THE FAMILY CHALLENGE IN FOR PEOPLE CARE SUFFERING FROM MENTAL DISORDER

O DESAFIO FAMILIAR NO CUIDADO ÀS PESSOAS ACOMETIDAS POR TRANSTORNO MENTAL

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ABSTRACT

Objective: to identify the challenges found by families living with people suffering from mental disorder. Method: it is descriptive exploratory research, conducted in 2013. The data collection was carried out through interviews with 19 relatives of CAPS II patients with schizophrenia disorders, bipolar disorder and depression in a city in the West of Santa Catarina/SC. The interpretation of information occurred from the thematic content analysis. The study had a favorable opinion of the project by the Research Ethics Committee, under Number 159,215/2012. Results: from the analysis four themes emerged: The emotional burden of the family; Impact that mental illness causes in caregivers; Family`s actions for care during crisis; and Family difficulties to handle the disorder. Conclusion: it is necessary to include the family in the treatment and the importance of looking for the family. Descriptors: Mental Health; Family; Mental Health Community Services.

RESUMO

Objetivo: identificar os desafios encontrados pelos familiares que convivem com pessoas acometidas por transtorno mental. Método: pesquisa descritiva-exploratória, realizada em 2013. A coleta de dados se deu por meio de entrevista com 19 familiares de usuários de um CAPS II com diagnóstico de transtornos de esquizofrenia, transtorno afetivo bipolar e depressão em um município do Oeste de Santa Catarina/SC. A interpretação das informações ocorreu a partir da análise de conteúdo temático. O estudo teve o Parecer favorável do projeto pelo Comitê de Ética em Pesquisa, sob nº 159.215/2012. Resultados: na análise, emergiram quatro temas: Sobrecarga emocional dos familiares; Impacto que o transtorno mental causa nos cuidadores; Ações do familiar para o cuidado na crise; e Dificuldades dos familiares com manejo do transtorno. Conclusão: há necessidade da inclusão da família no tratamento e à importância de se olhar para a família. Descritores: Saúde Mental; Família; Serviços Comunitários de Saúde Mental.
INTRODUCTION

The family as a group plays a central role in people’s lives since it is within the family that the individuals are grown, cared, fed, and acquire their conception, developing their beliefs and values about the world and they are prepared to face life. Thus, when individuals has a mental disorder, regardless of their stage of development, it is important family support in their treatment.

From this perspective, the family is the first network that references and complete the protection and socialization of individuals. Regardless of the multiple forms and shapes the family takes, the learning of affections and social relationships begging in it.¹

The Brazilian Psychiatric Reform brought contributions on how to design and realize the family in the context of mental health care. Before its implementation, the treatment available to people with mental disorders was based on isolation and exclusion, where subjects had no contact with their family and society. There were no incentives to mobilize families as key participants in care since the individual was seen isolated.²⁻³

From 1970 in Brazil, the need to rethink the mental health practices became evident for inhuman conditions exposed of treatment to people with mental disorders, away from society and their families.²⁻³ Thus, with the Psychiatric Reform, there were changes in understanding about the concept of mental health and the treatment and approach of people with expressions of suffering. One of the important consequences of the Psychiatric Reform was the creation of new community-based treatment devices and the involvement of the family, with the role of hosting, taking care and preparing for social life.⁴

The Psychiatric Reform advocates the process of deinstitutionalization with subsequent replacement of asylums by new hosting and treatment devices. As examples of these devices there are basic health units, the Psychosocial Care Centers (CAPS), the emergency units, Therapeutic Residential Services, the hosting units, the community centers and psychiatric beds in general hospitals. All of them are forms of treatment that break with the paradigms of the asylum model.⁵

Considering the reformulation of psychiatric care, the family unit plays an important role in the care and rehabilitation of individuals suffering from mental disorder. Therefore, it is necessary to know the family and how its members respond and live with psychological distress.

From the understanding that the family is this social group that will have great responsibility for the formation of individuals, it is understood that in the same way that affects and/or influence the subject, it is also influenced and affected by him. These facts justified the family and relatives with mental disorders be inserted in studies, considering that the individual with disorder is a social human being. The family is one of the organizers of human life, being relevant the research on how mental disorder can affect family life.⁶

Given the above, it was defined as the research question: What are the challenges faced by families living with people suffering from mental disorder?

It is considered important to address the topic of mental disorders and their challenges for the family because it enables to reflect the academic community and the health professionals who work with this population and may contribute to the development of prevention and health promotion strategies for these families.

This study aims to identify the challenges faced by families living with people suffering from mental disorder.

METHOD

This is an exploratory and descriptive research with qualitative approach. It was held in 2013 in the CAPS II, in a city in the West of Santa Catarina. At the time of the research, approximately 5,600 users were registered. Of them, 3,000 were active, that is they participated in activities as individual plan. Out of these active users, there were 76 in the intensive treatment modality: 48 women and 28 men. From these 76 members, 25 had schizophrenia, 15 had other psychotic disorders, 05 were diagnosed with depression and 07 had bipolar affective disorder.

The following inclusion criteria for the study participants were established: be older than 18 years old, be a family caregiver of the user with mental disorders being treated in the intensive care and have the capacity of oral verbalization to answer the interview questions.

There were 19 families interviewed. Initially, it was sought to information concerning the characterization of the participants, in order to record data such as gender, age, education, marital status,
relationship, affected type of disorder and disease development time. The next step consisted of semi-structured questions, formulated based on the research objectives.

The study began after the favorable opinion of the Ethics Committee of the University of Santa Catarina State (UDESC), under number 159,215/2012. To ensure the anonymity of respondents, they were identified by the letter “F” (family) and ordinal numbers (F1, F2, F3) as the order of the interviews.

For the interpretation of information all the steps of a thematic analysis were followed: data ordering, classification of data and final analysis. The ordering of data was carried out reading and rereading the material and the initial organization of reports, aiming to have an overview of what family members said and realize their particularities. The classification of data allowed to grasp the relevance between the lines of each family, classifying the central ideas and organizing them into categories. The final analysis was to elaborate an interpretative summary of the four themes that emerged: The emotional burden on family members; The impact that mental illness causes in caregivers; Families’ actions for care during the crisis; and Difficulties of families in caring for the person with mental disorder.

### RESULTS AND DISCUSSION

The characterization of the participants’ profiles contributed to a better understanding of representational structures of thought. The data showed that in the context of the 19 family respondents, there was a significant predominance of females with 63% of respondents. In age, 42% of family caregivers were from 41 to 60 years old; 37% aged from 21 to 40 year old; 16% from 61 to 80 years old and 5% over 80 years old.

The predominance of women providing care to people with mental disorders is consistent with a study conducted in Ribeirão Preto, São Paulo, with discharged patients’ caregivers of a psychiatric hospital. This may be explained by the historical context of the development of humanity in the care home and people with higher levels of addiction, such as children, elderly and sick people were functions aimed primarily at women.

Regarding the diagnosis time of mental disorder, it was observed that 47% of users had the disease less than 15 years; 22% between 16 and 35 years and 31% over 36 years. As for the time undergoing treatment at the CAPS II, it was observed that 53% of users attended the service less than 4 years and 47% were monitoring since CAPS began its operations in the city in 2001.

It is noteworthy that the CAPS were created from the Ordinance/GM, Number 336 of 2002 of the Ministry of Health. This ordinance meets the current Federal Law on Mental Health, Law 10,216 of 2001. This legal device redirected the Psychiatric Care Model in Brazil, by providing for the rights of people with mental disorder with having access to the best treatment, be treated with humanity and respect, be protected from abuse and exploitation, have guaranteed confidentiality, receive information, have access to the means of communication, be dealt with by less intrusive means possible and preferably in community service.

Next, the themes emerged from interviews with family discussed with literature will be explain.

- **The emotional burden on Family members**

Through the speeches of family caregivers, it was identified how much can be exhausting living with the mental patients. This care involves understanding and dealing with unconventional behaviors such as speaking alone, social retraction, mood swings, among others, ending up waking mixed feelings.

Thus, the interaction with family members of mental illness people was mentioned by respondents as a difficult and complicated task within the family:

> “It's complicated, I felt sorry because he’s like a child, is aggressive.” (F18)

> I do not feel good, because I cannot do anything to improve it. (F09)

The illness is an unforeseen event that may disrupt the organization of a family. Regarding mental disorders, people affected by diseases of this kind, have signs and symptoms that hamper their performance, creating obstacles and prejudices in society and even within the family. A study showed that the family of the person in psychic suffering feels overwhelmed not only by the fact of having to meet the daily difficulties of the patient, but also by insecurity and unpredictability of his behavior and reactions.

The family taking the role of family caregiver, monitoring medications, performing the care and monitoring extra hospital treatment. In these moments, the family encounters difficulties which end up arousing feelings of uneasiness, stress and fatigue. It can be seen that the person with

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mental illness affects the family unit and the emotional climate. The family is weakened, its internal and external relationships are compromised, but it is still a place of understanding, affection, care, although the objective and subjective burden.

Despite the daily stress, family members expressed that they wish to give them peace and security, as reported below:

I must give tranquility and security to my sister. (F03)

In the context of the patient with mental illness, care becomes a task sometimes difficult due to the lack of support and commitment of other family members, either by the demands of the sick family member because in many situations, care, even in large families, it is exercised by a single person decreasing the chances to invest in leisure activities and searching for health services. 12

One study13 shows objective and subjective burden for caregivers of people with mental disorders. Objective burden includes negative and concrete consequences and are related to losses in the routine, social and professional lives of the family, financial loss, attention to inappropriate behavior, physical and verbal abuse, time spent in care, changing the routine and life projects of the family and with decreased social life.

Subjective charges refer to how the family caregiver is assessed in this situation, for symptoms of anxiety, depression or psychosomatic, feelings of guilt and shame related to lack of information about mental disorders and social exclusion. 13 Some families interviewed reported feeling good about the condition of caring for their family member because they are “familiar” with the situation who experience long ago as evidenced in the reports:

Since a child I lived with this, I'm used to. (F02)

I feel good watching him, it is the duty of a family member [...] and I am who has more time to look after him. (F17)

These results meets studies identified in an integrative review where it was observed that even overwhelmed, caregivers also felt satisfaction in caring for their family member. 54 One explanation is that the company provided by the ill person is positive in family relationships, helping them to feel satisfaction in caring despite the distress that the mental disorder can cause. Moreover, it is cultural not sick family member providing care for needy family members, which raises satisfaction in the fulfillment of social obligations to the family.

The family challenge is to be patient so they can get along well. In general, respondents said that caring is a mandatory basis, as if there was no a choice. The family will be constituted on an informal system of zealous, concerned care and resignation. The speech of F12 show this statement:

I have to have patience because those who are healthy have to assist the patient. (F12)

The family tries to meet the needs of the person with mental disorder dispensing affection, patience especially in the relationship, and learning to deal with the situation. In such cases, they are dominated by ties of solidarity and tolerance because family members have to organize themselves for manifestations of mental disorder. Patience is an important tool in the care process, and essential in patient-family relationship. Thus, this sense of responsibility for family care is passed from generation to generation, so that they have compliance.

Being aware of the difficulties of the family, it is necessary maturation of the current care model in mental health and support actions to families because the more supported the family feels, the more satisfied the patient is with this care.10

Difficulties of families in caring for the person with mental disorder.

The most current challenge in patient care is this aggression and disobedience in the day-to-day of family caregivers. Study participants highlighted as a cause of these behaviors the rejection to medication, as shown by the lines:

[... ] Mainly because he is very stubborn. He does not want to take the medicine. The smoking thing, it he said he smokes a little, but he smokes a lot. He exalts and wants to draw attention. (F14)

Sometimes he did not want to take the medicine, he does not want to eat. (F12)

She does not obey, I need to talk things over once. She is violent, but in recent times she is quieter with the medicine use. (F02)

There was also some respondents who reported not finding challenges in care. This possibly is due to the fact that there is greater collaboration of the patients to accept their disease and treatment.

I think we do not have difficulties, he accepted the treatment, we care. (F13)

The moments of control and decreasing of manifestations of the mental disorder are possible if there is adherence to drug treatment associated with non-drug therapies. The psychopharmacology began in the 1940s and 1950s with the discovery of

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The moments of control and decreasing of manifestations of the mental disorder are possible if there is adherence to drug treatment associated with non-drug therapies. The psychopharmacology began in the 1940s and 1950s with the discovery of
antipsychotics. The arrival of these drugs, and later of antidepressants, were significantly in the mental health area treatment, as with decreased expression of acute symptoms arising from mental disorders, widened the participation of patient care procedures such as workshops and group therapy, among others. Despite the criticism of the abuse of these drugs due to side effects and the risk of chronicity of the clinical picture, there is no denying of the contributions to this technology in the care of psychiatric emergencies, outpatient and home care.¹¹

However, as evidenced in reports of this study participants, and similar with the results of a survey also developed with families of people with mental disorder, one of the difficulties faced by the family regarding the continuity of the treatment is non-adherence of the patient to drug therapy. Refusal to take prescribed medications implies relapse risk, generating conflict and interfering in family dynamics.¹¹

In the treatment of mental disorders, non-adherence to medication is shown in about 50% of psychiatric patients causing several injuries, hampering the therapeutic and psychosocial approaches, undermining the family and social life of the patient. In many cases, there are relapse and readmission of patients, which ultimately undermining the family structure.¹⁵

Thus, non-adherence to medication becomes a major challenge overloading the family caregiver and can also trigger new crises in the patient. The factors that are related to non-adherence are the sociodemographic conditions, the drug treatment scheme, the side effects, the type of disease, the relationship between patients and health care professionals and acceptance of the disease by the family and patient.

It is up to health professionals to know and better understand the reason for missing medication adherence. The nursing, as a profession directly related to the care and the patient’s daily life, can promote the establishment of a better adherence to treatment, supporting and maintenance therapy, creating a bond of trust and security for the person with mental disorder.¹⁵

Other situations have been reported, such as family members who are daily with the patient in psychological distress and do not have time to care for themselves, being an aggravating factor in the health of these family members. Lack of time becomes a challenge to these family members, as reported in the statements below:

- Lack of time, stop having my pleasure to take care of her, we live more for her than for us. (F05)
- I find it difficult because I need to pay the bills and I cannot leave him alone. He connects the gas and forgets to turn it off, then it’s bad to leave home. (F19)

Living with a person with mental disorder is complicated and stressful for the family. This is worst in cases where the disease has a history of long-term, with multiple recurrences of crisis manifestations, generating overload of physical, emotional and economic order, changing all family life and compromising health, social life of its members, and leisure is forgotten.¹⁶

♦ The actions of the family for care during a crisis

In the area of mental health, when people have a crisis, their overall functioning is compromised. It is a psychic imbalance and the individual is lacking in skills or unable to take personal responsibility. Examples of such situations has been acutely suicidal individuals with intoxication by alcohol or other substances, psychotic symptoms and uncontrollable rage.¹⁷

In crisis situations, the mostly used behavior by family caregivers is to communicate the health service or taking the patient to the hospital care, according to reports:

- I take her to the hospital or the health center. These days she was very nervous [...] and spent three days there. She received a lot of drugs and was well again. (F06)
- We call the SAMU, the fire department. (F13)

Dealing with crises is not a simple task requiring an intense and intensive care by professionals and family. Among the management strategies of the crisis can be mentioned: reception, continuous and permanent observation, home visits, accountability for medical care, health staff presence to ensure the success of the prescription, negotiation and concrete support to family for the hospitalization be the last resource used, preparation of booklets with guidance on how to deal with the crisis of people with mental disorders for professionals not specialized in mental health and family; implementation of crisis workshops at CAPS, setting limits for patients through coexistence rules to prevent the use of alcohol and other drugs in CAPS; and feelings of affection and understanding from family members.¹⁸

It is observed that the family is facing...
difficult situations in times of crisis, often they do not have enough technical and scientific knowledge about the disease experienced by the patient. Many families are unaware of the signs and symptoms, the patient’s behavior, the evolution of the clinical picture. The guidelines regarding the disease by health professionals should be clear and objective, addressing both the mental patients and the family, which helps the management in times of crisis, obtaining better behavior.

A study shows that in the patient’s hospitalization situations, even the family carrying out visits to maintain the relationship with the sick family member, in order to establish continuity in the relationship even in times of crisis, it is possible to minimize the importance of their role and do not see social and health services support to stop having hospitalizations. Thus, the logic can prevail that treating the patient means to be hospitalized, without establishing possibilities of care at home, in the family, in the community. 19

There are also crisis situations that the family member gives medicine to the patients seeking to control his picture, as reported by F01 and F10:

I do not do anything, I just take the medicine. (F01)

I tell him to go to bed and try some medicine to make him calm. (F10)

In other cases, the family tried to bring the patient to the “real world” as shown by the lines:

We have to try to bring her to reality, try to stop the cycle. It's hard because she does not accept. (F08)

I call her attention when she has a crisis [...] I say we have to respect because she understands [...]. I use authority to make her understand. (F17)

Some family members were found to have certain knowledge about the disease and can better resolve the crisis, using drugs that reduce anxiety and agitation of the family patient in crisis. The dialogue often helps, as can be seen in family speeches that seek to bring their family reality.

When crises occur with psychotic symptoms, families with a long history of mental disorder can best manage the situations of difficulties at the time of crisis, learning from their mistakes. They also control some symptoms of the patient with a mental disorder as behavior changes and aggression. Some families still know how to predict the starting a crisis with their experiences. 20

♦ The impact that mental illness causes in the family caregivers

The families first shows the impact the mental illness is in their life, mainly by stress, fatigue and accumulated familiarity with the psychological distress of the patient:

She is not good, I get nervous, I avenge eating sweets, puddings, cakes. I know it hurts me, but at the time is what calms me, I am also very tired. (F10)

My health was good, but in recent times I started to get tired of the situation. I'm always very nervous. (F18)

Lack of knowledge about mental disorders can corroborate the wear of the relationship between the family and the caring individual. It is important that the one who cares, accept the limitations and peculiarities of his family member and need a support network to be signed around that provide care actions, offering them information, sharing responsibilities and allocating them adequate support. 12

Professionals need to offer health care that includes care to identify and reduce the burden on family members. They should also promote skills training that encourage autonomy and psychosocial rehabilitation of people with mental disorders. 3

Respondents reported that they also feel ill, with little patience to take care of the family member/patient due to unstable behavior and the emotional, physical and economic burdens. As reported:

The problem is that I think I'm sicker than him. For me it is hard. There are times when I do not know what to think [...] I have diabetes, hypertension, and arm tendon broken. What agony! (F17)

I make treatment for depression that came the problem of my mother and also by family problems. (F02)

Living with mental patients can cause an inexplicable feeling, sadness, agony, low esteem, decreasing in quality of life. Feelings become part of the routine as fear, shame, fatigue, lack of patience, the emergence of other physical ailments that generate a cluster of actions that end up wearing the family caregiver, raising concerns and physical and mental harm. 20

It is no noted that, if the family was not included in the care provided to patients with mental disorders, this care will continue to suffer. The health professional should receive the family, listen to their suggestions and establish a conversation considering the understanding on a mental disorder. Together, health care professional and family
members can understand and consider the best way to care and treatment to be established for both.

In this context, similar to a study which states that health services should give more focus on caring for people in psychological distress and family, working on health education through therapeutic information and guidance to families.

When the family understand the therapeutic model, the family can provide care in an appropriate manner and facilitates the reintegration of families in psychological distress in society. Health professionals need to gain confidence by the family and the patient, demonstrating safety on the information they are going through, as well as providing a resource in promoting patient comfort, and investing in their recovery.

It can be seen in the story of many families interviewed that their mental, physical and social health was not affected. This leads us to consider the important fact to maintain a good relationship with the condition of their family, as evidenced in the reports:

I'm fine, I am a cleaner, then I have muscular pain, but I am healthy. (F12)
My health is good, okay. (F13)

For the family does not have overloads with the patient with mental disorder is necessary to work rehabilitation. This helps the individual to be able to establish positive emotional exchanges. The family environment, the community and the health service in the CAPS II should be prepared to take this behavior with the family and the patient.

The family involvement in the patient’s day-to-day is considered important, so the professionals can understand the difficulties and potentials faced by families in providing care and including rehabilitation measures and social reintegration of these individuals in the community.

In this context, the possibility of structuring a network of formal relationships that can be established by professionals or health institutions, and the link with informal networks, along with the relationships among the subjects, will constitute essential elements that enhance care to families, contributing positively in the care of the patient with mental disorder.

CONCLUSION

It is understood that the family develops actions to care, encourage, be present, be safe and reliable support. The family relationship with the person with mental disorder is sometimes unstable, but when the symptoms of the disease are controlled, there could be an harmonious living and the people in psychological distress contributes to the caregiver, including their company.

In this research, the care is exercised primarily by female subjects, with prevalence for the age group from 46 to 65 years old. As for the time patients have been diagnosed with mental illness, there was a predominant range of up to 15 years and 53% of patients attending the CAPS II for less than 04 years.

In living with family caregivers in CAPS II, it was clear the importance they have in the recovery and stabilization of the patient, because besides the home care accompany the activities proposed by the CAPS II team and engage in therapeutic activities that enable better understanding of illness of his family, they contribute to the daily lives of these families.

It is noticed that the mental disorder affects the family unit and emotional state. The family is weakened, its internal and external relationships are compromised, causing physical, emotional and financial burden. However, even family members being overloaded, they feel satisfaction in caring for the patient.

There was a need that families have to be heard, to share their experiences, their anguish and the victories won in treatment, as is the relationship with the family member who fell ill and the findings of the disease coping strategies.

With the crisis, many families do not know how to act. It is believed that due to lack of guidance on the measures adopted in case of crises. The study showed the need for effective proposal of family inclusion by professionals working with the mental health area. Health workers should enable this meeting and be open to know the other side of the family who looks after and the subject to mental disorder.

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