

ACCEPTANCE OF PATIENTS WITH MENTAL ILLNESS: A FAMILY PERSPECTIVE

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ABSTRACT

The aim of this descriptive and qualitative study is to analyse how acceptance of mental illness is perceived by family members of the patient and the surrounding community. This study was conducted with the help of 10 families of patients with mental disorders admitted to the psychiatric emergency unit of the Municipal Hospital of Maringá, state of Parana, Brazil. Data were collected from October to December 2010, in open interviews and submitted to thematic content analysis, resulting in three categories: "Care, a constant requirement", "Living with a patient with mental illness: a whirlwind of emotions", "A wall constructed with stigma and prejudice: the need for deconstruction". The conclusion is that an understanding of the disease is vital for acceptance of the illness itself and of the patient, and that healthcare professionals must remain close to the family to provide support, answer queries related to the disease, and help the family to face the difficulties of everyday life.

Descriptors: Family. Mental Health. Nursing.

RESUMO

Neste estudo descritivo, de natureza qualitativa, realizado junto a 10 familiares de pessoas com transtorno mental egressas da emergência psiquiátrica do Hospital Municipal de Maringá - PR, o objetivo é apreender de que modo é percebida a aceitação da pessoa com transtorno mental na família e na comunidade. Os dados, coletados no período de outubro a dezembro de 2010, em entrevista aberta, foram submetidos à análise de conteúdo, modalidade temática, da qual resultaram três categorias: "Cuidar, uma necessidade constante", "Convivendo com a pessoa com transtorno mental: um turbilhão de sentimentos", "Um muro construído com estigma e preconceito: necessidade de desconstrução". Conclui-se que a compreensão sobre a doença é essencial para aceitá-la e aceitar ao doente, e o profissional de saúde precisa estar próximo à família, dando-lhe suporte, esclarecendo dúvidas relacionadas à doença, e apoiando-a para que enfrente as dificuldades que emergem no cotidiano.

Descritores: Família. Saúde mental. Enfermagem.

Título: Aceitação da pessoa com transtorno mental na perspectiva dos familiares.

RESUMEN

Este estudio descriptivo de naturaleza cualitativa realizado con 10 familiares de personas con trastorno mental alejadas de la emergencia psiquiátrica del Hospital Municipal de Maringá-PR, tiene el objetivo de aprender cómo los familiares perciben la aceptación de la persona con trastorno mental en la familia y comunidad. Los datos, fueron recolectados en el período de octubre a diciembre 2010, por medio de entrevista abierta y sometidos al análisis de contenido de modalidad temática. Lo que resultó en tres categorías: "Cuidar, una necesidad constante"; "Conviviendo con la persona con trastorno mental: un millón de sentimientos" y "Un muro construido con estigma y prejuicio: necesidad de desconstrucción". Se concluye que la comprensión de la enfermedad es esencial para la aceptación de esta y del enfermo. El profesional de salud necesita estar cerca de la familia para darle soporte, Aclaraciones y dudas relacionadas a la enfermedad y apoyar en el enfrentamiento de las dificultades que surgen en la vida cotidiana.

Descriptores: Familia. Salud mental. Enfermería.

Título: Aceptación de la persona con trastorno mental en la perspectiva de familiares.

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INTRODUCTION

Around 3% of the Brazilian population suffers from a serious mental disorder and more than 12% require mental health services at some point in their lives⁽¹⁾. In light of such expressive case numbers, it is important to identify the manner in which family members and the community cope with a patient with a mental disorder (PTM), how acceptance of mental illness in both environments occurs, and which are the everyday difficulties the family must face when caring for the patient.

The essence of Mental Healthcare – which includes assistance for the family and community of the patient with a mental disorder (PTM) – started with the Psychiatric Reform that was debated in Brazil in the 1970s with the main objective of de-institutionalizing this types of disease: reintegrating the patient to society based on a return to the family environment and consequently reducing the number of psychiatric hospital admissions⁽²⁾.

For this change to occur, a transformation was needed in the mental health service system, which adopted the main goals of: ensuring healthier co-existence of patients with mental illness in the family and social context; supporting and aiding family members and patients with their difficulties and clarifying doubts of all the parties involved in this process⁽³⁻⁴⁾ in order to strengthen the patient-family-community bond and favour social acceptance of the disease itself and of patients with mental illness.

Living with this patient is laden with difficulties given a temporal imbalance caused by incompatibility between the pace of the patient's life and the lives of family members, which generates emotional and physical tension, guilt of family members in relation to appearance of the illness, financial burden and conflict and losses of varying degrees^(5,6). Possible alterations of the family and community structure alone justify the relevance of investigating how acceptance of this patient occurs within everyday domestic and social life, especially when considering that an understanding of the illness is important for success of its treatment and social rehabilitation.

Greater knowledge of this issue may allow the healthcare professional – the nurse – to practice within the scope of promoting healthcare or preventing potential harm or worsening of the

illness, and proposing intervention that aims to improve the quality of life of these patients and their families.

In view of this requirement, the aim of this study was to understand how family members perceive acceptance of a patient with a mental disorder within the family and community context.

METHODOLOGY

This descriptive and qualitative study was conducted in Maringá, state of Paraná, Brazil, with family members of patients with mental illness admitted to the Psychiatric Emergency Unit of the Municipal Hospital of Maringá (HMM) in 2008. This unit is considered a benchmark in emergency psychiatric assistance for the 66 municipalities of the three Healthcare Regions (RS) in the state of Paraná: the 11th Healthcare Region (25 municipalities), the 13th Healthcare Region (11 municipalities) and the 15th Healthcare Region (30 municipalities).

Patients with mental illness admitted to the unit were located using the database of the Psychiatric Emergency Service, which contains information on monthly consultations of patients, diagnosis, identification, address, admission date and release date, among other data. The database contained records of 4709 patients that underwent emergency care in 2008. Of these patients, 2947 with diagnoses of alcoholism, drug abuse and other unspecified complications were excluded considering that the objective was to study acceptance of patients with a mental disorder of a behavioural nature. The remaining 1762 records were for diagnoses of depression, schizophrenia and mania. Subsequently, only cases of patients (606) with these types of disorders who had been admitted to the psychiatric emergency unit (for a minimum period of 24 hours) were selected, considering that admittance proves the presence of crises, which influences acceptance of the patient.

Of the 606 admission records, all duplicates were excluded, resulting in 526 records. A total of 428 of these records were for patients in municipalities of the 15th Healthcare Region, 64 of the 11th Healthcare Region, and 33 of the 13th Healthcare Region. Families of patients in the 13th Healthcare Region were selected for this study as a lower number of municipalities facilitated transportation for data collection.

Selection criteria of informants for the study were: individuals who live with a patient with a mental disorder, individuals who are 18 years old or older, and individuals who reside in one of the municipalities of the chosen region. Contact with the families was initially over the telephone and those who did not have a telephone were visited at their residence. It should be noted that several families were not located because the telephone number or address provided in the records did not exist or the family had since moved to another address.

The families of 10 patients participated in this study. Interviews were conducted with family members of 12 individuals and, considering the inexistence of impediments, in some cases more than one family member participated in the interview although usually only to agree with the statements of the main informant. In three cases, patients also participated and, in two cases, mostly due to the disorder itself, these patients took the lead and did not allow the family member to speak. For this reason, these two interviews were excluded.

Data were collected between October and December 2010, in open interviews conducted at the family residence as this environment allows family members to feel more at ease to tell their story. Interviews were conducted in a manner that family members could speak about the background of the mental disorder and recall moments of acceptance, or not, of this patient in the family or community, starting with the following revealing question: Tell me what you remember about the illness of your family member from the very first incident to the present day.

Interviews were approximately 40 minutes long. Each interview was recorded after obtaining consent of the interviewees and subsequently fully transcribed. A field log was also used to record observations and thoughts of the researcher in relation to aspects of the interview that could not be detected in the recording (non-verbal language, such as gestures, posture and facial expression).

Subsequently, interviews were fully transcribed and submitted to thematic content analysis⁽⁷⁾. This method comprises a set of techniques that allow inference based on objective content of the recorded statements and consists of three stages: pre-analysis, study of material and treatment of data⁽⁷⁾.

Pre-analysis, which is the document organization stage, comprises scanning transcripts of

the statements, statement selection, formulation of hypothesis, index selection and preparation of indicators on which to base interpretation. The material study stage consists of finding clusters and associations that comply with the aim of this study, thus creating research categories. The results treatments stage is the moment of inference and interpretation of results⁽⁷⁾.

Study development complied with guidelines established by Resolution 196/96 of the National Health Council, and the study project was approved by the Permanent Ethics Committee for Research on Human Beings of the State University of Maringá (Decision 509/2009). All participants signed two copies of a Full Consent Agreement. To guarantee anonymity, transcribed statements were identified with the letter F of family member followed by a number that indicated the order of each interview.

RESULTS AND DISCUSSION

A total of 10 family members were interviewed in this study. Of these 10 members, seven were women, four of which were mothers, one sister and one was the wife of the patient; and three were men, two of which were husbands and one was a father.

Three categories were established based on the stages of content analysis⁽⁷⁾: "Care, a constant requirement", which discussed the daily care that the family member must provide to the patient; "Living with a patient with mental illness: a whirlwind of emotions", which discussed the feelings of family members; and "A wall constructed with stigma and prejudice: the need for deconstruction", which discussed prejudice and stigma in the community and family that may hinder social reinsertion of the patient with a mental disorder.

Care, a constant requirement

Statements of family members revealed that the provision of care is always present when living with a patient with a mental disorder. Care becomes a daily requirement due to the conditions in which the patient finds him or herself.

He didn't want to have a bath, he is the type of person that wouldn't eat if we didn't force him to, he wouldn't. It's really sad. [Field Notes -NC: change of facial expression followed by crying] (F3).

We have to give her medication every day [...] She stayed at home for eleven days, without sleeping or eating. She was skin and bone, so we took her to the doctor.(F8)

Family members evidently undertook the responsibility to supervise, stimulate and even do things for the patient that he or she cannot do alone. The incapacity to complete simple household or self-care tasks is common when addressing most patients with chronic or prolonged diseases, including mental illness⁽⁸⁾.

In the statement of F3, mother of the patient, it was perceived that she is the sole caregiver and was physically and psychological overburdened. It was also inferred she does not consider caring for her child a burden, but rather as something that is inherent to her role as a mother. In her statement, she does not mention exhaustion, but a concern for her son's well-being. However, her facial expression and tone of voice showed that she was physically and psychologically overburdened in terms of living with and caring for a patient with mental illness.

In other cases, care was provided by more than one family member.

There was this one night that my daughter said, 'Dr. I want to stay with my mother. She cannot handle taking care of my sister alone'. Then he said, 'You can stay'. Then my daughter, who lives in the state of São Paulo, stayed with me, she came to help me out [...]' (F6).

It is therefore perceived that families try to find ways to organize their lives so that they may divide the tasks of caring for the sick family member, minimizing the burden on the main caregiver. This tends to occur during the hospital admission period, when there is a rupture of the family's everyday life. In spite of the extra effort involved, caregivers generally accommodate daily tasks for which they are responsible with the tasks of caring for a patient with mental illness. In the event of hospital admission, however, this planning is altered, especially when the medical team requests that a caregiver accompany the patient during the hospital stay.

Social and family support may function as a protective factor, as it tends to minimize life's stressors and promote support-providing relationships that, in turn, promote wellbeing in the entire family⁽⁹⁾. Consequently, mutual aid within the family context is the main and most important

adaptation in living with a patient with mental illness. The family is the first social network of the individual and should therefore be considered the basic healthcare unit in a model of intervention that enables the solving of everyday problems, diminishes stress of the family and the patient, and prevent relapses/crises⁽⁶⁾.

Living with a patient with mental illness – a whirlwind of emotions

Since the start of implementation of the Psychiatric Reform, family is considered essential for mental healthcare and acknowledged as a group with significant potential for the support and re-socialization of these patients. It is also considered, by healthcare professionals, as an ally for the care they provide⁽¹⁰⁾. To implement the principle of family as a basis for mental healthcare, it is important to recognize the difficulties that arise from living with these patients, especially those difficulties that may be unperceived by healthcare professionals, such as feelings and emotions.

Living with a patient with mental illness within the family context may generate a wide range of emotions, including fear of the reactions and behaviour of the patient, especially when the patient becomes aggressive that, in these cases, is often unpredictable. In this scenario, the family may feel threatened by the patient, which hinders acceptance and may trigger disinterest in helping the patient.

[...] the other day he got this axe to kill me, I ran and hid, in my neighbour's house, I hid under the bed and he said 'I want her [...]. I'll kill her and I'll kill that other one (the neighbour)' [...]' (F3).

[...] he breaks things inside the house, the glass in the kitchen is broken. We only have one car that we divide and it's all broken, he does some serious damage, did you know that?(F5)

Fear is a huge obstacle for acceptance of a patient in the family and community because it limits interpersonal relationships. In addition to this emotion, there is also shame and embarrassment of family members in relation to the inadequate behaviour of the patient, which impairs harmonious co-existence, social interaction and, consequently, acceptance of this patient in the family and social environment. For these family members, receiving

and coping with the diagnosis of mental illness of another family member may trigger a wide range of emotions, most of which are negative, such as fear, sadness, shame and pity, and a cluster of actions or effects of emotions that eventually affect the quality of life of the entire family⁽¹¹⁾.

These emotions mainly arise from the moment in which specific aspects of living with a patient with mental illness become public, considering that society does not tolerate behaviour that is not within the normal standard it has established.

[...] when she leaves the hospital, she starts to do silly things. She goes out into the street and rips off her clothes if necessary, you know, she takes everything off [...] (F1)

Exclusion of the “insane person” has perpetuated in time in such a way that, even to this day, treatment chiefly consists of labelling, treatment of symptoms based on medication and keeping a patient in a psychiatric institution, removing him or her from the family environment, the labour market and from social interaction and relationships, that is, excluding the patient from life in society⁽¹²⁾. Moreover, crises generate negative emotions in the family, and even in the moments when they are not present, they continue to haunt family members. Concern with relapses therefore becomes a constant companion, making acceptance of the patient within the family environment even more difficult.

You panic because you cannot sleep, you cannot eat, and the entire family suffers [...]. And how many times my children came here and did not have the courage to leave [...] I cried day and night (F2).

Concern is always growing, because when she is at home, I cannot work in peace all day because, yes, every time the phone rings, I think it might be her, because you just never know (F9).

Statements show that mental illness compromises the emotional and organizational structure of the family and reflects on the work and social activities of its members⁽⁶⁻¹³⁾.

Another emotion that permeates the experience of living with a patient with mental illness is guilt, which often leaves one of the most visible and negative marks in the lives of these families. They search for mistakes that may have been made in the past to try to understand and explain the

emergence of the mental disorder and thus mitigate the suffering and sadness⁽⁵⁾.

My father always says that the we felt the difference gradually, she started to lock herself in her room [...]. And then he says, you know, that he neglected the signs, that if he had seen them earlier, she would not be this way today (F4).

Statement F4 shows that the family tries to find a plausible and concrete explanation for a reality that it considers unacceptable. It searches for someone to blame to eliminate the guilt. In statement F4, the father feels responsible for the unfavourable course of the illness and mentions neglect, which is influenced by the silent and progressive nature of the mental disorder.

The idea that someone is to blame for the illness is one of the aspects that interferes in the relationship between family members and the patient. In the case of mental disorders, guilt is one of the most visible characteristics of these families as, in a somewhat conscious manner, the members tend to immerse in the search for possible mistakes in the past, incessantly seeking explanations and meaning than can diminish the suffering caused by guilt⁽¹¹⁾.

In summary, the difficulties faced by families when dealing with mental disorders tend to undermine acceptance of the patient. The non-remission of symptoms, social failure and unpredictable behaviour of the patient with mental illness contribute to the appearance of tension in the family and community, and non-acceptance of the illness in these environments⁽¹⁴⁾.

A wall built with stigma and prejudice – the need for deconstruction

Today, after the replacement of mental institutions with new healthcare units, patients with mental disorders can return to the family environment and community, which are not always prepared to receive them due to lack of knowledge and information on the illness^(15,16), leading to possible stigma and prejudice, and even aggression on behalf of the community in case of crises of these patients.

Then I remembered he left at 10 at night, because he went out for walks to almost anywhere and then two boys found him in a bad state and beat him badly, ripped his clothes, dragged him along the middle of the road and he was badly hurt, he got home all beaten and crying

[...] The third time he had a crisis, there was a police officer. He beat my son so badly that he could not stand because his foot was swollen because the officer beat my son so badly, so he hopped with one foot in the air [...] my son was so badly beaten, he did not put his foot on the floor for about 8 days (F3). [NC: crying and altered tone of voice]

Unlike the cases of crises in other types of progressive illnesses, which usually receive much attention and compassion, crises in the case of mental disorders is considered as something that deserves punishment. Consequently, statement F3 leads to the impression that violence is inherent to the condition of mental illness, and that the individual deserves to be mistreated for conduct that is considered unacceptable in a so-called “normal” person who, for some reason, at any given time, presented aggressive behaviour.

Aggression on behalf of the community causes suffering to the patient with mental illness and forces family members to feel they are incapable of protecting their loved one and preventing these events from occurring. Statement F3 shows the muffled cry for help of a mother who has no one to turn to, and finds herself before a wall that traps herself and her son and shuts out all support resources that could change this scenario and provide the necessary aid.

One of the types of violence that mostly affects the patient with mental illness is interpersonal. This type of violence occurs in the relationship with neighbours and strangers in the streets and can be characterized by stigmatizing comments, senseless humiliation and abuse, such as throwing stones or frightening the patient⁽¹⁷⁾.

Another modality of violence is institutional, which specifically includes discrimination in the healthcare sector itself, in situations when the patient is ignored, neglected or denied care that may lead to worsening of the illness or even death of the patient. This type of abuse includes violence caused by the healthcare professionals and violence that characterizes healthcare services as a whole, branded as institutional culture⁽¹⁷⁾.

Regardless of abuse, however, it should be emphasized that this type of behaviour does not merely cause suffering to the patient. It also affects all family members who must watch those who are supposed to treat and protect the patient oftentimes resort to violence and aggressive behaviour.

Another difficulty this type of patient must confront is reinsertion into the labour market. Lack of knowledge and information lead the community to believe that these individuals are incapable of completing work activities, which pushes them to the margins of society.

Sometimes she gets desperate, and she says, I go to the factories to get work, I go into the shops [...], but she can't get a job, she can sense when people are looking at her with prejudice, so I tell her, ignore them, don't let it affect you (F7).

The patient with mental illness is discredited in the capitalist system because he or she does not produce like other people and is therefore excluded from productive life, resulting in unemployment and financial difficulties for the family⁽⁸⁾. On the one hand, the general population is not informed on the limitations and potentialities of these patients and, on the other, there is no support from public institutions that could enable them to work.

She is working as a seamstress, she started working again about three weeks ago and she is getting better [...] (F10)

Work activities allow the patient to become financially independent, which is valued by the family, and the patient is considered an active member of the family, which contributes to acceptance. In this context, the nurse plays a fundamental role: facilitating the process of reinserting the patient into society. This process may occur by means of lectures that clarify specific characteristics and aspects of the illness and demystify the incapacities of patients with mental illness, or by means of educational projects in the community.

Social reinsertion is a vital tool for the recovery of mental patients, and it may occur within the context of school, work, groups of friends or religious groups⁽¹⁶⁾. In fact, different sectors of society can participate in this process, especially when there is support of family members, as shown in the following statement:

[...] she has friends, here on Saturday, every Saturday our house is full of people, and she brings her friends, that she made at work, at church. She has the choreography work group. It's a blessing. That has helped a lot, thank God (F6).

Healthcare services for patients with mental disorders should not be restricted to solving problems of a somatic nature. The development of different activities in the form of workshops for manual crafts is an effective means of intervention, as patients see the end result of their work, which can be very pleasurable. In addition, these workshops promote the exchanging of experiences, the urge to get out of the house and occupy the mind and time of patients. In some cases, workshops are so successful that they enable reinsertion of patients into the labour market and, consequently, facilitate family and social acceptance.

Workshops are considered therapeutic and play an important role in the re-socialization and insertion of patients in groups by means of collective work, activities and thought that respects diversity, subjectivity and individual capacity⁽¹⁸⁾. Finally, it is important to highlight that, given the characteristics and importance of these activities for patients, this type of work should be conducted by a team of several professionals, as one professional will find it hard to deal with the complexity involved in conducting a workshop for patients with mental illness.

CONCLUSION

Results show that, from the family perspective, it is difficult to accept a patient with a mental disorder in the family environment. The entire family is forced to confront a wide range of difficulties when living with this type of patient that involve support for treatment and improving the living conditions of the patient. Emotions that seem to prevail in this relationship – shame and embarrassment related to behaviour of the patient in public, guilt related to appearance of the illness and fear triggered by aggressiveness — are an obstacle for acceptance of this type of patient in the family and community.

Stigma and prejudgement are evidently present in society and in the family environment, and negatively affect the living experience with these patients. An understanding of the illness is essential for its acceptance. This understanding, however, must be provided in conjunction with healthcare actions that promote community awareness on the nature of the disorder and consequently minimize intrinsic lack of knowledge and non-acceptance of patients with mental illness in the social environment.

Statements provided by participants of this study reveal the need for intervention of healthcare professionals who can help family members reduce

their focus on the illness itself so that they may encourage and direct efforts that seek potential for health and autonomy of the patient. Greater commitment on behalf of healthcare professionals provides the family with much needed support to continue caring for itself and the patient, and accept, in a more natural manner, the presence of the mental disorder in the family environment.

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