Adherence, knowledge, and difficulties related to pharmacological treatment for people with schizophrenia

Adesão, conhecimento e dificuldades relacionados ao tratamento farmacológico entre pessoas com esquizofrenia

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ABSTRACT
This study aimed to verify the adherence and knowledge of people with schizophrenia as regards their prescribed pharmacotherapy, and to identify the difficulties related to the monitoring of drug therapy. It was a retrospective, cross-sectional, and descriptive study conducted in an outpatient psychiatry clinic, with 21 patients with schizophrenia, through chart review and a semi-structured interview. The data were analyzed using descriptive statistics and content analysis showing that, although 76.2% of patients adhere to treatment, most were unaware of the treatment regimen. Limitations in the administration of drugs, troublesome due to side effects and conflicts regarding the need for the drugs, were the difficulties pointed out by the study participants. The contradiction between high adherence and lack of knowledge about prescriptions reveal that promoting treatment adherence and patient safety requires interventions that address the skills and knowledge of the individual, as well as the support available for the administration of prescription drugs.

Descriptors: Medication Adherence; Schizophrenia; Patient Medication Knowledge; Patient Safety.

RESUMO
Este estudo teve como objetivos verificar a adesão e conhecimento de pessoas com esquizofrenia quanto à farmacoterapia prescrita e identificar as dificuldades relacionadas ao seguimento da terapêutica medicamentosa. Estudo retrospectivo, transversal e descritivo, realizado em serviço ambulatorial de psiquiatria, com 21 pacientes com esquizofrenia, por meio de revisão de prontuários e entrevista semiestruturada. Os dados analisados por estatística descritiva e análise de conteúdo mostraram que apesar de 76,2% dos pacientes aderirem ao tratamento, a maioria desconhecia o esquema terapêutico. Limitações para administração dos medicamentos, incômodos por efeitos colaterais e conflitos sobre a necessidade dos medicamentos foram dificuldades apontadas pelos participantes do estudo. A contradição entre alta adesão e déficit de conhecimento sobre a prescrição revelam que promoção da adesão ao tratamento e da segurança do paciente demandam intervenções que abordem as habilidades, o conhecimento do indivíduo e o suporte disponível para a administração dos medicamentos prescritos.

Descritores: Adesão à Medicação; Esquizofrenia; Conhecimento do Paciente sobre a Medicação; Segurança do Paciente.
INTRODUCTION

Schizophrenia is a potentially disabling chronic condition that causes great impact to the sufferer, family, and society. In addition to the subjective experience of psychotic symptoms, the disorder affects the quality of life of the individual and is associated with significant functional impairment\(^{(1)}\).

Continuous drug therapy is essential to control the symptoms of the disorder\(^{(2)}\), especially when combined with other therapeutic modalities.

Adherence to pharmacological treatment and patient safety are important challenges in healthcare practice. The lack of adherence to drug therapy is associated with the exacerbation of symptoms, worsening prognosis, readmissions, high costs, unnecessary adjustments in prescriptions\(^{(3,4)}\), and drug refractoriness.

Non-adherence is a persistent and significant problem among people taking anti-psychotics. It is a complex and multi-factorial phenomenon. The background characteristics, culture, and beliefs of the individual significantly influence adherence to the drug treatment\(^{(3,4)}\).

The literature suggests that adherence is strongly influenced by the individual’s subjectivity\(^{(4-6)}\). Therefore, interventions to optimize adherence tend to be most effective when tailored to individual needs and perceptions of treatment and articulated to the factors that allow or prevent adherence \(^{(3-4)}\).

The difficulties in monitoring drug treatment for people with mental disorders need to be anticipated and addressed carefully during each contact with the patient\(^{(7)}\), because the patient’s participation is crucial to the treatment process.

In addition to non-adherence to treatment, the lack of knowledge about the therapeutic regimen stands out as a factor that compromises the safety and effectiveness of the treatment. The literature recommends the assessment of educational needs in healthcare for patients and families in order to promote effective actions\(^{(8)}\).

Given the above, the promotion of adherence and patient safety in drug treatment requires interventions that consider the patient’s knowledge of the therapeutic regimen and the elements which, from the individual’s perspective, are decisive for adherence.

Thus, it is important to investigate the patient’s knowledge and the difficulties related to the monitoring of drug therapy in order to implement actions that optimize adherence and contribute to the prevention of injuries resulting from the inappropriate use of medicines.

Therefore, this study aimed to verify the adherence and knowledge of people with schizophrenia as regards the prescribed pharmacotherapy, and to identify the difficulties related to the monitoring of the drug therapy.

METHOD

This is a retrospective, cross-sectional descriptive study with a qualitative and quantitative approach. The survey was conducted in a Mental Health Center (MHS) which is part of the National Health System and located in Sao Paulo, Brazil. The project was developed after approval by the Research Ethics Committee (Protocol No. 1327/2011  CEP-CSE-FMRP-USP), and all participants signed an informed consent form.

Patients who had scheduled medical appointments at the study site from March to May 2011 and who met the following inclusion criteria were eligible for the study: have diagnosis of schizophrenia; established by the physician responsible for diagnosis within the service; and have prescription for the continuous use of medications to treat schizophrenia. Patients who were under 18 years of age, unable to communicate verbally in Portuguese, and with no up-to-date phone number or address in the chart were excluded from the sample.

A review of the charts and recorded semi-structured interviews was conducted to collect the data, both guided by a script drawn up by the authors of the study, and containing questions about sociodemographic and clinical date related to the patient’s medical treatment, a test.
that assesses the individual’s adherence to the pharmacotherapy\(^{9}\) and a scale that assesses the knowledge of the respondent regarding the prescribed drug therapy\(^{10}\).

In this study, adherence was defined as the degree of concordance between the recommendations of the healthcare provider and the patient’s behavior related to the proposed therapeutic regimen. Thus, the degree of adherence was defined by applying the Adherence Measurement Test (AMT)\(^{9}\). This test consists of seven questions. For each question, the Likert-type responses are as follows. After obtaining the data, the values corresponding to the responses of each AMT question that are added together and divided by the total number of questions. The value found after this procedure is converted into a dichotomous scale to identify patients with adherence or non-adherence to the drug treatment.

To identify the patient’s degree of knowledge about prescription drugs, a scale\(^{10}\) already employed in previous studies was adopted. This instrument indicates how to translate into percentages the amount (numbers) of information that the patient possesses, and it directs the categorization of that knowledge.

This instrument assumes that the degree of knowledge of a person on every aspect related to medications (name, dose, and frequency of use) can be scored from zero to 100% and classified at regular intervals, representing the following classes: no knowledge (0%); very little knowledge (0%-25%); little knowledge (25%-50%); regular knowledge (50%-75%) and good knowledge (75%-100%).

Patient responses were compared with the data in the chart. The answer to each question was classified as right or wrong, considering the items assessed for each of the prescription drugs. The answer “don’t know” was classified as wrong. Thus, if 10 drugs were prescribed to a person who could correctly identify the names of three of them, their level of knowledge about the names of the drugs would be 30% and would be included in the “little knowledge” category, which corresponds to the score range of 25%-50%. It proceeded in this way for each variable related to prescription drugs.

Descriptive statistics, after double data entry in an Excel spreadsheet, were used for data analysis related to the characterization of patients, knowledge, and adherence to medication. Content analysis was adopted for the analysis of qualitative data\(^{11}\). First, the data were gathered and organized. Empirical categories were established through analysis of the material and, subsequently, articulation of the empirical material with the literature was performed.

To preserve the anonymity of the study participants, respondents were identified in their statements with the letter “P,” plus the number that corresponded to the order in which the interviews were conducted.

RESULTS

Characterization of the study subjects

Twenty-one subjects with schizophrenia participated in the study. The characterization of participants is available in Table 1.
Table 1. Characterization of people with schizophrenia participating in the study. 
Ribeirão Preto, São Paulo, Brazil, 2011.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>61.9</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 - 50</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>51 - 70</td>
<td>13</td>
<td>61.9</td>
</tr>
<tr>
<td>≥ 71</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12</td>
<td>57.2</td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td><strong>Occupation:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired/Removed</td>
<td>11</td>
<td>52.4</td>
</tr>
<tr>
<td>Unemployed</td>
<td>6</td>
<td>28.6</td>
</tr>
<tr>
<td>Working with Employment Contract</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Self-Employed Worker</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Can Read and Write</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Did Not Complete Elementary School</td>
<td>7</td>
<td>33.4</td>
</tr>
<tr>
<td>Completed Elementary School</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Did Not Complete High School</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Completed High School</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>Completed Higher Education</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td><strong>Monthly family income (minimum wages)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤2</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td>2&lt;x≤3</td>
<td>9</td>
<td>42.9</td>
</tr>
<tr>
<td>&gt;3</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>21</td>
<td>100</td>
</tr>
</tbody>
</table>

Most of the respondents were male (61.9%), aged 51-70 years (61.9%), with a monthly family income of up to three minimum wages (80.9%), with no spouse (80.9%), not employed (90.5%), and without complete elementary education (52.4%). The monthly per capita family income was equal to or less than one minimum wage in 13 (61.9%) participants.

Most of the study participants have already been submitted to hospitalization for treatment of schizophrenia (71.43%), and the number of psychiatric hospitalizations per patient ranged from zero to one. The time elapsed since the last hospitalization ranged from three to 30 years.

As regards access to prescription drugs, the majority of respondents (52.4%) had already experienced a failure in the provision of medication from the public health system.
Adherence and knowledge related to the prescribed pharmacotherapy

According to the evaluation of adherence performed using the AMT test, 16 (76.2%) patients reported adherence to the prescribed drug treatment.

This research also evaluated the patient’s degree of knowledge regarding the prescribed drugs. Therefore, the last medical prescription available on the patient’s chart was compared to the drugs that the patient reported using. Thus, the degree of knowledge regarding the name, dose, and drug administration frequency was analyzed, as shown in Figure 1.

![Distribution of the study subjects according to the degree of knowledge about the name, frequency, and dose of the drugs prescribed. Ribeirao Preto, Sao Paulo, Brazil, 2011.](http://dx.doi.org/10.5216/ree.v17i2.27636)

The lowest level of knowledge was in relation to the drug administration dosage, as most participants (57.1%) did not know the dose of all of the drugs they had been prescribed. In evaluating the information referred to on the dosage of the drugs, the responses considered correct were those that identified the quantity, in units of measurement (grams, milligrams and milliliters), to be administered at each scheduled time or within a period of 24 hours, according to the doctor’s prescription.

Difficulties related to the monitoring of drug therapy

The analysis of qualitative data related to the difficulties faced by patients during the monitoring of the drug therapy resulted in the construction of the following categories: “questioning the need or stating the obligation of the drug”, “believing that the drug makes you ill,” and “unable to carry out the administration of medications properly.”

Questioning the need or stating the obligation for the drug

This category reveals the difficulty of the study participants in accepting the pharmacological treatment. This difficulty is expressed in two distinct manners. The patient may find it difficult to adhere to the treatment due to questioning the need for and the effectiveness of the drug, or they may suffer in recognizing that they are required to submit themselves to drug therapy to control their symptoms.

Conflicts on the need for drug treatment are commonly identified among patients who do not admit the diagnosis. Thus, the understanding and acceptance of...
the existence of the disorder appear to be important for the drug to be considered useful.

What I feel there is all spiritual; it has nothing to do with disease. (P2)

Schizophrenia, I don’t think I have it, no. I don’t know what schizophrenia is. (P5)

Look, to be honest, I do not understand anything about it [schizophrenia]. Sometimes I talk to my daughter and she tries to explain. Then I get nervous, then she says I’m going crazy, because I do not want to accept it (...). No, I don’t really understand the disease very well. (P15)

There have been reports of questions about the need for taking the drug continuously in situations where the individual has not experienced symptoms.

I have already been without the medicine thinking that I had been cured and it all went wrong. It gets much worse. And there was one time that I was hospitalized, you know, because I got so bad. (P3)

Sometimes I say that I have taken them, but I haven’t, to see if I’m all right, you know. (P17)

For those who recognize the need to continue with the ongoing drug treatment, this condition represents an obligation and a lack of better options. Even in adhering to the treatment, patients characterize this situation as strange, tiresome, and unwelcome.

We think it’s a little weird having to take these medicines, right? But you have to take them, right? The way is to take them (...) the doctor has said that I can go without a meal, but I cannot go without the pills. (P3)

They make me feel lazy. But you have to take them, right? I take them. (P4)

It’s a must, right? (P8)

The drug arouses antagonistic feelings in respondents which, although they wish they didn’t need the drug, they perceive as a requirement for achieving a reduction of symptoms and disabilities, stabilization, better quality of life, and avoiding relapses and hospitalizations.

You get tired, feel sick. Now, I don’t stop taking them. I take them every day and I say it’s for my own good and for my happiness I take these drugs (...) I don’t like taking them. I stopped taking them, I came to the bad doctor, I had bad symptoms in the head, then I didn’t stop taking them again, no way. Until I die, if you need to take them, I’ll take them correctly. (P13)

I hear a lot of noise. It seems like it’s in my head, here in my head, it seems like a symphony orchestra, you know? Then I have to take medicine to see if I stop (...) without the drugs I don’t know how I would be. If it wasn’t for the drugs, I would not be here, no. (P16)

Once I got upset and I didn’t want to take the medicine, then my father admitted me to hospital. Because I cannot be without the medicine, if I run out of the drugs, then they may need to hospitalize me. (P21)

Believing that the drug makes you ill

By following drug treatment, a person with schizophrenia feels hampered by the side effects it causes. Such effects may have different impacts on the daily life of the patient.

I even ended up in hospital (...) I think it was because of the Haldol (...) I don’t remember, but my mouth began to twist like this. I started talking all slurry. (P6)

I can’t work right. It’s all very weakening. I feel limp. It’s bad, right? My body gets very tired, lazy. My head gets sleepy, because of the Haldol. (P18)

In the evaluation of patients, the side effects of the drug can be as intense as the benefits it provides.

I find it’s difficult to do anything! Physical exercise, study, relationship with my wife. (...) It seems like the drug is impregnated in the body. It makes everything really
difficult, tiredness, fatigue (...) I think it has more side effects than beneficial effects. I think that the medication has 30% positive side and the rest is what is left over, right? (P19)

The drug can be considered harmful not only for concrete experiments on the patient, but also for their beliefs.

I think it’s bad, because it’s a lot of medicine. It intoxicates. (P7)

I’m having treatment because I’m sick, my dear. I can’t take too much medicine, no. (P14)

Not being able to carry out the administration of medications properly

The difficulty for a person with schizophrenia to self-administer the drugs favors unintentional non-adherence behavior, because it hinders the rigorous monitoring of drug prescriptions, especially in the absence of supervision and when the treatment regimen is complex.

My head is already bad. I’m already forgetful. (P2)

I take a lot of medicine, so sometimes when I go to take the medicines I forget. (P3)

There are four medicines per day. I have difficulty in breaking the medicine, in breaking it. It’s difficult to swallow; it’s too bitter. (P14)

Assistance or supervision from family members, friends, and healthcare professionals can collaborate in the maintenance of treatment. However, there are situations where those responsible for the supervision of drug administration are also not sufficiently prepared for or committed to this activity.

I end up forgetting. My wife reminds me to take them; she gives me the medicine for me to take, you know? (...) She gives me them every day, you know (...) always on time, so that’s why I’m just a little lucid, right? (P16)

Not even he (husband) knows how to divide the drugs for me, when he gives me them; he either gives me too much or too little, do you understand? (P3)

Another condition that interferes with the possibilities of the person with schizophrenia to maintain treatment is the lack of access to prescription drugs, which was described as occasional, but it can cause impacting consequences.

It’s very expensive. It’s more than two hundred Brazilian Reals a box (...) My daughter, my son won’t have two hundred Reals, no. (P4)

My medicine is expensive, it is one thousand five hundred Brazilian Reals. I went to see the price already. (...) Where am I going to get this money from? I don’t earn that much. Either I buy the medicine or I go hungry (...) I tried suicide, I tried to cut my wrists. I don’t know, I went mad because I didn’t have enough medicine, as the doctor was on vacation and there was no one to give me the prescription for the medicine. So I was hospitalized. (P6)

DISCUSSION

Twenty-one individuals participated in the study. Most of them had more than 20 years of diagnosis, had already undergone hospitalization, used at least three types of psychiatric drugs, lived without a spouse, were not employed, and had poor education. Such characteristics may be related to the experiences, needs, and losses experienced over the years with schizophrenia.

Schizophrenia can cause functional impairment in different spheres of one’s life and have a significant impact on an individual’s quality of life. The disorder can cause loss of roles, financial constraints, constraints on the ability to make plans, and difficulties in interpersonal relationships (12-13).

As regards the prescribed anti-psychotics, an equal proportion of typical and atypical types has been identified. Typical anti-psychotic drugs have a lower cost,
but atypical ones are more efficient and better tolerated in the treatment of negative symptoms\(^{14}\).

Most respondents had already experienced occasional failure in access to the drugs prescribed. The monthly per capita income of most families did not exceed the minimum wage, suggesting unfavorable conditions for the maintenance of treatment with expensive drugs, as is the case with many atypical antipsychotic agents. These quantitative data corroborate the testimony of patients and the literature, which points out that possible failures in the provision of prescribed medications, associated with the user being unable to buy them, may compromise the continuity of the pharmacotherapy, as corroborated by other studies\(^{8}\).

Adherence to drug treatment among the participants in this study was higher than the rates of adherence commonly identified in the literature, as about half of the people with schizophrenia adhere to the drugs prescribed\(^{2,8}\). This aspect may be related to characteristics from the sample studied; however, self-reported questionnaires about adhesion, such as the one used in this research, have low sensitivity and high specificity, that is, they tend to overestimate adherence to treatment\(^{15}\).

Despite the high rate of adherence to treatment, this study identified the difficulty for patients to accept pharmacotherapy. There were patients who had conflicts over the use of the drug. On the other hand, those who recognized the need for the drugs considered it a tiresome and unwelcome obligation.

Conflicts related to treatment reveal the importance of constant interventions aimed at monitoring and motivating the individual to adhere to the treatment\(^{1,16-17}\).

A person with schizophrenia continually evaluates the need to follow the drug treatment to determine whether their priority is to adhere to treatment to reduce the symptoms of schizophrenia or to abandon treatment to minimize the wear and tear experienced with the prolonged use of drugs\(^{18}\).

Interactions with healthcare professionals can be opportunities for the reconstruction of meanings related to drug treatment\(^5\). Healthcare professionals can foster conscious and responsible decisions related to treatment adherence.

The participants in this study mentioned difficulties in the self-administration of drugs. Such limitations may favor unintentional non-adherence to drug treatment\(^8\).

The patient’s knowledge about the therapeutic regimen, which is a basic condition for self-administration of drugs, was also analyzed in this study. Most respondents were unaware of the information about the prescription, having a greater deficit of knowledge about the dose of the drugs prescribed.

Lack of knowledge about the dosage of drugs makes it easier for the individual to be exposed to higher or lower than indicated doses. Thus, the drug cannot be maintained in the therapeutic range, which increases risks of toxicity, accentuation of side effects, low tolerability, and a reduction in the efficacy of the treatment.

Besides the lack of information about the therapeutic regimen, patient limitations in administration of the drugs compromises prescription monitoring\(^8\), because cognitive deficits in schizophrenia are frequent and can affect the memory, attention, and executive functioning\(^{19}\). These limitations are compounded in the presence of complex treatment regimens\(^8\) and in the absence of assistance or supervision.

This reality requires nursing interventions aimed at the support and encouragement of family participation in patient support\(^{20}\), implementation of strategies that enhance the timeliness and memory in relation to the administration of drugs, as well as guidance for clients adapted to the needs, educational level, and cognitive functioning of the client.

Another element that complicates pharmacotherapy monitoring is the losses. In the evaluation of patients, the side effects of the drug can be as intense as their benefits.
The literature highlights side effects as among the main reasons for non-adherence.

To raise the effectiveness and customer satisfaction with antipsychotic drug treatment, an individualized approach is indicated, which considers current symptoms, comorbidities, previous therapeutic response, and adverse effects, as well as the choice and expectations of the patient.

Strategies for care related to treatment adherence should be based on the reality and subjectivity of each client, so that they can make decisions in adherence to the drugs.

This study addressed elements that, from the perspective of patients with schizophrenia, may be important barriers for the continuity of drug treatment. These difficulties and limitations in monitoring drug therapy by people with schizophrenia deserve to be investigated in different contexts and continuously addressed in nursing care in an individual and humane way.

CONCLUSIONS

This study identified a high rate of adherence with pharmacological treatment compared to the literature. However, a lack of knowledge was found about the therapeutic regimen and difficulties for the administration of drugs among people who did not have any supervision for this task. Such elements can harm strict and secure monitoring of drug prescriptions. This contradiction reveals that, in clinical practice, it is not enough to just evaluate adherence to treatment, but also the skills, the knowledge of the individual, and the support available for the administration of the drugs prescribed need to be monitored.

The difficulty of accepting drug treatment was present both among people who did not admit the usefulness of drugs and among those who were convinced of their need. Therefore, suffering arose both from living with a chronic mental disorder and from a drug regimen require nursing care.

The promotion of adherence to treatment and patient safety demand the recognition and intervention of a number of difficulties, suffering, and limitations addressed in this study.

Research is needed to explore the best strategies to intervene in the difficulties, conflicts, and the need for knowledge among people with schizophrenia to promote treatment adherence and patient safety.

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