

The family and the mental disturbance carrier: dynamics and their family relationship

A FAMÍLIA E O PORTADOR DE TRANSTORNO MENTAL: DINÂMICA E SUA RELAÇÃO FAMILIAR

LA FAMILIA Y EL PACIENTE CON TRANSTORNO MENTAL: DINÁMICA Y SU RELACIÓN FAMILIAR

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ABSTRACT

This exploratory study was performed from September to November 2008, with six families of patients with mental disorders from a patients and family association in Curitiba. Objectives: to learn about the role of the family of patients with mental disorders, and to identify the family's perception of mental health - mental disorder, the patient with mental disorder and the mental health treatment. The data was obtained through Group Discussions and organized into thematic categories. It was found that the role of the family is to care, encourage, be there; mental health is the ability to establish relationships, perform activities without suffering; mental disorder is the opposite, in face of which the families feel helpless; hospitalization is seen as suffering, and the highlight is on the importance of the drug treatment. It is necessary to discuss on these issues with the families and prepare health professionals to meet these new health needs.

DESCRIPTORS

Family
Mental health
Mental disorders
Family relations

RESUMO

Pesquisa exploratória realizada de setembro a novembro de 2008, com seis famílias de portadores de transtorno mental em uma Associação de pacientes e familiares em Curitiba. Objetivos: conhecer o papel da família em relação ao portador de transtorno mental, e identificar a percepção da família com relação à saúde mental-transtorno mental, ao portador de transtorno mental e ao tratamento em saúde mental. Os dados foram obtidos mediante a técnica de Discussão de Grupo e organizados em categorias temáticas. Constatou-se que o papel da família é cuidar, incentivar, estar presente; a saúde mental é a capacidade de se relacionar, desempenhar atividades sem sofrimento; transtorno mental é o inverso, diante dele as famílias se percebem impotentes; o internamento é percebido como sofrimento, e destaca-se a importância do tratamento farmacológico. Há a necessidade de discutir essas questões com as famílias e instrumentalizar os profissionais de saúde para atender essas novas demandas de cuidados.

DESCRIPTORIOS

Família
Saúde mental
Transtornos mentais
Relações familiares

RESUMEN

Investigación exploratoria realizada de septiembre a noviembre 2008 con seis familias de pacientes con transtorno mental en una Asociación de pacientes y familiares en Curitiba. Objetivos: conocer el papel familiar en relación al paciente con transtorno mental, e identificar la percepción familiar relacionada a salud mental-transtorno mental, al paciente de transtorno mental y al tratamiento de salud mental. Los datos se obtuvieron mediante Discusión de Grupo, fueron organizados en categorías temáticas. Se constató que el papel familiar es cuidar, incentivar, estar presente; la salud mental es la capacidad de relacionarse, desempeñar actividades sin sufrimiento; transtorno mental es lo inverso, ante él las familias se sienten impotentes; la internación es percibida como sufrimiento, y se destaca la importancia del tratamiento farmacológico. Existe necesidad de discutir tales cuestiones con las familias e instrumentalizar al profesional de salud para atender esas nuevas demandas de cuidado.

DESCRIPTORIOS

Familia
Salud mental
Trastornos mentales
Relaciones familiares.

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INTRODUCTION

Historically, the family has been excluded from treatment to patients with mental disorders, as psychiatric hospitals were built far from the cities, which made it difficult for families to get access to these institutions. Another factor that permeated the family's relation with mental patients was the understanding that it produced the illness, as the ill relative was considered a scapegoat, who carried all the family core's sores, and should be distanced from the people considered responsible for the illness. Thus, all the family could do was to forward their relative to the psychiatric institution, so that the technicians of knowledge could take charge of treatment and cure⁽¹⁾.

This distancing from the family was present in the subject-madness relation until about the 1980's⁽¹⁾, when new possibilities emerge for the family's role and relation with the mental patient. These perspectives derive from new mental health policies, resulting from the psychiatric reform movement in Brazil, which guide the transition from the treatment spaces of the coercive and restrictive institution to community health care services.

In view of this new reality, various knowledge areas have taken interest in the family and mental health theme, as the new mental health care model demands society's participation, teamwork and the family's inclusion in care delivery to people with mental disorders⁽²⁾.

Therefore, the family should be considered a fundamental social actor for psychiatric care to be effective, and also as a group with great potential for the welcoming and resocialization of its members. Examples of transformation in the mental health area that have required the family's inclusion in the care plan are the creation and expansion of a community care network for people with mental disorders and decreased internment periods in psychiatric institutions⁽²⁾.

For the family, taking care of a mental patient represents a challenge, involves feelings intrinsic in the experience of an unforeseen event and their own prejudices towards the disease. This implies perceiving the human being as a being with possibilities, abilities and potentials, independent from the limitations imposed by the mental disorder⁽³⁾.

It should also be taken into account that the family's contact with the mental patient is not always harmonious, but permeated by tensions and conflicts, as this is the space where emotions are more easily expressed. Hence, the family, as a social group, demands that its members be constantly able to rethink and reorganize their strategies and internal dynamics⁽⁴⁻⁵⁾. It demands respect for individuality from the subjects because, although people live in the same

house, there is a range of forms of being in the world, as they think, interpret facts and behave differently.⁽⁶⁾

The family is a complex and fundamental social unit for any human being's life process, which is concretized through experience, characterized as dynamics and singular. It comprises not only a set of people, but also the relations and connections between them. And, along the family trajectory, its members go through crisis situations, which can be foreseen or not, linked with transition processes like birth, job changes, children leaving home, or adverse situations like illness. The family's ability to adjust to new situations, such as living with a member with a chronic illness, depends on its strengths, the bonds of solidarity it aggregates and the possibility to request support from other people and institutions⁽⁶⁻⁷⁾.

Hence, the family and mental health theme in care delivery and resocialization of mental patients gains relevance in view of the psychiatric reform process. Thus, studies on the family's role in contact with mental patients and which promote discussions on the concepts of family, mental health-mental disorder and human being can contribute to care delivery in line with these clients' actual needs.

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OBJETIVES

Get to know the family's role in relation to patients with mental disorders, and identify the family's perception of mental health-mental disorder, the patient with mental disorder and mental health treatment.

METHOD

A qualitative and exploratory research was developed at an association for patients with mental disorders and relatives in Curitiba-PR, between September and November 2008.

Since 1994, this association has worked to promote the rights of people with mental disorders, through voluntary support work, assistance and attendance to mental health service users. The organization aims to integrate them with their family members and the community in general, and offers social, biodance and income generation workshops, such as general handicraft (embroidery, paper mache, Christmas decoration); activities like bazar mix, solidary listening, Reiki, stretching, chess, library, basic computer skills and psychological care for family members.

Study participants were six families, totaling 12 participants (Table 1). In this study, the family was considered as relatives of the patient with mental disorder, and the patient when present. To guarantee the family's participation, family members were included who were accompanied or not by the mental patient, were both older than 18, at-

tended the association and agreed to participate in the study. Subjects younger than 18 were excluded, as well as patients with mental disorders not accompanied by a family member and who did not agree to sign the Informed Consent Term.

Table 1 - Identification of study participants - Curitiba - 2008

Families	Participants	Coding
Family 1	Father Mother Sister	F1Pai F1Mãe F1Irmã
Family 2	Patient with mental disorder Mother	F2PTM F2Mãe
Family 3	Patient with mental disorder Mother	F3PTM F3Mãe
Family 4	Patient with mental disorder Mother	F4PTM F4Mãe
Family 5	Husband	F5Esposo
Family 6	Patient with mental disorder Son	F6PTN F6Filho

Approval for the project was obtained from the Institutional Review Board at *Universidade Federal do Paraná*, registered under CEP/SD: 617.154.08.09; CAAE 3168.0.000.091-08. Participants were informed about the aims and methods. To guarantee anonymity, they are identified by a code, as shown in Table 1.

The families were recruited as follows: the association's secretary elaborated a list with the names of the 56 families who attend. Based on that list, these families were invited by phone to participate in the study, and received clarifications about its goal and dynamics. A card was made with the date, time and address, highlighting the importance of the family's participation for the group to take place. Copies of this card were left at the association for users to take home. Nevertheless, only six families participated in the study.

To comply with the study goals and collect the information, the Group Discussion technique was chosen. This strategy permits *complementing information on a group's peculiar knowledge regarding beliefs, attitudes and perceptions*, in which the participants' opinions, relevance and values are considered important. From an operational viewpoint, in the Group Discussion, meetings are held with a small number of informants (6 to 12), generally including an animator, who intervenes in order to focus and deepen the discussion⁽⁷⁾.

Two discussion groups were held. To record the information, tape-recording and transcription were used. The first meeting took approximately one hour and thirty minutes. After the participants presented themselves, the group animator encouraged them through the following questions: What is family? What is the family's role in treatment and life with the mental disorder patient in the family relation? After the discussion, theorization was accomplished,

recovering the group's statements, the concepts of family and the role it plays in contact with mental patients. At the end of the meeting, participants were asked about the importance of a second meeting. They all demonstrated their interest and decided on a two-week interval.

For the second meeting, the subjects present during the first were contacted by phone to remind them about the date and time. The approximate duration was two hours and thirty minutes, during which the following questions were discussed: what is mental health-mental disorder? What is a human being? After the discussion, concepts were presented for theorization, following the same strategy as in the first meeting.

Information was analyzed in the light of Thematic Analysis, involving ordering, classification and final analysis. In the ordering phase, the tapes were transcribed, the material was read anew and data were organized. In the classification phase, data were subject to exhaustive reading, searching for central ideas, grouping them into similar parts with a view to understanding the connections between them. This gave rise to six theme categories. In the final analysis, the theoretical foundations of the data that emerged were established⁽⁸⁾.

RESULTS AND DISCUSSION

The data that emerged from the discussions were analyzed and grouped in six categories: 1. *The family as an important support in times of difficulty*; 2. *The family's role in care and treatment of patients with mental disorders*; 3. *Conception of mental health-mental disorder from families' perspective*; 4. *Human Being: a being with relations*; 5. *The family's feeling towards the mental disorder*; 6. *The family's perception about treatment spaces and mental health treatment*.

The participants declared that the family is the support they can count on independently from the difficulty they face. It is in the family core that the most authentic relations are established, and that solutions for problems can be elaborated. They recognize the ideal family as able to live in harmony. An expanded family concept is present, beyond blood bonds, the family core or people living in the same house, but also involves the relations that are part of and are important in its dynamics. They consider that, when experiencing a disease, the family experiences a crisis process that can cause misunderstanding and tension in joint life:

Family is where you can count on them. No matter whether nobody understands you, someone does. When I need help I ask my family. The thing is that there's logic in everything, if you're feeling bad you have to tell someone, and they're the people I count on (F4PMD).

It's a safe haven, a place where, in case of difficulty, you can count on someone, or, on the other hand too, the reciprocal is true [...]. My family is my family, me, my wife, and we have three kids, one's married, and the youngest one is living here with us (F5Husband).

Family is not just as religion preaches it. Besides mother, father, child, a friend, whom you can count on in times of need [...]. Family goes beyond father and mother, that blood thing (F6Son).

[...] besides being a safe haven, it's the place where we can tell the truth, not the one she wants to hear, but the one she needs to hear [...]. In the family, we not only can but need to tell the truth [...] being able to be authentic (F4Mother).

The participants' statements regarding the family concept as a support unit during adversities in the lifecycle are in line with literature findings, which consider it a primary care unit, which denotes a sense of security, a space for interaction, information exchange and identification of difficulties. It is dynamic and varies according to the historical and social moment the family is going through⁽⁹⁾.

The family is an organized social group, in which bonds are enhanced and a space for socialization and protection of its members is constituted. The need to know and value the family is evidenced, acknowledging that it is a point of connection between the subject and the social field^(4,10). As for mental health, this conception is fundamental as, in view of care reorganization in this area, the family started to be considered an important factor of resocialization and social reintegration for mental patients, who were sometimes distanced from their family and social life due to long internment periods at psychiatric institutions.

Also considered as the base of society, its members need to be capable of sharing life experiences, providing support in adverse times, interacting, enhancing dialogue and guaranteeing family members' healthy development, so that they can take charge of their personal and professional life⁽¹¹⁾.

Based on respect for individuality, the family is acknowledged as a privileged environment for socialization, appropriate for learning and the exercise of citizenship and democratic relations. It is also a space for tolerance, responsibility and joint search for survival strategies⁽¹²⁾. Like F6Son mentioned that family is more than father, mother and children, some studies present an expanded concept, in which the family comprises people joined by blood bonds, people who perceive themselves as part of the family and people united by affection, who live together in an organized way, within a given time and with common goals^(6,13).

The family's role in care and treatment of patients with mental disorders

For the study participants, the family's role for people with mental disorders is to be there, watching over, protecting, with affect and understanding. It also means getting equipped, attempting to get to know oneself, the mental disorder, the symptoms and possible limitations it imposes on the sick relative. The subjects acknowledged the importance of encouraging and involving the mental patients in daily activities, according to the following testimonies:

My son took no initiative. I work on fairs, more and more I'm letting him take the initiative to contact the clients and he has kept on doing that job. At first it was difficult for him, until now he's keeping the ticket. He's relating with people, they already know him, so he's gaining his own way of directing himself at people. On one of these fairs, I saw him go out and talk to people, things he wouldn't take initiative to do [...]. Such things are stimulating (F1Father).

[...] the most important, when you're ill, is to get to know the disease itself because each of us is different, each of us knows what's going on and what has happened, and we even know when our relative is getting worse. But you have to go for it, read, learn, talk [...] (F4Mother).

[...] I always try and learn how to deal with her, but that disease makes people difficult [...] you need a lot of patience, you need to be very tolerant, you have to help a lot [...] (F3Mother).

A trend exists to consider the family as an effective care unit, expecting it to assume the role of caregiver in times of its members' disease and health, aiming for their balance and wellbeing⁽⁹⁾. Hence, the family's function is to help its members, see to their needs and provide adequate means for growth and development⁽¹³⁾. Participants mention, however, that before the family manages to play that role, it needs to find strategies to face adverse situations and, often, first needs to know itself, work on its anxieties, and then take care of the other:

It means running to help [...]. Treatment's needed, you can't get around that, you have to face it [...]. As a mother I have to face it, not run away, you even have to go to therapy, to know your own pain. I think you have to do all that to be able to reach a certain moment when you master your traumas, my personal pain, and then I can turn myself towards the other and help. That's true for my husband and me, always in the same sense. We don't lie, we don't deny, we don't leave aside. I've always told the psychologist what I say, say when my son is there. There's nothing I say he can't hear (F1Mother).

It was difficult for me, it takes time to understand the problem. You start to watch the person, and she doesn't have that initiative, it's something very different. At a certain time I lost patience [...]. Over time I started to understand the disease, [...] after I started to understand the disease things got better (F5Husband).

In this perspective, a broad and problem-solving social network, in which professionals provide preparation, welcoming, support and orientation, can contribute for families to take charge of their role as caregivers and to turn into an effective basic health unit, capable of solving daily-life problems^(7,14). Often, however, health professionals have an idealistic view of the family and expect it to be able to produce *care, protection, learning of affection, construction of identities and relational bonds of belonging*. Thus, families can grant their members a better quality of life and social insertion⁽¹⁰⁾.

It should also be taken into account that the family lives in a given context and at a given moment in its trajectory, where and when its potential can be compromised, and it equally needs care and equipment for care⁽⁹⁾. But it should also be considered that the family, independently from its limitations and even when equipped for care, can choose not to do this.

Conception of mental health-mental disorder from families' perspective

Participants expressed that mental health means a balance between thinking and doing, being able to perform activities and establishing relations. On the other hand, they define mental disorder as limitation, commitment to accomplish daily activities, which affects the individual's life as a whole. Besides, they said that it is difficult to live with this situation:

Health, not just mental health, is not just absence of disease, it means feeling well, it means being able to do things at one's own rhythm, living together, being able to work, think, study, laugh, it means being able to participate. The disease is the opposite, it's the difficulty the human being faces, to manage and do the things characteristic of being, working, studying, relating, suffering to do things (F4Mother).

When the problem happened with my son, the feeling I had is that there are levels of mental health, various platforms, [...] I couldn't see a very big distinction between the mental patient and the rest of the population in general, that's because, in my concept, there were levels. But I see that there's a basic issue with the mental patient, as a mother you create an expectation for the person's development, there's an issue which is that person not projecting himself, not falling in love, I understood that, that my son's greatest limitation is not falling in love, he doesn't fall in love not even with an idea, neither with a job nor with a person [...] there's really a shortage, a limitation [...] today I'm aware that it's not just another level (F1Mother).

Having a mental problem generally affects the being in a continuous and complete way. The person needs help, is lacking [...] when you're mentally healthy it's very good because you're in harmony, that affects what you can do, what you program and do in a way that is well understood, well accepted (F2PMD).

The concept of mental health and mental disorder is abstract and subjective, as it cannot be observed. What is concrete, and can therefore be observed and classified, are the different manifestations of behavior⁽¹⁵⁻¹⁶⁾.

What expresses the mental disorder is disequilibrium in human dimensions, whether physical, psychic, emotional, cultural, manifested by feelings of sadness, anguish and suffering. Another important aspect is that the disease interferes in the subject's relations with the family, the community, and is closely related with his/her quality of life⁽¹⁶⁾.

Mental health means the ability to deal with the requirements and limits daily reality imposes. It means elaborat-

ing and working with emotions and feelings, whether pleasant or not; with social, family and professional relations; with differences in ideas and options, and reserving moments of leisure, among so many other things. To be mentally healthy, however, balance is needed between the biological, psychological and social aspects, besides feeling well with oneself and other people⁽¹⁷⁾.

Human Being: a being with relations

For the study participants, the human being is unique, special, does not manage to live in isolation, is understood as a being with relations who, with his qualities and limitations, needs to receive love, attention and affection. Despite the limitations the mental disorder imposes, these people are human beings able to perform activities and need to be treated with respect and dignity:

Human being is a being who needs affection, kindness to develop, to be able to participate in everything, in the world and to actually feel like a human being. The base of everything is needed, which is respect and affection (F1Sister).

I am a human being, so are you, she is with all of her problems, my son is [...]. I have my flaws, but I think that respect for one another, it means when we try and live well with everyone, accept them the way they are (F2Mother).

That's what he goes through, it's not solved, it doesn't go back to normal, but he has his intelligence, affection, kindness, need and silence too, which involves all this and where we cannot penetrate, but that's also part of us, so many areas in our life contain silence, there's something we cannot pronounce, we cannot have access to (F1Father).

[...] he (the son) does quite a large part, he helps a lot, collaborates a lot, there are many things he can actually do (F4Mother).

Human beings are rational, intelligent to make choices, granting them decision power and making them responsible for their actions. They are unique, affective and need to establish bonds and social networks to guarantee their survival. Human beings are multidimensional as, besides the biological aspect, the psychological, spiritual and social need to be taken into account, and that is what makes them singular and complex⁽¹⁶⁾.

For the participants, human beings, independently of their limitations, are marked by a particularity: the power to reflect and express what they feel. Hence, they are beings with both positive and negative feelings, and this characteristic of feeling and being able to express emotions distinguishes them from other living beings⁽¹⁶⁾.

The family's feeling towards the mental disorder

The participants expressed that, in most cases, when facing the mental disorder diagnosis, the family feels impotent, weakened, guilty and can deny the existence of the disorder. They show their frustration regarding their expectations for the development of the relative who got ill, and mention

not knowing how to help. If the problem were physical, on the other hand, they would be able to deal with the situation better, according to the following statements:

[...] it's not easy. I think the mental illness is the worst because there's not much to do, if it's another disease you pass a remedy on your leg, treat it, give a medicine against pain, we don't know what to do with this, I get really desperate, at first I struggled a lot because I didn't want to accept that my daughter had this, I wanted her to be good, I didn't want her to take drugs, I didn't want any of this (F3Mother).

There's nothing sadder for parents [...] you see your child suffering like that and there's not much you can do, because I think like, if it's physiological, it's a dressing, a surgery, you're there, help, relieve the pain, now, with emotional suffering you can't help (F4Mother).

[...] he'll never be an independent professional as I thought he would be when he was small. According to his performance in school, the student he was, there came a certain time when, it won't work, it's not that [...] there's really a deficit, a limitation, he won't be autonomous, he won't take risks, he won't fall in love, he won't. He's gonna stay her, at our house, work with us, work at the association (F1Mother).

[...] I used to blame myself a lot for his disease, now I don't blame myself anymore [...] (F2Mother).

The difficulties the families face in the relation with the reality of the mental disorder are permeated by a time gap (patient-family-society), feelings of guilt (the family does not understand what it did wrong, how it did not perceive the symptoms earlier), loss, communication and interaction difficulties and family conflicts. The non-remission of mental patients' symptoms, their social failures and *abnormal* behavior contribute to the emergence of tensions in the family core, which alters its daily routine⁽¹⁴⁾.

Family members experience the mental disorder unequally, each member elaborates this process differently. For the family, in general, it represents "the collapse of efforts, the certification of the inability to take adequate care of the other, the failure of a life project, the wasting of many years of investment and dedication"⁽¹⁸⁾.

A study⁽¹⁹⁾ involving families of schizophrenic patients supports (F1Mother)'s statement, revealing that the mental disorder diagnosis is reached unexpectedly, jolts expectations for the sick person's future, as the children's formerly healthy development did not allow the parents, at first, to accept the restrictions the mental disorder causes.

Besides, it should be considered that the mental disorder affects not only the sick patient's life, but reflects the group's experience. Each member interprets it and mobilizes feelings in a unique way. The disease is an adverse and unexpected event that disorganizes the family's way of being, demands a new organization and adaptation to the new situation⁽⁹⁾.

The family's perception about treatment spaces and mental health treatment

As for the treatment of the mental disorder, participants expressed that, for treatment to be effective, patients need to be aware of their condition and want to find help. That includes medication treatment adherence. They also consider that treatment should include other activities.

There's no mental health treatment that works with drugs only (F3PMD).

My daughter went through so many and so difficult phases that I had to give her medicine in hiding as she couldn't take it and, if she didn't, she wouldn't leave hospital (F3Mother).

The importance of pharmacological therapy in mental disorder treatment is undeniable, and it would be utopic to think of deinstitutionalization before psychopharmacology. This resource, however, should not be used in isolation, but associated with other treatment alternatives available for mental patients, allowing them to express themselves and gain the highest possible level of autonomy, as the lack of activity negatively influences improvements in their health condition and behavior⁽²⁰⁾.

The participants also reported intense suffering due to their relative's internment at a psychiatric institution, but that this is the only way out they find in certain situations. They also consider the psychiatric hospital part of the support network when symptoms get worse. The participants perceive the transformations in care delivery to mental patients, due to the ongoing psychiatric reform movement in Brazil, as important strategies for care humanization:

[...] that's the good side (referring to ongoing changes in mental health care), this opening is very good, mainly even questioning a little [...] because, in the end, segregating as if it were a shame? Because mental illness has a meaning for the family and for society, so it's a way of reflecting this entire situation, as a whole (F6PMD).

At home, we do whatever we can and can imagine not to reach this point (need for internment), because his internments meant a lot of suffering, the human being suffers so much when in crisis, when an episode happens and then we know we have to accept the internment (F4Mother).

It was horrible, I've lost track of the more than 10 times he was interned, and suffered, some day I wanted to cry because I endured the situation as far as I could, when I saw it didn't work I sought help to get interned because, alone, at home, I didn't have a husband, there was no other man to help me, what was I going to do with him with different attitudes, it was harsh because he didn't accept it. So it always had to be somewhat by force (F2Mother).

[...] there are both sides, of safety, care, having a multidisciplinary team, having a fixed routine, but there's also the side of being taken from one's family environment, from one's home (F1Mother).

All participants report suffering when their relatives are interned at a psychiatric institution, as they feel impotent, and this situation disorganizes daily routine. When families decide to seek help from health services and sometimes request the internment of the member with a mental disorder, this happens because they normally can no longer sustain the situation, do not know how to act in view of certain behaviors, accompanied or not by delusions and hallucinations. When adopting this discourse, however, health professionals mostly label families as uncooperative and unwilling to take their of their relatives^(7,11).

Another noteworthy aspect is the importance participants attribute to treatment in community mental health services:

[...] my son, when he discovered the CAPS it was really good for me, for him too, I'm sure he'll say it was, because the internments stopped, he has never been interned since, he became aware that he needs to take the medication (F2Mother).

In the substitutive service mode, Psychosocial Care Centers (CAPS) are open community services that function within the Unified Health System (SUS). They arise as an innovative therapeutic strategy, emphasizing interdisciplinarity and multiple intervention forms. These characteristics are in accordance with the new mental health care model. Through care delivery to the population within its range, the goal is to guarantee access to work, leisure, recover citizenship and reintegrate mental patients in their cultural and social environment, so that they can coexist with society and their family. This practice takes into account each person's subjectivity and individuality in his/her concrete experience of existence-suffering⁽³⁾.

It is fundamental, however, to expand the community network of mental health and rehabilitation programs capable of offering support to the families, welcoming difficulties so that the family can actually serve as an important facilitator in the psychiatric care reorganization process that is ongoing in Brazil⁽¹⁹⁾.

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CONCLUSION

Experiencing care practice with families of mental patients means working with their suffering, their frustrations and the binomial denial-acceptance of the mental disorder, which mobilizes feelings and perceptions in those involved.

In this study, it was evidenced that families need to talk, share their experiences, have someone to listen to their anguish and victories they conquered in treatment, in the relationship with relatives and in the discovery of coping strategies.

It is highlighted that the family's role is taking care, encouraging, being there, being safe and reliable support, as the family sphere is where its members look for support and understanding and discern possibilities. The family's relation with the mental disorder patient is sometimes tense, but when the symptoms deriving from the disorder are under control, contacts can be harmonious. This means understanding the human being with mental disorder as a unique being with abilities and who, despite some limitations, is able to relate him/herself and develop activities.

The small number of participating families, i.e. six in a universe of 56 invited to participate, is highlighted as a study limitation. This marks the need for mental health professionals to develop further research on this theme and include these clients. These data underline the need for mental health professionals to try and include family members into therapeutic projects of their relatives with mental disorders, with a view to behavioral change to participate in activities that permit sharing, as well as knowledge acquisition about mental health, mental disorder and the family-patient relation.

Also, difficulties to mobilize the family to participate in moments like what was offered in this study can be related with a recent past of treatment history in this area, where the family should remain distant from treatment and health professionals took the sole responsibility for care. Further research on this theme can contribute to expand data in order to equip professionals and family members to understand the different aspects involved in this phenomenon.

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