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THE EXPERIENCE OF BEING A MOTHER OF AND INDIVIDUAL WITH SCHIZOPHRENIA

Luana Cristina Bellini*
Mayara Soares Cunha**
Thamires Fernandes Cardoso da Silva***
Bianca Cristina Ciccone Giacon****

ABSTRACT
The aim of this study was to describe the experience of being the mother of an individual with schizophrenia. It is a qualitative study based on symbolic interactionism. Data collection was conducted through an open, single interview with 11 mothers of people diagnosed with schizophrenia. The information collected was organized and then submitted to the Thematic Analysis. From the mothers' reports, four moments were identified: "The dealing with the unknown"; "The discovery of diagnosis and initiation of treatment"; "The unfolding of the experience with the child with schizophrenia"; and "The experience of being a mother of a Schizophrenic individual". It isnoted the difficulty of mothers in dealing with the disorder of the child, both for their symptoms and for access to health services. That way, it is necessary that the assistance be based on the holistic view of the human being, incorporating the family in the care, providing better prognosis and reducing the suffering.

Keywords: Schizophrenia. Mother-Child Relations. Life Change Events.

INTRODUCTION

Schizophrenia consists of a severe mental disorder of chronic evolution, which can cause changes in the whole family dynamics and generate conflicts, making it difficult to keep the balance of the group(1). This disorder may be accompanied by specific demands and problems, especially for parents, including complete dependence on self-care tasks, financial and emotional overload, uncertainty about who will care for the individual in the future(2).

This way, relatives sometimes feel incapable of performing such care and are rarely prepared to face the consequences of the disorder, generating a variety of feelings: isolation, frustration, anguish, fear, apathy, among others(3). All individuals inserted in the family system are directly or indirectly affected, and there may be conflicts and difficulties in dealing with the situations that arise due to the disease(4).

Each family member takes responsibility, and, in an attempt to facilitate the coexistence and care of the sick relative, roles can be modified. This responsibility - or role - assumed by the person, regarding the other, ends up triggering another overload, becoming a factor of imbalance in the family group(3).

There are, in the Brazilian literature, a variety of studies related to the overload and family experience in living with an individual diagnosed with schizophrenia. However, few address the experience of mothers in this context. Therefore, it is important to develop psychiatric nursing research that produces knowledge about mothers' experience of caring for and living with their with na schizophrenic son/daughter.

Based on it, the objective of this study is to describe the experience of mothers in the care and living with a son/daughter diagnosed with schizophrenia.

METHODOLOGY

It is a qualitative, descriptive research, based on the presuppositions of symbolic interactionism. It was chosen the qualitative approach to collect and analyze the data because this approach allows the exploration of the life experiences of individuals, groups or institutions in their socio-cultural context(5).

The participants of this study are mothers of individuals diagnosed with schizophrenia who are followed up by the mental health services of

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*Nurse. Coxim, Mato Grosso do Sul, Brazil. E-mail: luana.bellini@hotmail.com
**Nurse. Coxim, Mato Grosso do Sul, Brazil. E-mail: mayarasoares.com@hotmail.com
***Nurse. Master Student in Nursing at the State University of Maringá. Paraná, Brazil. E-mail: tamifernandes2009@hotmail.com
****Nurse. Doctor in Nursing. Adjunct Professor in Nursing of the Federal University of Mato Grosso do sul – Campus of Coxim. Mato Grosso do Sul, Brazil. E-mail: biagiacon@gmail.com

a municipality in the northern region of the State of Mato Grosso do Sul (MS). The inclusion criteria to participate in this study were: being a mother of an individual with a medical diagnosis of schizophrenia (according to the 10th edition of the International Classification of Diseases/ICD-10)(6); not have another medical diagnosis of mental disorder; be over 18 years of age; and to reside in the urban area of the municipality of study.

Initially, it was collected the information about the subjects diagnosed with schizophrenia from the Family Health Strategy Teams (ESF): names of the individuals and the mental health services in which they are monitored. In a second moment, some information was collected - through a previously elaborated instrument - on these individuals in the two mental health services of the municipality: the Psychosocial Support Center I (CAPS I) and the Specialized Outpatient Clinic.

In CAPS I, the survey was based on information contained in the "Register of Outpatient Health Actions (RAAS)", which is completed monthly by the team. Consultation of the medical records was carried out at the specialty clinic.

From these surveys, 37 individuals with schizophrenia were selected, and the active search for the mothers of these subjects started, through home visits, moment in which the objectives of the study were presented and the invitation to participate in the study was made.

Among the selected mothers, 17 could not be found due to the out-of-date information contained in the medical records and also because of the difficulty in finding them in the residences after two or three visits; six had died; two did not agree to participate because of the fear of exposing their children; and one, after confirming the participation, gave up. Therefore, eleven mothers met the eligibility criteria and agreed to participate of the study

The data were collected in the months of July and August of 2015, in an open, individual interview, recorded in digital media. The interviews were based on two guiding questions: "How did you, as a mother, experience the illness of your child?"; "What is it like to be the mother of na individual diagnosed with schizophrenia?". Additional questions were used in order to deepen into aspects that proved to be important. In order to preserve the identity of the deponents, we adopted the M (mother) code followed by the numeral order of the interviews.

The content of the speech was organized and submitted to the Thematic Analysis, which consists of discovering the nucleous of meaning that make up a communication, whose presence or frequency has analytical significance. Interpretive synthesis subsidized by the objectives of the study and the assumptions of the adopted theoretical framework were discussed and elaborated(5).

The study followed the ethical precepts established by Resolution 466/12 of the Ministry of Health, and was approved by the Ethics and Research Committee Involving Human Beings of the Federal University of Mato Grosso do Sul, under Opinion n. 1,136,624. All participants were informed about the purpose of the study and signed the Informed Consent Form.

RESULTS AND DISCUSSION

The 11 participating mothers were aged between 45 and 79 years, classified as: seven of them were 60 years old or over; five were married; five had incomplete elementary school; eight reported being housewives; end eight received only one minimum wage.

From the strenuous reading of the stated stories it was identified that this experience is marked by a trajectory characterized by four categories: "The deal with the unknown"; "The discovery of diagnosis and initiation of treatment"; "The unfolding of the experience with the individual with schizophrenia"; and "The experience of being the mother of na individual with schizophrenia." These categories are sequentially discussed.

Dealing with the unknown

The mothers reported that their children exhibited behaviors considered inadequate since childhood and adolescence: rebelliousness, abusive use of alcohol and other substances, nervousness exacerbated in stressful situations, aggression, among others. At this stage, such behaviors were associated with the education received by parents and family, or the typical characteristics expected for this period (child and adolescent).

> He [son] was a piece of work, I would leave, he would make a mess in the house, he did horrors in my house, at 12,13,14 years old, I began to call him a brat, uneducated, lacking in respect, without limits. [...] Then he grew up in this rhythm, in that rebellion, with that lack of discipline ... The father gave him alcoholic drink, then he began to drink. 'Oh my God' At the age of 10 he started drinking alcoholic beverages [...] (M8).

The literature shoes that the manifestation of some symptoms of schizophrenia, especially those considered negative, may begin years before the most clinical manifestations characteristics of psychosis(7). This way, parents and family members may have difficulties in noticing illness.

Mothers searched for professional support to learn how to deal with their children and solve doubts. By seeking to psychologists and doctors, they entered the health system.

> I went to the doctor (psychiatrist), I asked him to help me get my son out of jail, I thought he was not good in the head. And I did not know what it was, what was his problem [...] The doctor helped me start the treatment. [...] The support came from the health, from the Secretary of Health, from the nurses, from the doctors that I am always going after. I ask for help (M11).

When the mothers themselves or others around the youngster could no longer justify inappropriate behavior, they began to search for health services to try to understand what was happening. Other studies on the onset of schizophrenia and family experience in this period demonstrate that the search for health services only occurs when family members are no longer able to cope or explain the behaviors presented by their youngsters(8, 9).

When they were sought, the health professionals informed the mothers of the existence of the mental disorder, however, the difficulty of these women in understanding this diagnosis is perceived. Research(10) conducted with a similar public identified that when they arrive at a health service, mothers do not have knowledge about the disease. Although the health team provided the information inherent to the diagnosis, most of the deponents said they did not know it.

Because they are unaware of the issues surrounding this disorder, for mothers the diagnosis becomes a time marked by incomprehension and denial, related mainly to the historical stigma of mental illness. The literature registers the difficulty of mothers accepting this diagnosis, due to the chronicity of the disease and lack of curative measures. Another aspect mentioned is the measure of protection against the first signs and symptoms of the disease, revealing the vulnerability with which these women are confronted with the present difficulties and uncertainties of the future(10, 11).

The discovery of diagnosis and initiation of treatment

The mothers reported that they discovered their children's schizophrenia diagnosis through specialized medical consultations or at meetings in the hospitals where they were hospitalized. They also said that in both cases they were explained about the disorder, the need for ongoing treatment and the possible difficulties to be faced, the chronicity, the impossibility of cure and the prospects of several hospitalizations throughout life.

> The doctor called me, we talked ... 'Mother, your son has a problem that is called, which is a beautiful name, but nobody will ever want to have it, it's called Schizophrenia' [...] (M6)

However, some mothers said they did not know about the diagnosis of their children, and that they did not receive clear information about the disorder from their health professionals, their correct name, only hearing the expressions mental disorders and/or disorders.

> No, he [doctor] never clarified it to me, he never told me, in another city they did several tests, nor did the specialist from that place told me, no one ever spoke. [...] Neither there, nor here, nor anyone [...] (M3).

Faced with the impossibility of having a "perfect", "normal" child, the mothers denied the existence of schizophrenia.

> I would cry every time I talked to him [doctor], because I did not accept that, why is my son sick? My head would not accept, my [other] children were healthy, each one with their family? [...] (M11).

Health care was requested, at times of outbreak and for periodic follow-ups, used as a way to deal with the disorder. During the first years of discovery there was no treatment due to lack of the specialized service in the municipality, being necessary the displacement to neighboring cities to have treatment.

> There [another council] had a good doctor ... at that time here [place of residence] almost had no doctor. [...]. Every three months I had to take him to consult. It was difficult here, there was no doctor. Then the doctor prescribed the medication for three months, it was controlled prescription (M1).

Another aspect pointed out was the difficulty of adherence to drug treatment: the children found ways to trickle the mothers and did not take the medications. And they only found it out due to worsening symptoms.

> I was confident he [son] was taking it. When I got home and I said, 'I'm going totake a good look , it can´t be possible' /.../ I was going to clean and I did not see anything in the trash, [...]in his room, there was a hole [on the floor], so every time I gave him the medicine, he threw it [on the hole], there was all the medicine there, [he] would not take them! (M6).

The beginning of the treatment was permeated by hospitalizations at times of outbreak and periodic follow-ups. In most cases, the treatment was carried out outside the municipality of residence, being difficult to follow up. Such a reality can be considered a barrier to adherence and maintenance of therapy, since it is known that the success of individuals with severe and persistent mental disorders depends, among other factors, on facilitated access to health services(12). However, this aspect alone is not enough, there is a need for professional guidance regarding symptomatology, characteristics of therapy, approach and coexistence, in order to understand how complex the psychiatric picture is, and , this way adopting effective strategies of care(13).

That way, several obstacles in the health service can lead to poor prognosis, favoring chronicity, prolonging psychopharmacological treatment and increasing the dosage of medications(7,12).

In view of the above, adherence to medication use was mentioned by mothers as a fundamental element in their experience. Among the factors associated with the difficulty of non-adherence are the adverse drug reactions, the complexity of the therapeutic regimen, the high cost of medication and even the fact that the individual does not consider himself ill (10)

Deployment of living with an schizophrenic individual

Living the sickness caused some mothers to not take care of the son/daughter, being necessary to divide it or delegate it to a relative or other people. However, these women made the decision to become the primary caregiver.

> I took care of him [son] all my life, It´s me who buys clothes, I give food, medicine, shoes, everything it is me, I've been fighting for him for 15 years. [...] So, I feel that I have to do everything, I am responsible for everything [...] (M2).

The decision to assume full care was reflected in the daily activities of these mothers, and it was difficult for them to maintain an employment, in addition to the decrease or absence of leisure activities. It is noted, in the speeches, that when adopting such position, the mothers had their daily life totally modified.

> It's not easy for me. Besides stopping his life [son], he stopped mine too. I live only for him, only for him the whole time. It stopped my life, because before I could go to work, I could go in peace. When someone calls, I'm scared, rthinking it's him (son) who did something. It's very bad for me [...] (M4).

Mental disorder, especially schizophrenia, is considered something unexpected and an impact for the family. Care is in most cases intended for the mother figure. And, in exercising this function, mothers become overloaded and end up compromising their own care. Simple actions - shopping or visiting relatives - become a challenge(3).

Another factor to be highlighted is the direct and exclusive relationship with the child, which sometimes triggers conflicting situations, especially when the mother tries to perform basic care. They believed that the oppositional behavior occurred by their children's will, making them feel rejected and sad.

> It's very difficult, it's sad. Because it's a person that you can not even take care of, you try to caress, offer something, a fruit, a snack, a thing,

> [son] get angry, throw it away. If I would offer the lunch, he would take it and throw it away, I had to leave him, if he wanted to have lunch, he had lunch. If he did not want to, he would not have lunch, but I could not offer it [...] (M1).

Initially, the caregiver's relationship with the family member becomes aware of tensions due to recurrent symptoms of the disorder. However, when these are not present the coexistence improves. At that moment, the sick person becomes someone with some limitations, but who has the ability to relate harmoniously with others(14).

Over time, as they gained experience in caring for and interacting with their children, with other parents and mental health professionals, the deponents said they accepted the disorder by building strategies to deal with problems related to the disease.

> From time to time, thank God, I learned to live with her [daughter], I find it easier, I had no understanding before. But today I understood, it is also well controlled [...] (M3).

The break out periods were cited as the most difficult to deal with. This experience was reported as permeated by suffering and by the state of alert or wakefulnes.

> The first time it is such a big pain, I cried a lot. It is very painful that you, the mother, have to tie your own son, have to help put handcuffs on your own child understand?! [...] It was painful for me, at that moment! (M8).

The crises, reported by the mothers, are constantly alert, with a marked presence of feelings that involve suffering and anguish. In that sense, if hospital admission becomes a solution to anxiety it also generates fear in the family. Although it represents an outlet or measure of relief for those who surround the individual with schizophrenia, this extreme attitude generates the feeling of impotence, making it even more difficult to relate to sick family member. However, this resource was only used by mothers as a last resort and because they did not know how to deal with and/or deal with outbreaks(10, 14).

> Poor thing, he would get doped, could not even speak,It's not easy to see a son in the hospital getting half doped, it is lake, he can not speak properly, he talks kind of twisted, like stoned [...] (M7)

The experience of being the mother of a son/daughter with schizophrenia

Bad feelings about experiencing bizarre behaviors and schizophrenia break outs, such as pity, sadness, fear, despair and loneliness, were identified in the mothers' reports. These feelings were reported at other times, but they were more intense during the crisis and, consequently, hospitalization.

> Only he [son] was lucky enough to be like that, what can we do? Now we have pity, we have pity, sadness, put everything together. [...] As a mother these things, I pitifully, with pity, with that love that I for him, did not want to be without him (M1).

The loss of vanity and self-care was one of the consequences reported by mothers after their children became ill. In addition, they felt emotionally worn out.

> I was losing weight, I'm very vain, I really like to be neat, I was not connecting with style anymore, my pants were falling, I was tying a string in my hair and would go out like that, it was normal for me to et around that way, I would even go barefoot to the hospital, to see him every day [...] (M6).

The study participants also showed guilt feelings about their children´s illness.

> I prognosticated my son, I felt for sure that he would get sick. I do not know, something happened because when he left for the farm I would stay at the gate crying, I would watch the taxi disappear, today I think that's it, is it augur? Because it is not good, it says that people cry, right, all of this I think [...] (M2).

This guilt is permeated by doubts about mistakes raising children and also by empirical beliefs. Corroborating what the literature says, people closest to individuals with disorders tend to think about what they might have done, improved to avoid that situation, especially mothers, since they take care of their children from birth to adult development(14,15). These caregivers seek answers to the cause of the disease, and, over time, seek meaning to understand it, lessening the burden of having a family member with schizophrenia(10).

However, to experience having a child with schizophrenia does not always only provide negative aspects. Some mothers have stated that they nurture good feelings - love, joy, and union - in which they have relied on difficulties.

> It was a difficult situation, but it brought us closer, and for me to realize, I do not know, it was a failure, and I felt very guilty. So it was only love to overcome this situation ... It is love, it was a lot of love that brought us closer, if it were not for love, we could not have won, love in general, son, wife, family (M6).

Thus, being the primary caregiver is not always indicative of dissatisfaction. Some people feel satisfied to perform this function, which provides positive feelings, corroborating the literature findings(10).

Another frequently reported aspect is concern about the future of who will look after their children when they are no longer present. The fear of death was identified; to leave and leave the son/daughter helpless.

> Sometimes I get very sad, how about when I die? Who will take care of him [son]? [...] Only sadness. It's very sad to know that he's going to stay like this for the rest of his life, to be dependent, and when I die who will take care of him? If you think his sister has the patience to take care, she does not! Only the mother! [...] (M4).

The future of the mentally ill is uncertain for family members, which leaves them fearful. This concern was documented in another work, confirming the findings of this research, especially regarding the guarantee of a decent future for the child: the mothers wish that the other family members can keep the child stable, regarding to their health, making him/her independent, resulting in its own family constitution(15).

Regarding the limitations of this study, the difficulty in having access to the individuals and their mothers is mainly due to the outdated information in the medical records and the reduced number of participants.

FINAL CONSIDERATIONS

This study aimed to identify the experience of being the mother of a person with schizophrenia, which begins with the changes in the child's behavior from his/her illness to the emergence of concerns about the future due to advancement of the mother´s age. being this experience permeated by physical and mental suffering.

When faced with this reality, mothers have difficulty in understanding the disorder of the child and its symptoms as much as the access to the health service for a quality and continuous treatment. It was also found that the mother figure is primarily responsible for seeking treatment and dealing with the child's resistance to accepting it.

In view of these results, new actions in public health aimed at this population can be proposed and implemented. These actions would have as main objective a more complete service to the individual and his family, reducing the suffering of the whole family group and providing a better prognosis for the sick individual.

Few studies have been found on the subject. Therefore, there is a need to carry out new studies covering the maternal figure and the implications of caring for a child with schizophrenia, or another mental disorder, in order to obtain a new conception of the reality experienced within the family.

A EXPERIÊNCIA DE SER MÃE DE UM INDIVÍDUO COM ESQUIZOFRENIA

RESUMO

O objetivo deste estudo consistiu em descrever a experiência de mães no cuidado e convívio com um filho com esquizofrenia. Trata-se de um estudo qualitativo, baseado no interacionismo simbólico. A coleta de dados foi conduzida por meio de entrevista aberta, individual, realizada com 11 mães de indivíduos com diagnóstico de esquizofrenia. As informações recolhidas foram organizadas e submetidas à Análise Temática. A partir dos relatos das mães identificaram-se quatro categorias: "O lidar com o desconhecido"; “A descoberta do diagnóstico e início do tratamento”; “O desdobramento da vivência com o filho com esquizofrenia”; e “A experiência em ser mãe de um filho com esquizofrenia”. Nota-se a dificuldade das mães em lidar com o transtorno do filho, tanto pelos seus sintomas quanto pelo acesso aos serviços de saúde. Assim, faz-se necessário que a assistência seja pautada pela visão holística do ser humano, incorporando a família nos cuidados, propiciando melhores prognósticos e a diminuição do sofrimento enfrentado.

Palavras-chave: Esquizofrenia. Relações mãe-filho. Acontecimentos que mudam a vida.

LA EXPERIENCIA DE SER MADRE DE UN INDIVIDUO CON ESQUIZOFRENIA

RESUMEN

El objetivo de este estudio fue describir la experiencia de madres en el cuidado y convivencia con un hijo con esquizofrenia. Se trata de un estudio cualitativo, basado en el Interaccionismo Simbólico. La recolección de datos se realizó a través de entrevista abierta, individual, realizada con 11 madres de individuos con diagnóstico de esquizofrenia. Se organizaron las informaciones recogidas y luego fueron sometidas al Análisis Temático. A partir de los relatos de las madres fueron identificadas cuatro categorías: "El lidiar con lo desconocido"; "El descubrimiento del diagnóstico e inicio del tratamiento"; "El despliegue de vivir con el hijo con esquizofrenia"; y "La experiencia de ser madre de su hijo". Se percibe la dificultad de las madres de lidiar con el trastorno del hijo, tanto por sus síntomas, como por el acceso a los servicios de salud. Por lo tanto, es necesario que la atención sea basada en la visión holística del ser humano, incorporando a la familia en los cuidados, ofreciendo un mejor pronóstico y la disminución del sufrimiento enfrentado.

Palabras clave: Esquizofrenia. Relaciones madre-hijo. Hechos que cambian la vida.

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Corresponding author: Luana Cristina Bellini. Aparício Mendes Fontoura, n.325, B. Senhor Divino. Coxim, Mato Grosso do Sul, Brasil. Telefone: (67) 9 98572740. E-mail: luana.bellini@hotmail.com

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