International Journal of Nursing Sciences 5 (2018) 249–254

HOSTED BY

Contents lists available at ScienceDirect

International Journal of Nursing Sciences

journal homepage: http://www.elsevier.com/journals/international-journal-of-nursing-sciences/2352-0132

Original Article

Where to seek help? Barriers to beginning treatment during the first-episode psychosis

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

[a] Department of Psychiatric Nursing and Human Sciences of University of São Paulo, Ribeirao Preto College of Nursing, Brazil
[b] Federal University of Mato Grosso do Sul, Brazil

ARTICLE INFO

Article history:
Received 7 December 2017
Received in revised form
26 April 2018
Accepted 28 June 2018
Available online 30 June 2018

Keywords:
Caregivers
Family
Mental health
Psychiatry
Psychotic disorders

ABSTRACT

Objective: As decreasing the duration of untreated psychosis has been highlighted as key indicator in relation to improved prognosis, this study aims to identify the access barriers to beginning early treatment of young people in first-episode psychosis (FEP), based on family reports on the experience of perceiving illness and help-seeking.
Method: A qualitative research was carried out with 12 relatives of 12 young people passing through their first psychiatric hospital admission as a result of their FEP. Depth interviews were used for data collection and thematic content method for data analysis.
Results: Barriers to beginning treatment were lack of knowledge and difficulty in recognizing mental illness, lack of knowledge on where to seek specialized treatment, and stigma and resistance to psychiatric treatment.
Conclusion: It was demonstrated that the family members are protagonists in the search for treatment of young people in their FPE, given that the initiative for seeking treatment came from them.

1. Introduction

Schizophrenia is classified as a psychotic disorder, which normally begins during the transition period between adolescence and adulthood, and is manifested by the first-episode psychosis (FEP) [1,2]. Studies indicate that the individual generally does not seek assistance on the first occurrences of psychotic symptoms being presented. The person may spend between one and two years presenting psychotic symptoms without seeking adequate treatment [1,3,4]. This period is known as the duration of untreated psychosis (DUP) [1]. Extensive periods of DUP may result in worse response to treatment and poor general functioning, worsening of the positive symptoms, deterioration in quality of life and greater difficulty in achieving remission of the symptoms [5,6].

Thus, decreasing the DUP has been highlighted as a key indicator in relation to improved treatment response [3,7]. As such, the reduction of this period is one of the principal factors in the intervention of young people suffering their FEP. Unfortunately, those experiencing the initial symptoms of psychosis rarely seek treatment, the responsibility for which falls principally to family members [4,8]. Studies with the objective of understanding the experiences of family members in the search for treatment of their young with initial symptoms of psychosis highlight the decisive role that the family exercises in the recognition of these symptoms [9–11]. The individual with the first signs of psychosis usually presents with difficulties talking about these symptoms with other people or even seeking help at all [12]. So the family member, as the main point of support, becomes responsible for the search for treatment in the health services [9–11].

However, family members also find it difficult to relate behavior change with a possible mental illness. As an aggravating circumstance, if the individual or the people with whom he or she associates suspect that some type of mental disorder is forming, the associated stigmas and lack of knowledge tend to make it difficult to seek care [9–11]. Thus, for an extended understanding of the

* Corresponding author. University of São Paulo at Ribeirão Preto College of Nursing, World Health Organization (WHO), Collaborating Centre for Nursing Research Development, Avenida Bandeirantes 3900, sala 49,Campus Universitário, Bairro Monte Alegre, CEP:14040-902, Ribeirão Preto, Brazil.
E-mail address: carolzan@eerp.usp.br (A.C. Guidorizzi Zanetti).
Peer review under responsibility of Chinese Nursing Association.

https://doi.org/10.1016/j.ijnss.2018.06.007

reasons related to the delay to start treatment and for the consequent implementation of prevention strategies, it is fundamental to understand how the relatives of young people in the initial phase of psychosis experience this period.

Therefore, the objective of this study was to identify the access barriers to beginning early treatment of young people in their FEP, based on the reports of family members on the experience of perceiving the illness and seeking help.

2. Method

This is a qualitative research with thematic analysis, carried out with relatives of young people passing through their first psychiatric hospital admission as a result of their FEP. The search for participants occurred at the two main health services that receive the psychiatric admissions for 26 municipalities in the interior of São Paulo (Brazil), covering a region with around 1,468,323 inhabitants.

All the medical records of individuals in their first psychiatric hospital admission, in the period from January 2011 to June 2011, were reviewed. This period was chosen for its short amount of time between first psychiatric hospital admission and data collection. Inclusion criteria for the family relative included: being age 18 years or older, being related to a patient whose first hospital admission due to FEP occurred with the patient in the age range of 10–25, with a confirmed diagnosis of schizophrenia by a psychiatrist from the health service using the International Classification of Diseases - 10th Revision (ICD-10) [13], without a history of hospital admission or previous treatment being reported in the patient's records and without a diagnosis of neurological morbidities and the relative's experiencing the initial period of the patient FEP.

One hundred and fifty seven families were identified. Of those, 111 did not meet the inclusion criteria, leaving remaining 46 families. Contact with relatives was made by telephone, followed by home visits to invite the relatives to participate in the study. From the remaining 46 families, 26 were excluded because they could not be found due to a change of telephone number and address, and nine families refused to participate in the study.

Thus, considering the period for the study and the number of refusals, 13 relatives from 11 families participated in the study. Of the 13 family members, nine were mothers, three fathers and one husband, so the majority was female (69.2%), mean age was 47.5 years and 81.8% did not complete elementary school.

Data collection was carried out through in-depth interviews with the family members during the period from July 2012 to April 2013. All the interviews were carried out by two nurses, who were experienced and trained researchers with master's degrees and no professional link with the participants prior to beginning the study. Each interview lasted an average of 60 min and was conducted by the two trained researchers.

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. Data collection began with completing a form on the family's social demographic and the construction of a genogram. Then, the family members were asked to report on the initial period of the illness of the young person and the measures adopted by the family up to the first psychiatric hospital admission. We used the following questions to guide the first interview: "How did you realize that your relative was getting sick? What would have helped you understand the behavior change of your sick relative? What would have helped in the search for care during the beginning of the changes in behavior of the sick family member? Given the behavioral changes observed in the sick family member in recent times, what information would you like to receive about the onset period of the illness you are experiencing?"

Subsequent interviews were performed in order to validate the researchers' understanding of the information collected in the first interview, investigate further and clear up doubts arising during analysis of the first meeting. All families were invited to participate in this stage, but only nine families expressed their willingness. During the meetings, the data from the previous interviews were presented to family members to clarify doubts and confirm the information provided (validation of the data). The research was conducted entirely in Portuguese by native Portuguese speakers and subsequently translated into English.

The thematic analysis was used for analysis of the collected data [14]. It was chosen because it offers a flexible and systematic approach for exploring patterns in the dataset. The interviews were heard and transcribed in their entirety. The resulting text was revised a number of times and 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 letter F followed by a number was used to identify each family.

The interviews were analyzed with the objective of identifying excerpts that highlighted the barriers found by the family to accessing the mental health service and beginning treatment for the young person suffering their FEP. Statements were considered in which the family member reported situations, behaviors and issues indicative of problems requiring attendance at a mental health service, in any period of the patient's life. Concomitant to this stage, notations were made formulating an initial understanding of the issues raised. Then, the identified issues were grouped according to similarities in the information reported by the family members, constituting each category of the results. All the data analysis was performed by two independent researchers. Discordant data between researchers were discussed during the meeting until there was an agreement between them.

The main strategies used to promote rigor in this research were: critically following thematic analysis procedures; transparency in the description of the methodology; returning to the participants for validation when the accuracy/interpretation of interview transcripts was in question; and promoting regular discussions about both the reflexivity and credibility of the preliminary interpretations with a group of researchers.

The study was authorized by the health services and approved by a Committee on Ethics in Research with protocol n°1349/2011. All the ethical standards and guidelines involving human beings were respected [15].

3. Results

The analysis of these reports resulted in three categories of barriers related to the experiences of the interviewees.

3.1. Lack of knowledge and difficulty in recognizing the mental illness

Lack of knowledge about mental illnesses and difficulty in recognizing illnesses define the context in which the FEP occurred. The family members had no knowledge of the mental illness and presented difficulties in recognizing the first symptoms and behavioral alterations as being indicative of a mental illness.

"When could I possibly imagine that feeling down was a disease?! And we are there, aren't we, arguing with the person, even hitting