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The significance of having family members assisted in a CAPSi: a phenomenological study

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ABSTRACT

This study aims to understand the meaning that family members attribute to the fact of having a relative being treated in a Child Psychosocial Care Center. This is a qualitative piece of research utilizing the theoretical and methodological framework of the phenomenological sociology of Alfred Schutz. The field of study was a Child Psychosocial Care Center in Cascavel, state of Paraná. Data collection took place between October and November 2010, through phenomenological interviews with 11 relatives of users of that service. In a comprehensive analysis of the testimonies, aspects have emerged about the difficulty of dealing with the disease, the prejudice and lack of knowledge with regard to the symptoms of mental illness. This study allows us to understand the meaning given by relatives to the fact of having a family member assisted in a substitutive service in mental health and even further, we point to the need for support on the part of the family with regard to the work of the multidisciplinary team.

Keywords: Mental Health, Family, Mental Health Services, Nursing

INTRODUCTION

The attention to children's health, such as mental health care in childhood, has become important from the eighteenth century onwards due to the social, economic and political changes which have arisen from the new modes of production which took effect as a result of the Industrial Revolution. This is because, since the Middle Ages, the child was seen as a miniature adult, and childhood was not considered to be a period of growth and development for human beings.

This change of concept in relation to childhood has contributed so that the health care services, including mental health care, were restructured according to the specific needs of the child as a being who is engaged in growth and development.

In Brazil, the movements for the re-democratization of the country in the late 1970s allowed a new visibility with regard to the health situation of the child. From this time onwards, the movement for the redirection of mental health care began. In this context, we may include the mental health of children and adolescents, which began to be discussed at the Second National Conference on Mental Health in 1992, when the perverse effects of the institutionalization of children and youth were pointed out; and at the Third National Conference on Mental Health in 2001, which discussed the urgent need to establish a new direction to the political and assistance actions for the care and treatment of the juvenile population. As a consequence, the National Forum on Mental Health of Children and Adolescents was set up, in order to consolidate the services networks for the care of children and adolescents in psychological distress⁽¹⁾.

Therefore, there came the introduction of Child Psychosocial Care Centers (CPCC) for "...taking care of mental disorders involving severe and persistent losses, and establishing guidelines for the intersectoral coordination of mental health with other public sectors, aiming at the coverage of the most frequent problems that involve more specific damages" (2:392).

Furthermore, in order for the mental health care of children and adolescents to be implemented, it was necessary to consider the fact that they are in a phase of growth and development, which may influence the diagnosis of mental and behavioral disorders. Therefore, the professionals involved in multidisciplinary team of the substitutive services should be trained to understand the social context, family, school and religion, in which the individual exists, in order to establish a diagnosis of mental illness and the implementation of such care, or perceive that it is just about behaviors regarding the development process of childhood and puberty.

In the process of restructuring care services to meet the needs of individuals in psychological distress, professionals working in the area of mental health have changed their roles and their way of caring, and have begun to have a therapeutic function with regard to users in order to reintegrate them into society and family life.

In this sense, the family members who, during the patient's treatment in a mental health home care mode, were seen as victims or originators of a psychological distress framework or even mere informants about the patient's health status, became, as a result of the Psychiatric Reform and the redirection of mental health care that culminated in the psychosocial approach, the protagonists of care for the individual in psychological distress, as their experiences revealed important elements for reflection on practices designed to ensure mental health care.

Therefore, the objective of this study is to understand the meaning that family members attribute to the fact of having a member being treated in a Child Psychosocial Care Center.

METHODOLOGY

This is a qualitative study using a phenomenological approach, developed in a Child Psychosocial Care Center, located in Cascavel, Paraná, and is part of the results of a doctoral thesis.

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Data collection was conducted through semi-structured interviews, after the study was approved by the Ethics Committee in Research of the Faculty Assisi Gurgacz, under Opinion 54/2010, in accordance with Resolution 196/96 of the National Health Council of the Ministry of Health⁽³⁾. Inclusion criteria were: that family members who were the main caregivers of children who attended the CPCC should agree to participate in the study by signing the consent form. The exclusion criterion was not to agree to participate.

Information was collected between October and November 2010, through phenomenological interviews with 11 family members, including eight mothers, two grandmothers and a sister-in-law, of users of this service. This was based on the question: "**How is it for you to have a relative in psychological distress?**" the interviews were scheduled at a time and location that was convenient for the participants. The interviews were recorded using a digital recorder and later transcribed in their entirety.

Statements were identified by letters, according to the order in which the interviews were held, in order to ensure the anonymity of the participants.

To understand the information, we have used the phenomenological method for the construction of concrete categories, performing a sequential, detailed and exhaustive reading of the testimonies. We have sought to identify and read the meaning units, grouping them according to their convergences, in order to form concrete categories originating from the experiences of these individuals. This comprehensive analytical movement of the categories is based on the philosophical and methodological referential of Alfred Schütz⁽⁴⁻⁵⁾.

RESULTS

From the analysis of information regarding the meaning ascribed by relatives to having a family member being treated at a mental health substitute service, it was possible to identify the following concrete categories:

Reporting difficulty in dealing with the disease

"Look, for me, in the beginning, it was very hard, very hard." c

"Well, actually, it's something new and in a way, you know, we were a bit concerned." g

"Oh, it's hard because we're faced with a situation in which you don't know ... how to act in terms of his behavior at home, you know [...]." h

"So, I confess that it's not very nice, it isn't. [...] It is also hard for me to take him there, to be honest with you, I don't like it " i

In the testimonies, family members talk about the difficulty in dealing with mental illness; it is a situation that is often scary, new and challenging for the caregivers. This is because the fact of having a family member in psychological distress leads to situations of embarrassment within the family and for the individual, between them and the other individuals that make up society, in which family members report not knowing how to act.

Experiencing prejudice against the disease

"We are savvier, but people are [...] we still have the prejudice of other people, which is more complicated. When you say that my child is treated at CPCC, the first thing people say is : 'Oh, he's crazy. He has a head problem?' " b

"Yeah [...] they are [...] right now I do not know the right word [...] rejected. Both schoolmates and parents of students [...]. So the prejudice, the rejection; when he goes out to play with his playmates, it also exists [...]." f

"I do not know if it's my bias or what it is, but I don't like it either that my child gets involved with the children there. [...]." i

"All the mothers complain that when they enter the bus the others go like: 'Look, the freaks of CPCC! The freaks of CPCC.'" j

Family members report that there is prejudice within society and on the part of other relatives in relation to the child, due to the fact that he or she attends the CPCC. Additionally, you can also see that prejudice is present in how the relatives talk as well. It shows that they feel uncertain about the CPCC environment.

Bias is also revealed in the attitudes of classmates and even in situations in which users need to use public transportation to go to the CPCC.

Reporting ignorance regarding the symptomatology of the disease

"[...] We don't know things, we don't know; we think it's one thing and it's something else." c

"[...] At first, we saw him as a normal teenager, in the daily experience we have with him; uh, [...] in our everyday life we hadn't paid attention to it [...]" d

"I, in my way of thinking, didn't need to go there, you know? But the school said that he had to go to CPCC; he's being well treated. It's just that I think that it's not helping at all, for me, you know; he continues to be agitated anyway, and stubborn in the same way." k

The testimonies of the relatives reveal ignorance of the symptoms of the mental illness presented by the CPCC users.

The lack of information about the symptoms of the disease leads the family to believe that users do not need the recommended treatment or even to confusion about the actual diagnosis of mental disorder, especially in cases in which the user presents hyperactivity.

DISCUSSION

In the concrete category **reporting difficulty in dealing with the disease**, we discuss aspects of the relationship of family members with the mental illness, which is seen as a new, daunting, challenging and embarrassing situation, and which highlights ignorance on their part as to how to act in the relationship with the individual in psychological distress due to the child's unpredictable behavior.

In this sense, we can understand that mental illness is part of daily life and the specific biographical situation of their relatives, keeping in mind that the biographical situation is determined in every moment of life in which a man finds himself, considering the physical and socio-cultural context in which he is operating and his experiences. Therefore, this is something transient and dynamic, because, as time goes by, the individual accumulates knowledge and experiences that make him understand the situations experienced.

However, the amount of knowledge on the part of the relatives of CPCC clients about such a situation does not provide enough support to help them deal properly with the individual in psychological distress, which makes the relationship of the user with his family and society more difficult.

The specific biographical situation of a man is built into every moment of life in which he finds himself, that is, in the physical and socio-cultural environment in which he is placed, both in terms of physical space and external time, status and role within the social system, as well as in his moral and ideological position. Thus, the specific biographical situation is related to the story of the life of a man, and it is the sedimentation of all previous experiences, organized according to his amount of knowledge at hand, which are possessions that belong solely to him, given to him, and belong to him alone⁽⁴⁾.

This biographically specific situation includes certain future practical or theoretical possibilities, which, in short, are referred to as the purpose at hand. This purpose is what defines those elements among all the others contained in such situations, and that are significant with regard to it. The meaningfulness of the system determines, in turn, that elements should be converted into a generalizing typicality substrate, and that characteristics of these elements must be elected as characteristically typical, and which are designed as unique and individual. In other words, this system determines at which point we must enter into the horizon of typicality⁽⁵⁾.

In this context, the amount of knowledge at hand is formed by both past and present experiences, and consists of activities and past experiences in our consciousness, which become the unique possession of the social actor. From this body of experience, man is able to interpret his current experiences and anticipate future ones.

Thus, "The stock of knowledge at hand works as a code of interpretation of the current experience in progress. This reference to acts already experienced, presupposes remembrances, and all its functions, such as memory, retention and recognition"^(4:75).

In this context, we can say that the relatives of CPCC users experience a specific biographical situation, which is characterized by the fact that they have a family member in psychological distress, from which they build a body of knowledge at hand, covering such life experience, in the attempt to interpret the current experiment.

In this attempt, they verbalize the difficulties associated with being connected to the relative in psychological distress and understanding his behavior. Moreover, they report not knowing how to deal with situations that are imposed by the manifestations of the mental illness in the relative.

Thus the family is an important place for the treatment of an individual in psychological distress, but living with him is characterized as a problem for the family members in the sense of triggering wear, tension and conflict. These situations happen due to the fact that the family is unprepared to keep this individual out of an institution⁽⁶⁾.

In this regard, in the relationships that individuals in psychological distress have with their relatives, there arise some conflicting relationships. It is through this that we can refer to the difficulties encountered by family members in terms of their familiarity with a person in psychological distress⁽⁷⁾.

The difficulty in dealing with mental illness is related to the inability, at first, of dealing properly with the behavior of the relative in psychological distress. This situation happens both in face to face relationships and in indirect ones, in view of the fact that the unpredictable behavior of the user hampers his intrafamily and social coexistence.

Thus, the family members may have a vague quantity of knowledge at hand with regard to this situation which arises from an indirect relationship with the mental illness. That is, they are aware that there are other individuals in psychological distress, as well as contemporary relatives experiencing the same situation, but have not had past experiences that can support their actions.

This is because "my mere contemporary (or" contemporary ") is someone I know that coexists with me in time, but that I do not experience immediately. [...] And, in its present status, the contemporary can only be accessible indirectly, so that their

subjective experiences can only be known in the form of general types of subjective experience "(4:217).

This is because the social relationship between contemporaries occurs so that each participant perceives the other through an ideal type, and becomes aware of this mutual apprehension. Furthermore, each one expects that the interpretative scheme of the other is congruent with his⁽⁸⁾.

With this concrete category, we could understand that the family members of CPCC users have a vague understanding of the signs and symptoms of the mental illness, which makes it impossible for them to have a satisfactory relationship with the individual in psychological distress, and which leads to the difficulty of dealing with the disease. This situation happens because the knowledge that family members have in relation to the mental illness comes from indirect relations with individuals affected by this type of problem, which generates different interpretations about the manifestations of mental illness. Moreover, the situation being confronted reveals itself as something new and challenging.

In the concrete category ***experiencing prejudice against the disease***, prejudicial situations, derived from actors who are part of the daily lives of family members of individuals with psychological distress seen in CPCC, are evidenced.

In this sense, we believe that "...the world of everyday life is the intersubjective world that existed long before we were born, lived and interpreted by others, our predecessors, as an organized world. Now it is at the mercy of our experience and interpretation. [...] The world of everyday life is the scene and also the object of our actions and interactions "(4:71-2).

The everyday world can also be understood as the place in which we operate, not only inside it, but also over it. Thus, this is the scene of social action in which men enter into a mutual relationship and get along with each other, as well as themselves⁽⁵⁾.

Thus, we can understand that society, schoolmates, friends, and people who share transportation with CPCC users, other family members, and even the subjects of the

research, show prejudice against the disease, which can be noticed both in face-to-face relations and in indirect relations with the users of the CPCC.

In a face-to-face meeting, the "We" relationship is experienced in the same environment by the actors, and it is in this situation that the inter-subjective world is composed. That's because "...in the face-to-face relationship, I literally see my partner before me. While I look at his face and his gestures and hear the tone of his voice, I become aware of much more than what he is deliberately trying to tell me. [...] For this encounter with the other person, I bring a whole repertory of knowledge previously made."^(4:186-87).

In a face to face relationship, each co-participant has equal access to a certain sector of the outside world, and has objects of interest and significance that are common to it. For each one, the other's body, his gestures, his bearing and his facial expressions are immediately observable, not only for their physiognomic significance, but also as symptoms of the other's thoughts. Sharing a community of time means that each of the participants is involved in the ongoing life of the other, and can capture in a present moment lived, the thoughts of the other as he builds them. Therefore, individuals age together and live a pure relationship of "We"⁽⁵⁾.

The prejudice against mental illness is also present in indirect social relations, in which social actors recognize the individual in psychological distress as a contemporary; a subject characterized by typical actions.

In an indirect relationship of "We", namely, in a mediated experience of contemporaries, the other is experienced in a way that is not given in a pre-predicative manner, meaning that the "I" does not perceive directly the existence of the other. All knowledge of the other is mediate and descriptive, and their characteristics are established by inference⁽⁴⁾.

In this relationship, there arise some ideal types of people. This is the way in which individuals, CPCC users in psychological distress, are seen by their peers and contemporaries. It is understood as similar in terms of individuals who are part of the everyday world and who develop a face-to-face relationship with each other; and as

contemporaries, as individuals who are part of the inter-subjective world and who develop among themselves, indirect social relationships, leading to the classification.

In the typification, the synthesis of recognition does not understand the unique individual as he exists within his living present. Instead, it is pictured as usually the same and homogeneous, without considering all the changes and defined contours that are part of individuality. Therefore, no matter how many people are categorized under the ideal type, he does not correspond to any particular one⁽⁴⁾.

Thus, we always expect that the others behave in a definite way, and for me they always seem to be anonymous entities exhaustively defined by their actions. Thus, they are defined as types⁽⁵⁾.

Furthermore, we can understand that the bias introduced by society in relation to mental illness comes from an amount of knowledge at hand that the social actors have concerning insanity, and the forms of treatment that individuals in psychological distress have – in this case, the service in a CPCC.

This is because the relationship that society has with the users of CPCC is grounded in the stock of knowledge available with regard to those individuals and the social type built about them. Thus, society sees those who attend the CPCC as belonging to the "group of madmen," without considering the different pathologies and needs presented by the users.

Thus, there is a need to combat the symptoms and disabilities that result from the disease and, on the other hand, face the challenges which exist in terms of the stereotypes and prejudices that result from misconceptions about mental illness. In modern societies, historically and traditionally, these have been marks printed more intensely on the person who lives the experience of mental illness⁽⁹⁾.

This category has allowed us to understand that there is social and familial bias towards the users of CPCC. This situation often leads relatives to prevent one of its members from using that service, as a way of preserving that person from constraints, although their own relatives also report that they have prejudice when it comes to having a family

member in psychological distress receiving treatment in a CPCC, and even about other users.

In the concrete category ***reporting ignorance about the symptoms of the disease***, family members report a lack of information on the course of mental illness. Therefore, they believe that there is no need for treatment, perhaps because of the confusion presented concerning the diagnosis of mental illness.

This way, we believe that family members often believe that the CPCC user does not have a psychological distress, but is just demonstrating the normal behavior of a child and of pubertal development. Also, they are unaware of the signs and symptoms that can be manifested by individuals in psychological distress.

We can understand, therefore, that the relatives of CPCC users have little information about the symptoms of mental illness, which means that they experience a specific biographical situation in which the amount of knowledge at hand is not enough to enable them to interpret what is happening to their loved family member.

The biographical situation is mainly characterized by what the individual has in any moment of his life, that is, the amount of knowledge at hand, built by typifications of the common sense world. The accumulation of typifications is endemic in the lives of common sense because, since childhood, the individual adds a great deal of information that he uses immediately as techniques to understand or, at least, to control, certain aspects of his experience⁽⁵⁾.

However, family members of CPCC users do not have the amount of knowledge at hand that enables them to understand the situation experienced by an individual in psychological distress. This knowledge is built from the experiences that such children are facing in dealing with mental disease in their daily lives.

On this, we can say that, with regard to certain problems, the amount of knowledge at hand is more than enough, but compared to other situations, improvisation based on typically possible outlines may be necessary. In addition, it depends on the imaginative

possibilities of the subject and the unique situation that that person occupies in the social world⁽⁵⁾.

Relatives seek to understand mental illness and accept that it is part of their lives. However, they come upon a psychosocial phenomenon which is little understood and accepted, and even, to some extent, feared. These unique experiences of living with an individual with a mental disorder, are perceived as being difficult and do not allow them to feel relaxed⁽¹⁰⁾.

With this concrete category, we realize that ignorance concerning the disease leads the family to fantasize about it, in an attempt to interpret what is happening with the individual in distress. This issue makes them seek several explanations about mental illness, which often creates ambiguity regarding the need for treatment.

CONCLUSION

The information reported in this research by families of users of a Child Psychosocial Care Center showed that there is difficulty in dealing with the mental disease in that it is seen as a dreadful, challenging and new situation, in which the family cannot establish a satisfactory relationship with the user due to the unpredictability of that person's behavior.

It happens because, despite the fact that mental illness is part of the specific biographical situation of relatives of the subjects in this study, they do not have a sufficient amount of knowledge at hand over the course of the process of health and mental illness. This hinders the management of different situations that arise in face-to-face relationships with CPCC users and society. Somehow, the family members have a vague knowledge of insanity, often derived from indirect social relations with contemporaries who suffer from that disease. Thus, they present a diversity of interpretations of mental disorder.

Another aspect highlighted by this study is the prejudice that is experienced by the family regarding mental illness. This bias appears both in face-to-face relationships as, for example, in the relationship between users and schoolmates, friends, neighbors and relatives, and in indirect social relations, such as when users utilize public transportation. This is because the knowledge we have about madness is built from social experiences of the "Crazy" type, which consists of the typical actions of this individual and the treatments offered to the mentally ill, and does not consider the different pathologies treated in the Child Psychosocial Care Center. Thus, family members seek to omit the participation of its members in that service in order to preserve them from possible embarrassment.

Another feature of this research, is the ignorance of the family regarding mental illness. In this context, they report not knowing the course of the mental disease and often believe that the user does not have a diagnosis referred by a psychiatrist, but that it is just a normal condition of the child and pubertal development, and therefore, does not require treatment.

Thus, the relatives start to seek interpretations about what has happened to the individual in distress. This is because the amount of knowledge that they have at hand concerning the mental disorder is insufficient to enable them to understand the situation experienced. Moreover, this knowledge is being built from the everyday experiences of the family members from the moment in which one of its members is diagnosed with the mental disorder.

In this sense, the family members need the support of the multi-professional team that performs substitutive care services in mental health, and specifically from the nursing staff, in order to understand the condition of their loved family member and to learn to deal with situations that are imposed by interaction with the individual in psychological distress. In addition, family members are a source of information about the health status of users, allowing them to contribute to the individual treatment plan.

Thus, this research stands as an introduction to new perspectives of analysis aimed at revealing the meaning that family members give to the fact of having a relative being treated in a substitutive mental health service facility.

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