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Family experiences in the identification of the first-episode psychosis in young patients☆

Bianca Cristina Ciccone Giacon*,[1], Kelly Graziani Giacchero Vedana, Isabela dos Santos Martin, Ana Carolina Guidorizzi Zanetti, Lorena Fendrich, Lucilene Cardoso, Sueli Aparecida Frari Galera

Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing, World Health Organization (WHO), Collaborating Centre for Nursing Research Development, Ribeirão Preto, Brazil

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ABSTRACT

The study aimed to understand the family experience in the identification of the first-episode psychosis in young family members. Qualitative research using symbolic interactionism and narrative. Data were collected through depth interview with 13 relatives of 11 young patients treated for the first-episode psychosis. The families showed behavior consistent with the meanings they gave to the disease process of the young relatives, represented by categories: "waiting move: trying to justify the behavior of the adolescent", "not understanding the psychosis", and "seeking help". This research fostered the understanding of how families decided to seek help in the healthcare system. The nursing interventions with these families could contribute to early detection and beginning of treatment.

Introduction

The first-episode psychosis (FEP) occurred in the adolescence, can constitute the initial phase of a mental disorder. In a period prior to the FEP, young people begin to show changes in behavior, such as irritability, social isolation, child behavior, persecutory thoughts, interruption of studies and aggressively (Renwick et al., 2015; Tso et al., 2017; Woodberry et al., 2014).

Family and parents feel confused by these changes and try to explain them in different ways. At that time, the family can experience a long period of uncertainty, fear, and hope, which cause suffering to them and to the affected youth (Cairns, Reid, & Murray, 2015; Hasan & Musleh, 2017; Tanskanen et al., 2011).

Because of the difficulty to understand the behavior changes as a possible process toward a mental disorder, especially due to the non-specificity of the symptoms at the early stages of the disorder, the family takes some time to seek expert help. In most cases, this only happens when the psychotic symptoms become severe and unbearable for the young people and for the families. It is often at this point that the first psychiatric hospitalization takes place (Cairns et al., 2015; Hasan & Musleh, 2017; Tanskanen et al., 2011).

The interval between the onset of psychotic symptoms and the beginning of the treatment is defined as duration of untreated psychosis (DUP) (Marchira, Supriyanto, Soewadi, & Byron, 2016). The DUP, which has a significant impact on treatment, may vary from individual to individual, taking some time for individual or caregivers to seek heath care. Studies show association between longer DUP and worsening in prognosis (Compton et al., 2007; Compton et al., 2011; Norman & MALLA, 2001).

A study stated that the average DUP may vary according to factors such as the condition denial by individual and relatives, isolation from friends and family, diagnosis errors, distorted view of the mental health treatment, and presence of negative symptoms (Souaiby, Gaillard, & Krebs, 2016). Thus, developing community educational strategies for this population and training health professionals `may contribute to the identification of individuals facing the onset of psychotic symptoms, facilitate specialized treatment, and reduce treatment time (Louzã, 2017).

There is a consensus in the literature about the importance of early detection of mental illness in order to start the pharmacotherapy and psychosocial interventions in the early stages of the disorder. These interventions at the onset of illness may prevent or decrease the

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* Corresponding author at: Bianca Cristina Ciccone Giacon for Nursing Program of the Integrated Health Institute of the Federal University of Mato Grosso do Sul.
E-mail addresses: biagiacon@gmail.com (B.C.C. Giacon), kellygiacchero@eerp.usp.br (K.G.G. Vedana), ismartin@eerp.usp.br (I.d.S. Martin), carolzan@eerp.usp.br (A.C.G. Zanetti), lofendrich@gmail.com (L. Fendrich), lucilene@eerp.usp.br (L. Cardoso), sugalera@eerp.usp.br (S.A.F. Galera).
[1] Present address: Nursing Program, Federal University of Mato Grosso do Sul, Campo Grande, MS, Brazil.

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physical, mental and psychosocial deterioration of individuals, and reduce the suffering of patients and their families (Albert et al., 2017; Chang et al., 2013; Souaiby et al., 2016).

The studies on FEP aim to identify factors contributing to delaying the beginning of treatment and emphasize the important role of the family in the recognition of the disease process and beginning of treatment (Albert et al., 2017; Chang et al., 2013; Souaiby et al., 2016); however, few of them investigate, in depth, the influence of family members and the difficulties they experience at that time. It is believed that understanding the experience of the family in the recognition of a process toward a mental disorder in the young family member, fosters the reduction of DUP.

Given the above, the objective of this study is to understand the family experience in the process of identifying a first-episode psychosis in young family members.

Method

This is a qualitative research, carried out under the theoretical framework of symbolic interactionism. This approach assumes that behavior (observable external act and internal experience) is driven by the conceptions the individual has of the surrounding reality, and that these conceptions, in turn, are originated in the social interactions, so that active individuals influence each other (Blumer, 1969; Charon, 1995).

The narrative was adopted as methodological framework, because it allows understanding the first-episode psychosis chronologically, dynamically and in a significant manner, based on a particular construction of the families in the relational and social context in which they are inserted (Elliott, 2011; Riessman, 2008).

Participants

The participants were relatives of youths treated in two public units of psychiatric hospitalization, in a city of the state of São Paulo, Brazil. All medical records of patients who had their first psychiatric admission in the 18 months prior to the beginning of data collection (January 2011 to June 2012) were initially reviewed. Being a retrospective study, such timeframe was adopted for granting a short interval between the first psychiatric admission and the interview.

A script previously developed by the researchers guided the medical-record review. Its purpose was to identify subjects, aged 10 to 25 years, admitted for first-episode psychosis, with a diagnosis of schizophrenia made by physicians of the unit (in accordance with the 10th edition of the International Classification of Diseases/ICD-10) (World Health Organization, 2000) and with no history of previous hospitalization/treatments (reported in medical records) or diagnosis of neurological morbidities.

Then, the families of patients initially identified were contacted, through phone calls and home visits, to invite them to participate. At least two members of each family were invited (preferably the mother-father dyad), provided they were aged over 18 and had experienced the initial period of behavioral changes and the first-episode psychosis of the patient.

From January 2011 to June 2012, 157 young patients had their first psychiatric hospitalization; 46 of them meeting the study criteria. However, 26 of these patients could not be found, due to telephone and/or address changes, and nine refused to participate. Thus, 13 relatives of 11 young patients agreed to participate and were included in the study.

Data collection

Data were collected through depth interview, from July 2012 to April 2013. Two experienced and trained nurse researchers (not part of the clinical staff of the study site) carried out interviews together. Interviews were recording in audio to collect the data and they had an approximate duration of 60 min.

Each family participated in at least one interview; specifically, there were three interviews with four families, two interviews with five families and one interview with two families. The interviews were conducted only with family members of young people passing through their first psychiatric episode. All the interviews occurred in a private place at the mental health service or at the family member's residence.

In the first interview, participants were asked about family's social demographic and the construction of a genogram. After that, the family were ask to relate the story from the onset of the disease process of their relative to the first contact with the specialized healthcare or hospitalization service, and to describe how the family experienced that process. We used the following questions to guide the first interview: “How did you realize that your relative was getting sick?” “What were the perceived changes in the behavior from your relative before the first psychotic episode and how did it occur?” “How did these changes were understood or interpreted by your family?”.

Subsequent interviews were conducted to validate the researchers' understanding, deepen and clarify the up doubts arising during analysis of the first meeting.

Data analysis

Two researchers analyzed the data independently. The data were analyzed by thematic analysis with the objective of identifying passages that described the meanings given by the families to the behavioral changes observed and to the process of a mental disorder occurred in the context of the adolescence.

Such passages were chronologically rearranged and were highlighted those events, themes or patterns that interfered in the process of meaning construction. The reports of the families were written and presented, in this study, chronologically in the form of narratives by the researchers as the methodological framework used. All the references that might identify the participant or people cited by them were removed. In order to preserve the identity of the study participants, the names were change for fiction names, and the letter F followed by a number was used to identify each family.

The main strategies used to promote rigor in this research were: transparency in the description of the methodology; validation of the accuracy/interpretation from data; critically following thematic analysis procedures for two researchers independently; reflexivity and credibility of the discussion of the data by a group of experienced researchers.

Ethical approval

The study was authorized by the health services and approved by the Ethics Committee of the Ribeirão Preto School of Nursing, University of São Paulo (by resolution 1443/2011). All participants were informed about the objectives, procedures for collecting and analyzing data, and presenting the results. For the authorization, all signed a term according to the participation of the study according to ethical standards and guidelines involving research with human beings (Brasil. Ministério da Saúde, 1996).

Results

Sociodemographic characteristics

The age of the patients ranged from 19 to 27 years. Of the 11 patients, 5 were female and 6 male, most were with incomplete primary education, history of substance abuse, and antecedents of mental disorder within the family. At the time of data collection, the majority did not have a job, studied or were under regular follow-up in a mental health service.

The 13 relatives included in the study were aged 37 to 75 years. Most families consisted of four members and owned their homes. The sample included nine mothers, three fathers and one spouse.

The family journey of the discovery of the first-episode psychosis

The disease process experienced within the family setting was described by the families as dynamic, because of the constant influence exerted by the social environment and by events occurred within and outside the family itself.

Despite each journey being unique and peculiar, there are some common elements in the experience of the families, such as the gradual identification of symptoms, the pain, the seeking of support from close people (informal support) before seeking specialized treatment, uncertainty, and doubts regarding psychotic symptoms.

In general, families also have to adapt to new demands, experience a certain ambivalence regarding behaviors (autonomy/surveillance, proximity/distance) and have the hope of having the youth back into the condition prior to the disease process. Frequently, families also find it difficult to discern if the symptoms are characteristics of the adolescence, are due to the presence of stressors in the context of life of the youth or to the abuse of substances, or if they result from a mental morbidity.

In this study, it was evidenced that families showed behavior consistent with the meanings they gave to the disease process of the young relatives, as shown in the following categories.

Waiting move: trying to justify the behavior of the youth

In most interviews, family members reported having noticed the changes gradually. In the beginning, they identified changes in youths' behavior in the form of social isolation, difficulties to maintain or abandonment of studies or work, less care with appearance, changes in eating habits (reduction), conflicts, insubordination to parents, and aggressive or inappropriate attitudes for their age. The following statements describe these initial perceptions:

> "*By the age of 18, Isabel started to become shyer, quieter and still at home.* […] *Over time, she started to not want to go to school and to the Spanish course; she stopped eating, got a sad appearance and got more and more insolated. In phone calls, Ilda* (*the mother, who lived in a different city*) *realizes her daughter's voice is changing, and conversations become shorter*" (*F9*).

In the beginning, the families found these new behaviors were associated to events or problems typical of the adolescence and to other personal factors in adolescents' lives, such as conflicting relationships, disruption of family relationships (parents' divorce, estrangement from parents or family), abandonment or rejection, family violence, social vulnerability, influence of friends, personality, substance abuse, insomnia and losses. Some statements also show how the family or other people are blamed by the changes in youths' behavior:

> "*Doralice realized the change in her son's behavior and believed he had a shock because of the death of his twin brother. New friendships also were bothering the mother, who thought they helped to worsen her son's behavior*" (*F4*).

As can be seen behavioral changes were mainly attributed, in the beginning, to psychosocial characteristics inherent to the youth and/or to external events, and were not directly linked to the disease process. Guided by this construction, the families adopted meanings that made them tolerate, accept or modify the changed behavior of the youth, hoping it would cease at some point. Some of them adopted positions of greater flexibility, protection, behavior control, punishment, surveillance. Actions taken with the aim of compensating loss and suffering of the youth were also identified, as well as those taken to ease the guilt felt:

> "*The youth kept the odd behavior; he refused to take any responsibility and follow the rules set by the parents, and they were no longer able to control him. Feeling desperate about the situation, they sought help of various kinds* (*friends, family*), *including the church* (*religion support*), *to help guide the child and try to make him change his behavior*" (*F2*).

Not understanding the psychosis

At this stage, after the emergence of severe, bizarre or less controllable symptoms, or symptoms associated to risks, the family identified a marked difference between the behavior of the adolescent and that which would be expected from a youth in this stage of life. These manifestations represent a break and some instability in relation to projects and expectations of a normal life.

Several behavioral changes considered alarming, being cited among them: attempted suicide, aggression, delusions, hallucinations, bizarre behavior, mutism, restrained eating, engagement in risky situations, and abandonment of home to live in the street, as shown by the following statements:

> "*With the intensification of symptoms, Danilo starts to exhibit more aggressive and disorganized behavior, also intensifying the use of drugs, soliloquies and unmotivated laughter.* […] *When Danilo was about 22, he went to the cemetery and tried to dig up and remove the dead brother from the grave*"(*F4*).

At this stage, youths' behavior was no longer understandable or justifiable and began to be considered enigmatic, mysterious or abnormal. Thus, it was associated with symbols linked to madness, supernatural reasons or mysticism:

> "*Geraldo says everybody was telling he was that way because he was using drugs. However, at this point the father was thinking it was not the drugs, because he was familiar with the behavior of people under the effect of drugs from his experience with the other two children, who were drug users. For the father, the son was not aware of what he was doing, so he couldn't understand what was happening to Gabriel, and believed it could be a spirit that was in the mind*" (*F7*).

Families experienced ambivalence and suffering linked to the worsening/persistency of symptoms and to the need to get adapted to new demands. They reported alternation between feelings of emotional wear, incomprehension, estrangement and desire to have the youth back to their previous behavior, as well as responsibility for caring them:

> "*The mother justifies the use of drugs with the fact the son having been raised by himself, without the love of the father and with no rules, as she needed to get away to work to support the family. She believed that, as a mother, she was responsible for caring for the son, for trying to guide him on the use of drugs and to help him to stop*" (*F8*).

Despite the worsening of symptoms, some families kept considering justifiable and understandable some changes and behaviors, such as others' right violations, socially unacceptable behaviors, substance abuse, and incidents with the police. Thus, it is observed that the boundary between what is and is not normal in youth varies, and is related to the meanings given in the context of each family.

Seeking help

In general, the changes identified in young people during the first-episode psychosis are resignified by the families in a dynamic and continuous process through dynamic and interpretive interactions, so that the meaning attributed to each situation determines the decision making of the family. Frequently, the first support resources sought upon milder symptoms, not linked to a mental disorder and able to be understood by the family, are relatives, friends, and church people,

because of the easy access, proximity, and relationship with the family. The following reports show the main sources of help:

> "*John suggests putting her sister (Joana) in a rehab center, but the mother was not aware about what was happening: she believed her daughter could be having withdrawal symptoms of drug use or being sick, but she knew she needed help. Joana did not want the son to put her in a distant rehab, because, she states, the daughter was her companion and she didn't want to stay away from her. For this reason, she seeks help in a health service near home*" (*F10*).

The school was also mentioned in the interviews, mainly due to behavioral changes that undermine studies and cause trouble in school environment. However, it has not been identified by the family members as a support resource; furthermore, most youths left school after the appearance of the condition.

After the outbreak of risk behaviors and the manifestation of more evident, less controllable, understandable and tolerable symptoms, the families began a more active help-seeking, which included other support sources. At this stage, several resources were sought, including women-protection police, mental healthcare services, churches, and people linked to the family and work setting. It can be noted the difficulty of the family to identify the type of alteration shown by the youth and the lack of information on where to seek help:

> "*At the beginning of 2011, due to drug abuse and aggressive, psychotic, and disorganized behavior, constantly having incidents with the police and being frequently at risk, the mother seeks the women-protection police for help, at the station of her hometown. The police officers, however, argued being unable to help her. Then, Ana (the mother) seeks help in the Mental Health Clinic of the city and is able to hospitalize her son before being killed in an incident with the police*" (*F1*).

The testimonies of the relatives also reveal the lack of preparation of health practitioners to recognize the first-episode psychosis and provide information on specialized services:

> "*When the symptoms get more intense, Carolina (daughter) becomes agitated and aggressive, breaking things of the house. The mother said she was afraid, at that point, that Carolina could get hurt or hurts someone, even her own little brother. When she returns to doctor's visit, the doctor says to the young patient that the tests are fine, and that she has nothing*" (*F3*).

The relatives also complained about judgments and about being blamed by the illness of the youth. These behaviors overburden the family and make it feel unassisted. It should be highlighted that, within this study population, this support resources were sought by youth's relatives, as in most cases the youths did not acknowledge the need for help entailed by their possible condition and did not participate in the help and treatment seeking.

Discussion

The families perceived the changes in the behavior of their young members through its own lens and, based on this perception, build particular and unique meanings for the processes of changes. Despite each journey being unique and peculiar, it is possible to identify common elements in the experience of these families.

The construction of meanings occurs through social interactions (Blumer, 1969) and depends on several factors, such as values, history, and socio-cultural and life context in which the individual and the family are inserted.(Wright & Bell, 2009) During social interactions, people interpret the actions of others by "taking other's role"; that is, trying to envisage being themselves in other person's place and found explanations for each act observed in that person (Charon, 1995).

In this study, it was learned that relatives interpreted the initial symptoms of the youth based on elements which are common in their life context; thus, symptoms were initially construed as a response to stressors or to events that exist in the life of the youth, typical adolescent behaviors or behaviors resulting from the use of psychoactive substances.

Guided by this understanding, families built expectations that these changes would cease. Studies involving family members in other contexts report to have found explanations similar to those found in this study, and state there is, in the beginning, an intention to explain the behavior change through the history of life of the patient.(Bourgou, Halayem, Bouden, & Halayem, 2012; McCann, Lubman, & Clark, 2011; Otero et al., 2011)

The meanings built for each situation experienced determine human behavior.(Charon, 1995) Each family member interacts with its own self and with others in an attempt to rebuild the meaning of their experiences and identify possible support resources.

In the present study, the family sought, firstly, to minimize the interference of the symptoms on the family context, in order to restore balance and promote cohesion and care in the internality of the group. At this stage, relatives make use of monitoring, control, flexibility, protection or punishment, as measures to tolerate, contain or modify the behavior of the youth. The support sources actuated are informal, such us people from the church or friends from the school, as they are more accessible and are already linked to the context of the youth and the family.

According to the literature, the first symptoms manifested by the youths are non-specific and less intense. The suspicion of an illness process is less reported at this stage (Uttinger et al., 2015), causing the treatment being sought later by the family. Family members feel confused and worried, and find it difficult to identify the cause of the signs and symptoms, both in the prodromal period and the first psychotic break (Cadario et al., 2012; Chang et al., 2012). The narratives indicate this stage is marked by lack of information and expert support, so that the family has a fundamental role in seeking treatment and actuate support resources, because, frequently, the youths do not recognize the need for help and do not participate actively in the seeking process (Cadario et al., 2012).

The non-recognition of the mental disorder avoids the quick access to effective treatment (Cadario et al., 2012). Early detection and intervention in a first-episode psychosis enable better prognosis (Chang et al., 2012; McCann et al., 2011; Otero et al., 2011).

Research on the interference of several factors in the help-seeking concludes the family is an important variable (Albert et al., 2017; Cairns et al., 2015; Charon, 1995; Souaiby et al., 2016). Some studies (Bergner et al., 2008) indicate family involvement has helped to reduce the DUP in the UK, while some others (Compton, Goulding, Gordon, Weiss, & Kaslow, 2009) highlight that the involvement of relatives is independently associated with longer time to seek help in the United States. The present research found that families explained the changes in the behavior of the young patient linking them to their history of life, this perception making families more flexible and inclusive and delaying recognition of the disorder.

In line with this study, the literature indicates that the delay in seeking treatment is associated with the non-recognition of the need for expert help, the lack of information about where to seek support, the expectation that the symptoms will cease without intervention, and the lack of training of health workers to recognize the first psychotic break and stigma (Bay, Bjørnestad, Johannessen, Larsen, & Joa, 2016; Bourgou et al., 2012; Chang et al., 2012; McCann et al., 2011; Otero et al., 2011).

The delay in seeking treatment was not the only problem identified in this study; most of the young patients had their psychiatric treatment discontinued less than a year after the first admission for a psychotic break. In addition, most of them had not resumed studies or jobs at the time of data collection. This makes clear the importance of research and interventions that analyze or promote the maintenance of treatment beyond the first episode, psychosocial rehabilitation and social reintegration through work.

The presence of signs and symptoms that precede the first-episode psychosis causes a level of strangeness, about youth's behavior, and imbalance in the family context, which are less significant than those experienced at a later stage, where there is a direct association of this behavior with the manifestation of psychosis. Once manifested the psychosis, the family cannot explain the behavior of the young patient based on their own life context, so it starts to be considered enigmatic or abnormal. Furthermore, the sources of support initially used by the family show to be insufficient to provide further help for understanding and handling the psychosis, compelling the family to seek other support sources.

Some studies (Bourgou et al., 2012; Chang et al., 2012; McCann et al., 2011; Otero et al., 2011) indicate that the family acknowledges the possibility of illness late, when the youth shows intense, bizarre and uncontrollable symptoms that represent a risk or cause social disturbance. Thus, these symptoms and risk behaviors act as a catalyst that triggers the beginning of treatment (Bourgou et al., 2012; Chang et al., 2012; McCann et al., 2011; Otero et al., 2011).

This study showed events in the family trajectory in which primary care could intervene earlier both to detecting and treating illness and to support the family to found adaptive ways of managing situations of greater stress and suffering.

When health practitioners, especially nursing staff, understand the experience and the meaning of the illness process under the family perspective, a new understanding, about the condition itself and the suffering of the family, can be reached (Marshall, Bell, & Moules, 2010; Wright & Leahey, 2013). This brings opportunities for acquiring deeper understanding on the unique suffering each family undergoes when faces stressful events or when a mental disorder harms a loved one (Marshall et al., 2010).

The small number of families involved and the predominance of participants of a low-income socioeconomic condition should be pointed out as limitations of the study. Thus, it is recommended to carry out additional studies involving more participants and encompassing different socioeconomic, educational and cultural layers.

Conclusion

The experience of the families in the illness process of a young member who suffers a first-episode psychosis proved to be permeated by representations, specificities, suffering, and blaming. It also revealed ways of coping with the issue, which may favor the health practitioners' understanding on this process, aiming at providing skilled care for these families.

This research also fostered the understanding of how families, when realizing and construing behavior changes, decided to seek help in the healthcare system.

It is also emphasized the importance of qualitative research in the research of the different meanings attributed to the problems faced, to understand and evaluate the different ways of coping and the various family constructions regarding psychosis among youths, as well as the conducts they adopt before this disease process.

The adopted methodological theoretical framework proved to be very appropriate to guide the learning and the development of studies on the meanings given by families to mental illness process in the face of mental illness.

Conducting earlier nursing interventions with these families could contribute to a quicker detection and beginning of treatment. It could also contribute to expand the understanding of the disease process experience and to provide appropriate support, aiming to reduce the suffering and to enable families to cope with this situation and the burden resulting therefrom.

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