

## CARING FOR A LOVED ONE WITH SCHIZOPHRENIA: NARRATIVES ABOUT THE FUTURE

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The onset of schizophrenia usually occurs during the adolescence. From there, the family becomes the caregiver and tries to adjust to the new situation. This study aims to discuss the expectations that the relatives living with a person with schizophrenia, for over ten years, have in regard to the future care giving. The life history was the method of choice for collecting and analyzing the interviews (fourteen families). The answers demonstrated hopes in science, in medications to promote either a cure or improvement of symptoms, and in the ability to find care resources within the family. The results demonstrate that the family approach should consider the reflections on the future.

Descriptors: Schizophrenia; Family; Social Work.

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## **O CUIDADO FAMILIAR A UM ENTE COM ESQUIZOFRENIA: NARRATIVAS SOBRE O FUTURO**

A esquizofrenia ocorre geralmente na adolescência. A partir daí, a família torna-se cuidadora e procura se ajustar à nova situação. Neste estudo, o objetivo foi discutir as expectativas das famílias que convivem com um portador de esquizofrenia há mais de dez anos, sobre o cuidado no futuro. Adotou-se a história de vida como método de coleta e análise das entrevistas (quatorze famílias). Os relatos indicam que há esperança na ciência, em medicamentos que promovam cura ou melhora dos sintomas e de se encontrar recursos para o cuidado dentro da família. Conclui-se que a abordagem familiar deve considerar as reflexões sobre o futuro.

Descritores: Esquizofrenia; Família; Serviço Social.

## **EL CUIDADO FAMILIAR A UN ENTE CON ESQUIZOFRENIA: NARRATIVAS SOBRE EL PORVENIR**

La esquizofrenia ocurre generalmente en la adolescencia. A partir de allí, la familia se vuelve cuidadora y busca ajustarse a la nueva situación. Este estudio objetiva discutir las expectativas de las familias, que conviven con un portador de esquizofrenia hace más de diez años, sobre el cuidado en el porvenir. Se adoptó la historia de vida como método de colecta y análisis de las entrevistas (catorce familias). Los relatos indican que hay esperanza en la ciencia, en medicamentos que promuevan cura o mejora de los síntomas y, de encontrar recursos para el cuidado dentro de la familia. Se concluye que el abordaje familiar debe considerar las ponderaciones sobre el porvenir.

Descriptorios: Esquizofrenia; Familia; Servicio Social.

### **Introduction**

The Mental Health Policy is supported by the Brazilian Constitution of 1988 (the social order title, health section, Article 196), which guarantees health care as a right of the citizens and a duty of the state<sup>(1)</sup>. And the Law No. 10.216, of April 6, 2001, charge the State with the development of the mental health policy, redirects assistance to community-based services and provides for social involvement in its Article 3: “The assistance and promotion of health actions to mental disorder sufferers, with the needed participation of society and relatives, [...]”<sup>(2)</sup>.

The mental health policy requires a strong involvement of the family in the actions and projects developed in the health units, and in conjunction with the care provided in the family context. However, families are ill prepared to

care for their mentally ill loved ones and require support and guidance<sup>(3)</sup>.

The Social Work has gone through several forms and models of intervention in the mental health field; however, it remained constant in the attentiveness to the families. “Historically, the social worker was responsible for the family affairs in the psychiatric hospitals, possibly because the patients were poor”<sup>(4)</sup>.

When we refer to the new care under the community perspective, the Social Service has been directing its activities toward the process of building new care practices aimed at the inclusion of the mentally ill and their families. Thus, the purpose of this study is to contribute to the construction of knowledge regarding the family care giving, during a singular experience.

*Becoming a caregiver - a family experience*

At the onset of a first schizophrenic episode, the family faces a stressful situation similar to the trauma experienced by victims of major disasters, which disrupts the entire group. Family life is disrupted, and the trajectory of life may suffer changes<sup>(5-7)</sup>. The family tries to adapt to the new situation, searching for answers to everyday challenges, learning from experience, through trials and errors<sup>(8)</sup>.

The research<sup>(9)</sup> on the significance of parental care, among parents of young people diagnosed with schizophrenia, describes that the onset of the illness was always narrated as a fateful event that turned the course of the family. After the diagnosis, the care giving was approached with contrasting feelings of sadness, anxiety and constant worry, guilt and shame, and hope of a better life for their child. The provision of parental caregiving has emerged as a lifelong effort to help and support the mentally ill adult child; thus, suggesting that it is rooted on the devotion<sup>(9)</sup>.

Another study, conducted with caregivers of patients suffering from depression, manic depression, and schizophrenia, highlights the intense emotions surrounding the care of the sick member. Before the diagnosis, when the individual begins to present behavioral changes, the relatives present an emotional experience called anomie, i.e., the inability to explain the feelings and thoughts regarding what it is happening. The medical diagnosis releases feelings of hope, compassion, and sympathy. The realization that the mental illness can be a permanent condition introduces negative emotions of anger and resentment in the caregivers and the eventual acceptance that they cannot control the disease afflicting their relatives allow the participation without guilt<sup>(10)</sup>.

To understand the family journey and the process of the illness, another study identified six stages of this journey<sup>(11)</sup>. Stage one, "cycle of consciousness," brings the first changes in behavior, and the family needs to recognize them as a health problem that should be evaluated by a professional. In stage two, "crisis", the problem exacerbates beyond the control of the family; the resulting mental illness diagnosis; huge emotional distress; problems communicating with health care providers, and financial concerns. Stage three, "instability and recurrent crises", is characterized by feelings of anger, grief and loss, search for explanations, treatments, and knowledge; increasing financial concerns; occasional recognition of new treatments and technologies; dissatisfaction with the mental health services and its providers, as well as reports of stigma.

In stage four, "motion while maintaining stability," the participants are finding ways to regain control, dealing with the guilt and helplessness; putting perceptions and expectations under control, while accepting the limits of managing their disease. In stage five, "continued stability", there are efforts toward the management of symptoms

and in the decision-making processes, with varied use of support systems (mental health systems, professionals, friends, and support groups). The last phase, "growth and coping", although apprehensive with relapses, the relatives describe getting the meanings, values, and personal growth from their own experiences.

The research presented here demonstrate that, over time, the families need to manage the transition periods of the illness together, building up their lifelong journey as a caregiver for a member with severe long-lasting mental illness. However, further exploration on the subject of the future expectations of care is required. Some authors argue that the families, who care for people with chronic health problems, tend to live in the present without giving a lot of thought to the future. Thus, this research poses the following question: What are the expectations that the relatives who, for over ten years, are caring for a loved one with schizophrenia have in relation to the future?

**Objective**

The objective of this study is to discuss the expectations of the relatives who, for over ten years, are caring for a loved one with schizophrenia have in relation to the future care.

**Methodology**

This study relied on the theoretical framework of a biographical research, which understands the life trajectory as a sequence of events that occur in the life of an individual or a group within a sociocultural and historical context, from their social involvements, the dynamics of their relations, and the internal and external elements that directly or indirectly affect them<sup>(12)</sup>. To allow a delineation of the trajectory followed by the care giving families, the researchers chose the life history methodology for the collection and analysis of the data. The life history methodology enables the person to narrate the facts or situations that he experienced or still experiences and while narrating them to reflect on his life and its context<sup>(13)</sup>.

*Participants*

The sample included persons diagnosed with severe mental illness under the long-term care, and their families, members of the Group Using Atypical Antipsychotic Medications (GRUMA), at the Clinics Hospital, from the Medical School of Ribeirão Preto-USP, under the following inclusion criteria:

-People with schizophrenia: being a participant in that group, having the disease for over ten years, and agreeing to participate in this research by signing the Term of Free and Informed Consent Form (TFICF).

-Family: living with the patient since the onset of the mental disorder, both parents, one parent and a sibling, a parent and a grandparent, two siblings, or other relatives

who were in contact with the patient at least twice weekly, not required to share a home; voluntary participation in the study.

Because this is a group, in which participants are encouraged to express themselves, exchange experiences, and make contact, it was concluded that this context would be particularly promising for the collection of narratives regarding the topic under study. Besides, the researcher is a member of the professional team.

Twenty-two patients and their families, divided into three groups attend monthly meetings. All patients had a diagnosis of schizophrenia, are using atypical antipsychotic medications, and are encouraged to participate in the group activities; their relatives who have been their long-term caregivers, sixteen of them for over ten years, accompany them.

Thus, sixteen of the patients met the inclusion criteria; however, two were excluded, one because the caregiver was undergoing radiation treatment and the other did not show up for the interview.

#### *Procedures for Data Collection*

The data collection employed the open interview structure, a genogram, and a social demographic questionnaire.

In an open interview, the respondents are asked to describe how the family became the caregiver of a relative suffering from schizophrenia, from the onset of illness until the present time, followed by a request for a contemplation of the future.

In the initial phase of each interview, a genogram was constructed as a strategy of approach and preparation of the environment. This tool represents the internal family structure and its examination leads to the knowledge of its participants, the roles each one plays, the bonds that arise between its members, and the relationship with the outside world<sup>(14)</sup>. At the end, each family was required to complete a social demographic questionnaire providing information, such as gender, age, marital status, education, and occupation, family composition (number of children and persons residing in the same household), housing (type, infrastructure, location), and monthly income.

#### *Procedures for Data Collection*

Following the inclusion criteria selection, each family received a phone call inviting them to participate in the study, along with information regarding its purpose, and the ethical issues involved. Upon their return to the outpatient facility, they received a verbal proposal of the study, and the suggestion to bring at least two relatives. All those who have expressed interest were considered. With the acceptance of the family, an interview was scheduled by phone.

The two hours interviews were conducted and audio recorded by the researcher from March 2010 to November 2011.

#### *Data Analysis*

The researcher transcribed interviews immediately to prevent loss of any significant data. After a revision of the text, any identifying references of the participants, persons, or services were removed to protect their identities.

Analysis of the family narratives was delineated by three moments in the history of the participants' lives; the past, present, and future. Thus, the first reading aimed at identifying the chronological time of the reported experience. Then, the narratives were grouped according to the central theme proposed by Galera (2009)<sup>(15)</sup>.

#### *Ethical Aspects*

The ethical aspects involving human research followed the guidelines determined by Resolution No. 196/1996 of the CNS-MS. The research project was evaluated and approved by the Ethics Committee on Research of the HCRP and FMRP-USP, HCRP Protocol No. 6497/2010.

The invitation to participate in the study was accompanied by the Term of Free and Informed Consent Form (TFICF). The schizophrenia sufferer signed the TFICF (Patient) in agreement with his and his family's participation. When the patient refused to participate, but agreed with his family's participation, he signed the TFICF clarifying this aspect. The family also signed the TFICF (Family). All participants received a copy of the signed TFICF, and researcher safeguarded the originals.

## **Results**

Interviews were conducted with the relatives of fourteen persons with schizophrenia. For the interview, the number of participants could vary, limiting itself to two relatives and the person with the schizophrenia diagnosis. Six people diagnosed with schizophrenia refused to participate, but agreed to the participation of their relatives. Thus, resulting in twenty-six participants, eighteen relatives, and eight persons diagnosed with schizophrenia.

Of the fourteen with a diagnosis of schizophrenia, eleven were men, with ten singles, and one divorced. All women were single. Their ages ranged from thirty to fifty-three and the duration of the illness from eleven to twenty-seven years. Five of them were retired on disability, three were on disability, one on a death pension, one on benefit assistance, and three had no income. Only one worked.

Among the eighteen relatives, fifteen were females, between forty-three and seventy-seven years old. Now, the ages of the males were from sixty-eight to seventy-six. Twelve were the mothers, three sisters, two fathers, and a maternal uncle. The majority had no formal education, three attended high school, and four attended college. Regarding occupation, eight women were homemakers, four were retirees, and four worked. All of the men were retirees. As for the marital status, ten married, four

widowers, and four singles. Family income ranged from two to eleven (monthly) minimum wages. Eight of the families lived in Ribeirão Preto and six in nearby cities.

In this article, the analysis was outlined on how the caregiving relatives envision the future.

#### *Hope as a perspective to envision the future*

The accounts of the participants indicate that they cling to a sense of hope when they think about the future. They have hopes in the science - to discover the cure, and with the correct drug treatment, that promotes a cure or at least an improvement of the symptoms. When cured, the loved one will no longer need "to stay on medication". If, the symptoms improve there will be more acceptance within and outside the family.

Regarding the care giving responsibilities, the respondents also have hopes of finding resources within the family and in their sociocultural context. Two categories were created by grouping the stories regarding the future.

#### *Hope for a cure*

This category refers to the expectations of the families in relation to scientific advances, defined as a treatment that promotes a cure, or that at least improves the symptoms and prevents the psychosis.

*We have to go on, go till the end, because you need right? And we hope that with time there is an improvement with the treatment.* (Family 2)

*The future, we always hope for the best you know, we always want to have the best. That one day will have a cure for his treatment, no need to stay on medication, he is already much better with the medication. To prevent the crises from coming back, because they say that even with the medications there may a problem and everything may come back, but we hope that in the future, with studies they can figure out how to avoid it.* (Family 7)

#### *Hope to find care giving resources within the family*

The hope for a cure is soon replaced by a more pragmatic hope, facing the day-to-day care to a loved one with a long-term severe mental illness.

The relatives were emphatic in expressing their feelings as caregivers. The stories are rich with a reflection on other elements: the son can marry a woman who will not accept the sick brother, the solitary nieces, who help the caregiver at various times. The outlined possibilities for the future care are found within the family.

*Oh, I think that there is no cure; I believe that it will always need to be monitored. Then, I think that it will need always to come over, it will need help in the future. ... I think that (help) is from my family, in the home and from my family there. I think it will always be like that.* (Family 1)

*This is also part of the care, right? (E) does. Whatever, I'm really scared. I wonder who will bring her (P) here (HC) three times, to draw blood, to see the doctor, to pick up medicine. It's all me. ... It's a big responsibility, isn't it?* (Family 12)

Therefore, the respondents reported their reflections and conversations with relatives about the future of the

person who is ill, the possibility of the primary caregiver dying before him.

*... I try to hand it over to them, right?. Family has always remained united, right.* (Family 5)

*I tell him "(P) don't worry about it, because in life no one is abandoned", and if some day we are gone, and will be gone for sure, either I (mother), and him (father), one will go first, have to go in order, it can be, then you do not have to worry about it, you will not go hungry, will not be abandoned, your brothers understand you better now, you will not going to be abandoned, and if we can leave him (talking to E, referring to P) safe, we will try, for my part I will try to do something, I do not know how yet.* (Family 8)

In some reports, the respondents relied on conversations held with their relatives about the future, in the case of death of the current caregiver. Under these scenarios, the care for their loved one would be delegated to third parties, leaving the relatives with the task of finding such resources in the community.

*(P) for what we see, he will not be able to work, no. You see there is no way, he comes out to do get something, forgets it, he goes away, if he wants to grab a pan, I even fear that he will burn himself, you know? ... Then, (P)'s problem is that you need to keep an eye on him, pay a helper, right?, he cannot be neglected, we are always worried, right?* (Family 6)

*Do you ever talk about it? (E) I've talked already. Once or twice, if the mother dies, never let her go without anything (referring to P), if you think about the pension that she will receive, need to think about a clinic for her, right? If you cannot look after her and if your wife does not want to do it.* (Family 12)

*I am very afraid of who gets to take care of her, I don't know, my son, not because of him, you know, his wife, I don't know. Because he will be the only one left. So, I've been thinking of so many things, and I tell him "have you thought about the care giving? Place her in a home when I die."* (Family 12)

## **Discussion**

When a young person is diagnosed with schizophrenia, he and his family experience this event as a destructive force that can transform their entire lives. This trajectory is divided into two stages, before and after the onset of the illness<sup>(9, 15)</sup>.

With the illness, the family becomes the caregiver of someone with a mental disorder and tries to adjust to the new situation. It seeks to develop the provision of care, learning from living with the a mentally ill loved one, through trial-and-error, and the possibilities found in the context of their lives, by social, economic, political, demographic, and cultural contingencies.

In the world of care, it is important to be aware of the sense of temporality in the experiences of people receiving care, and to envision the time as the conduit for the care. The sense of temporality expands the understanding of the caring process. The health professional should be aware of the trials experienced by the relatives and their expectations about the future<sup>(16)</sup>.

The focus of this study was to address how one sees the care in the future. Specifically, it identified reflections on two aspects of the future care, the cure and the treatment, and the

daily care that falls under the responsibility of the family. Reflection on the life journeys of the participants allowed for the narration of important events of their daily struggles as caregivers, which is likely to persist in the future.

Regarding the future, the discourse is still vague, but there is hope on the psychopharmacology advances and in the ability to find care giving resources within the family. The certainty that these resources will come from the family itself, indicates the strength of this feeling of belonging that the respondents have in relation to their families.

It is also interesting that the family is seen as the first and only institution of care, even after more than twenty years of legal protection for the mentally ill. The family builds its trajectory alone, even though it possesses information relative to the mental illness and its treatment. Information acquired during the visits to the mental health services. Moreover, for the future, it is considering passing on this care to third parties, in the absence of its own resources.

The family, therefore, is an essential resource, which needs assistance as it adapts to the caregiver role, experiencing the phases of the disease, goes through treatment stages and make adjustments during their enduring trajectory of care.

It is known that the “family caregiver approach, as a partner and co-responsible for the care, is under construction, and its limits, potentials and challenges will depend on each context”<sup>(4)</sup>. However, it should be noted that the mental health services should contribute to the inclusion strategies, developing partnerships and providing support for the families who now face this “new” responsibility of providing care for a loved one with a mental disorder.

### Final Considerations

The main objective of this study was to bring a contribution to the provision of care for families dealing with a member suffering from a mental disorder, describing some reflections made by families who have traveled a long way as caregivers.

For this article, the analysis of the interviews allowed the delineation of important events, involved in the care, into categories of topics that address the future.

The discourses regarding the future indicate that the families cling to the feelings of hope in relation to the scientific contributions to the cure and/or control of relapses and of finding resources in themselves and in the social context in which they live.

Thus, it becomes necessary for the health professionals, including the social worker, to consider the assistance in terms of the family and social contexts, searching for interventions that meet the demands of all the subjects involved in this adjustment process, as well as listen to the mental patients and their families with regard to this “new” family responsibility.

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