

Family relationships with people who have bipolar affective disorder

A relação familiar com pessoas que possuem transtorno afetivo bipolar

La relación familiar con personas que tienen trastorno afectivo bipolar

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Abstract: Objective: to know the perspective of family members about the relationship with people who have bipolar affective disorder. **Method:** qualitative study carried out with seven family members. Data were collected through interviews in March and April 2014 and analyzed according to content analysis. **Results:** the relationship is based on the way in which the family organizes the support network between its members and the challenges in everyday family relationships. Among the challenges are mood changes, emotional, physical and financial overload, difficulty in adhering to the use of psychiatric drugs, and non-acceptance of the diagnosis. **Final considerations:** it is important to embrace and provide moments of listening to family members in health services so as to understand their needs and implement assertive strategies to improve the care provided by the health team.

Descriptors: Family; Family relationships; Bipolar disorder; Mental health; Nursing

Resumo: Objetivo: conhecer a perspectiva de familiares acerca da relação com pessoas que possuem transtorno afetivo bipolar. **Método:** estudo qualitativo, realizado com sete familiares. Os dados foram coletados por meio de entrevista, em março e abril de 2014 e analisados conforme análise de conteúdo. **Resultados:** a relação está pautada no modo com que a família organiza a rede de apoio entre seus membros e os desafios no cotidiano das relações familiares. Entre os desafios, encontram-se as alterações de humor, a sobrecarga emocional, física e financeira, a dificuldade na adesão ao uso de psicofármacos e a não aceitação do diagnóstico. **Considerações finais:** é importante

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acolher e proporcionar momentos de escuta aos familiares nos serviços de saúde, para que seja possível compreender as suas necessidades e implementar estratégias assertivas de melhoria da atenção pela equipe de saúde.

Descritores: Família; Relações familiares; Transtorno bipolar; Saúde mental; Enfermagem

Resumen: Objetivo: conocer la perspectiva de parientes sobre la relación con las personas que tienen trastorno afectivo bipolar. **Método:** estudio cualitativo, llevado a cabo con siete parientes. Los datos se recopilaron mediante entrevista, en marzo y abril de 2014, y se analizaron según el análisis de contenido. **Resultados:** la relación se basa en la forma en que la familia organiza la red de apoyo entre sus miembros y los retos en el cotidiano de las relaciones familiares. Entre los retos, se encuentran los cambios de humor, la sobrecarga emocional, física y financiera, la dificultad para adherirse al uso de psicofármacos y la no aceptación del diagnóstico. **Consideraciones finales:** es importante acoger y brindar momentos de escucha a los parientes en los servicios de salud, para que sea posible comprender sus necesidades e implementar estrategias asertivas para mejorar la atención del equipo de salud.

Descriptor: Familia; Relaciones familiares; Trastorno bipolar; Salud mental; Enfermería.

Introduction

The Brazilian psychiatric reform was a movement inspired by Italian democratic psychiatry that aimed to deconstruct a reality based on the perspective of asylums through deinstitutionalization. Thus, deinstitutionalization is seen as a deconstruction of psychiatric knowledge and practices in which the production of life for individuals in different social spaces starts to be valued.¹ It is emphasized that, through the psychiatric reform, people who had mental disorders had their rights guaranteed and were gradually reinserted into families and society.

Bipolar Affective Disorder (BD) is among the mental disorders that affect the population and causes psychological and social changes. With regard to social changes, there are personal, family and social difficulties. This disorder is related to the incidence of relapse and has the potential to disable people because of the barriers, losses and limitations with which people have to deal in different spheres of daily life.²

Bipolar disorder involves mood and affects people of both sexes, aged thirty years on average, and may occur in two poles, mania and/or depression. The causes of this disorder can be related to heredity and stressful situations. The person affected suffers constant mood

changes and this situation can cause suffering for himself/herself, and for the family and the community.³

The presence of a person with BD in the family changes its dynamics and the way in which intra-family relationships occur, generating wear and tear and requiring understanding in the face of unusual behaviors presented by the affected person. The family caregiver stands out among the family members because he/she is the one who assumes the greatest responsibility in daily care, and the existence of such assigned duty may make this caregiver to experience exhaustion and suffering in view of the range of feelings he/she needs to deal with.⁴

Mental health is built from the interaction and protagonism of the people involved, assuming that family members are fundamental in the construction of psychosocial care. Listening to them and valuing their knowledge and understanding, knowing about the family relationships with people who have BD, can be a way to improve the work with families in this field.⁵

In this sense, it is considered important to understand how family relationships with a person who has BD take place because this understanding will make it possible to reflect on the needs of families and the changes that are essential in health services, taking a holistic view to place the family in evidence.

Given the above, this study had the question: how do family relationships with people who have BD take place from the perspective of family members? And the objective was: to know the perspective of family members about the relationships with people who have BD.

Method

Qualitative, exploratory and descriptive study conducted in an Association to support people with BD, family and friends, linked to a University Hospital in the countryside of the

state of Rio Grande do Sul, Brazil, which provides care through the Unified Health System (SUS). The Association is a non-profit entity that offers a therapeutic approach based on the psychosocial paradigm, that is, people-centered care, pointing to the unique dimensions of human living, valuing the subjective and objective aspects and considering biological, cultural and social dimensions.⁶ This scenario was chosen because it is in the Associations that family members find the cooperation and support necessary for living and caring for people with mental disorders.

In order to participate in the study, the following inclusion criteria were adopted: being a relative of people with BD, over 18 years of age, a member of the Association to support people with BD, family members and friends. Seven family members agreed to participate in the study, with an age range of 20 to 61 years and the following degrees of kinship: sister, aunt, child, mother and cousin. To ensure the secrecy and confidentiality of family members, it was decided to use the letter 'F' (Family member), followed by a number (F1, F2 ..., F7).

Data collection took place between March and April 2014, through an open interview with each participating family member. The following question was asked: how does the family relationship with (name of the family member diagnosed with BD) occur? Some interviews took place in a private room at the University Hospital and others at home, in previously scheduled visits, according to the availability of the family members. Interviews were recorded on an audio device. The time for each interview was not limited, but the average duration was 50 minutes. The closure of the interviews occurred when there was theoretical saturation, that is, it was interrupted when there was no addition of new pertinent information to support the desired theorization.⁷

Data analysis was made through Content Analysis, following its three stages: pre-analysis, material exploration and treatment of results, inference and interpretation. First, with the help of the Atlas Ti 7.0 software, the first inferences of the transcriptions of the participant's

speeches were made. Then, the raw data were treated, highlighting similarity and difference points present in the content. The results were grouped into categories and related to relevant literature, so that the family relationship with the person with BD from the perspective of family members was understood.⁸

The study met the ethical requirements present in Resolution number 466/2012 of the National Health Council, initially being presented to the Board of the Association, which granted the authorization letter. The study was approved by the Human Research Ethics Committee of the Federal University of Santa Maria under Opinion 460,037, of November 18, 2013, and CAEE number 23017413.1.0000.5346. Anonymity of family members was ensured by reading and signing two copies of the Informed Consent Term, one of which remained with the participant and the other with the researcher.

Results

Two categories emerged from the analysis of the interviews: Family support as a facilitator of the family relationship, and Being a family member of a person with bipolar affective disorder: challenges in everyday relationships.

Family support as a facilitator of family relationships

For family members, the primary source of support for the person with BD is the family itself. In this sense, family members consider family support to be essential. However, they recognize that some family members do not know how to support and embrace the person with BD.

[...] What helps a lot is having the support of the parents, who take care of her and take care of her daughters. What does not let her give up entirely is the support of the family. (F2)

Monitoring the family is important. I see the difference from my other sister [person with BD], who is just her and her husband. The husband does not share in much; he doesn't know how to handle everything. (F1)

The role of the family for the person with BD is attributed to being present, to avoid social isolation, and to include the person with BD in daily activities. Understanding the health condition provides the family with a greater understanding of the possible limitations that this psychopathology can cause in family relationships.

I try to create a lot of activities, in the sense of: “let's go out for dinner, let's go out for lunch”. I try to give the best possible comfort. From material issues, to psycho-emotional issues. I have a wider view because I know about the disease, I understand how the disease works and I try to be as patient as possible. (F6)

The effectiveness of the treatment is related to the way the family relationship is built. In this perspective, family members consider that drug treatment is something important, but it is complementary to family care.

[...] Our other brother who doesn't live here doesn't know the reality. In his opinion, she [person with BD] does the treatment and is doing well. He thinks it's just the medication. He thinks attention from the family is not necessary; that it doesn't have any influence. And it does have an influence [...]. (F2)

If she takes the medication, goes to the physician, comes home and whoever lives with her mistreats her, shows no consideration, this makes treatment useless [...]. (F7)

Family members directly involved in care aim to have emotional support and help from other family members. However, they realize that family members who are not close, perhaps due to little understanding of the diagnosis, of the affective instability, the symptoms and the behavioral changes, tend to be distant, making the family relationship with the person who has BD difficult.

I have cousins who don't spend much time with her [family member who has BD]. I see that they have no patience, they don't give attention to the matter. They ignore the family because of this disease [...]. (F5)

[...] My sisters, I think they are a little negligent. They could come here sometimes to visit. They avoid contact because she is bipolar. They don't know how to deal with it. And it causes suffering. (F6)

Family members express their concern about the attention and care provided. They mention that excessive care, for fear of re-hospitalization, could interfere with the exercise of the autonomy of the person with BD.

Sometimes, because of the care we have, we suffocate her. It may be excessive, but if we don't have this care, we know the consequences, because of the hospitalizations that she had [...]. (F2)

The fact of having a person who has TAB in the family significantly changes the way the other members carry out their day-to-day activities. Family members try to develop fraternal activities, but feel insecure and apprehensive about the future, care, treatment and about possible events.

[...] We have meetings, have lunch together, and have dinner. And there are always happy moments. You can live life like that. But I don't know what it will be in the future. This even scares me at times. (F5)

This category showed that the family relationships with a person who has BD are related to the way the family is organized to provide care. Thus, knowledge about the health condition, symptoms, management and treatment and the strategies developed have a direct influence on the prognosis of the disorder. It is observed that the family constantly reorganizes itself to keep its relative inserted.

Being a family member of a person with bipolar affective disorder: challenges in everyday relationships

The family relationships with a person who has BD imply experiencing situations that are related to the symptoms of this psychopathology. At times these circumstances lead to challenges and difficulties, causing the caregiver to become emotionally overwhelmed and burdened, which can negatively change the relationship with the family. The oscillations

between the manic phase, in which hetero-aggressiveness (aggression towards others) is a behavior manifested, and episodes of depression, with some manifestations such as crying, are considered a challenge in daily family relationships:

She attacks with the answer she gives [...] sometimes, she offends us without realizing it. Sometimes, I get upset about what she says to me. But, then I leave it like this [...]. (F1)

[...] Sometimes, she is fine and, sometimes, she is aggressive. She didn't want to socialize with people [...] Her emotions are much stronger, sometimes, she is very well, happy, playing with the children and, sometimes, she spends all the time crying. (F3)

Aggressive behavior represents a barrier to family relationships, causing situations, sometimes unsustainable, of disagreements that, in consequence, lead to isolation and withdrawal from living with other family members.

[...] Until recently, we always sided with him. Until he attacked his father. Since then, he has been estranged from his family. (F7)

Among the challenges that are evident in family relationships, we highlight the cyclical changes in mood and the need for the family member who is the caregiver to have a preserved space to allow him to develop activities inherent to his/her private life.

[...] Whatever we say, she cries a lot, things are very extreme. So, you have to give a warning: she rages, makes exalted gestures and you have to set limits so that there may be a beneficial coexistence for both. I also have my space, I have my life, and she has to respect that. (F6)

Overload was mentioned by family members as an experienced circumstance resulting from the changes that happen in their lives, which cause emotional, physical and mental exhaustion. Family members, especially caregivers, sometimes want to get away from social and family life and give up caring. The feelings of affection and zeal are some reasons that lead them to maintain a caring relationship.

[...] There are times when we, caregivers, want to give up, because it is very tiring. It is not just the bipolar individual who suffers; everyone who is involved suffers a lot. Sometimes, family members, friends are more overwhelmed than the bipolar person because they have to live in function of that person, they have to take care of the medication, they have to take care for them not to have a crisis [...] And the parents, it is difficult for them. Because nobody wants to see a sad son. That's why they don't give up. (F2)

[...] Nowadays our relationship is good, I try to ignore certain things and understand that it is a disease. But at the same time, there are times I can't take it. So, I think the relationship just isn't really better because this is a disease that hurts. [...] It affects not only the subject who is suffering from that, but also those who are at home, the family members themselves [...]. (F4)

Among the challenges of having a member with BD in the family are routine changes in terms of schedules, attending school and working. In addition to daily tasks, family caregivers must also perform activities that would be the responsibility of the person with the disorder, such as household chores and the care of other people, such as younger siblings.

[...] There were days when she went until dawn and we couldn't sleep well and the next day I had class in the morning. There were days when she was in some depressive condition, she slept all day practically, and the things in the house stayed there. I had to take on this role of taking care of the house and of my brother, who is younger [...]. (F4)

Due to my work schedule and activities, I can't be very present at home. And when I'm there, she really wants my attention. This is a problem because I have my life. I have my other things to handle [...]. (F6)

In episodes of mania, impulsive behaviors can generate physical risks and moral damage for family members. Compulsion for purchasing was mentioned among the manifestations of this phase of the disorder, causing a financial burden for the family.

Sometimes she would go out, buy a lot of things. And then my father didn't even know how he was going to pay for it. (F4)

For family members, mood changes such as euphoria and psychotic symptoms related to hallucinations and delusions represent the biggest challenges in the family relationships with the person with BD.

The day-to-day is soft [...]. But there are some issues related to her mood instability that make things a little complicated [...] sometimes she is very euphoric, she is a person who has a very difficult temper. (F6)

The problem is that she was getting slowly worse and worse, because she started hallucinating. She was creating a universe for her as if that was real. (F4)

In some situations, because of emotional exhaustion, suffering, impotence and lack of perspective of changes in the way of living, family members who live with the person with BD appeal to alternatives that allow them to move away from this scenario, as a way to preserve themselves and avoid further damage to the family relationship.

[...] She [daughter] said: I left the house because of him [brother who has BD]. I didn't want to leave, I wanted to stay in my place, I didn't want to get married yet. I went because I couldn't take life with him at home anymore [...]. (F7)

The non-acceptance of the diagnosis by the person with BD makes adherence to the use of psychotropic drugs difficult. The reluctance to use psychotropic drugs was perceived by family members as a challenge for care and interaction. For the family, the return or worsening of symptoms caused by the interruption of medications destabilizes the family dynamics, generating frustration, discouragement and anxiety.

[...] He doesn't like people saying that he takes medicine. He doesn't like to be told that he is undergoing treatment and that he has this type of problem. He doesn't accept it. (F7)

When she started to feel a little better she just didn't take the medication. All the symptoms came back. That fight again and we couldn't take her to the physician, my father didn't know what to do [...]. (F4)

The family relationship with the person who has BD tends to be difficult when he does not adhere to the correct use of psychiatric drugs. However, coexistence can be harmonious when symptoms are controlled.

The day-to-day, when he was with us, it was very good, when he was not in crisis, it was good. (F7)

Being a family member of a person with BD imposes a number of challenges on the family routine, in which hetero-aggressive behaviors, mood changes, psychotic symptoms and emotional, physical and financial overload, refusal to adhere to the use of psychiatric drugs and non-acceptance of the diagnosis may sometimes be present.

Discussion

The Psychiatric Reform in Brazil initiated in the 1970s has Law 10.216/2001 as an important landmark. This law aims to achieve the recovery of people with psychological distress - who were formerly isolated in asylums - by insertion in the family, work and community.⁹ However, family caregivers do not always have the cooperation and support necessary to supply the instrumental aspects of family functioning (routine aspects of daily life such as eating, preparing meals, administering medications), among others.

For the relatives of people with BD, this is an important aspect, as the changes in the daily routine take on greater significance due to this disorder in the family member.¹⁰ This is directly related to the reasons that lead the relatives to seek the Associations, because these entities fill a gap that exists in the assistance to families within mental health services, which do not always provide spaces for family members to share their feelings and to manage to live in a less arduous way with the manifestations resulting from mental disorders.³

The understanding of the diagnosis and the search for specialized assistance to the sick family member occur progressively, that is, as they become aware of the processes they are

experiencing. Thus, in certain situations, mental health team professionals need to offer conditions to make it possible to maintain healthy family relationships. The family is, most of the times, the embracing support for the clarification of doubts that may arise in relation to the period that is being lived by the person who has BD.

This support can come through care that provides access for the person with BD and their families to the Psychosocial Care Network (RAPS), promoting the link between them and the points of care, such as Primary Health Care, Specialized Psychosocial Care, Urgent and Emergent Care, Transitional Residential Care, among other services.⁹ This articulation must therefore be built so that ways of thinking and acting in mental health can be expressed, consistent with the valorization of people, their life context, their demands and needs.¹¹

In this sense, the role of nurses is important. By developing therapeutic and educational actions with family caregivers, they can effectively contribute to the family relationships with people with BD. Working on difficulties and promoting knowledge about medications, therapeutic plans, and everything that involves treatment and diagnosis in general, can contribute to reducing intrafamily conflicts.¹² It is also worth highlighting the importance of research that enables a connection with daily family relationships, which take into account individual fluctuations and choices, without this being subject to judgment.¹³

At times, there are difficulties in providing care to family members who have BD, with regard to provision of adequate care, especially in episodes of crisis.¹⁴ As evidenced in the present study, the attention given to people with BD can be excessive due to fear of new psychiatric hospitalizations. In general, hospitalization happens when suffering is present among family members and when they cannot find other solutions besides this one.¹⁵

Non-adherence to psychotropic drugs directly interferes in family relationships because it may cause behavioral changes and instability of the bipolar person. According to a survey that evaluated adherence to drug therapy by people with mood disorders, most participants had

already forgotten to use the medication every once and a while. However, noticing an improvement or worsening of their condition was not a reason for interrupting treatment.¹⁶ The perception of improvement in symptoms by the person who has BD is considered a factor for discontinuing the use of psychiatric drugs.

Some situations are considered challenging in the daily lives of family members, as they weaken the family nucleus and relationships, demanding patience and affection. They include, for example, moments when the person with BD presents hetero-aggressive behavior, as well as non-acceptance of the diagnosis, physical, emotional and financial stress, and an increase in daily tasks, resulting in family burden.

Support for family participation in therapeutic groups and participation in Associations can be a support strategy, providing a space for listening, clarification of doubts, alleviating the suffering before care demands. For professionals, these spaces provide a better understanding of the family context and the reality in which they are inserted, and thus provide adequate support, focusing on the needs of people in psychological distress and their families.¹⁷

Based on the ideals of the psychosocial paradigm, the results of the present study showed the importance of the role played by the family in caring for the person who has BD. It also pointed out the need for a different look and support from health professionals to family members.

Final considerations

The family relationships with the people who have BD can be positive, influenced by the existence of family support in care. However, there are difficult moments related to the manifestation of exacerbated symptoms of the psychopathology, which may be linked to

adherence to the use of psychiatric drugs and acceptance of the diagnosis by the family member who has BD. There are challenges to be overcome in terms of comprehension on the part of the family regarding the needed care, and understanding of the diagnosis in its complexity by family members and by the person with BD.

As a reflection of the current mental health care model, family members perceive the territory and the family as the main place of care. They did not mention the hospital as the first option for care, but rather the family nucleus that when well-articulated has the potential to avoid readmissions.

It is noteworthy that the family members pointed out the difficulties in the family relationship, but they did not mention whether they have support or who provides this support to ease the burden. Therefore, the results of this study emphasize the importance of embracing family members in health services, aiming at a greater understanding about their needs and perceptions in listening moments for the implementation of assertive strategies for improving care by the healthcare team.

As limitations, family members of only one specific Association participated in the study, not covering other scenarios of mental health care. The realization of further investigations such as the present one may point out other aspects, not shown here, related to family relationships with people who have BD.

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Interpretation of data and writing and critical review.

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