



Does the interaction between people with schizophrenia and their families interfere in medication adherence?*

A interação entre pessoas com esquizofrenia e familiares interfere na adesão medicamentosa?

La interacción entre personas con esquizofrenia y familiares interfere en la adhesión medicamentosa?

Kelly Graziani Giacchero Vedana¹, Adriana Inocenti Miasso²

ABSTRACT

Objective: To identify, from the perspective of the people with schizophrenia and their family members, what occurs in the patient-family interaction related to medication adherence. **Methods:** A qualitative study using the methodological framework of Grounded Theory, and assumptions of Symbolic Interactionism. Participating in the study were 36 people with schizophrenia in outpatient treatment and 36 family members. To obtain the data, we used recorded interview and observation. **Results:** The depositions obtained revealed that family members can provide support and motivation, providing patient adherence to treatment; but they may also encourage them not to adhere to pharmacotherapy. Also highlighted was the influence of burden and the unpreparedness of family caregivers about the quality of care provided. **Conclusion:** Health professionals can intervene, together with families, encouraging interactions that contribute to successful treatment and encouraging them to modify interactions that can compromise it.

Keywords: Schizophrenia; Nursing; Family; Medication adherence; Interpersonal relations

RESUMO

Objetivo: Identificar, na perspectiva da pessoa com esquizofrenia e de seu familiar, como ocorre a interação paciente-familiar relacionada à adesão ao tratamento medicamentoso. **Métodos:** Estudo de abordagem qualitativa, com referencial metodológico da Teoria Fundamentada nos Dados e pressupostos do Interacionismo Simbólico. Participaram do estudo 36 pessoas com esquizofrenia em tratamento ambulatorial e 36 familiares. Para obtenção dos dados, usadas a entrevista gravada e a observação. **Resultados:** Os depoimentos obtidos revelaram que familiares podem fornecer apoio e motivação, propiciando a adesão do paciente ao tratamento, podendo também incentivá-lo a não aderir à farmacoterapia. Destacaram-se ainda a influência da sobrecarga e o despreparo do familiar cuidador sobre a qualidade dos cuidados prestados. **Conclusão:** Profissionais da saúde podem intervir junto aos familiares, encorajando as interações que colaboram com o sucesso do tratamento e incentivando-os a modificar as interações que o comprometem.

Descritores: Esquizofrenia; Enfermagem; Família; Adesão à medicação; Relações interpessoais

RESUMEN

Objetivo: Identificar, en la perspectiva de la persona con esquizofrenia y de su familiar, cómo ocurre la interacción paciente-familiar relacionada a la adhesión al tratamiento medicamentoso. **Métodos:** Se trata de un estudio de abordaje cualitativo, con referencial metodológico de la Teoría Fundamentada en los datos y presupuestos del Interaccionismo Simbólico. Participaron del estudio 36 personas con esquizofrenia en tratamiento ambulatorio y 36 familiares. Para la obtención de los datos se usó la entrevista grabada y la observación. **Resultados:** Los discursos obtenidos revelaron que los familiares pueden ofrecer apoyo y motivación, propiciando la adhesión del paciente al tratamiento, pudiendo también incentivarlo a no adherirse a la farmacoterapia. Se destacaron aun la influencia de la sobrecarga y la falta de preparación del familiar cuidador sobre la calidad de los cuidados prestados. **Conclusión:** Los profesionales de la salud pueden intervenir junto a los familiares, haciendo que estimulen las interacciones que colaboran con el éxito del tratamiento e incentivándolos a modificar las interacciones que lo comprometen.

Descriptores: Esquizofrenia; Enfermería; Familia; Adhesión a la medicación; Relaciones interpersonales

* Study extracted from the PhD thesis entitled "Living with an assistance that interferes: the significance of drug therapy for people with schizophrenia" - presented to the School of Nursing of Ribeirão Preto, University of São Paulo – USP – Ribeirão Preto (SP), Brazil.

¹ Graduate student (PhD) Psychiatric Nursing Graduate Program – School of Nursing of Ribeirão Preto, University of São Paulo – USP – Ribeirão Preto (SP), Brazil.

² PhD Professor from the Laboratory of the Department of Psychiatric Nursing and Human Sciences School of Nursing of Ribeirão Preto, University of São Paulo – USP – Ribeirão Preto (SP), Brazil.

INTRODUCTION

Schizophrenia is a disorder of chronic development that requires prolonged treatment with antipsychotics. Adherence is crucial for treatment success, since there is an association between non-adherence and relapse, re-hospitalization and persistence of psychotic symptoms ⁽¹⁾.

Adhesion to treatment can be defined as the degree to which the patient follows the recommendations of medical or health professionals, returns and maintains the indicated treatment ⁽²⁾. Thus, it comprises the use of medications exactly as the physician's prescription.

To act effectively on problems related to non-adherence to treatment, it is necessary to investigate the factors which lead the patient not to adhere to the prescribed therapy ^(3,4).

In the context of deinstitutionalization, it is often family members who assume responsibility for the care of the schizophrenia carrier member ⁽⁵⁾, including with regard to drug therapy. Consequently, the final step in drug therapy is the responsibility of patients and their families.

Thus, the family is a privileged space for the practice of care, therefore, it has to be inserted effectively in the discussions of this new paradigm of care, as a facilitator, ally and focused on interventions ⁽⁶⁾.

Health professionals need to know the characteristics inherent to the process of family participation in care related to pharmacotherapy, so that effective actions are implemented for the preparation and support for family care.

Given the importance of adherence to medication to control schizophrenia and the inclusion of family members as collaborators in treating people with the disorder, this study aimed to identify, from the perspective of the person with schizophrenia and their family members, how the interaction between patient and family occurs, with regard to medication adherence.

METHODS

This study is part of a PhD thesis entitled "*an assistance that interferes: the significance of drug therapy for people with schizophrenia in their and their family's perspective.*"

The research was conducted in an Ambulatory Service of Psychiatric Clinic of a general hospital, a Mental Health Unit and a Psychosocial Care Center – located in a city in the state of Sao Paulo. Data collection was conducted between July 2008 and October 2010, after approval by the Ethics Committee (HCRP No. 10183/2007). All study subjects signed a Consent Form.

The recorded in-depth interview and observations were used to obtain data.

The study included 36 patients and 36 relatives. The number of subjects resulted from a process of theoretical sampling, as recommended by the methodological framework chosen. The criteria for including patients in the study were: to have a medical diagnosis of schizophrenia, to be using psychotropic drug (s) and to be able to express themselves verbally. To confirm the diagnosis of the patient and acquire information about the prescribed medication, the patient's medical records and healthcare professional were consulted.

Inclusion criteria for the family members for this study were: to be mentioned by a person with schizophrenia participant of the study as the family member most involved in the treatment and to be able to express themselves verbally.

The recorded interview had the following guiding question for patients: "*Tell me about how is it for you to use the medicines prescribed by the physician's psychiatric service.*" And for the family members: "*Tell me about how is it for your family member to use the medicines prescribed by the physician's psychiatric service.*"

The main question only addressed to the starting point to be explored. New questions were added later in order to clarify and substantiate the experience. It is worth noting that the observation was performed on participants of study during the waiting period for consultations and home visits.

To preserve the anonymity of the participants in the study, they were identified during the research, with the letter "P" for patients and "F" for family member, plus a number that corresponded to the order of the interviews.

In this study, Grounded Theory (GT) was used as methodological approach, and Symbolic Interactionism was chosen as the theoretical framework. Symbolic interactionism assumes that individuals are active and give meaning to things in the present, based on interactions with others and with themselves ⁽⁷⁾.

GT enables the construction of substantive theories supported by data collected on a systematic comparative analysis of them. In studies employing the GT, the collection and data analysis are conducted in parallel ⁽⁸⁾.

Encoding is performed in three stages: opened coding, the data is fragmented into units of analysis and resulting codes are appointed. The codes are compared according to their similarities and differences constituting provisional categories. In the next step (axial coding), the connections between the categories and subcategories are prepared and tested in the field of the study. In selective coding, all categories are aggregated around a central category and thereafter, the analysis of their relations is performed. The result

of this process consists, in reality, of a theoretical formulation under investigation ⁽⁸⁾.

The core category identified in the study in question was called “an assistance that interferes” and represents the significance of drug therapy for people with schizophrenia. In this article, the connection between the categories that express the “Interaction with family members” and the option to adhere or not to the medicine will be explained.

RESULTS

Data analysis of the study revealed that the interaction between patients and family members is constituted as an intervening factor in action strategies that the person with schizophrenia implements in relation to drug therapy. Among these actions is the option to adhere or not to the medicine, as described in the following categories.

Considering the received support

When interacting with family members, people with schizophrenia may receive various forms of support which may interfere with their treatment, highlighting the assistance and supervision for administration of prescribed drugs, the acquisition of these drugs where they are available, attendance of patient consultations and examinations, as well as the motivation for the patient to keep drug therapy.

“When I give the medicine, she takes it correctly.” (F5)

“They help you remember to take the medicine; they help me maintain regularity to take the medicine.” (P11)

“She (stepsister) gets (the drug) for me here and give them to me, because before that I would get it and take it all at once, and now she controls.” (P30)

The family member’s assistance in the administration of medications is crucial, especially when the patient has limitations for the self-administration of prescribed drugs or when they are predisposed not to adhere to the medication by internal motivations.

“I say, ‘I will take my medicine’, because once in a while, I forget the drugs, I don’t know if I took it or not.” (P13)

“For him, he wouldn’t take the medication, he wouldn’t do the treatment. He has nothing, he has no pain. Because if you have pain, you want to be relieved.” (F12)

“That little drip medicine is difficult because I cannot see. So sometimes, when my brother is at home, he does it. The boy, when he’s at home, he can do it. But many times, I do it myself. I do not know how many drops fall.” (P19)

Especially in these cases, in which there is a propensity of patient non-adherence to treatment, if the supervision of self-medication is overlooked, the patient may be exposed to risks.

“It has to be supervised and make sure she is taking her medication. We thought she could take this medication without

any supervision, so there was a family mistake right there. She became very ill.” (F8)

The support provided by family members may provide greater patient safety in the continuity of drug therapy. Recognizing the importance of the person who provides care for patients, who are afraid of the absence of the caregiver, as it will be discussed in the next category.

Fearing or experiencing the absence of the caregiver

A person with schizophrenia, when assesses the importance of the care provided to them, may fear the absence of the family member who assumes the role of caregiver and provides their needs.

“Then I got like this. So, there are times when I’m afraid, like, I am afraid I am going to lose my dad, my mom, because I no longer know how to work for other people, I just can’t.” (P3)

The fear that the patient is unattended by the absence of someone who takes care can be shared by those who see themselves as caregivers.

“As to his illness, we do worry, right? Because I won’t be here forever ... I wanted to be eternal, I wish I could stay by his side until the end of his life, right? But I will not live forever, so I do worry about his illness.” (F6)

There are respondents who have experienced the death of a caregiver. In these cases, there is an adaptation of a new family situation, which may cause the election of one or more new caregivers. However, closest people to the patient are not always willing to care, in the absence of former caregiver.

“My sister was the one who took care of him, but she died. After my sister passed away, it became my responsibility.” (F20)

“His sister did not want to hear about him. There were three children, him, her and my dead husband, who was the oldest, and the youngest. Since my mother-in-law died, his sister did not even want to know if he is alive or dead. If I turn my back on him, he has no one. He looks at me like I had an obligation to take care of him.” (F29)

Among caregivers who replaced the deceased caregiver, there are those who recognize that the old caregiver, who previously had assumed this function spontaneously, was more dedicated.

“My father died about 8 years ago. When my father was alive, he would pay more attention ... He was always there, he would medicate him (...) Now, we just take care of him.” (F8)

The presence of the caregiver and the support he provided to the person with schizophrenia are of fundamental importance. However, to assume the role of caregiver, there are family members who suffer an intense deterioration which may influence the quality of care provided, as it will be discussed in subsequent category.

Overload and unprepared family

This category demonstrates that the caregiver burden interferes with their role, and therefore it influences the treatment of individuals with schizophrenia. Among family caregivers of the patient, maternal presence was emphasized.

It was found that living and caring for the person with schizophrenia may interfere with the lives of families with different intensity. Family members participants in this study reported overload due to the multiplicity of tasks, conflicts, aggression, unpreparedness and deterioration when handling with patient, financial losses, difficulty in maintaining an employment bond, restrictions in social and leisure activities, feelings of guilt, helplessness and fear of behavior of the patient.

It is worth noting the existence of relatives who claimed that they require psychiatric treatment because of the emotional burden related to the care and interaction with the patient.

"So it was (the crisis of the patient) for me, the end of the world. There wasn't... He was everything to me, he was always (...) My daughter even tells me things like, 'mom, stop suffering like this (...) I went to psychiatry as well. "(F2)

"I'm also going through psychiatric treatment, because of him, right?" (F31)

It was evident that the caregiver burden is a factor in intervening in the course of patient treatment. The deterioration of the family caregiver can be intense to the point of interfering with their ability, willingness and patience to care for and support people with schizophrenia.

"He stayed a week like this, we couldn't stand each other, for example, when he was in here, I needed to get out. (...) When he was out, I would go back inside. "(F3)

"There are three people, and I'm the only one who cares for them. It doesn't make sense, I have to remember to give their medicine on time, for my husband and for my little brother ... it is too much for me. "(F6)

The unwillingness of others to help the individual who undertake the care is cited as a factor that intensifies the burden of family caregivers.

"So, she (sister) is not feeling that willing to look after me. She is always arguing with me and another brother because he does not want to help. "(P4)

Besides overloaded, the family member can also identify themselves as unprepared to care for the patient. It was verified that some family members expressed having little knowledge on schizophrenia. Among the respondents, there were those who could not properly name the disorder.

"The doctor would rather for me to go along, even to clarify. Sometimes she (aunt who is also a caregiver) is not able to tell me in detail, she is a simple person, you know! So it's easier for a person..., right? Who knows best, to go along with him. "(F13)

"It was never mentioned that it is 'schizophrenia'. "(F2)

"He has 'schizophrenia'. "(F6)

"So, the doctor never explained much about his medication for me. "(F14)

"Look, about his illness I do not know anything, I do not know how to explain. "(F20)

"I cannot say the name right (laughs) ... I cannot say the right name. "(F34)

In an attempt to mitigate the overload, there are family members who share the responsibility of caring for other family members and delegate responsibilities to the patient.

"We started a rotation between the three brothers ... There is a schedule we follow. My sister is on Mondays and Wednesdays. Fridays and Saturdays is my brother's responsibility. Then, on Sundays, we take turns. Nowadays, we give the P8 drugs strictly ... because of the schedule, everyone does their part. We have a schedule here (at the clinic) as well. A schedule to bring the P8, a schedule to do the blood test. "(F8)

"I don't need to miss work anymore to bring him to the doctor ... Now, he is able to take the bus correctly. By the time he gets there I also get there ... So we meet each other here and then we go home together. "(F9)

Previous categories indicate interactions with family members, as support relationships, assistance and promotion of treatment. However, these interactions, in some situations, may predispose the patient to not follow the treatment accordingly.

Being unmotivated to follow the prescriptions

In interaction with family members, the patient may be discouraged from following the drug therapy.

Ignorance about the evolution of schizophrenia and not acceptance of the patient with a mental disorder can cause the family member to consider drug therapy unnecessary. Thus, they can encourage the patient to discontinue treatment.

"Well, my brother once said to me: "you don't have anything, stop that (drug therapy), drink 'pinga' (Brazilian vodka) and you will be fine "(P2)

"Well, my wife has already said this (to stop the drug therapy), but I said: Oh, no way, it's been a while since I started, there's no way to stop it now' that's because she does not understand." (P24)

Opposition to maintenance of drug therapy can also be identified among family members, especially when the drug causes side effects. In cases in which an individual has a stable marriage relationship, the interference of the drug on the patient's libido may cause it to be encouraged by their sexual partner to discontinue treatment.

"If I had to buy some medicine, and sometimes, I still had a bit of side effects, he was against my will to take my medicine. "(P10)

"She (wife) also wants me to reduce the dose because our relationship has been difficult. "(P16)

Using the definition that medication adherence consists of the fulfillment of prescription drugs, the use of non-prescribed drugs, is considered as a non-adherence to the treatment. There are situations in which the patient's family member, who is not part of the medical area, "prescribe" medications to patients', exposing them to the risk of misuse of medications.

"Do you know why I started (taking medication)? Because of my sister-in-law, when I got sick, I went after her for resources, then she prescribed me Diazepam." (P27)

"She was living in the back of her mother-in-law's house, and she was getting worse (...) instead of him taking her to the doctor, his mother worked at the hospital and brought medicine every day, each day a different drug. So, when I went there, she was drugged, she was impregnated, she urinated in bed, she couldn't even move her tongue anymore, I had to take her to 'desimpregnate', you know?" (F27)

Another form of interaction that is in an intervening condition in the behavior of the person with schizophrenia is the contact with other people with mental disorder in the family.

Watching other people with mental disorders in the family

There are respondents who have family members who also received a diagnosis of a mental disorder.

"He (brother) also has (Schizophrenia). And I'm a twin of a boy who also has it, there are two and me." (P7)

"My son. He has the same disease I have. And this one (daughter) has Bipolar disorder. In my family, there is no one else, only them, in my family." (P28)

The interaction with family members with mental disorder can provide the example of some patient outcomes disorders experienced by such people. Thus, individuals with schizophrenia may realize through the experiences of others that stopping drug use can be risky.

"I know my mom has a problem, she takes drugs, and all that. I know that if I she doesn't take the drugs, we will have a problem. My grandmother too. My aunt has three children who give her problems ... they are always hospitalized. They give her trouble, I know this much! My mom's brother used the medication, and then he stopped, so it came to a point when he committed suicide. Another uncle of mine, whose wife is my mother's sister also committed suicide ... The same problem, he was being assisted, and all, but then he abandoned the drug therapy." (P1)

In interactions with other family members with mental disorder, individuals with schizophrenia may identify the experiences of those subjects which make people reflect on the importance of drug therapy adherence.

The experiences reported in the results of this research allow the understanding that, in the interac-

tion established with the person with schizophrenia, family members can both facilitate medication adherence, or invest in actions, so that pharmacotherapy is interrupted.

DISCUSSION

The data from this study revealed that family members have a privileged position close to the patient and may interfere in promoting or impairing drug therapy adherence, which is a challenge in the treatment of Schizophrenia.

Studies have shown that 40% to 50% of patients with schizophrenia do not take their drugs as prescribed⁽⁹⁻¹¹⁾, although there is a tendency among patients to deny problems of non-adherence⁽¹²⁾.

Family involvement in patient support is recommended because there is evidence that this may significantly contribute to the success of the treatment, including with regard to drug therapy^(9,13).

Family support, supervision of self-administration of drugs and the continue evaluation of motivation, limitations and abilities of the patient to exercise the self-administration of medication are important elements that might promote adherence to treatment, giving greater safety to the individual with schizophrenia.

It was found that there are concerns and fears regarding the possibility that the patient is unattended by the absence, death or aging of the caregiver. However, in cases in which the caregiver is unable to fulfill that role, often, the family members organize themselves to adapt to this situation. It is recommended that strategies include psychoeducation preparation and support for family members to deal with such situations.

In testimonies of this study, it was possible to perceive overload and lack of preparation of family caregivers, as well as the impact of these factors on the quality of care being provided. It is worth noting that the unwillingness of others to help the caregiver constitutes an aggravating factor in the overload of the family member. In addition to providing support, health workers may encourage the family caregiver of the patient to seek for help by third parties.

Family members of individuals with mental disorders may experience financial, physical, emotional and care burden⁽⁶⁾, experiencing changes in family dynamics, might make the caregiver feel disadvantaged and unprepared to care for patients^(6,14,15).

A good therapeutic alliance between health professionals and family members of patients with schizophrenia reduces the burden on them and the propensity for relapse and re-hospitalization of patients⁽¹⁶⁾.

The Psychiatric Reform cannot be reduced to the return of patients to families, without the preparation of the families for patient care ⁽⁵⁾. It is necessary to provide orientation to the family of people with mental disorders by organizing social support to minimize their overload and meet their demands and support ⁽⁶⁾. So that they can effectively collaborate in the treatment of patients with Schizophrenia, family members should receive the preparation and support that suits their needs

Interaction with family members is not always a factor that can affect adherence to treatment by promoting it. Family members may discourage the patient to follow the prescribed treatment, and may also encourage them to use non-prescribed drugs and other psychoactive substances. In this regard, the study reveals that the quality of family interactions play an important role in stabilizing the patient ⁽¹⁷⁾.

Psychosocial interventions can be adopted to increase patient adherence and should also be extended to family members ^(1,18 to 19).

CONCLUSION

Based on data of this study, it was possible to apprehend that the interaction established between patients and family members can be identified as potentiality or barriers for monitoring drug therapy. Thus, it is imperative to research and implement strategies which include family members as partners and target in the care.

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We advocate family involvement in patient support and their preparation to assume this function properly.

We highlight the importance of knowing the concerns, experiences, beliefs, knowledge and characteristics of the interactions between patients and families regarding treatment. Thus, health professionals may intervene with families encouraging interactions and encouraging them to modify the interactions that affect the success of treatment.

We recommend that family members cooperate in supervising the self-administration of prescribed drugs, as well as continue the evaluation of motivation, abilities and limitations of the patient to exercise that task.

It should be offered, for both families and patients, an individualized, humanized, personalized and longitudinal care, which could encourage them to participate actively in decisions related to the treatment.

This study demonstrates that the monitoring of drug therapy aimed at the management of schizophrenia is not limited to the biological dimension.

The suggestions mentioned here were based on analysis of the study data, we emphasize that a deeper detailed investigation in other contexts and evaluation of its impact on them is recommended.

We believe the findings could significantly contribute to improve the quality of care for people with schizophrenia and their families.

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