

An elderly couple and their long life raising four schizophrenic children

UM CASAL DE IDOSOS E SUA LONGA CONVIVÊNCIA
COM QUATRO FILHOS ESQUIZOFRÊNICOS

UNA PAREJA DE ANCIANOS Y SU LARGA CONVIVENCIA
CON CUATRO HIJOS ESQUIZOFRÊNICOS

Renata Marques de Oliveira¹, Antonia Regina Ferreira Furegato²

ABSTRACT

The objective was to identify, among parents of schizophrenics, elements of their daily life in coping with the disorder and the care offered and received through the health system. This is a field research, using thematic oral history. The parents of four patients with schizophrenia took part in this study. Interviews were conducted, recorded and transcribed, based on three instruments (two specific questionnaires and a field diary). Three categories were identified that reflect difficulties experienced in daily life: limitations in knowledge about schizophrenia; fatigue and burden with impairment of quality of life; and uncertainty about the future and resilience strengthened by faith in God. The concept of care was associated with technical procedures, revealing general satisfaction with the care received. The suffering related to living with schizophrenic relatives is intense, and professionals must be prepared to deal with these experiences of pain and suffering from patients with mental disorder and their relatives.

DESCRIPTORS

Schizophrenia
Family
Aged
Psychiatric nursing
Mental Health Services

RESUMO

Objetivou-se identificar, entre pais de esquizofrênicos, elementos de sua convivência diária com o transtorno e com o cuidado recebido através do sistema de saúde. Pesquisa de campo na vertente história oral temática. Participou um casal, pais de quatro portadores de esquizofrenia. Foram realizadas entrevistas, gravadas e transcritas, usando três instrumentos (dois questionários específicos e um diário de campo). Identificaram-se três categorias que retratam dificuldades vivenciadas no cotidiano, entendimento da esquizofrenia com sentido de limitações, cansaço e sobrecarga com prejuízo da qualidade de vida, incerteza em relação ao futuro e resiliência fortalecida pela fé em Deus. A concepção de cuidado foi associada a procedimentos técnicos, mostrando satisfação com a atenção recebida. Concluiu-se que o sofrimento ocasionado pela convivência com portadores de esquizofrenia é intenso e os profissionais precisam estar preparados para lidar com as vivências de dor e sofrimento do portador do transtorno mental e seus familiares.

DESCRIPTORIOS

Esquizofrenia
Família
Idoso
Enfermagem psiquiátrica
Serviços de Saúde Mental

RESUMEN

Se objetivó identificar, entre padres de esquizofrênicos, elementos de su convivencia diaria con el transtorno y la atención recibida a través del sistema de salud. Investigación de campo, vertiente historia oral temática. Participó una pareja, padres de cuatro esquizofrênicos. Se realizaron entrevistas, grabadas y transcritas, utilizando tres instrumentos (dos cuestionarios específicos y diario de campo). Se identificaron tres categorías que retratan dificultades experimentadas cotidianamente, comprensión de la esquizofrenia con sentido de limitaciones, cansancio y sobrecarga con perjuicio de calidad de vida, incertidumbre relativa al futuro y resiliencia fortalecida por la fe en Dios. La concepción de cuidado se asoció a procedimientos técnicos, mostrándose satisfacción con la atención recibida. Se concluye en que el sufrimiento derivado de la convivencia con esquizofrênicos es intenso, los profesionales necesitan estar preparados para enfrentar las experiencias de dolor y sufrimiento del enfermo mental y de sus familiares.

DESCRIPTORIOS

Esquizofrenia
Familia
Anciano
Enfermería psiquiátrica
Servicios de Salud Mental

¹RN. Master's student, Graduate Program in Psychiatric Nursing, University of São Paulo at Ribeirão Preto College of Nursing. Grantee, Brazilian Scientific and Technological Development Council (CNPQ). Ribeirão Preto, SP, Brazil. renatamarques@ymail.com ²RN. Full Professor, Psychiatric Nursing and Human Sciences Department, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. furegato@eerp.usp.br

INTRODUCTION

Schizophrenia is a severe psychiatric disorder that tends to evolve towards chronicity. Its severity can be better understood in the family structure when considered the harm it causes in patients' lives, in their daily activities and in all of their personal relations⁽¹⁻⁵⁾.

Schizophrenia was associated with a deteriorating course, which contributed to strengthen the idea of social isolation. For many years, its patients were kept in asylums^(3,6). International criticism against this institutionalization, since the mid-19th century, influenced the current Brazilian psychiatric reform, together with the creation of the Unified Health System (SUS) in Brazil.

Thus, mental disorder patients who remained confined to asylums for many years can return to social life, which concrete proposals to transform mental health and illness concepts and concerning care in this area^(3,6-8).

In the deinstitutionalization process, the family context is considered *a privileged space for care* and essential in each mental disorder patient's therapeutic plan, demanding the efficient reorganization of health services and professional preparation. In view of these transformations, it is fundamental to broaden care to the family^(3,8-10).

Living with schizophrenic patients is considered a *commitment to fight the suffering*⁽³⁾. It is important for professionals to work with the family as an ally in the therapeutic process, without remaining limited to care for the harm the disease causes^(9,11-12).

Therefore, in view of the situation of suffering among relatives of schizophrenic patients, the aim of this research is to identify, among parents of these patients, elements of their daily contact with the mental disorder and the care received through the health system.

METHOD

Study design: A qualitative field research design was used, aiming to understand a certain reality in depth, based on the psychiatric nurse's direct contact with the stakeholders⁽¹³⁾. Thematic oral history was used, which comprises a set of procedures (project elaboration, definition of the colony and study network, elaboration of questionnaire, interview, transcription and analysis), based on recorded testimonies, aiming to overcome periods of silence and reveal the complexity of a given experience (specific theme) from the witness' perspective, arousing the feeling of playing an active part in the construction of his/her history⁽¹⁴⁻¹⁵⁾.

Place of study: The study was developed in the coverage area of a Family Healthcare Unit (FHU) in an interior

city in São Paulo state, which attends 876 families, totaling 2,784 inhabitants; 45% attend the unit, 9.5% of whom have a confirmed diagnosis of some mental disorder.

Population and sample: In line with the premises of thematic oral history, this research defined the family as the study colony (population) and an elderly couple, parents and legal representatives of four schizophrenic children as the network (sample). The subjects were identified during a curricular training program as part of an undergraduate nursing course. Hence, the sample was intentional as, despite the restricted number of participants, the life experience of one single family with four schizophrenic children is relevant.

Instrument: Three data collection instruments were used: 1) Identification questionnaire for the schizophrenic children; 2) Identification questionnaire for family members' perception about daily life with schizophrenia and about the care received through the city's health system (IPERESQUIZO); and 3) Field diary.

In the
deinstitutionalization
process, the family
context is considered
a privileged space for
care and essential in
each mental disorder
patient's therapeutic
plan, demanding the
efficient reorganization
of health services
and professional
preparation.

The identification questionnaire for the children with schizophrenia contains identification data for each child and 26 closed questions on the gestational history, delivery and birth conditions, childhood illnesses and developmental characteristics, perceived interests in adolescence, previous and current history of health conditions, medication used, psychiatric hospitalizations and main personality characteristics.

The identification questionnaire of family members' perception about daily life with schizophrenia and about the care received through the city's health system (IPERESQUIZO) is structured as follows: A) Identification of study participants, B) Current health conditions, C) Family history and D) Semistructured questions about daily contact with schizophrenia and the care received.

The field diary contains notes about important events and the researcher's key impressions during the data collection period.

Ethical aspects: This study received approval from the Institutional Review Board at EERP/USP (Protocol No. 1183/2010), after which data collection started. Questions about the subjects' participation were explained in detail and, after clarifying any doubts, two copies of the Informed Consent Term were signed.

Data collection: The participants were invited to take part in the research in advance. A psychiatric nurse interviewed them in October 2010, at their home, as no direct care/authority relation existed. Initially, the identification questionnaire for the children with schizophrenia was completed, involving two study subjects (the parents). Then, each participant was interviewed separately, following the

identification questionnaire of family members' perceptions about daily life with schizophrenia and about the care received through the city's health system (IPERESQUIZO).

During the entire course of data collection, the field diary was also used. The interviews were recorded and fully transcribed.

Analysis procedures: After transcribing the interviews, floating reading was used to understand the vital tone⁽¹⁵⁾, that is, the meaning the research participants gave to the interview and which, consequently, they also attribute to their stories. Based on the identification of the thematic categories, a dialogue was established between the data found and scientific literature about the theme. The subjects are presented at the end of their statements as father and mother, following the codification criterion to guarantee anonymity.

RESULTS

To organize the results, first, the study subjects are presented based on the two data collection instruments used. Next, the thematic categories are discussed, including the vital tone attributed to their life histories.

Chart 1 – Identification of subjects, parents of four children with schizophrenia, demographic data and health conditions.

IDENTIFICATION	Father	Mother
Age	82	80
Origin	Abaíra/BA	Guaxupé/MG
Education	Illiterate	Unfinished secondary education
Marital Status	Married	
Time of Marriage	60 years	
Occupation	Retired	Housewife
Monthly Family Income	Three minimum wages	
Religion	Catholic	Evangelical
Religious Practice	No	Yes
HEALTH CONDITIONS		
Medical Diagnoses	Hypertension	Hypertension and heart problem
Current Medication	Opposed to medication treatment	Atenolol, Enalapril and Amlodipine Besylate
Habits	Smoker for 72 years (twost tobacco)	Former smoker
Sleep/rest	Satisfactory (12 hours per night, uninterrupted sleep)	Unsatisfactory
Appetite	Unaltered	
Physical Exercise	Walks daily	No
Memory	Unaltered	Recent memory difficulties
Leisure	No	
Daily Activities	House maintenance and accompanies consultations	Housework and child care

A) Presentation of subjects

Five children live with the elderly couple in this study, four of whom are schizophrenia patients and one displays eccentric behavior, demonstrating resistance and aggressiveness towards health professionals' presence. The only information that could be obtained about this fifth child is that of alcohol abuse. The elderly couple has four other children, but they do not live with their parents, have a family and a job and there are no reports of mental illness.

The schizophrenic patients' parents reported a history of alcoholism in their parents, denying any other mental disorder, history of psychiatric hospitalization or suicide attempt.

The second figure summarizes information about the four schizophrenia patients' identification and their previous and current history of health conditions.

The pregnancies of the four children were planned and no problems occurred during this period. The mother smoked during the pregnancy of children 1 and 2, but this habit was not present during that of children 3 and 4. All deliveries were normal and full-term. The only problem occurred in the delivery of daughter 3, who was anoxic, but without the need for ICU and special care after this event.

The children's birth order, including the five children without diagnosed schizophrenia, can be presented as follows: daughter 1 (schizophrenic), five non-schizophrenic children, daughter 2 (schizophrenic), daughter 3 (schizophrenic) and son 4 (schizophrenic).

In childhood and adolescence, children 3 and 4 had poliomyelitis and, consequently, started to present hemiplegia, affecting their walking skills. Only daughter 3 suffered language development alterations, did not study and experienced difficulties to interact with other people. The other children showed neither language development alterations nor learning difficulties. Daughters 1 and 2's main interests during adolescence were getting married and son 4 painted and dreamt about selling his painting.

Daughters 1 and 2 were diagnosed with schizophrenia at the age of 15 years. In both, the start of psychotic symptoms coincided with problems in their affective life, when love relations broke up. The parents could not inform when the first schizophrenia symptoms appeared in daughter 3 due to the interaction difficulty she always experienced. Son 4 was diagnosed at the age of 18, after an accident, when he started to display limitations and the symptoms characteristic of the disorder, which culminated in his first and only psychiatric hospitalization. Daughter 1 was hospitalized only once, during 30 days, on the occasion of her first episode; daughters 2 and 3 had never been interned.

Figure 2 – Identification data, previous history and health conditions of four schizophrenic children

IDENTIFICATION	C1	C2	C3	C4
Gender	F	F	F	M
Age	57	47	44	42
Education	Unfinished	Unfinished	Illiterate	Unfinished secondary
Marital status	Single	Single	Single	Single
Religion	Evangelical	Evangelical	Evangelical	Evangelical
Religious practice	No	No	No	No
PREVIOUS AND CURRENT HISTORY OF HEALTH CONDITIONS				
Accident	----	----	----	Run over by a truck
Surgery	No	No	No	No
Psychiatric diagnosis	F20	F20	F20	F20
Comorbidities	Hypertension	Anemia	Gallstones	No
Medication	Captopril Clorpromazine Prometazine	Biperiden Clorpromazine Haloperidol Prometazine Sulpiride	Biperiden Fluoxetine Haloperidol Levomepromazine	Biperiden Clorpromazine Haloperidol Risperidone
Habits (cigarettes, alcohol, drugs)	Passive smoker	Passive smoker	Passive smoker	Smoker
Suicide attempt	No			
Personality characteristics	Anxious, communicative	Anxious, communicative	Agressive, anxious	Aggressive communicative

A cordial relationship exists among the schizophrenic siblings. Daughters 1 and 2 help their mother with housework, according to their possibilities, and help to take care of daughter 3 and son 4, who display further limitations, including basic hygiene and food care. Contact between the schizophrenic children and the four non-schizophrenics who live in their own homes is scarce, as they are involved in their own families and job situations. The relation with the son without a confirmed schizophrenia diagnosis who lives with the parents is based on fear and submission to avoid aggressive behaviors, as he does not understand his siblings' limitations.

B) A couple's life with four schizophrenic children

In contact with the elderly couple with the four schizophrenic children, three thematic categories were identified that picture this life: 1) Knowledge and perception about the disease as from the start of schizophrenia, 2) Difficulties and limitations in daily life with schizophrenia and 3) Parents' perception about the care received and their care conceptions.

1) Knowledge and perception about the disease as from the start of schizophrenia

Despite their long life with the four schizophrenia patients, their lack of knowledge about the disease and the father's opposition to talk about the subject are evidenced.

The head doesn't work, right. (...) I don't know what disease it is. I just know that their head is messed up (...) (Mother)

[emphatic] No! None [psychiatric disorder]! My family's health is excellent, really! (...) That thing [visual hallucinations] he doesn't see anything, no. Never! (Father)

The meaning these parents attribute to the mental illness is based on the limitations.

He wasn't like that, he was a student (...) He hurt his head, then he lost everything (Father)

The father attributes the cause of the changes one of the children experiences to an accident he suffered in the past, in the belief that the problem can be discovered through tests and solves. The mother attributes the schizophrenia to the fact that it was not recognized from the start.

I asked the doctor to have the head tested (...) to see what he has, if there's pus (...) That's what I'm interested in, discovering what it is to get rid of these problems (Father)

They [the children] were raised on the farms, we didn't bother to take them to the doctor to have their disease looked at. I think that is why the disease took over (Mother)

Although the professionals from the Family Health Unit (FHU) suspect that the father and mother of the four schizophrenic children are cousins, the mother strongly denies this family relation.

The doctor said that my blood did not match with my husband's blood, that's why my children is [sic] like that. My husband comes from Bahia and I from Minas, we're not family (Mother)

It seemed to be easier for the mother to describe the children. The start of psychotic symptoms in daughter 1

was attributed to the fact that she suffered romantic disappointment. In son 4, the start of the schizophrenia, after an accident, seems to have been more difficult to accept, as he was the son who most dreamt and displayed better intellectual performance.

He started to cry, yell, we used to look: where? But we couldn't see [haunting], it was in her head. She dated a boy and when she heard he was married she got like this (Mother)

He used to study! He said he wanted to arrange a factory for him to make the paintings and sell them (...) He saw werewolves, at night he was yelling in the street. Today he doesn't care about anything anymore, not even about reading. He doesn't know any feeling anymore (Mother)

When asked, during the identification data collection, whether the children had already taken any illegal substances, the father seemed to feel offended and defended them.

Oh God! Dear God! Nobody takes that here, no. God protect me! Dear God! My kids is [sic] all straight (Father)

2) Difficulties and limitations in daily life with schizophrenia

As the interviews took place in the family environment, the researcher was present during some daily-life difficulties and limitations in daily life with the schizophrenic children. The parents reported on their difficulty when they perceived the start of the schizophrenia in their children.

Ih, there she is, bothering [referring to daughter 1] Dear God! Stop! Stop that! (Father)

Ah, that's hard, really! It's very difficult. They were are healthy and look... Nobody was expecting it, it had to happen. (...) Everything changes, right! Look at that one, she was a hard worker and got like this (Father)

Imagine that they was [sic] growing up healthy. It wasn't like that, right, you needed consolation (Mother)

The father demonstrated great opposition to talk about his feelings with regard to the schizophrenia. At first, he remained silent with his eyes full of tears, apparently thoughtful; then, he attempted to show that there are no difficulties according to him. After that episode, he got impatient to finish his part of the interview, got out and, when he returned, it was perceptible that he had cried.

[silence] There's a lot of things that... we... [silence. Eyes full of tears.] No, for now, thanks God, everything's going well. (...) With God's power nothing's difficult to me, no (Father)

For the mother, in turn, it seemed to be easier to talk about her feelings. According to her, the main difficulty is the responsibility for housework, in addition to the responsibility for care for the children, living on their behalf.

Ah, I felt very sad [about the start of the schizophrenia]. I even got...[silence] When he's [Child 4] agitated he's all talking, yelling, he yells all day! (...) One [child] stops, the other one starts. It's that noise! Sometimes I say like: that house, it seems that there's something bothering. It's like that all day! (...) Nobody can stand the noise here when they're messed up (Mother)

The most difficult is when they're like sick and sometimes you need to work and nobody helps (...), even more I with the children all messed up. The doctor ordered me to walk, but I can't because I can't leave the house (Mother)

Although the responsibility for the house and children is something difficult for the mother, when asked about what she likes most, these are the functions that most satisfy her. One of the difficulties seems to happen when the children are in a crisis, with patience as a crucial element to bear the difficulties and limitations of the schizophrenia.

Taking care of my house and do the shopping, food for them to eat (Mother)

We need to be patient, right! You need to be patient... (Father)

I lose patience, I get nervous and stay outside. I only enter when they calm down (Mother)

Besides the four schizophrenic children, another child lives with the couple who, despite the lack of a confirmed schizophrenia diagnosis, causes great suffering to the family. The presence of the aggressive son at home, in combination with the parents' perception of their advanced age, makes them afraid for the schizophrenic children's future.

We have suffered a lot because of this boy, oh dear! He's always been like, evil (Mother)

Ours [future] is already finished, right, we're old already. They [schizophrenia patients], poor things, they don't care about any future. I'm very sad, right. I hand it over to God (...) I imagine us dying and him [aggressive son] being left in charge [of the schizophrenic children] and wanting to hurt them (Mother)

Faith in God was something recurrent in the interviews, and a component that seems to be important in this family, helping to live with the difficulties and limitations of schizophrenia. Based on their faith in God, they also feel hope that their children will be cured.

I felt very sad [about the start of the disease], but I've started to be God's servant and God has consoled me a lot. I put everything in God's hand. There's nothing else to do... (Mother)

What God gives only he can take. If he gave that destiny for me to bear, that's what I'm doing, right! (...) It may take time, but God's always there (Mother)

3) Parents' perception about the care received and their care conceptions

Despite the lack of family monitoring at specialized psychiatric services, professionals at the Family Health

Unit (FHU) have been able to see to their needs; the parents feel that these professionals support them. Although nursing professionals were mentioned, as well as other professionals, this study focuses on physicians, as they are responsible for prescribing the drugs needed to calm down the children.

Oh, it's difficult to have this kind of doctor! That doctor here is number one, everybody consults with her (...) The girls there [from FHU] are nice (Father)

The unit has really helped us a lot, oh dear! The doctor gave me some really good medication for him [Child 4]. Now he's calming down, he's quite calm (Mother)

Everyone wants the best for us, madam I. [nursing auxiliary], D. [nursing auxiliary]. D. is a nurse, that helps a lot! There are some very good people there (Father)

Despite their advanced age, the parents monitor and take charge of their children's healthcare. The professionals' attitude seems to mitigate the feeling of fatigue due to this task and the perceived chronic nature of the disease.

I'm already tired, oh Dear! It's hard work, it's just that they see to you so well! (...) It's tiresome just walking from here to there with sick people (Father)

I told [the doctor]: she takes so much medicines and doesn't get well. He said: Ah, lady, this disease really can't be cured, it just gets better. You need to take it for the rest of your life (Mother)

In the reports, the family's technician conception of care came forward. Besides the procedures, the father summarized what he finds important in the care received.

I fell, I got five stitches here in the head (...) He [physician] prescribed an antibiotic, afterwards he removed the stitches here and I took three injections [demonstrating satisfaction]. (...) The treatment is very good, he forwards for tests... (Father)

It also depends on the way of knowing how to talk, getting out the questions, looking for our doubts, forwarding everything right... We're very well, the care is blessed (Father)

The reports evidenced the super-valuation of physicians, which participants present as the holders of all knowledge.

Only the doctors can help. God first, below God the doctors (Father)

The doctor understands everything. (...) I'd like to know what they have. The doctor doesn't tell, no, he just says that they're suffering in their head, but he doesn't say what illness it is (Mother)

This family had contact with the city's Psychosocial Care Center (PCC).

I took her, she stayed for two days and didn't want to go anymore. I liked it a lot there, but she... (Mother)

The daughter's resistance to participate in CAPS activities seems to be due to the lack of contact with people beyond her family cycle.

DISCUSSION

Considering that all people have their own trajectory of life, with events, values and recollections inherent in each person's history and which guarantee human beings' individuality, listening becomes fundamental to consolidate the person as a subject of his/her own history⁽¹⁵⁾.

Listening to an elderly couple, parents to four schizophrenic patients, disclosed some aspects of daily life with this disorder and some perceptions about the care received that lead to a reflection on the importance of professionals being prepared to deal with these experiences of pain and suffering.

Care for people with a severe and sometimes disabling mental illness like schizophrenia becomes a task for the parents and more intensely for the mother. In fact, that is what happens in the family that was studied, as the greater burden and exhaustion are the mother's responsibility, who abstains from any other type of activity than care for the house and the schizophrenic children, even those activities that were medically ordered for her health, as reported in other studies^(8,10).

The advanced age (80 and 82 years) of the parents of these four schizophrenia patients stood out, which is a source of concern, as they fear for their children's future. When the parents are of advanced age, role changes among family members are common; when the children suffer from a severe disorder like schizophrenia though, the parents cease to experience the natural aging process and invert care. They demonstrate their concern with the future, because they do not know who will continue the care when they will no longer be able to⁽¹⁶⁾.

The quality of life of caregivers to mental disorder patients is impaired, entailing different consequences, such as lack of social support, isolation, stress, fatigue, frustration, anxiety, low self-esteem, lack of hope, impaired leisure activities and concerns with the future. These consequences can also be expressed in terms of financial burdens, in the family routine and in the form of physical or emotional disease manifestations^(4,10-11,17-18).

The quality of life of the four schizophrenia patients' parents is clearly impaired. As perceived, however, they found ways to bear the charge of such a heavy burden. The father's opposition to assume the difficulties experienced and his feelings seems to be due to the paternal figure of strength who takes up the responsibility to take care of and protect the entire family.

Faith in God, a very recurring issue in the interviews, plays an essential role in these parents' life, a source of consolation and inspiration to live with the difficulties and

limitations of their children's schizophrenia. The hope to cure the schizophrenia through divine power is reported in scientific literature and serves as a great source of consolation for family members who acknowledge their own and professionals' limitations in view of this severe mental disorder. The importance of encouraging family members' religious practices or mere spirituality is also reported, which can be considered therapeutic to the extent that it is capable of granting a new meaning to life, enhancing self-esteem, the feeling of wellbeing and satisfaction^(8,19), characteristic of resilience.

The overvaluation of medical professionals and technical procedures present in the parents' report seems to be an inheritance from the medical paradigm of the asylum model, as acknowledged in other studies, which can happen after the relatives feel that their internal and external resources are no longer capable of attending to the needs of difficult life with the schizophrenia, transferring the responsibility and hope to overcome the needs to the medical professional, who detains all knowledge⁽⁸⁾.

Primary care at health services, which used to be focused on medical care only, now prioritizes the entire team in the care process. Due to the advanced age and fatigue in care for the four children, however, the parents see the medical professional as their major support source, as he is responsible for prescribing the necessary drugs to control the psychiatric symptoms, which is fundamental for them to be able to live with their children peacefully. Neither nursing nor team members reported any action that goes beyond the medicalization of the mental illness. Some studies suggest that the lack of actions that transcend the medicalization is due to professionals' lack of preparation to cope with psychiatry in the primary care context⁽²⁰⁻²¹⁾.

Considering that, usually, health professionals' perception of family members' life with schizophrenia patients differs from actual experiences, this research can contribute to enhance professionals' understanding, so as to further the quality of care delivery. Researchers need to discuss this further though, so that the overcoming of the difficulties relatives of schizophrenia patients experience

can go beyond theory and turn into a recurring practice at health services.

Health professionals can play a fundamental role to help family members in this life with schizophrenia, helping them to become more resilient and to take care of the return appointments and drugs needed to support the situation, which can be facilitated by knowledge on the family history⁽²²⁾.

Limitations: As the interviews took place in the studied family's home environment, reality could be experienced intensely, in all of its nuances and limitations: difficulty to follow an order in the application of the instruments and difficulty to listen to the interview contents, as the children frequently interrupted; the parents had to take turns to see to their needs.

CONCLUSION

Despite the long and intense life with schizophrenia, in the couple, parents of four schizophrenic patients, aspects could be identified that reflect the difficulties experiences in daily life, such as the denial of the disease and the need to deny their weaknesses as parents, difficulties to express their feelings, understanding about the schizophrenia in the sense of limitations, reported fatigue and burden, impairing their quality of life and entailing uncertainty about the future.

Based on the analysis of the interviews, the resilience in the parents' attitudes was observed, strengthened by faith in God, as a source of consolation and relief. The care conception is related to technical procedures, but the parents reported being very satisfied with the care received, showing that the primary care team has been able to attend to the family's needs, despite the limitations as they are not specialized psychiatric professionals.

Through the identified of aspects of daily life with schizophrenia and the care received, this research can help professional in different specialties and healthcare services, to grant proper importance to their preparation to deal with these experiences of intense pain and suffering.

REFERENCES

1. Sadock BJ, Sadock VA. Kaplan & Sadock compêndio de psiquiatria: ciência do comportamento e psiquiatria clínica. 9ª ed. Porto Alegre: Artmed; 2007.
2. Mauritz M, Meijel BV. Loss and grief in patients with schizophrenia: on living in another world. Arch Psychiatr Nurs. 2009;23(3):251-60.
3. Shirakawa I. O ajustamento social na esquizofrenia. 4ª ed. São Paulo: Casa Leitura; 2009.
4. Richieri R, Boyer L, Reine G, Loundou A, Auquier P, Lançon C, et al. The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL): development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia.. Schizophr Res. 2011;126(1-3):192-201.
5. Organização Mundial da Saúde (OMS). Classificação Estatística Internacional de Doenças e Problemas relacionados à Saúde – CID-10. 8ª ed. São Paulo: EDUSP; 2000.

6. Organização Mundial da Saúde (OMS). Classificação Estatística Internacional de Doenças e Problemas relacionados à Saúde – CID-10. 8ª ed. São Paulo: EDUSP; 2000.
7. Amarante P, organizador. Franco Basaglia: escritos selecionados em saúde mental e reforma psiquiátrica. Rio de Janeiro: Garamond; 2005.
8. Osinaga VLM, Furegato ARF, Santos JLF. User of three psychiatric services: profile and opinion. *Rev Latino Am Enferm*. 2007;15(1):70-7.
9. Randemark NFR, Barros S. O modo de cuidar da pessoa com transtorno mental no cotidiano: representações das famílias. *REME Rev Min Enferm*. 2009;13(4):515-24.
10. Nagaoka AP, Furegato ARF, Santos JLF. Psychosocial Care Center users and their experience of living with a mental illness. *Rev Esc Enferm USP [Internet]*. 2011 [cited 2011 Sept 15];45(4):912-7. Available from: http://www.scielo.br/pdf/reeusp/v45n4/en_v45n4a17.pdf
11. Zauszniewski JA, Bekhet AK, Suresky J. Effects on resilience of women family caregivers of adults with serious mental illness: the role of positive cognitions. *Arch Psychiatr Nurs*. 2009;23(6):412-22.
12. Koga M, Furegato ARF. Convivência com a pessoa esquizofrênica: sobrecarga familiar. *Ciênc Cuidado Saúde*. 2002;1(1):69-73.
13. Furegato ARF. Mental health policies in Brazil [editorial]. *Rev Esc Enferm USP [Internet]*. 2009 [cited 2010 Nov 16];43(2):258-9. Available from: http://www.scielo.br/pdf/reeusp/v43n2/en_a01v43n2.pdf
14. Minayo MCS. Pesquisa social: teoria, método e criatividade. 22ª ed. Petrópolis: Vozes; 2007.
15. Meihy JCSB. Manual de história oral. São Paulo: Loyola; 1996.
16. Gonçalves RC, Lisboa TK. Sobre o método da história oral em sua modalidade trajetórias de vida. *Rev Katálysis*. 2007;10(n. esp):83-92.
17. Zanetti ACG, Galera SAF. O impacto da esquizofrenia para a família. *Rev Gaucha Enferm*. 2007;28(3):385-92.
18. Caqueo-Urizar A, Gutiérrez-Maldonado J, Miranda-Castillo C. Quality of life in caregivers of patients with schizophrenia: a literature review. *Health Qual Life Outcomes*. 2009;7:84.
19. Zahid MA, Ohaeri JU. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry*. 2010;10:71.
20. Cohen CI, Jimenez C, Mittal S. The role of religion in the well-being of older adults with schizophrenia. *Psychiatr Serv*. 2010;61(9):917-22.
21. Vecchia MD, Martins STF. Concepções dos cuidados em saúde mental por uma equipe de saúde da família, em perspectiva histórico cultural. *Ciênc Saúde Coletiva*. 2009;14(1):183-93.
22. Ribeiro LM, Medeiros SM, Albuquerque JS, Fernandes SM-BA. Mental health nursing and the family health strategy: how the nurse is working? *Rev Esc Enferm USP [Internet]*. 2010 [cited 2010 Nov 22];44(2):376-82. Available from: http://www.scielo.br/pdf/reeusp/v44n2/en_19.pdf
23. Monteiro IS, Maia AC. Avaliação psicométrica de três questionários sobre a história familiar. *Rev Psiquiatr Clin*. 2010;37(3):97-104.