



Acta Scientiarum. Health Sciences

ISSN: 1679-9291

eduem@uem.br

Universidade Estadual de Maringá  
Brasil

Oliveira, Renata Marques de; Rodrigues, Priscila Cristina Bim; Furegato, Antonia Regina Ferreira;  
Siqueira Júnior, Antônio Carlos

The meaning and implications of schizophrenia from the perspective of people who experience it

Acta Scientiarum. Health Sciences, vol. 35, núm. 1, enero-junio, 2013, pp. 77-84

Universidade Estadual de Maringá  
Maringá, Brasil

Available in: <http://www.redalyc.org/articulo.oa?id=307226203011>

- How to cite
- Complete issue
- More information about this article
- Journal's homepage in redalyc.org

redalyc.org

Scientific Information System  
Network of Scientific Journals from Latin America, the Caribbean, Spain and Portugal  
Non-profit academic project, developed under the open access initiative



# The meaning and implications of schizophrenia from the perspective of people who experience it

Renata Marques de Oliveira<sup>1\*</sup>, Priscila Cristina Bim Rodrigues<sup>2</sup>, Antonia Regina Ferreira Furegato<sup>1</sup> and Antônio Carlos Siqueira Júnior<sup>2</sup>

<sup>1</sup>Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, Av. Bandeirantes, 3900, 14040-902, Ribeirão Preto, São Paulo, Brazil.

<sup>2</sup>Faculdade de Medicina de Marília, Marília, São Paulo, Brazil. \*Author for correspondence. E-mail: [renatamarques@ymail.com](mailto:renatamarques@ymail.com)

**ABSTRACT.** This study identified at the moment of psychiatric hospitalization in a general hospital the meaning and implications of schizophrenia from the perspective of people who experience it. Interviews were conducted with ten patients with schizophrenia, diagnosed with the disorder for at least five years, hospitalized in the psychiatric ward of Clinical Hospital of Marília, based on the following question: what is the meaning and implications of living with schizophrenia? The interviews were taped, transcribed and subjected to thematic analysis. It was identified the category 'Discovering the schizophrenia' and three themes: Feelings experienced in the discovery and acceptance process; Knowledge about the disorder, diagnosis and treatment; Expectations for the future from the discovery of the disease. The results led to a greater understanding of the perception that patients with schizophrenia have about the disease and treatment, the implications for the future, as well as the difficulties and the suffering experienced in the discovery, identified during the acceptance process. This discovery can contribute to understanding these issues by professionals and to improve the implementation of nursing care.

**Keywords:** psychotic disorders, mental disorders, psychiatry, qualitative research, psychiatric nursing.

## O significado e as implicações da esquizofrenia na perspectiva de quem a vivencia

**RESUMO.** Este estudo tem como objetivo identificar, no momento da internação psiquiátrica em hospital geral, o significado e as implicações de ser portador de esquizofrenia, na perspectiva de quem a vivencia. Foram realizadas entrevistas com dez portadores de esquizofrenia, diagnosticados há pelo menos cinco anos, internados na Enfermaria de Psiquiatria do Hospital das Clínicas de Marília, com base na seguinte questão norteadora: qual o significado e as implicações de ser um portador de esquizofrenia? As entrevistas foram gravadas, transcritas e submetidas à análise temática. Foi identificada a categoria: 'Descobrendo a esquizofrenia' e três eixos temáticos: Sentimentos vivenciados na descoberta e o processo de aceitação; Conhecimento sobre o transtorno, o diagnóstico e o tratamento; Expectativas para o futuro a partir da descoberta da doença. Os resultados permitiram maior compreensão sobre a percepção que os portadores de esquizofrenia têm sobre a doença e o tratamento, as implicações para o futuro, bem como as dificuldades e o sofrimento vivenciados na descoberta, identificados durante o processo de aceitação. Essa pesquisa pode colaborar para compreensão destes aspectos por parte dos profissionais e para melhora da implementação do cuidado de enfermagem.

**Palavras-chave:** transtornos psicóticos, transtornos mentais, psiquiatria, pesquisa qualitativa, enfermagem psiquiátrica.

## Introduction

In the past, people with mental disorders were excluded from society and family environment. Therefore, the responsibility for these people was limited to professionals involved in the direct care provided in mental hospitals. The society only had the preconceived ideas about mental illness, based on religious ancient beliefs, to supernatural phenomena and knowledge of the time. There was no need to disclose more knowledge about mental disorders, since the dominant paradigm was that of exclusion.

The Law n° 10.216/01, fruit of the psychiatric reform in Brazil, ensures to mental health patients the right to be treated with respect and humanity, in order to achieve recovery from an ethical treatment and social reintegration. This law goes against the precepts of mental hospitals that work with the idea of social exclusion, with consequent depersonalization and annihilation of human potentials.

If in the past there was no need for more knowledge about mental disorders and those affected, today this is a critical issue, because as the therapeutic approaches are increasingly occurring in

community-based services, it is a duty for everyone to treat them with respect and humanity.

To follow the constitutional provisions it is necessary to know the mental disorder and its meaning for who experience it, without preconceived ideas. This is remarkable with schizophrenia that is the disease most negatively seen by the society, supporting the stigma about their patients (BRASIL, 2001; HSIUNG et al., 2010; JENKINS; CARPENTER-SONG, 2009; PINHEIRO, 2010; POSTEL; QUÉTEL, 1993).

These ideas are because schizophrenia is a mental disorder with peculiar clinical features, which arouse curiosity of the lay public and health professionals. The people with schizophrenia have, in their clinical manifestation, delusions that often make them behave in bizarre ways, as well as several types of hallucinations (auditory, visual, tactile, gustatory and olfactory), among other characteristic symptoms. This curiosity is because this disorder goes beyond the experiences of most people, and the little understanding of this experience generates fear and repulsion (ARARIPE NETO et al., 2007; HOLMES, 2001).

The term schizophrenia was created in 1911 by Bleuler, a Swiss psychiatrist, from the union of two Greek words: *Skizo* + *Phrem*, translated together as *Divided Mind*. When adopting this term Bleuler aimed to make understandable that in schizophrenia there are divisions of thought, emotion and behavior (BLEULER, 1967; SILVEIRA, 2009).

It is estimated that the prevalence of schizophrenia in Brazil and other countries is 1%, with an incidence of one to seven new cases per year for each 10,000 inhabitants. Usually the disease begins between 18 and 25 years in men, and a little later in women, between 25 and 35 years (MARI; LEITÃO, 2000; OMS, 2000).

For its occurrence, besides a genetic predisposition, it may also be necessary an intrapsychic and interpersonal stimulation. Thus to trigger schizophrenia does not depend on a single factor, but involves complex events, justifying numerous theories about its genesis, such as dopaminergic theory, serotonergic theory, glutamatergic theory, cerebral blood flow theory, neurodevelopmental theory, genetic theory, stress theory, among others, still doubtful (ARARIPE NETO et al., 2007; SADOCK; SADOCK, 2007).

The period with intense and identifiable symptoms is known as active phase, when positive and negative symptoms may be noted. Positive symptoms are those with additional behaviors consisted of: delusions, hallucinations, changes in speech, and bizarre behavior (catatonia, movement disorders). The negative are

those with behavioral deficits, such as: emotional dullness, poverty of speech, anhedonia and reduced attention (HOLMES, 2001; OMS, 2000; SADOCK; SADOCK, 2007; SHIRAKAWA, 2009).

The symptoms presented by a patient with schizophrenia are responsible for an intense suffering. As consequence, the quality of life is significantly affected, due to losses in social and occupational life, as well as interpersonal and familiar relationships, and daily activities in general. Objective and subjective aspects of the life of individual are impaired, affecting the whole life structure. It is also recognized an increased risk for suicide (HSIUNG et al., 2010; MAURITZ; MEIJEL, 2009; MOLL; SAEKI, 2009; SANTANA et al. 2009; SHIRAKAWA, 2009).

The society is affected since it bears the costs of illness. A consultation of the DATASUS site revealed that in Brazil, in 2009, the schizophrenia, schizotypal and delusional disorders, grouped into CID 10, presented the highest number of hospitalization (37.2%), compared to other psychiatric disorders. Among these admissions, the most prevalent age range was from 20 to 49 year (74.6%), i.e., an age in which people are most productive socially. The total expense related to hospitalization in Brazil, in 2009, regarding schizophrenia, schizotypal and delusional disorders was R\$261,797,941.69 (BRASIL, 2009).

As for the consequences for the family, the onset of schizophrenia often cause great shock, by occurring unexpectedly, providing a stress condition for everyone, which can cause familiar breakdown, with three types of overloads: financial, on family routines, or in the form of physical or emotional illness (KOGA; FUREGATO, 2002; SILVA; SANTOS, 2009).

Thus, the schizophrenia can not be considered just another chronic psychiatric illness added to the others, but a disease of great complexity, involving not only the individual affected, but also the family, the health professionals and the society.

Considering all the suffering experienced by the patient of schizophrenia and family, it is important to remember that behind the definitions of this disorder, there is a person needing to be accepted, recognized and valued, since is the protagonist and lives daily with the disease and its consequences. In this way, it becomes essential to discuss the meaning of this experience.

Therefore, this study aimed at identifying the meaning and implications of schizophrenia from the perspective of patients who experience it, at the moment of psychiatric hospitalization in a general hospital.

## Material and methods

This study was subjected to the Research Ethics Committee of Famema, with approval under the protocol no. 227/08, in accordance with the resolution 196/96.

To achieve the goals of the present study, it was used field research with qualitative approach.

Through qualitative methodology the researcher can understand the reality experienced by the involved subjects, from the direct contact with those who experience it. By working with the universe of meanings, reasons, aspirations, beliefs, values, and attitudes, the qualitative research allow the researcher to describe what observes, as well as interpret the content of reports and attitudes (MINAYO, 2006).

As a strategy to identify the meaning and the implications of having schizophrenia from the perspective of who experience it, at the moment of psychiatric hospitalization in a general hospital, interviews were performed with ten patients hospitalized in the psychiatric ward of Clinical Hospital of Marília, based on the following question: what is the meaning and implications of living with schizophrenia? The interviews were taped, and then transcribed integrally to ease data analysis.

The interviews were only performed after the participant of the study and familiar responsible have received information, and signed the Consent Statement. Inclusion criteria were considered the diagnosis of schizophrenia performed at least five years ago, and the absence of delusions and hallucinations at the time of interview, which could be obtained when the person has a scheduled discharge.

In order to analyze the content of the interviews, the Thematic Analysis was employed, consisting of discover the units of meaning that compose a communication whose presence or frequency signify something to the analytical objective (MINAYO, 2006). It was used in this study the stages of pre-analysis, material exploration, and discussion of the obtained results.

## Results and discussion

Ten patients (6 men, 4 women) with schizophrenia participated in this study. The average age was 41.8 years (21-66 years), and the average time of diagnosis of the disorder was 15 years (5-30 years). Four were divorced, four were married, and two were single. Only one was illiterate, three had incomplete elementary school, one had finished elementary school, three had not completed high

school, one had finished high school, and one had incomplete higher education.

Half of the interviewees were Catholic, four evangelic, and one spiritualist. As for activities developed before being diagnosed with schizophrenia, two were students, one did not perform any activity, and the others had different occupations. After the onset of the disease, seven interviewees have not engaged in any activity, two became users of the Center for Psychosocial Care (CAPS) and only one kept on working.

In this study, although the interviewees had been diagnosed with schizophrenia for at least five years, when they reported the meaning and implications of this disorder, it was evident the difficulties and suffering in its discovery. Thus, from the process of data analysis, it was identified the category 'Discovering the schizophrenia' and three themes: Feelings experienced in the discovery and acceptance process; Knowledge about the disorder, diagnosis and treatment; Expectations for the future from the discovery of the disease.

### Category: Discovering the schizophrenia

Discovering that one has a mental illness severe and disabling such as schizophrenia can be one of the most difficult times experienced by the individual. According to literature some people compare this moment to a 'descent into hell'. The perception of the mental health commitment by the patient with schizophrenia is very painful, because living with the onset of the disease also means living an internal collapse with commitment of their hopes, dreams and life projects, and also of their families (MAURITZ; MEIJEL, 2009; NOISEUX; RICARD, 2008). In this category, three themes were identified:

#### Feelings experienced in the discovery and acceptance process

The discovery of the disease can be understood as a time of great difficult, since it is unexpected. Some feelings can be present due to the first psychotic episode, such as: grief, depression, guilty, denial, surprise and anger, so that the individual experiences a real grieving process (LOUZÁ NETO, 2000; MAURITZ; MEIJEL, 2009). But in the interviews it was possible to identify other feelings reported by the individuals, such as: shock, despair, anguish and suffering.

It was a shock for me [...] was desperate with a too great anguish [...] It was difficult, when I remember, I remember the suffering I went through [...] I prayed and asked God in my prayers for that was nothing [...] I was suspicious, like a sixth sense. I

asked, weeping for my mom [childish voice]: mom what's going on? (Cravo).

With the report of Cravo, it was evident the intensity of suffering experienced at that time, when the interviewee reported having sought spirituality with the hope that the first outbreak was nothing serious and out of control. Importantly, the childish voice that the patient had expressed his suffering, when remembering the contact with the mother during the first outbreak, can demonstrate that psychotic adults hardly overcome the psychotic anguish of childhood, and that they are prone to regress when psychosis emerges (DIATKINE et al., 1993).

The onset of the disease is quite impressive for those who experience it, mainly when the person discovers that is often not possible to keep the emotional status and the life under control (COELHO; HOLLANDA, 2002; MAURITZ; MEIJEL, 2009; NOISEUX; RICARD, 2008). Orquídea clearly reported the effort that she had to do for not losing contact with reality and the suffering derived from this fact:

[...] I was really scared. On the first day it had happened [outbreak], I thought I was crazy because I saw people talking normally near me and I was hearing voices. Nobody listened. [...] I try to control myself to be the most lucid [...] I'm out of reality, we get a very horrible fear [...] (Orquídea).

The impact of the onset of the disease on the life of the individual, like fright and fear, affect the process of accepting the new condition. The patient with schizophrenia, when discover the disorder, may deny the diagnosis, need for treatment, limitations imposed and adjustments that will be needed in everyday life. Thus, one of the first attitudes may be hiding the first symptoms, either by fear or shame (MAURITZ; MEIJEL, 2009).

I hid the outbreak for three months, I was already hallucinating. It began on April 8<sup>th</sup> 2001 at 4:15 a.m. [...] I hid for three months for fear [...] I thought it was some kind of crazy [...] horrible the first day, I recorded the hour, the day, the year [...] was the worst thing of my life (Orquídea).

One of the consequences of the attitude of hiding the first symptoms, whether consciously or unconsciously is to postpone the treatment, which can last for several years. As the first psychotic episode typically occurs during the active phase of the individuals, hiding the onset of the disease and not seeking treatment causes a disruption of social relationships, with successive relapses, increasing the risk for suicide attempt. In this way, the social relationships are hardly restored, since the

commitment caused by the disease prevents them from continuing with normal activities (LOUZÁ NETO, 2000; NOVICK et al., 2010).

The difficult experienced when discovering the schizophrenia is because this disorder is seen by the society and by the patients and families as a form of madness. Be 'crazy' means in assuming the lack of control on the life, behavior; means in being discredited to others, lose the citizenship and lose the rights as a person (SPADINI; SOUZA, 2006). In this way, denying the disease is an alternative to fit the standards of normality and be more accepted by the society. The denial and the non-acceptance were reported by the interviewees:

[...] I have this opinion, I don't think it is schizophrenia [...] to be on my way, my way of talking [...]. Schizophrenic... I don't have schizophrenia! (Violeta).

I should not have that, it's the worst thing! [...] it's hard to for people to have this problem [...] (Tulipa).

After the stage of isolation, denial and anger, the person may tackle and better understand the disorder when become more active in developing the treatment plan. The denial observed in the reports is not something constant and unchanging. When achieved, the acceptance process may help decrease the occurrences of episodes and hospitalizations (COELHO; HOLLANDA, 2002; MAURITZ; MEIJEL, 2009).

### Knowledge about the disorder, diagnosis and treatment

Noteworthy, at the moment of discovering schizophrenia, both the fact of having information about its severity, as also the fact of not having any knowledge about it, may impair the coping strategy in the initial phase of the disease. As consequence, the individual may have doubts about the onset of schizophrenia:

[...] this disease that I recently came to know, I don't know if I ever had it before and I didn't know [...] I was retracted, you know, because it's a disease that we don't know much [...] we are always in doubt, because actually we don't know the base of this disease [...] we're a bit goofy of having a disease like this (Girassol).

In the literature is given that there is no certainty of the exact moment in which the disease appeared, which is in line with people information, since the compromising of mental functions derived from schizophrenia can occur before the appearance of the first psychotic symptoms (MONTEIRO; LOUZÁ, 2007; OMS, 2000; SADOCK; SADOCK, 2007).

The unawareness about the diagnosis is a factor which can contribute to intensify the suffering of the individual, making feel anguish and anxiety in front of the waiting of an explanation for lived changes. Rosa says that the discovery of the diagnosis, despite has been a mixture of feelings, was also a relief:

It was a joy and a sadness, but less sadness than joy. I always wanted to know what I had, if it had how to solve, if it had hope for cure, but the doctors never spoke, I pressured them to know [...] I was happy, at least I have a hope, I have a cure in quotation marks, and medication is a cure in quotation marks [...] (Rosa).

In her speech, Rosa seemed to be hopeful in front of the diagnosis, because she believed that the medicine could help her. However, this attitude may not occur in all patients of schizophrenia when discovering the disease, because in front of the diagnosis and the stereotype of this mental disease given by the society, the individual can play with resignation the role of patient.

To assume with resignation the role of patient means to be at the 'mercy of schizophrenia'. This attitude prevents that people with this disorder take part of the changing process of the new condition of their existence. Hence, is fundamental that the professionals, when revealing the diagnosis, encourage the patients of mental disease to fight for to control the pathologic situation and to take control of their lives (COELHO; HOLLANDA, 2002; MAURITZ; MEIJEL, 2009).

Considering the knowledge about disorder and diagnosis, it is also important to think about perception of the treatment, whose purpose consists of promoting quality of life for patients with this disease and not only to mitigate the symptoms in the acute phase (SADOCK; SADOCK, 2007; MOLL; SAEKI, 2009). In this way, the biological aspect of the disease, dealt with drug treatment, is fundamental. We must also consider the several spheres of the individual's life, when, then, is possible to expand the look to the mental health.

In the speeches of Margarida and Dama da Noite it was very highlighted the importance of psychosocial approach in schizophrenia treatment, when they referred the Psychosocial Attention Center (CAPS). The purpose of CAPS is to promote the mental health through the psychosocial rehabilitation, by helping the individual to adapt to the new living condition. It is based on the principle of humanization and reintegration of patients of mental disorder into the society, aiming an active citizenship that can allow the recognition of

mechanisms of adaptation, discovery of abilities and the facing of difficulties (BRASIL, 2004; CARDOSO; GALERA, 2009; MELLO; FUREGATO, 2008; MOLL; SAEKI, 2009; TOMASI et al., 2010).

[...] when I had been admitted to CAPS I was getting better, and before the CAPS I'd never did anything [...] I love the CAPS, it's a nice place [...] (Margarida).

However, the effective psychosocial approach must move together with the success in drug treatment, which is closely related to the patient adherence. The non-adherence rate to drug treatment is around 50% in such disorder. The factors related to this trend are: sociodemographic factors, duration and perception about this disorder, type and severity of symptoms, loss of insight, complexity of the treatment, side effects of drugs, perception of the drugs benefits, patient education and link established with the professionals.

Another recognized factor concerns the perception by the patient about the stigma associated with using medication. The patient may be reluctant to join the treatment, fearing that other persons perceive the need for continued use of a psychiatric medication. On this occasion, they can stop to take the medication or merely begin to take it in situations that they can find privacy (CARDOSO; GALERA, 2009; JENKINS; CARPENTER-SONG, 2009; NOVICK et al., 2010; ROSA; ELKIS, 2007; SADOCK; SADOCK, 2007).

In the interviews it was possible to identify some factors related to the non-adherence:

They [drugs] help and hinder. There are many side effects, a lot of them! [...] blurs vision, weight gain, increases hunger, which is what I'm more afraid, constipation [...] twists the tongue quite a lot to speak, is difficult [...] (Orquídea).

Orquídea reports some side effects attached to the used drugs for schizophrenia control, showing to be aware of this relationship. The side effects must be explained to patient and minimized as much as possible, in order to encourage adherence, regarding that effects generate too much stress in daily life of the patient (MAURITZ; MEIJEL, 2009; ROSA; ELKIS, 2007). On the other hand, they clearly feel the changes caused by these psychoactive drugs, especially minimizing the changes of perception, thought and mood.

Another factor identified in the interviews related to the non-adherence refers the recognition about the chronicity of the disorder, which was also significantly found in a research conducted by Noiseux and Ricard (2008), when over half of

respondents have compared the schizophrenia to chronic health problems, such as hypertension and diabetes. In this research, Girassol comparing psychiatric disorder to hypertension showed to be aware of the needing of continued use of medicines for its control:

[...] I'd never imagined such a disease because I already have problem of high blood pressure. I have to take medicine every day. I have a life based on medicines [...] this medicine is continuous, for a lifetime (Girassol).

The continued use of antipsychotic drugs makes the individual remember the condition of carrier of incurable mental disorder, with the medication signaling the disease itself (COELHO; HOLLANDA, 2002).

In front of the non-adherence to drug treatment, the reactivation of the disease symptomatology is not usually associated to the individual failures in the following of prescriptions, once the recurrences can take from 3 to 7 months to occur.

In this way, information is essential and must be the first step to psychiatric intervention, so that there must be knowledge about the disease, the drugs to be used, as well as their purposes, possible side effects and the implications on quality of life of the person (CARDOSO; GALERA, 2009; MAURITZ; MEIJEL, 2009; SADOCK; SADOCK, 2007).

The factors attached to pathology itself can affect negatively the adherence to the treatment (SADOCK; SADOCK, 2007).

[...] I didn't want to take the medicine because I thought that in the drug there was some kind of chip for me to become evil too, the world was evil, the entire humanity! (Cravo)

Although Cravo has reported resistance to adhere to the treatment due to the symptomatology of schizophrenia, in a second part of the interview he affirmed that had accepted the proposed interventions after establishing a relationship of trust with the psychiatrist:

When I told my problems to the psychiatrist in the first hospitalization I decided to take the drugs naturally. I understood that the medicines made me calmer, that the world was not evil [...] (Cravo).

This relationship of trust is defined as a therapeutic alliance, known as the cooperation and the understanding established between therapist and patient. The therapeutic alliance is difficult to be achieved in schizophrenia. The proper medicine prescribed and provided can be an ally to reduce symptoms and enable the person to realize what

happens and the importance of the involvement in this process. Despite obstacles, the professionals must recognize this fragility, accept the individual, a carrier of mental disorder, and seek alternatives to improve the link, in order to treat the individual as well as possible (CARDOSO; GALERA, 2009; SADOCK; SADOCK, 2007).

### **Expectations for the future from the discovery of the disease**

Take control of life means also to wait for a better future. For this purpose, is fundamental that schizophrenia patient can find the necessary support in this difficult phase of discoveries and coexistence with the disease. This conception must be present in the practices of daily life of health professionals in relation to the mental disorder patients, professionals whose tasks, together with family, are to value and enhance the efforts of schizophrenia patients, as well as their achievements and assist them during recurrences or when their efforts have not the expected results. Encouraging them to try and persist, respecting the limits set by the mental disorder.

Considering that in schizophrenia, a progressive deterioration can occur both in the mental functions and in the interpersonal relationships, it becomes very difficult to wait for a better future, once the conception of future is built from the perception of what we are and from the experiences, which may lead to many uncertainties and inquietudes of what is expected (DIATKINE et al., 1993; MAURITZ; MEIJEL, 2009; NOEISEUX; RICARD, 2008).

[...]My life will be always this way? With fights, hospitalizations? With unhealthy symptoms? Or will God helps me to get through the problems? [...] (Cravo).

Additionally to the motivation for a better future, it is primordial that the professional does not forget the inevitable difficulties attached to schizophrenia, providing appropriate support for the individual to confront the reality through the clarification of the limitations and the joint construction of coping mechanisms.

Margarida, during the interview showed the will of studying higher education and Rosa the will of writing a book with the purpose of helping people with the same disorder. Due to the cognitive losses attached to disease these activities become more difficult for schizophrenia patients. However, this issue is something to be worked out by the professionals, so that the difficulties can be confronted respecting the motivations, limitations, internal resources available and the time of each

patient (DURÃO et al., 2007; MAURITZ; MEIJEL, 2009; MONTEIRO; LOUZÃ, 2007).

I'm retired now, but I've heard that retired people have the right to study and work and I'm thinking about that, I'll go work and study again. Do you know what I wish for? I love pets, oh gosh, veterinary! (Margarida)  
[...] to develop my book 'The pleasure of being yourself' [...] and I'm searching into myself the answers for how to feel good even being schizophrenic [...] a book to help people, to have the pleasure of being themselves, and not to seek stereotypes (Rosa).

Although it may be hard to write a book, this motivation in schizophrenia patients is interesting, because through the willingness to help others, it is sought to explain the disease and its consequences starting from their own experiences. Both the helper and the helped are benefited, because the report of the experiences and suggestions contributes for the others to find new perspectives to face their reality; at the same time that the individual who reports the lived experience is revealed as someone different and can report it in a coherent way, which raise the individual's self-esteem (COELHO; HOLLANDA, 2002).

## Conclusion

Through this study it was possible to identify in schizophrenia patients the difficulties and sufferings lived in the discovery and in the coexistence with the mental disorder.

Although the subjects of this study are patients for at least five years, the moment of the discovery was reported in a very lively way, which may have happened due to the way they were found in the interview, that is, confined to a psychiatric ward of a general hospital, in the same place where it was performed the diagnosis of many of them few years ago.

In the reports, we identified the difficulties, feelings, steps of acceptance process, difficulties to comprehend schizophrenia, the relief due to the discovery of diagnostic, and uncertainty in relation to future, despite some of them had quoted new perspectives.

Furthermore, it was identified the valorization concerning the follow-up conducted at CAPS, the recognition of side effects of the drugs, and the chronicity of disease, some reasons for non-adherence, and the importance of the therapeutic link influencing the whole process.

In this way, it becomes essential the role of health professionals, able to provide the support and the necessary incentive so that the schizophrenia patient

can confront difficulties and limitations, in such a way that occur, in fact, the social reintegration, with guarantee of the citizenship rights.

## Acknowledgements

The authors thank to Prof. Dr. Maria José Sanches Marin, Prof. Dr. Valéria Garcia Caputo, Adriana Marques de Oliveira, for their collaboration, and the entire psychiatric team of the Clinical Hospital of Marília.

## References

- ARARIPE NETO, A. G. A.; BRESSAN, R. A.; BUSATTO FILHO, G. Fisiopatologia da esquizofrenia: aspectos atuais. **Revista de Psiquiatria Clínica**, v. 34, supl. 2, p. 198-203, 2007.
- BLEULER, E. **Tratado de psiquiatria**. Madrid: Espasa-Calpe, 1967.
- BRASIL. Lei n. 10.216, de 6 de abril de 2001. Dispõe sobre a proteção e os direitos das pessoas portadoras de transtornos mentais e redireciona o modelo assistencial em saúde mental. **Diário Oficial da República Federativa do Brasil**, Brasília, 9 abr. 2001. Seção1:2.
- BRASIL. Ministério da Saúde. **Base de dados DATASUS**: Departamento de Informática do SUS. Brasília, 2009. Available from: <<http://www.tabnet.datasus.gov.br>. Access on: Aug. 2, 2010.
- BRASIL. Ministério da Saúde. **Saúde mental no SUS: os Centros de Atenção Psicossocial**. Brasília, 2004.
- CARDOSO, L.; GALERA, S. A. F. Doentes mentais e seu perfil de adesão ao tratamento psicofarmacológico. **Revista Escola de Enfermagem da USP**, v. 43, n. 1, p. 161-167, 2009.
- COELHO, V. L. D.; HOLLANDA, D. M. Quando o usuário é autor: reflexões sobre depoimentos redigidos por pacientes com esquizofrenia. **Jornal Brasileiro de Psiquiatria**, v. 51, n. 6, p. 341-352, 2002.
- DIATKINE, R.; QUARTIER-FRINGS, F.; ANDREOLI, A. **Psicose e mudança**. São Paulo: Casa do Psicólogo, 1993.
- DURÃO, A. M. S.; SOUZA, M. C. B. M.; MIASSO, A. I. Cotidiano de portadores de esquizofrenia após uso de clozapina e acompanhamento grupal. **Revista da Escola de Enfermagem da USP**, v. 41, n. 2, p. 251-257, 2007.
- HOLMES, D. S. **Psicologia dos transtornos mentais**. Porto Alegre: Artmed, 2001.
- HSIUNG, P. C.; PAN, A. W.; LIU, S. K.; CHEN, S. C.; PENG, S. Y.; CHUNG, L. Mastery and stigma in predicting the subjective quality of life of patients with schizophrenia in Taiwan. **The Journal of Nervous and Mental Disease**, v. 198, n. 7, p. 494-500, 2010.
- JENKINS, J. H.; CARPENTER-SONG, E. A. Awareness of stigma among persons with schizophrenia. **The Journal of Nervous and Mental Disease**, v. 197, n. 7, p. 520-529, 2009.



- KOGA, M.; FUREGATO, A. R. F. Convivência com a pessoa esquizofrênica: sobrecarga familiar. **Revista Ciência, Cuidado e Saúde**, v. 1, n. 1, p. 69-73, 2002.
- LOUZÃ NETO, M. R. Manejo clínico do primeiro episódio psicótico. **Revista Brasileira de Psiquiatria**, v. 22, supl. 1, p. 45-46, 2000.
- MARI, J. J.; LEITÃO, R. J. A epidemiologia da esquizofrenia. **Revista Brasileira de Psiquiatria**, v. 22, supl. 1, p. 15-17, 2000.
- MAURITZ, M.; MEIJEL, B. V. Loss and grief in patients with schizophrenia: on living in another world. **Archives of Psychiatric Nursing**, v. 23, n. 3, p. 251-260, 2009.
- MELLO, R.; FUREGATO, A. R. F. Representações de usuários, familiares e profissionais acerca de um centro de atenção psicossocial. **Escola Anna Nery Revista de Enfermagem**, v. 12, n. 3, p. 457-464, 2008.
- MINAYO, M. C. S. **O desafio do conhecimento: pesquisa qualitativa em saúde**. Rio de Janeiro: Hucitec, 2006.
- MOLL, M. F.; SAEKI, T. Social life of people with diagnosis of schizophrenia, attended at a psychosocial care center. **Revista Latino Americana de Enfermagem**, v. 17, n. 6, p. 995-1000, 2009.
- MONTEIRO, L. C.; LOUZÃ, M. R. Alterações cognitivas na esquizofrenia: consequências funcionais e abordagens terapêuticas. **Revista de Psiquiatria Clínica**, v. 34, supl. 2, p. 179-183, 2007.
- NOISEUX, S.; RICARD, N. Recovery as perceived by people with schizophrenia, family members and health professionals: a grounded theory. **International Journal of Nursing Studies**, v. 45, n. 8, p. 1148-1162, 2008.
- NOVICK, D.; HARO, J. M.; SUAREZ, D.; PEREZ, V.; DITTMANN, R. W.; HADDAD, P. M. Predictors and clinical consequences of non-adherence with antipsychotic medication in the outpatient treatment of schizophrenia. **Psychiatry Research**, v. 173, n. 2, p. 109-113, 2010.
- OMS-Organização Mundial da Saúde. **Classificação Estatística Internacional de Doenças e Problemas relacionados à Saúde – CID-10**. São Paulo: Edusp, 2000.
- PINHEIRO, G. H. A. **Comentários a Lei da Reforma Psiquiátrica**: uma leitura constitucional da lei n. 10.216, de 6 de abril de 2001. Fortaleza: Tear da Memória, 2010.
- POSTEL, J.; QUÉTEL, C. (Comp.). **Historia de la psiquiatria**. México: Fondo de Cultura Económica, 1993.
- ROSA, M. A.; ELKIS, H. Adesão em esquizofrenia. **Revista de Psiquiatria Clínica**, v. 34, supl. 2, p. 189-192, 2007.
- SADOCK, B. J.; SADOCK, V. A. **Kaplan and Sadock compêndio de psiquiatria: ciência do comportamento e psiquiatria clínica**. 9. ed. Porto Alegre: Artmed, 2007.
- SANTANA, A. F. R. A.; CHIANCA, T. C. M.; CARDOSO, C. S. Qualidade de vida de pacientes com esquizofrenia internados em hospital de custódia. **Jornal Brasileiro de Psiquiatria**, v. 58, n. 3, p. 187-194, 2009.
- SILVA, G.; SANTOS, M. A. Álbum de família e esquizofrenia: convivência em retrato. **Psicologia em Estudo**, v. 14, n. 1, p. 83-91, 2009.
- SILVEIRA, R. D. Psicanálise e psiquiatria nos inícios do século XX: a apropriação do conceito de esquizofrenia no trabalho de Hermelino Lopes Rodrigues. **Revista Latino-Americana de Psicopatologia Fundamental**, v. 12, n. 3, p. 582-596, 2009.
- SHIRAKAWA, I. **O ajustamento social na esquizofrenia**. São Paulo: Casa Leitura, 2009.
- SPADINI, L. S.; SOUZA, M. C. B. M. A doença mental sob o olhar de pacientes e familiares. **Revista Escola de Enfermagem da USP**, v. 40, n. 1, p. 123-127, 2006.
- TOMASI, E.; FACCHINI, L. A.; PICCINI, R. X.; THUMÉ, E.; SILVA, R. A.; GONÇALVES, H.; SILVA, S. M. Efetividade dos centros de atenção psicossocial no cuidado a portadores de sofrimento psíquico em cidade de porte médio do sul do Brasil: uma análise estratificada. **Caderno de Saúde Pública**, v. 26, n. 4, p. 807-815, 2010.

*Received on August 27, 2010.*

*Accepted on August 1, 2011.*

License information: This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.