

Living with mental disorders: family members' perspective have on primary care

CONVIVENDO COM TRANSTORNO MENTAL:
PERSPECTIVA DE FAMILIARES SOBRE ATENÇÃO BÁSICA

CONVIENDO CON EL TRANSTORNO MENTAL:
PERSPECTIVA DE FAMILIARES SOBRE ATENCIÓN BÁSICA

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ABSTRACT

The objective of this qualitative study was to identify the service that is offered to the family members of patients with mental disorders at Primary Care Units, and understand the everyday life of that family. Data collection was performed from May to June 2007, by means of semi-structured interviews and observation of five families at their homes. Thematic analysis of the data was performed, generating two categories: 1) mental disorder from the family's perspective and the relation with the health service; 2) living with the mental illness. Result confirm the importance of seeing the family of patients with mental disorders as clients of the care process, and the need to prepare health professionals to answer the needs of the people that seek these services.

DESCRIPTORS

Mental disorders
Family
Primary Health Care
Deinstitutionalization

RESUMO

Trata-se de um estudo qualitativo cujo objetivo foi identificar o atendimento que é oferecido aos familiares de portadores de transtornos mentais nas Unidades Básicas de Saúde (UBSs) e compreender o cotidiano da família do portador de transtorno mental. Os dados foram coletados no período de maio a junho de 2007, por meio de entrevistas semi-estruturadas e observação de cinco famílias nos respectivos domicílios. Os dados foram submetidos à análise temática que gerou duas categorias: 1) o transtorno mental na perspectiva da família e a relação com serviço de saúde; 2) convivendo com a doença mental. Os resultados corroboram a importância de, em casos de transtorno mental, ter a família como cliente do processo de cuidado, e a necessidade do preparo dos profissionais para suprir as necessidades das pessoas que frequentam estes serviços.

DESCRIPTORES

Transtornos mentais
Família
Atenção Primária à Saúde
Desinstitucionalização

RESUMEN

Se trata de un estudio cualitativo cuyo objetivo fue identificar la atención ofrecida a familiares de portadores de trastornos mentales en Unidades Básicas de Salud (UBSs) y comprender el cotidiano de la familia del portador de transtorno mental. Los datos fueron recolectados entre mayo y junio 2007, mediante entrevistas semiestructuradas y observación de cinco familias en los respectivos domicilios. Se sometieron los datos a análisis temático, lo que generó dos categorías: 1) el transtorno mental en la perspectiva familiar y la relación con servicios de salud; 2) conviviendo con la enfermedad mental. Los resultados corroboran la importancia de, en casos de transtorno mental, tener a la familia como adyuvante del proceso de cuidado, y la necesidad de preparación de los profesionales para suprir las necesidades de personas que frecuentan estos servicios.

DESCRIPTORES

Trastornos mentales
Familia
Atención Primaria de Salud
Desinstitucionalización

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INTRODUCTION

The National Mental Health Policy is based on deinstitutionalization, which consists of moving care delivered to mental patients in closed facilities to extra-hospital services capable of meeting the needs of individuals with mental suffering and that of their families so that this process occurs as close as is possible to the community, valuing the maintenance of social and family ties⁽¹⁾.

In Brazil, the deinstitutionalization process was initiated in the 1980s and it emerged as a possibility to change the traditional hospital centered model. This movement, called Psychiatric Reform, seeks to reconstruct practices to restore and maintain the person experiencing mental suffering within social life so that s/he can maintain, mainly, her/his family ties⁽¹⁾.

From this perspective, the family is seen not only as an important ally but also a recipient of care delivered by health professionals⁽²⁾. This new role requires family members to participate in the care provided by mental health care professionals to those suffering psychologically so as to establish a network of relationships that enable them to have healthy relationships with other users, health professionals, relatives and society⁽¹⁻³⁾. In this context, affection, emotional ties and participation in groups are determinants of family composition, and these are essential in the construction of individuals' lives. This is especially so in the case of mental health patients, since human beings do not live by themselves but in a social context in which the family is the closest support network^(2,4).

If on one hand, in this new context of mental health care, the family has a delimited place, the burden to which it is subjected is undeniable. The family has become responsible for playing an active role in the treatment of its family member with mental disorder⁽⁴⁻⁶⁾. Because of that, the health services should consider the family a potential recipient of care given its difficulties in the daily routine and overload that accompanies the patient's therapeutic process, while at the same time bearing in mind the need to give the family tools to share in the care of its member who requires care⁽⁴⁾.

For that the family depends on devices in its own community. In this context, the Psychosocial Care Center (PCC), because is the nearest service, is usually the most used mechanism. On the other hand, in the field of primary health care, the Family Health Program (FHP), given its philosophical conception, seems to gather attributes to help the families, even though it is a great challenge for its professionals and managers^(3,6-10).

This interaction among the services has motivated discussion and questioning both by professionals and the academic

community given the strategic position of the FHS related to care provided to mental health patients living in the community and the various possibilities available to provide better care to patients with mental disorders and their families.

It is, therefore, essential that we identify the main problems and potentialities that emerge in the context of primary health care and its interface with mental health, especially because it is the role of each service and its set of professionals to seek specific solutions for its community, consider the resources available and create possibilities for improvement, creating and reinventing strategies and mechanisms to solve their own problems.

Based on this issue and on the experience of witnessing moments of families who accompany patients to mental health services in Maringá, PR, Brazil, we posed some questions regarding the local context. What are the peculiarities of care provided to families of patients with mental disorders in Primary Health Care Units in Maringá? What is it like for families to live with their deinstitutionalized member and what are their needs?

This study was proposed in the attempt to clarify these and other questions related to the theme.

OBJECTIVES

To identify the care offered to families of patients with mental disorders in Primary Health Care Units (PHC) and understand these families' routines.

METHOD

This is an exploratory-descriptive study with a qualitative approach conducted with five families of patients with mental disorders who are residents in the scope area of the Mandacaru PHC unit in Maringá, PR, Brazil. All cases of patients with mental disorders cared for in this unit were included except those with disorders resulting from alcohol or drug abuse.

Community Health Agents (CHAs) of an FHS team were contacted to provide the addresses of the families registered in the program for the selection of the study's participants. The families were then contacted through home visits and the study's objectives were clarified to them. Hence, inclusion criteria were: living in the PHC unit scope area, being a patient with a mental disorder (in treatment or not) and agreeing to participate in the study.

Data collection was carried out during May and June 2007 through semi-structured interviews divided into two stages. The first contained questions that characterized the family and second contained issues concerning difficulties faced when living together with a patient with a mental disorder,

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and the observation process as a whole. The researchers carried out the interviews in the participants' houses, taking approximately 25 minutes each. The interviews were recorded on k-7 tapes and immediately transcribed to ensure the rigor of data collection. Five families participated in the study, two of which had more than one member with a mental disorder. The sample totaled 12 informants.

The participants signed free and informed consent forms and all ethical precepts involving research with human subjects according to Resolution 196/96 of CONEP were complied with. In addition, the research project that gave origin to the study was approved by the Research Ethics Committee at the State University of Maringá, protocol No. 110/2007.

After data collection and transcription, content analysis was carried out following a set of techniques aimed to obtain indicators that enable a critical interpretation of obtained data, whether these are common sense or subjective data. Systematic and objective procedures for the description of message content were utilized⁽¹¹⁾.

The process of analysis followed the steps of content analysis that includes pre-analysis, exploration of material and treatment of data. The latter occurs based on the analysis of objective and subjective communication of this material, using systematic procedures⁽¹¹⁾ to understand the content expressed in the family members' reports.

The identification of core meanings allowed us to establish two categories: 1) Mental health from the family's perspective and its relation to the health service; 2) Living with a mental disease.

RESULTS AND DISCUSSION

The study's group of participants was composed of biological families with varied characteristics: nuclear, branched, extensive, families with only the mother or the father, family of siblings only, families without children, and families without parents. Therefore, the conceptualization of family is object of this study, one that considers the possibility of variations of the traditional nuclear family up to the post-modern family.

Only one of the patients was an adolescent (family 3); the remaining were 35 years old or older. Two of the five families had two members with mental disorders. In the case of Family 4, the patients were two sons (36 and 46 years old). The daughter (35 years old) and the sister (50 years old) of the interviewee of Family 5 had mental disorders. The male gender predominated and all patients were single, while the level of education varied from incomplete primary school up to a bachelor's degree. Five of them contributed to the family income, four of which were retired and one had an occupation.

Table 1 - Characterization of families of patients with mental disorders in the PHC unit in Mandacaru, Maringá, PR, Brazil - 2007

Family	Family Members	Kinship and Age of the interviewee in relation to the patient	Interviewee's educational level	Family income	Religion	Type of house	Other health problems
1	Mãe, pai e três filhos	Sister 50 years old	Bachelor's degree	Six times the minimum wage	Spiritist	Owned	Diabetes, hypertension and depression
2	Mother, father and son	Mother 74 years old	Completed high school	Two times the minimum wage	Catholic	Owned	Depression and smoking
3	Mother, father and three children	Mother 48 years old	Completed high school	Five times the minimum wage	Adventist/ no religion	Rented	Fibromyalgia, chronic migraine, alcoholism/other drugs and smoking
4	Mother and two children	Mother 70 years old	Illiterate	Two times the minimum wage	Catholic	Owned	Smoking
5	Mother, sister and one daughter	Mother/sister 67 years old	Incomplete high school	One time the minimum wage	Spiritist	Rented	Syphilis, hypertension, diabetes, hyperthyroidism

The maternal figure is present in all the interviewed families, which is not the case with the paternal figure. Similar to other studies, women appear as caregivers, which shows that care is linked to home chores and care delivered to sick individuals^(4,12).

The caregivers are mainly adults and elderly individuals, varying from 48 to 74 years old. It shows that often people who should be the ones being cared for are actually playing the caregiver role: in addition to being an elderly individual, they have limited self-care abilities because they are also sick. These individuals often assume such roles

because they are imposed by circumstances and not by choice, though they consider this mission to be naturally theirs, as some mothers reported.

In relation to the level of education we find that caregivers are generally either illiterate or have a high school education, though there are people with a bachelor's degree, such as a pharmacist. Based on observation, we realized that the level of education does not interfere in the quality of care provided to patients — affection, interest, physical care, hygiene, food and other sorts — but it interferes in the way individuals require quality of care and the care itself

Two families have an income of only one times the minimum wage, another has income equivalent to two times the minimum wage and the others have income above four times the minimum wage.

In relation to religion, two families are predominantly spiritist, two Catholics and one partially Adventist, since some of the members reported no religion. This fact should be taken into account because religion is often one of the sources of understanding and acceptance of disease, since the Brazilian culture is strongly influenced by the religious dimension⁽¹²⁾. Additionally, religion and spirituality are currently considered to be an important factor of support to families of patients with mental disorders.

Three families reside in their own house and two in rented houses, all with good urban infrastructure (basic

sanitation, electrical energy, number of rooms consistent with the number of residents).

In relation to other diseases affecting the health of family members, Table 1 shows that the use of alcohol and other drugs are observed in only one family, smoking is observed in three families and other pathologies such as depression, hypertension and diabetes were mentioned by two families, hypertiroidism, syphilis, fibromyalgia and chronic migraines in one family.

When we attempt to map the development of the condition of the patients with mental disorders, the diagnoses are diverse, though they do not affect the feelings and experiences of families. Table 2 illustrates the characterization of patients with mental disorders.

Table 2 - Map of development of the psychiatric condition of patients with mental disorders of the families interviewed in the PHC in Mandacaru, Maringá, RR, Brazil - 2007

Family	Diagnosis	Age and gender	Age when symptoms began	Age when the diagnosis was confirmed	Hospitalization
1	Schizophrenia	53 male	24 years old	29 years old	Yes
2	Depression and obsessive-compulsive disorder	41 male	10 years old	28 years old	---
3	Bipolar disorder	16 female	12 years old	14 years old	Yes
4	Bipolar disorder	46 female	30 years old	30 years old	Yes
	Schizophrenia	36 male	18 years old	30 years old	Yes
5	Schizophrenia	50 female	31 years old	31 years old	No
	Schizophrenia	35 female	15 years old	44 years old	Yes

A fact that draws our attention in this table is the late diagnosis in most of the patients, which suggests that health practices are still focused on clinical interurrences, not taking into account that psychological health directly reflects on other spheres of an individual's health.

The mental disorder from the perspective of families and its relation with health services

When we sought to reconstruct the experience of mental disorder and its relationship with the health service provided, from the perspective of the interviewed family members, we observed that in general, even though the study was conducted with distinct families, many meanings and perceptions are similar. This is especially so in the face of the diagnosis.

Lack of knowledge concerning the meaning of the disease and lack of clarity concerning what really occurs with a patient with a mental disorder causes family members to feel the need for quality information; they feel lost in relation to attitudes they should adopt with the patient; and also feel isolated from the health service. Studies show that this is a reality at a national level^(7-8,12-15). Hence, family members often see themselves obligated to dedicate a large part of their time to the patient as shown in their reports.

Most of the interviewees report that patients have good treatment adherence. One patient opted for treatment with

medication only and four have medication associated with psychiatric follow-up, while one patient does not follow any type of treatment. It is important to reaffirm the right of mental patients to have access to good quality treatment performed with humanity and respect, to receive information concerning their disease and be protected against any type of exploitation (Law 10.216)⁽¹⁶⁾.

The families report the importance of following the medication treatment to control the symptoms, an attitude that directly reflects on improved social life.

[...] He takes the medication all right, every day. (mother F 4);

[...] I get concerned with the time of taking the medication, if he stops taking the medication I know it comes back, you know (mother F5).

The medications mentioned most by the six patients were: Clomipramin, mentioned by four patients; Olanzapine and Biperiden, used by three patients; and Haloperidol, Levomepromazine and Clorpromazine, each used by two patients. Two medications, Fluoxetine and Divalproex sodium, were mentioned only once.

Of the seven patients with mental disorder who live with the five studied families, six are in psychiatric follow-up through the public network, Unified Health Service (SUS) in the Integrated Center for Mental Health, and one in the

private health care network. All these patients receive medication in the public network. It might be related to the fact that health insurance plans offer only consultations and some psychiatric medications are considered expensive and that is why they are provided by the public network, as observed in the following report:

[...] My brother has delusions of grandeur and does not accept treatment from the SUS, but we get the medication without him knowing it [...] we go there and get it at the end of the afternoon, when there are no more consultations, so we don't risk meeting some neighbor there [...] nobody needs to know about his problem [...] (sister F 1).

The interviewee sees the option for private care in this case as a prerogative of the patient, though we can consider the possibility that this can also be an effort the family makes not to expose the patient to the community in which they live. Being cared for in public services, the chance of meeting with family people is higher. This fact reaffirms the issue of prejudice that historically accompanies the trajectory of people with mental disorders and their families^(4,14-15).

Five of the seven patients were already hospitalized in psychiatric facilities, though this is one of the last resorts reported by families. According to them, only when they are not able to *control* the patient at home do they seek this treatment option. At that point, they feel they have exhausted all other resorts.

Additionally, taking into account the reduced resources for mental health existing up until the 1990s, families had few options in previous times because care was restricted to psychiatric hospitals and outpatient medical consultations. Currently, family members depend on some substitutive services, though these are still insufficient to meet the demand and do not always have the ability to care for an individual in crisis, which in some cases, leads to hospitalization as the last resort^(3,6-7,12,14).

Hospitalization in this case appears as a solution for an unbearable situation of anxiety and fear families live with when they perceive the emergency of decompensation and it may represent an attempt to maintain the family structure^(4-6, 8,10).

In relation to the use of support services, as previously mentioned, only two patients go to the PCC. The remainder, though they are familiar with the service, opted not to utilize it and often ignored how to access these programs, as evident in the following excerpt:

[...] They don't know to where to send us [...] We waste time going to these places and nobody resolves anything [...] then they send you to another who doesn't resolve it, either (sister F 5).

The testimony of this interviewee reveals a certain lack of belief in the service, from which we can infer the family did experience a solution to their problem, leading the family to give up on this type of care. A recent study reviewing the Brazilian literature on the topic⁽¹⁴⁾ shows two primary

reasons for services being discredited and family overload: inefficiency on the part of substitutive services (among other aspects); and the inefficiency of the PHC unit in meeting the needs of patients with mental diseases and their families, since a peregrination in search for help without an effective resolution causes exhaustion and disappointment in relation to the resources of the health system.

When we asked the families about the mental health care received in the PHC unit, they reported that in general only the patient receives care. Two families received visits from professionals but three of them do not. In general, they report being well cared for and consider the service good though it does not meet all their needs, such as specialized services, transportation and medication.

The Family Health Program has a characteristic that is essential to caring for families because it includes the house as a therapeutic space and humanized care as a facilitator to create bonds and bring professionals knowledge of the families' routine^(3,6,8,10). Therefore, the PHC unit could become an appropriate strategy to care for patients in the mental health services, since it works in the scope area of families of patients with mental disorders.

However, such care is a challenge for the FHS professionals and managers since mental health care from the formal point of view is not acknowledged by the program as its focus of attention. Actions in the scope of mental health care are not even officially recorded in their productivity reports⁽¹⁷⁾.

The interviewees' reports show that the care provided by the professionals from the primary health care service is still focused on meeting the clinical needs of the patient with mental disorders and is performed only in the PHC unit without the participation of the family, as most of the participants reported.

I'm well cared for in the unit, now there are consultations, medication, it wasn't like this in the past; but the ladies never come to my house (mother F 4). T

hey do not meet all my needs of transportation, dental, medications, I need to insist a lot (mother F 5).

I don't get any visits, only medication (sister F 1).

These testimonies are corroborated by other studies that show dissonances in mental health care in the context of primary health care. Most of them signal that the PHC unit, even though it should be the entrance door to the health system, does not have qualified professionals to meet to the specificity of care in this field and for this reason mental health care within FHS is still a great challenge^(3,6,8,12,14,18).

In the specific case of the setting where this study was conducted, we verified that there were courses administered to educate professionals from the primary health care services in Maringá, such as Mental Health Actions/Services and Programs and Protocol in Mental Health and Alcohol-

ism. Despite this, these reports reveal that these are still focused on meeting the emergency needs of the disease and not on integral care, including the family context.

When the families report their knowledge concerning mental health, their testimonies are accompanied by memories and expressions of great emotion. These gradually gave place to an account of their experience of being in contact with the disease: denial, lack of knowledge concerning its meaning, despair when noticing the patient's change of behavior, concern, sorrow, anxiety, and so many other feelings.

[...] It was really difficult because I didn't know about the disease, she'd not accept medical care, there was much suffering (mother F 4). [...] I got desperate at the time...didn't believe it, I thought it was only depression (sister F 5B). At the beginning I felt guilty because I didn't know the disease [...] (sister F 1).

The idea of suffering refers to something that repeats itself and drags on, overwhelms, unbalances, makes the relationship complicated, causes suffering and difficulty. It is not easy to accept living with the anguish of having a mental patient in the family. Additionally, the family may feel guilty for the disease and feel anguished for not knowing how to deal with the patient's behavior. As an aggravating factor, the family rarely seeks or receives information, so it feels insecure concerning the best way to care for the patient. Many family members report feelings such as anger, insecurity, fear, anxiety, guilt and loneliness. The testimonies attest to the findings of other studies addressing the moment of initial contact with the disease and its vicissitudes^(2,4-6,18).

When asked about guidance received concerning the disease, most of the interviewees' reported that they received little or no guidance at all at the time of the diagnosis and that they had the initiative to seek information on the disease:

I searched in bibliographies because I didn't get guidance from the service (mother F 5). At the time I had no guidance; after many years, I went to a psychologist to learn how to deal with her disease (mother F 4). As much as the professionals provide guidance, it is not sufficiently clear to understand the illness, only through living together you manage to get clarified about it (sister F 1).

Given the mental disorder, as well as other pathologies, it is essential that guidance be provided to the patient and the entire family, because knowledge is another facilitator of understanding and acceptance of the disease, as well as treatment adherence.

Lack of knowledge and poor information provided on mental disorders contribute to the dissemination of problems, complications and conflicts in family relationships^(12,14).

Living with a mental disorder

Life with a patient with a mental disorder may be marked by feelings of anxiety, affliction, and sorrow on the part of

patients and family members. It means to live constantly with instability, given the patient's unpredictability of actions, and with the expectation that a new crisis may burst any time^(12, 14-15).

Despite the fact that family members express that under certain conditions life follows its own course, we observe in their eyes, behavior, facial expressions and posture of these people that the situation they experience causes them much suffering and a very heavy emotional burden. The interviewees complained about the condition they assumed by exclusively dedicating themselves to the patient. One of them reported her dedication was so intense that she did not remember when she received care for herself or even a hug.

Studies addressing the issue of family overload indicate that this can reach different levels and be classified as physical, emotional and economic overload⁽⁴⁻⁸⁾.

I don't see her as a sick person, she has normal treatment, we can't yell or fight (mother F 4).

In the good times it's easy, but in moments of crisis, it's difficult [...] (mother F 3).

It is difficult, because he is very concerned, gets mad easily, isolates himself so he doesn't hurt anyone (mother F 2).

[...] I don't remember the last time I was hugged [...] (the researchers stood up and hugged her)... he (son F2)

Cried a lot during the scene (note in the field diary June 2007).

These testimonies show that overload is related both to issues directly related to the patient's behavior and feelings that living together causes. According to a study that characterizes this process, objective overload refers to problems or difficulties verifiable and observable and that are caused by the patients' behavior, while subjective overload refers to personal feelings about the act of caring and to the consequences of the objective overload⁽⁴⁾.

For some family members, dealing with a mental disorder patient is a malady, a task that never ends, which makes this experience traumatic, and reported by some as a *cross* that hurts, leaves marks on the patient and on the relatives who very closely accompany this process of becoming sick⁽⁴⁻⁶⁾.

The family routine is changed because generally the families caring for mental health patients become emotionally overloaded and are not able to establish other relationships given a lack of time; they end up putting the disease of the patient in the center of their lives, making demands in relation to the patients and themselves; they isolate themselves from society, including friends and relatives⁽¹⁸⁾.

The manifestation of the mental disease causes behavioral changes both in the patients and other family members. Such changes are reported by all the interviewees and are perceived as a phenomenon that causes suffering not only in the individual experiencing it but also in those in his/her social surroundings, especially the family.

I gave up working because she requires much care (mother F 5).

There was a total change. The entire family lives for him. We gave up travelling, left jobs and social life because he can become aggressive even when taking the medication (sister F 1).

His siblings accept the disease, he (patient) is no longer working and I'm the only breadwinner (mother F 4).

I think a lot at night... can't sleep...I can't talk to anyone, otherwise my mom closes me up and won't let me leave the next day... I don't talk to my brothers because they don't follow my thoughts... My parents are old and I know my mom suffers a lot because of me... and my father too, because there're days I go to work with him, sometimes I can't, and he has to support the house by himself (patient F 2).

The testimonies illustrate the various expressions of overload that fall on the family members, especially of a financial nature, because to overcome the new financial needs such as the high cost of medication, someone needs to increase their workload. It is important to consider that oftentimes the patient with a mental disorder becomes unproductive and other family members need to take responsibility for the treatment, clothing, transportation, food, etc. Additionally some changes are required in the household routine such as in the time of meals, laundry, household chores, groceries, etc., since the patient cannot take care of his/her tasks given the disease and such tasks are delegated to others⁽⁴⁻⁶⁾.

When the family reports about the experience of living together it also highlights the issue of prejudice and discrimination to which it is subject, indicating that not only does the patient experience discrimination, but the entire family is also socially marked.

People in the community are not clear about the mental disease and discriminate against him. Society is not prepared for it (sister F 1). He is very discriminated, people don't allow him to get close, it seems they feel disgusted (mother F 4). She came to live with me a year ago, her brothers saw her as an unoccupied person (sister F 5).

These reports only reinforce what has been happened historically over the years in relation to mental disease in the social context. Even though much has been achieved in relation to the attitude of professionals and society in the face of mental disease, even today we still face many difficulties permeating the entire process of change due to the complexity that is involved in mental diseases and the diverse facets related to it. Actually, transforming this reality requires a paradigmatic change of the relations of the human being in the world, which involves the concept of normality, relations of power in the process of disease treatment, among other as-

pects, which are great challenges to be overcome for achieving a more dignified and equal care delivered to the patient with a mental disorder and his/her family^(2,4,10).

CONCLUSION

This study was not intended to define truths concerning the most appropriate way of living with a patient with a mental disorder nor how patients and families should deal with health services. Rather, the goal is to lead one to reflect upon how it currently occurs so that we can construct new views and knowledge concerning the topic. This study showed the importance of having the family included as a recipient of care in this care process since it also presents specific needs. Regardless whether it is a family or biological, or affective or social ties, the common point is the finding that everyone suffers in the face of a mental disease. The disease causes conflicts, limits social life and hinders the experience of living together. Still, the family is the core where knowledge can be exchanged, enabling the identification of the real care needs.

The family members' reports clearly present the difficulties faced in daily living with patients with mental disorders and how much suffering it causes. Hence, caregivers need to be the focus of care of professionals in health services in the same way the mental disorder patient is. Services need to meet the real needs of the family as a unit of care.

Hence, considering that this study addresses a specific reality, we provide evidence that even with investments to better educate professionals working in the primary health care to deal with the needs of patients with a mental disorder and their families, this context does not signal significant changes in favor of families. Among other aspects, the methodology adopted for the process of updating professionals' knowledge needs to be reconsidered so that it becomes, in fact, significant in promoting transformations in care delivery.

So when we refer to the principles that guide both SUS and the Psychiatric Care Reform and the evidences presented by the experiences of family members in living with patients with mental disorders, we reaffirm what other studies have also stated, that the existence of a gap between the recommendations of health policy and practice should not be denied but faced as a great challenge that involves managers, professionals and the community.

The care delivered to patients with mental disorders and their families requires an urgent positioning of all segments of the society if we envisage care that seeks citizenship and respect for the individuality of patients with mental disorders and their family members.

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