoid of support. The family feels powerless, as they do not have their own mechanisms to make the patient maintain treatment:

[...] in this case, he didn't want to take the medication, he didn't want to be monitored at CAPS; he wanted to roam around all night instead of sleeping, so it's a very difficult situation as an only child to witness this whole situation. (E-02)

Class 2: Understanding of the patient's non-adherence to medication

Some patients, even if they are willing to undergo treatment, due to family fragility and social vulnerability, remain exposed to the possibility of consuming psychoactive substances and alcohol, which contributes to not achieving satisfactory treatment results. From the families' reports, it was found that the use and abuse of psychoactive substances, including alcohol and other drugs, is one of the factors that contributes to interruption and consequently non-adherence to treatment:

I believe that her readmissions are due to lack of treatment and because she is a drug user, right. So, it becomes difficult, because at the same time that she wants the treatment, she stops it and goes back to drugs. (E-04)

Added to this, the disarticulation of the mental health network and long periods for scheduling returns is another factor that compromises the maintenance of treatment, contributing to relapses and worsening of the health condition, with decompensation of the clinical condition, involving imminent risks of self and external aggression.

If she scratches herself, she gets hurt, so that's why we constantly hospitalize her, she's completely dependent on me. (E-17)

These reasons favor, in many cases, an increase in the demand for compulsory hospitalization requests from the family, who are not aware of the problem experienced in their daily routine:

He was admitted there seven times, but on other occasions he was admitted more times, but I don't remember how many. The last one had to be compulsory hospitalization because I was no longer able to cope. (E-11)

In addition to this context, the situation is often aggravated when caregivers are elderly (father, mother, siblings and others), constituting a difficult factor for adherence to treatment:

The streets make people worse than they already were, without treatment, without anything, that makes things complicated, right? It was complicated for us here, because my father was elderly, I had to, sometimes he was violent and wanted to attack my father, my mother couldn't really care for him either. (E-18)

Class 6: Vulnerability in the practice of care

Caring for psychiatric patients in the family becomes an arduous task for the caregiver, and they often have to share this activity with other people in the family group, who may also be ill. In addition to the burden arising from the daily practice of care provided, the family is exposed to deprivation, with harm to their social relationships, physical and mental well-being:

But it's not, I think that only the person who lives and who has lived with a patient who has a problem like schizophrenia, depression, knows how difficult it is to fight, it's like a prison. (E-01)

Other aggravating factors in the family context, such as the use of psychoactive substances, and often the presence of other mentally ill people among family members is another important factor that compromises and contributes to the fragility of care for the patient and for themselves:

And I'm very sad, because she doesn't want help. Her eldest son is also discouraged, you know, it hurts me a lot. I have depression, you know, when she doesn't use drugs or alcohol, she's a very good person. (E-13)

Through the reports contained in classes 1, 2 and 6, it is possible to observe that families have difficulties in providing care to the patient, resulting from the lack of adherence to treatment, which can alter and disorganize the dynamics of the family nucleus.

Furthermore, care is provided and centralized by a single caregiver, sometimes elderly, which makes it an exhausting activity, both physically, emotionally and economically. Such demands create significant levels of emotional overload for family members, affecting their quality of life, which makes them vulnerable to physical and, mainly, psychological illnesses.

Second block – Stable daily life

Stable daily life concerns the time that the sick person can adhere to treatment and stay at home. This period appears to be short, ranging from days to weeks. After this period, the patients becomes non-adherent to treatment and stops staying at home, going out on the street.

Class 3: Family and the use of social and health equipment

Patients with mental disorders, in most cases, remain susceptible to several risk factors, which are associated with difficulty adhering to treatment, which can lead to a worsening of their health condition and, even, social fragility.

Families also have difficulty providing adequate care to the patient, as they have to share the same care with other members of the family group, who are also ill, and without the collaboration of a community support and protection network:

[...] even more so because it's not just her; She has my other sister too, but thank God she has her husband who now takes care of her, but it was me and there is also my nephew who also has an issue, I was the one who took care of her. (E-06)

In situations involving crises in patients with decompensation of their clinical condition, the family has great difficulty in managing and staying with the patient in the Emergency Care Unit, due to the need to reduce the risks arising from the acute crisis, waiting for a place for hospitalization with low support from the local team:

[...] and I only managed to admit him like that, I had to stay all day because they don't take responsibility. During the time I was at the UPA, when I only left a few times, he ran away, he ran practically naked down the avenue, he lay down on the ground, he was tied up. (E-01)

It is observed, therefore, that when there is adequate guidance from the team and family support, bonds are created and strengthened, with a greater possibility of adherence to treatment.

In some cases, the family still resorts to support from the police and SAMU to guarantee their protection and that of the patient when they feel threatened by episodes involving aggression during crisis episodes.

Thus, in many cases, hospitalization is seen by the family as a resource as a protective measure in the face of exposure to various risks, due to the difficulty in managing the patient resulting from their lack of adherence to treatment.

Class 4: The family and the search for hospitalization

The family has difficulty guiding and maintaining daily care for the patient, due to difficulty adhering to treatment and lack of support from both the family and the healthcare teams. And, as the symptoms of the disease worsen, difficulties in managing it within the family context increase, which leads the family to resort to hospitalization.

From the families' perspective regarding the patient's hospitalizations, the vast majority understand that the longer the stay during a hospitalization, the better their adherence to treatment after discharge. With this view, some families turn to the judiciary system to request compulsory hospitalization, often believing that the patient's length of stay in the hospital in this type of hospitalization will also be longer, when compared to normal hospitalization.

[...] because, if he is there for a week or fifteen days and he is well, he already wants to leave, now in fairness he will stay a little longer. (E-16)

In the view of the vast majority of families, the hospital is the only or main resource for patient treatment given the difficulty of management in the family context, not considering other mental health equipment for support and assistance to the patient.

Class 5: The family: mental illness and other comorbidities

The conditions resulting from the consequences of mental illness and other types of illnesses are numerous, which affect different areas of the patient's life and their entire family. In this study, it was observed that, in some situations, care with treatment is made difficult by the association of other diseases/conditions such as the use of psychoactive drugs and the patient living with the HIV virus or Acquired Immunodeficiency Syndrome (AIDS).

According to reports from some family members of patients with mental disorders, they are more exposed to violence, thus violence increases vulnerability to HIV infection.

Talking about the topic of HIV/AIDS is still a prejudice for the family. It is also clear in one of the cases that the social isolation experienced by the family in the face of the patient's HIV status generates a feeling of not knowing how and with whom to talk about this disease.

Not to mention it like that, right, the HIV virus, so that everyone doesn't know, everyone talks, I get scared and then I talk about this disease that he's got. (E-16)

In this way, it is also clear that the patient's lack of adherence to treatment affects their health, as well as that of their family, which compromises the dynamics of the entire family group..

I could continue with the treatment so he can have a life, because what I am experiencing with my son to this day is not life, it is survival, I am surviving. (E-01)

The reports contained in classes 3, 4 and 5 reflect the daily lives of family members marked by many nuances and surrounded by weaknesses, vulnerabilities and difficulties. These families are mostly made up of women and elderly people, who assume direct responsibility for the patient's daily care, and in some cases also have other comorbidities.

The care offered to patients by families is carried out alone, with few resources and a very weak support network. The reports deal with the relationship between caregiver and patient. The psychiatric hospital is seen as the only possibility of therapeutic resource for patient treatment.

DISCUSSION

In the individual factors of frequent hospitalization, family factors are repeated in the two blocks of categories, called in this study stable daily life and critical daily life. Regarding the total number of readmissions in the period from 2019 to 2022, the average was 3.11 per patient.

Stable daily life refers to the time that the sick person can adhere to treatment and stay at home. This period appears to be short, varying from days to weeks, after which non-adherence to treatment occurs and people stop staying at home and go out.

And a new moment begins in the family, the critical daily life, which points to the pre-hospitalization of the sick family member, SAMU, UPA and Hospitalization trajectory. This period can last weeks or days and the family caregiver becomes very tired.

The family member, when exercising their role as caregiver in daily practice with patients with mental disorders, encounters several obstacles, with the majority of cases arising from the very fragility of the structure of their family nucleus, with other people also suffering from illness, in addition to of a precarious support network for their surroundings, which involves emotional, economic, physical, psychological, as well as relational factors, manifesting itself in the form of stress, anxiety, depressed mood, among others¹¹.

The activities carried out by the caregiver are heavy, and include everything from supervising treatment, administering and monitoring medication and monitoring appointments at health services, to those relating to the maintenance and supervision of daily life care, involving basic routines, such as tasks linked to hygiene and food issues. This care is generally centered on a single caregiver, which contributes to a heavier burden. Such demands impact the routine of the family nucleus, directly affecting the main caregiver, compromising their quality of life, as their physical and mental health is compromised, in addition to the economic burden resulting from this practice of care.

The average care time and the daily burden (13.6 years/11.2 hours, respectively) are important factors and indicate the overload of these families and their certain disbelief in the possibility of improvement for the patient, sometimes the ill family member also argues with their mother that there is no point in taking any more care. It's suffering at home. Also, the burden on the caregiver, who in some cases worked on a paid basis, has difficulty reconciling with the care to be provided, generally having to choose between one situation or another.

One study¹¹ considers that caregivers face many difficulties in this task and end up putting their own lives aside and, thus, end up getting sick, and only then do they realize that they need to take care of themselves.

The family's burden when faced with management difficulties is increased by the association of other diseases and conditions, such as the use of psychoactive drugs and alcohol, and other comorbidities, such as the patient living with the HIV virus.

The presence of mentally ill people among family members weakens care for the patient and for themselves. The worsening of the patient's disease symptoms due to their low adherence to treatment increases the caregiver's difficulties, with a heavy burden, in addition to contributing to new relapses and increased hospitalizations^{10,11}.

In moments of crisis, the family faces several difficulties in admitting the patient, moments experienced by recurring stress due to not having support from the team when waiting for a place to be admitted in pre-hospital care. The burden suffered by the caregiver shows the need for family caregivers to work together with a network of health and psychosocial services. That is, that health and psychosocial care services include families in care planning¹¹.

In the same sense, human suffering occurs to the extent that the individual loses their freedom or part of it, and the health professional, by accepting this suffering, can favor its reframing, which helps the caregiver to envision alternative ways of dealing with daily demands and feel validated as a person¹².

In the family environment, it has been demonstrated that patients with mental illness and difficulty adhering to treatment favor ruptures within the family nucleus, triggering stressful situations among family caregivers. In the same sense, another research⁹ pointed out that, after the diagnosis of the disease, the functional capacity and independence of the sick individual is compromised and family relationships, in particular, responsibilities and roles are visibly altered and, even if the patient and family members adapt to the new reality, changes occur in relationships and family dynamics, whereby work overload, difficult coexistence with the patient and reduced time for self-care favor the caregiver's illness, especially when there is great dependence of the patient⁷.

As a result, the caregiver is unable to care for the individual with mental illness, often generating a tense and conflicting environment with risks of self and external aggression, especially in moments of crisis for the patient. In a study on the family's feelings regarding mental disorders, participants reported that, faced with the diagnosis, they experienced feelings of impotence, weakness and guilt, being able to deny the occurrence of the disorder, feeling frustrated in relation to their expectations regarding development. of the patient and who did not know how to help¹.

The same feeling is frequently seen in some situations involving the patient, related to the concomitant use of medication with psychoactive substances (PAS) that occurs when living on the street for several days. The use of SPA and alcohol and, often, the presence of other mentally ill people among family members is another factor that contributes to disarray among family members. Also, in some circumstances, there is difficulty for the caregiver in dealing with daily life, including caring for the patient's minor children.

Prejudice and stigma in relation to mentally ill people in society was observed, impacting the entire family nucleus, which is corroborated in research that shows that it is constant in the daily life of the caregiver and that society's lack of understanding leads to greater social exclusion both from the patient and family members, which leads them to isolate themselves, justifying this isolation as a way of protecting their sick family member from mockery and mistreatment⁷.

In circumstances of a patient crisis, the family situation is aggravated by disrupting the balance of the entire group, sometimes having to resort to police intervention. The symptoms of mental illness during times of crisis generate a situation of discomfort and stress for the family, in the relationship with the people who live around them, especially with the close neighbors, with possibilities of conflicts in daily coexistence.

Similar cases happen to some patients who, despite having family ties, in crisis situations worsened by the use of SPA, the family is unable to maintain control of the situation and, in some cases, has to resort to police support.

There are reports from the family regarding the difficulty in keeping the patient at home, as they spend most of their time on the streets. Thus, the family member is placed in a situation of neglect and threatened with physical violence by the local community, who believe that the patient is "thrown" on the street.

Sometimes, the option for hospitalization is used by the family as a resource or protective measure, given the exposure of various risks due to the patient's difficulty in adhering to treatment, and, in some cases, the family has to go to court to request of hospitalization in compulsory mode.

The study also showed that, in some cases, health equipment such as CAPS is also seen by a number of family caregivers as strengthening the bond between the family and the patient. The family feels strengthened when they have good support from the healthcare team. In the same sense, during the stay of patients and their caregivers in a hospital during the day, there was a decrease in the feeling of helplessness as they felt protected by the health team's guidelines¹³.

In comparison to another research¹⁴ carried out in two psychiatric inpatient units of a General Hospital, with the participation of 210 people, an age range was observed ranging from 18 to 80 years old, with an average age of 41.5 years old and a predominant age group between 30 and 49 years old, male, data similar to the data found in the study presented here. Regarding medical diagnoses of readmission, the results of this study indicate that there was an increase in mental and behavioral disorders due to the use of alcohol and drugs. A previous study¹⁶ found a rate of 12% of this diagnosis while our study showed a rate of 38%.

Regarding the prevalent diagnoses at discharge, 26% were recorded for schizophrenic disorders, 22% for bipolar affective disorders and 10% for mental and behavioral disorders, due to the use of alcohol and drugs, which was corresponding in these readmissions, which were similar to another investigation¹⁴ in a psychiatric unit of a General Hospital, with information from medical records.

Other work carried out with family caregivers showed that participants over 50 years old reached 80%, with 56% being in the age group >60 years old, ranging from 35 years old to over 60 years old¹⁷.

In relation to the income of the families participating in this study, a low-income profile stands out, similar to another work¹⁷ that revolved around three minimum wages for 60% of the participating caregivers.

The predominance of women responsible for caring for the sick patient verified in this study are similar to those found in other research^{9,18,19} and reveal the tendency of women to assume this role in different contexts. These women have dedicated themselves to care for 13 years on average, and spend 11 hours of their day on care.

Composing the profile of caregivers, the vast majority are women and elderly individuals, who assume direct responsibility for the daily care of the patient and, in some cases, with fragile health conditions. The care provided is often carried out alone, with few resources and a weakened support network.

The family's coexistence with a relative with a serious mental disorder and frequent hospitalizations is marked by an overload of care and a certain disbelief in the possibility of improvement for both the sick family member and the care he or she receives from the health system. There is disbelief in psychotropic drugs and community-based services such as CAPS are barely known and, when they are, they are generally little used.

These aspects of coexistence have already been described in quantitative research that describes disorganized and dysfunctional families, who only know the hospital as an alternative for their sick family member^{22,23}. However, this study highlighted the drama and

dysfunctionality of the family, not made visible by the health system, and not seen as a priority group. These people's relationship with the health system is painful, overloaded and lonely²³.

The burden of family care has been known since the 1950s, but to date little has been done to alleviate this phenomenon, which is closely related to frequent hospitalizations^{10,24} and the high level of emotion expressed in the family environment, mainly criticism and high involvement^{10,21}.

The family member, when exercising their role as caregiver in their daily practice with the person with a mental disorder, encounters several obstacles, such as: the presence of other people who are also ill and a precarious support network around them.

In a survey carried out in Greece comparing families of people in the first episode of psychosis and people with a chronic mental disorder, lower scores were found in the aspects of family cohesion and flexibility for the group of families of chronic patients. On the other hand, caregivers of chronic patients scored significantly higher in criticism, reporting greater burden, psychological problems and suffering compared to the group of families of patients with a first psychotic episode²².

The difficulty in adhering to psychosocial and medication treatment, in itself, can lead to readmission, according to families. Continuity of care is an essential element to guarantee good quality care and keep people with mental illness in the community. Improving continuity of contact with care providers may have an important role to play in the overall process of improving care for this group of patients, which deserves greater attention²³⁻²⁴.

CONCLUSION

The analysis of the reports highlighted the difficulties families face in caring for people with mental disorders, whereby the ambiguity of feelings regulate relationships in the family context. The limits and challenges of care, the family's not knowing how to act in the face of the intensity of patients' feelings and unpredictable behaviors, are actually aggravated by low adherence to treatment and, in some cases, exacerbated by the association with other types of comorbidities, especially those related to the use of psychoactive substances. This situation contributes to the weakening of family and social ties. The family often perceives hospitalization as the only alternative due to a lack of support and not knowing how to manage the situation.

It was possible to observe that the roles that the patient plays in the family and the family, in relation to him, take on very peculiar forms, which depend on a supportive network.

Therefore, it is necessary that the approach to patients with mental disorders includes interventions with the family and the social environment and considers continuity of care.

The study also showed that it is necessary for the family to participate in the focus of discussions and practices in their territory through the Psychosocial Care Network (PSCN), expanding links and practices that can produce spaces for coexistence, listening, help and exchanges between families and mental health service teams.

Among the limitations of the research are: difficulty for family caregivers in knowing or remembering the patient's history in their journey through health services, as many have experienced several hospitalizations throughout their lives; and sample size. Despite this, this research qualitatively shows the dilemmas of a family with an individual in mental distress, which can sensitize health services to this reality.

The development of more research covering this topic is necessary, given the scarcity of investigations involving the challenges of families in the context of frequent readmissions of sick family members.

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