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Original Article

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



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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.

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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

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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

them, thinking that it is shamelessness, you know, but it's not. Today I see people differently." (F1: mother).

Some family members argued that they did not suspect mental illness, thinking that these disorders only manifested at birth and left the individual extremely limited, helpless and not responsible for his or her own acts, as opposed to their perception of young people in their FEP.

"I don't know why, in my head I thought that when a person had a mental illness, they were already born sick, I never thought that it could happen at the age she was." (F9: Mother).

The interviewees reported that, upon perceiving the changes in behavior of the young people, they didn't identify these changes as oncoming illness, because they believed that the behavior changes were consequences of personality characteristics of the young person, lack of intelligence, alterations typical of adolescence, stressors identified in the context of the young person's life, abuse of psychoactive substances, bad influences, suffering from unrequited love, consequences of physical attack, possession or other supernatural causes.

"I thought it was drugs, because I think he was smoking weed, now doing cocaine, I don't know ..." (F7: father).

"Sometimes she likes someone, and as she's really quiet, sometimes she's suffering, sometimes she's in love ... I didn't think it could be something more serious." (F9: mother).

Of the 11 patients included in this study, only three had finished high school. It can be highlighted that the other eight young people had abandoned school, five having presented problems since childhood, interrupting their studies even before starting high school. The other three had shown good performance at school, however, suddenly their performance declined and they had abandoned school.

Undisciplined and disinterested behavior of the patient during the school period and the consequent abandonment of school were cited as the first signs that something was not right with the young patient. Despite not being clearly alarming or bizarre behavior promoting the recognition of a possible mental health problem, the behavior did prejudice the academic performance of the young people and generate demands on the families, who were often called by the school. However, the families associated this behavior with lack of commitment and discipline of their children with their studies, while the school did not know how to orientate the family.

"Yes, he studied ... he was always a little hyper. He only studied up to the sixth grade ... after he would go to school and say that he'd studied, but he hadn't, he was a little weak (laughs) ... he decided he wouldn't go any more and that was it." (F2: mother).

"Yes, there was a change, because how can a person be so studious, never give me any trouble, get to the first year (first year of high school) and do this? (...) Until getting to the first year, you know ... got to the first, stopped!" (F6: mother).

Therefore, we can observe that the lack of knowledge and the difficulty in recognizing mental illness is a barrier also related to the professionals that were part of the context of these families; in this case, the teachers.

3.2. Not knowing where to seek specialized treatment

The family members reported that they did not know where they should seek help for the young person when they presented signs and symptoms of their FEP.

"For me, it was very difficult, you see. I didn't know what to do, because I'm going to look for what? (...) Which doctor deals with this, you know? (...) Where do I look ... ? Because I didn't know ... I look for whom? Which doctor? Where do I go?" (F5: husband).

In the presence of milder symptoms, the first form of support sought out by the family members were people from their own family, friends, neighbors, religious people and trusted professionals. These resources were characterized by their easy access, closeness and connection to the family of the patient.

"His mother would cry and take people to her house; people from the evangelical church would come to the house to talk to him" (F2: father).

"We took her to the church, you know, the pastor came, prayed for her. Then we got her and took her to a faith healer as well to see what it was. (...) We were looking for help, you know." (F9: father).

With the manifestation of less controllable or more alarming symptoms, the family called on various social apparatuses like the police, women's police station, the guardianship council and radio.

"And I was always going to the women's police station. And they didn't tell me either, did they, 'Go to the Mental Health Clinic,' I don't know, something was lacking you know, I don't know, there was a lack of understanding." (F1: mother).

"I went there to Conselho tutelar (Guardianship Council)." (F7: father).

The health services were the last resort. Furthermore, the statements of the family members revealed that in the service itself there were difficulties in recognition and problem solving in managing the FEP. There were reports of young people submitted to exams that, by not confirming an organic alteration, were interpreted as revealing an absence of any illness. Moreover, some young people were repeatedly taken to emergency services, where they were only medicated to reduce acute symptoms, with no subsequent follow up or referral for psychiatric treatment.

"When she got there to the doctor, the doctor looked at the exams and said 'Congratulations, you don't have anything, there's nothing on the exams.'" (F3: mother).

"I would take her to the emergency room, I'd call an ambulance, take her to the emergency room ... They said that, 'but, this is a problem in the head, where you have to take her is the Mental Health clinic.'" (F9: mother).

From the perspective of the family members, the lack of knowledge on where to seek help increased the suffering, the overload on the family and the sensation of being helpless. They argued that if treatment had begun sooner, it could have reduced the suffering of the young persons and their family members.

"If I had looked for the Mental Health Clinic before, if I'd had this information, that this had a solution, was an illness, I'd have resolved it before, wouldn't I?" (F1: mother).

3.3. Stigma, prejudice and resistance to psychiatric treatment

It was possible to learn from the reports of the family members that they were afraid to seek psychiatric treatment due to the stigmatized perception of mental illnesses and their treatment, especially when this includes hospital admission.

“And also the psychiatrist, you know, ah, that ... (cites the name of the psychiatric hospital), everyone is scared to death ... ‘Oh they’ll put him away, oh he’s crazy, you know, they are going to judge’ ... these things came into my head.” (F1: mother).

“It was a shock when they said he needed to be admitted to a psychiatric hospital. (...) We imagined that he’d stay there tied up ” (F9: mother).

There were family members that took the trouble to not reveal the young person’s situation, as they feared that other people may have stigmatizing reactions directed at the patient and the family.

“I didn’t want the neighbors to know about her problem, so being like that, it got on top of me ... I couldn’t open up to anyone who might say that my daughter was mad; I didn’t want anyone to know that my daughter was going through this. That’s why it was so difficult.” (F3: mother).

4. Discussion

The present study identified the following factors as barriers to beginning treatment: lack of knowledge and difficulty recognizing mental illness, lack of knowledge on where to seek specialized treatment, and stigma and resistance to psychiatric treatment. It was also revealed that the family members are protagonists in the search for treatment of the young person in their FEP.

The children of Latin American families are considered more dependent on family members for a longer period of time [16]. Some of the aspects discovered in the present study corroborate with international papers, although they occur in a context with important specificities because, in Brazil and Latin America, there are peculiar characteristics related to family dynamics. In Latin American families, family emotional climate is influenced mainly by *familismo* (which reflects the relevance of the family in Latin American culture), respect for family hierarchy and gender roles [16]. Although these factors may contribute to different expressions of the relationship between family members and people in FEP, family perspectives converge with different aspects inherent in other cultural contexts.

Thus, it is possible that, in the case of Latin American youngsters in FEP, the family’s participation in the search for and maintenance of treatment is even more decisive, since the initiative to seek treatment often eluded relatives. Thus, it is suggested that educational interventions for this audience may be strategic [4,16].

The lack of knowledge about becoming ill makes it difficult for the family to recognize the behavioral alterations of the patient as indicative of mental illness [8,17]. Therefore, the participants in this study reported that in the beginning they explained these behavioral alterations in accordance with their cultural beliefs and the context in which they were inserted. Such explanations were related to the day to day life of the patient, personality characteristics of the young person, lack of intelligence, alterations typical of adolescence, stressors identified in the context of the young person’s life, drug use, bad influences, suffering from unrequited love, consequences of a physical attack, possession or other supernatural causes.

Four studies [4,8,18,19] carried out in Brazil, the United Kingdom, Canada and the United States, with the objective of discovering the paths followed by individuals experiencing their FEP up to beginning treatment, found similar results to those observed in this study. That is, the families also reported that they initially attributed behavioral alterations of the mentally ill relative to the phase of adolescence, drug use, spirituality or stress. Such explanations confuse and delay seeking adequate treatment.

As can be observed, different socio-cultural contexts present similar explanations for the behavioral alterations observed, indicating that there appear to be standard elements masking the FEP, which are present in various cultures and deserve special attention [4,18]. However, other studies indicate that the paths followed in the search for help may have a cultural and ethnic influence [20,21].

Furthermore, it can be highlighted that many family members attribute the behavioral alterations of the young person to the effects of drug use or withdrawal. The tenuous line between alterations caused by drug use or by untreated psychosis makes the recognition and diagnosis of an illness difficult and delays the beginning of treatment [8]. Therefore, the evaluation and use of instruments that enable identification of the FEP and enable the differentiation between psychotic illness induced by the use of psychoactive substances and primary psychotic disorders may contribute to early detection, adequate treatment and follow up, promoting a better prognosis [22].

The stigma related to mental illness may also be a barrier to help-seeking [4,8,18]. The family members in this study feared that the young person would be considered “mad” and in order to protect them, they stopped sharing what was happening with the young person with other family members, friends or neighbors. Moreover, the stigmatized perception of mental disorders and its treatment made acceptance of the possibility of diagnosis and hospital admission even more painful for the family members. Stigma complicates the process of recognition, seeking treatment, obtaining information and support from family members or friends [23,24].

The lack of knowledge about the symptoms of schizophrenia and other mental illnesses tends to make seeking assistance difficult [17,18]. Thus, the lack of information on mental illnesses and stigma may be mutually reinforcing, which complicates the search for help and access to mental health services [17,24,25].

This study also identified problems in academic performance as a first sign that something was not right with the young person. It is known that some years before their FEP, the young person may present the first clinical manifestations of becoming ill. This period of time is known as prodrome. It occurs prior to the appearance of psychotic symptoms and is characterized by non-specific alterations in behavior, such as mood swings, anxiety, insomnia, concentration or attention difficulties, a decrease in the ability to carry out everyday activities and social isolation [1,2].

It was at school that the first behavioral alterations became evident. However, the hypothesis of this being the manifestation of symptoms of a mental illness was not raised. Reports of prodromic signs during childhood and adolescence have been studied and have not been highlighted as being uncommon [26]. Schools are institutions that are both close to young people and have easy access to families. Therefore, they may be in a strategic position to identify those requiring treatment, to contribute to the development of non-stigmatizing actions and to coordinate community and health services in promoting mental health and well-being in young people [27]. Although at this stage of life it was still not possible to associate such behavior with mental illness, we understand that these young people could have been referred to a mental health service.

With the manifestation of less-controllable symptoms, the first form of support sought out by family members was based on easy access, closeness and connection to the family. However, frequently, the people they sought out also could not offer adequate orientation on how to proceed.

The primary care services, like emergency rooms, are also cited as the first places to seek help, in both our study and research carried out in the United Kingdom [25]. However, the difficulty that the professionals from these services encounter in identifying mental illness and beginning adequate assistance is not restricted to our context.

It is of great concern that, on most of the occasions, the health services and professionals sought out by the participants in this study were not able to help the patient and their family. This occurred either because they did not identify the illness or because they did not know where to refer them. This result suggests that the principles of connection, accessibility and completeness of care envisioned in Brazilian healthcare policy [28] need to be improved.

Besides health services, the participants reportedly sought various social apparatuses, including the police. Although other studies indicate high rates of police involvement in referrals of individuals to psychiatric services [25], the literature also shows that individuals involved in the criminal system present longer DUP [21]. Police training in the management of people with mental illnesses may retard or reduce the use of force in dealing with this section of the public, which could diminish the risk of physical confrontation, injury [29] and negative experiences for the mentally ill and their family members [7].

The quality of preparation and knowledge in the area of mental health of healthcare professionals, whether acting in the area or not, complicates the path between the patient and a specialized service [7,20]. One way to overcome this barrier would be coordination between the different types of services (schools, social services, judicial services and health services) with the aim of integrating care programs in order to reduce the DUP [25,30]. However, a study [30] developed in the United Kingdom showed that even in places where early intervention services function, difficulties can be observed in coordination between the services and patients' access to them, leading to increased DUP [30].

Considering the necessity for integration between services, another study [18] carried out in the United Kingdom offered training to professionals in community services not acting in healthcare, but with ample contact with the community. The training aimed to enable these professionals to identify a FEP and consequently diminish DUP. The impact of the training was evaluated by the DUP and the trajectory in seeking treatment of people that sought out the early intervention service existing in the region, comparing these variables in two periods before and after training. The study indicated that there were no significant changes in the DUP, although the professionals involved in the training evaluated it as positive. They indicated that the training provided knowledge on psychosis and the FEP, on the existence of specialized services, and on how to offer support and information to an individual that is becoming ill. However, the fact that the training did not reduce the DUP indicated that the barriers to early intervention remain. The authors identified such barriers as the difficulty in communication and coordination between the community and the early intervention service, the operational limits on community services and the insecurity of the professionals in making referrals. This insecurity was explained as a certain discomfort in unnecessarily increasing the demand on early intervention services and stigmatizing the young people who might have a mental illness. Furthermore, it was observed that the early intervention service presented resistance to coordinating

with community centers, as they feared that they would make indiscriminate referrals [18].

5. Conclusions

The present study identified the access barriers to beginning early treatment of young people suffering their FEP, based on family member reports on the experience of perceiving the illness and help-seeking. The study identified that the lack of information on mental illness, on where to seek help in the initial period of the illness and the stigma associated with the mental illness cause a great deal of suffering for patient and family, and constitute important barriers to beginning treatment. Moreover, lack of information is a barrier that is present in the families and professionals from different institutions that had contact with this group. There are certain limitations in our study. A possible limitation is that the study was conducted with a unique and small number of participants and represents a single setting, so the findings may not be generalized. Future research should include larger samples.

The study offered clues on the difficulties in accessing mental health services related not only to the family nucleus, but also to lay professionals and healthcare professionals that came into contact with the families at this difficult time. This study also demonstrated that the family members are the protagonists in seeking treatment for the young person during their FEP, given that the initiative for seeking treatment came from them.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijnss.2018.06.007>.

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