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# THE EXPERIENCE LIVED BY CLIENTS' FAMILY MEMBERS OF A CHILD PSYCHOSOCIAL CARE CENTER

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## ABSTRACT

The objective of this study was to understand the lived experiences of family members of children attending a Child Psychosocial Care Center. This study is a qualitative research with a phenomenological approach, developed at a Child Psychosocial Care Center (CAPSi as per its acronym in Portuguese) located in the municipality of Cascavel, State of Paraná. Participants were eleven family members of clients attending the above mentioned service and who, more actively, took part in the clients' care. Semi-structured interviews were performed and the gathered data were then analyzed by means of social phenomenology methodology. The experience lived by the family members of children attending the Child Psychosocial Care Center included experiences in dealing with clients' behavior; seeking referrals to other services; waiting for treatment; hoping to see an improvement in the clinical profile of the patient and experiencing the service support provided to the family. Thus, this present study may contribute to a reflection on mental health nursing practice in caring for clients and their families.

**Descriptors:** Family. Mental health. Mental health services. Nursing

## *RESUMO*

*O objetivo desta investigação foi compreender o tipo vivido de familiares de usuários de um Centro de Atenção Psicossocial Infantil. Trata-se de um estudo qualitativo, de abordagem fenomenológica, desenvolvido em um Centro de Atenção Psicossocial Infantil (CAPSi), localizado no município de Cascavel, Paraná. Os participantes da pesquisa foram onze familiares de usuários do referido serviço e que mais participavam dos cuidados com os usuários. Realizaram-se entrevistas semiestruturadas, e as informações foram analisadas por meio da metodologia da fenomenologia social. O tipo vivido dos familiares de usuários de um CAPSi mostrou-se como sendo: aquele que vivencia o comportamento do usuário; refere o encaminhamento de outros serviços; espera por tratamento; deseja a melhora do quadro clínico e vivencia o apoio do serviço aos familiares. Nesse sentido, o estudo pode contribuir para a reflexão sobre as práticas de Enfermagem em saúde mental aos usuários e familiares.*

***Descritores:*** *Família. Saúde mental. Serviços de saúde mental. Enfermagem.*
***Título:*** *O tipo vivido de familiares de usuários de um centro de atenção psicossocial infantil.*

## *RESUMEN*

*El objetivo de esta investigación fue comprender el tipo vivido de familiares de usuarios de un Centro de Atención Psicosocial Infantil. Se trata de un estudio cualitativo de abordaje fenomenológico, desarrollado en un Centro de Atención Psicosocial Infantil (CAPSi), ubicado en el municipio de Cascavel, Paraná. Los participantes del estudio fueron once familiares de usuarios del referido servicio y que más participaban de los cuidados con los usuarios. Se realizaron entrevistas semiestructuradas y las informaciones se analizaron por medio de la metodología de la fenomenología social. El tipo vivido de los familiares de usuarios de un CAPSi se mostró como siendo: aquel que convive con el comportamiento del usuario; refiere el encaminamiento de otros servicios; espera por tratamiento; desea la mejora del cuadro clínico y convive con el apoyo de servicios a los familiares. En este sentido, el estudio puede contribuir para la reflexión sobre la práctica de la enfermería en Salud Mental a usuarios y familiares.*

***Descriptores:*** *Familia. Salud mental. Servicios de salud mental. Enfermería.*
***Título:*** *El tipo vivido de familiares de usuarios de un centro de atención psicosocial infantil.*

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## INTRODUCTION

Mental health care has been through significant transformations since the Psychiatric Reform that guided the confining care model with psychosocial features for the purpose of understanding the health-sickness process, parting from socio-cultural and psychic determination and considering conflicts and contradictions within individuals, as well as taking horizontal actions in order to organize intra-institutional relations[1].

Moreover, psychosocial care means that if reality is constructed, it can also be transformed based on ethical and therapeutic actions to enable citizenship and the power of social negotiating features to individuals suffering from psychiatric disorders[2].

This new mental health care model enabled the implementation of substitute services. One of these services is the Psychosocial Care Centers (CAPS as per its acronym in Portuguese), also comprised of the Child Psychosocial Care Centers (CAPSi as per its acronym in Portuguese).

These deinstitutionalizing services assist in reinserting individuals suffering from a psychiatric disorder back into society, providing comprehensive care to the mentally ill with a view to avoiding confinement.

CAPS facilities may be considered mental health facilities that fall under Regulation 336/2002[3]. These centers are characterized by clinical services providing intensive, semi-intensive and non-intensive care, supported by an articulated multidisciplinary team with the objective to enable the psychosocial rehabilitation of clients[4].

Within the mental health care substitute services network, therapy is continuous and all psychiatric disorders manifested by clients are observed and incorporated into the therapeutic process. In CAPS, communication channels among clients, family members and the multidisciplinary team are always open[5].

Within this context, family members are invited to take part in CAPS clients' therapeutic projects, with a view to contributing to the care, and receive professional care from a multidisciplinary team within this service.

In this present study, family members were considered as the people who take care of the clients, whether they are mothers, fathers, grandparents or other family members (with or without blood ties) who live with the child or adolescent undergoing care, and are responsible for their treatment in the service and for the social environment and care provided at home.

Hence, we feel the need to understand what motivates family members to look for substitute services for mental health care and what is expected from the care provided in these locations, always observing that mental health care is provided differently following Psychiatric Reform, encouraging the clients' psychosocial rehabilitation and the insertion of the family.

This present study features the characteristics of families who seek care from CAPSi and the nature of their expectations regarding the care offered by these services; in other words, the study was intended to reveal how these family members react within the social environment when dealing with the researched phenomenon.

The experiences lived by these families was considered important, since they face a large number of uncertainties while caring for these clients throughout the mental health-sickness process. This may help to establish an understanding of the care required not only by the clients, but also the family-client dyad.

This present study becomes relevant in assisting mental health teams, especially nurses, in reflecting about the way they develop their practices and the possible restructurings needed to provide quality care to CAPSi clients and their family members.

In this context, nurses might be the ideal professionals to implement unique therapeutic projects with CAPSi clients, using Nursing Care Systematization to develop practice tools in mental health care, guiding their actions according to the experience lived by the family members of clients of the service.

Therefore, the objective of this study was to understand the experience lived by family members of clients receiving care in a Child Psychosocial Care Center.

## METHODOLOGY

This research was a result of a doctoral degree thesis[6]. It was performed from a phenomenological approach, consisting of a qualitative study developed in a Child Psychosocial Care Center in the municipality of Cascavel, in the State of Paraná.

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Information were collected through semi-structured interviews, after the approval of the study by the Research and Ethics Committee of Assis Gurgacz College, under Statement 542010 and according to Resolution 196/96 of the National Council of Health of the Department of Health[7]. Inclusion criteria included being the family member who is most responsible for the care of the CAPSi client, and the exclusion criteria excluded family members who had no responsibility in caring for the CAPSi client.

For data collection, a phenomenological interview was performed with the following guiding questions: "What drove you to seek care for your family member in CAPSi?" and "What do you expect of the care delivered to your family member in CAPSi?" Interviews were booked at times convenient for the subjects, were recorded by digital recorder, and were fully transcribed afterwards.

Statements were identified by letters according to the order in which the interviews were performed in order to preserve the individuals' privacy.

To understand the gathered information, the phenomenological method for building concrete categories[8] was used, with a view to revealing the motivations expressed by CAPSi clients' family members and to build the experience lived by the interviewed group.

Throughout the process, a sequential, detailed and exhaustive reading of the statements was performed with a view to finding meaningful units. Reading of meaningful units, grouped by convergence, was then performed to form concrete categories expressing the experiences lived by these individuals. When categories were being formed, those expressing reasons for actions – *reasons why* (reason for the action) and the *reasons for* (expectations of the action) were identified. Analysis of the categories in building the experience lived by CAPSi clients' family members was based on the Alfred Schütz' philosophical -methodological reference (social phenomenology)[9;10].

## RESULTS AND DISCUSSION

Family members who were responsible for caring for the client the majority of the time were the subjects of this study. They comprised a group of eight mothers, two grandmothers and one sister-in-law.

Throughout the construction of the experience lived by these individuals, five categories were identified, which were then grouped into two axes: the identification of family members' *reasons why they sought care from* CAPSi; and the identification of *reasons for* regarding the CAPSi service (expectations of actions).

### The identification of family members' *reasons why* they sought care from CAPSi

In the concrete category **experiencing clients' behavior**, changes in the CAPSi clients' behavior affected intra-family relationships and relationships with other individuals in society.

> *It's because we noticed her behavior was not normal anymore [...] she didn't want to study, didn't eat, she lost weight, and [...] started becoming agitated, started fighting, seeing things that were not there. That's when we took her to the psychologist (c).*

> *...and he started by telling us he had no motivation to live, no reason to live anymore, that he felt liking killing himself sometimes, even stated how he might do it [...] (d).*

> *...yes [...] during one of these nervous episodes, he mentioned suicide, he wanted to kill himself [...] (e).*

> *[...] since he has learning disabilities, he can't keep up at school and his friends mocked him in the classroom [...] then he started becoming aggressive and violent [...] (h).*

All *reasons why* are related to previous experiences that determined the individuals' actions, characterized by the projection of an already-concluded action[9].

Therefore, *reasons why* are related to prior events, environments or the psychiatric condition of the actor; in other words, determined by past events comprising an objective category[10].

Evaluations performed with children and adolescents with psychiatric disorders, aided by information provided in family reports, demonstrated the clients' behaviors considered to be criteria for the diagnosis of a mental health disorder, including irritability, disobedience, nervousness, impulsiveness, restlessness, shyness, apathy, upsetting and abnormal behaviors[11], agitation, and aggressiveness[11;12], in addition to theft.

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Therefore, we observed that family members in this study referred to aggressive behavior and suicidal ideation as situations that drove them to seek help from CAPSi. This characterization is evidence that service professionals need to be able to deal appropriately with family members and the individuals who experience these events.

In the category **referring to other services**, aspects leading to the search for specialized care for the individuals with a psychiatric disorder were discussed. Family members reported many institutions where clients had contact with CAPSi, including the school, Child Protective Services and Basic Health Units, among others, who forwarded them to mental health substitute services.

> *[...] Child Protective Services, through a court order, referred him to CAPSi [...] (b).*

> *[...] we were referred by the health unit. They referred us because of his disorder (d).*

> *[...] I talked to the pediatrician and he thought it best to refer him to CAPSi (e).*

> *The school referred us. [...] once he had a serious fight there with another schoolboy, they asked for him to be referred [...] (f).*

The *reasons why* mention past experiences. Therefore, we can say that the *reasons why* an action occurs are only accessible when they become an action; in other words, when they have already been performed[9].

Hence, CAPSi clients' family members disclosed what led them to seek care or to be referred from other services. This was possible due to an action that was performed in the past and can only be observed and explained by those individuals, in addition to being interpreted by social investigators.

Regarding clients referred to the service, CAPS is articulated with the individual psychiatric disorder care network, as well as with family, friends, and others interested in mental health care.

In this context, a clinical-institutional program may be enhanced with services provided outside its facilities, including other services of a clinical nature and non-clinical social agencies, which, by being involved in the lives of these young individuals can be thought of as borders surrounding its territory[13].

As in other studies[12] demonstrating CAPSi referral formats, in this present study social institutions such as health care services, schools and child and adolescent protection services have somehow mediated access to CAPSi, serving as important social support network points.

### The identification of *reasons for* regarding CAPSi care

*Reasons for* are those that "imply objectives to reach, and the means to achieve them; they regard a future time and compose a subjective category, since the social actor involved in its action, understood as part of the ongoing project process, defines and interprets his actions in terms of *reasons for*. In this way, the subjective category refers to the relationship the action has with the actor's conscience, not relating to introspective notions, psychological conditions or private attitudes"[10:26].

Therefore, *the reason for* means a state of things, or a purpose for which the action was performed; in other words, *reasons for a purpose.* In the actor's point of view, this class of reasons relates to his future[9].

In the concrete category **waiting for the client's treatment**, some aspects of *reasons for* were demonstrated through the expectations of family members regarding the care provided to clients by CAPSi. The individual is expected to recover or adjust to the psychiatric disorder.

Also, some might expect them to become "normal" again. This is due to a lack of knowledge about mental disorder symptoms and their course, which led family members to unconsciously reject the idea that there is no cure[14].

> *[...] so he can be treated and recover from this, become a normal child again, the way he was before (d).*

> *At least he is going there and is receiving the necessary treatment and psychological, therapeutic support, workshops [...] (f).*

> *We try to go through all the treatment so that, in case he really is affected, he can adjust and learn to control his hyperactivity (g).*

In this context, we were able to observe that CAPSi clients' treatment is characterized, according to family members' statements, as an objective,

or a target to be achieved; in other words, *reasons for* regards the search for care in that service.

Regarding CAPS care service, clients and family members may expect treatment provided by a multidisciplinary team and supported by an individual therapeutic plan built based on the needs presented by clients and their families.

CAPS were developed to provide primary care to patients with severe and persistent psychiatric disorders, employing treatment alternatives supported by an individualized therapeutic plan [15]. Moreover, comprehensive care and the defense of individuals' citizenship rights are conceptual strategies sustaining this care model of mental health[16].

In the concrete category hoping **for improvement in the client's medical profile,** *reasons for* were also found in relation to CAPSi care provided to clients. In this way, family members express hope that the individual suffering from a psychiatric disorder will get better, learn to deal with the disorder and behave appropriately in different social situations, stating this wish as a subjective category of the experience they are going through.

> *The cure [...] there is no cure, because depression has no cure; there are ups and downs, but at least he can learn how to deal with the disorder he has, and so can we (b).*

> *So that this treatment, both the medication that was prescribed by doctors and the occupational therapy and the psychological follow up he has there, that all this can really help him to find something he likes [...] (d).*

> *I hope he can cope better with these nervous moments he has [...] so that he is not so explosive in difficult times (e).*

> *It's so good, I wish he could go every day [...] he improved a lot every day, I hope he'll get well (j).*

> *I kind of hoped he would get better, right? (k)*

Family members reported expectations of improvement in the clients' medical condition as an outcome of the biological and psychosocial mental disorder treatment they receive, mentioning obstacles to adjusting to the disorder and interactions with others. Moreover, they have not discarded the possibility that the client might be cured of the mental disorder.

This possibility is demonstrated as *reasons for;* in other words, it is one of the expectations that family members have regarding improvement in the CAPSi clients' medical condition.

Therefore, "meanings attributed by family members to results from the team work are characterized by the stabilization of the psychiatric symptoms experienced by their family member-client, even when this stabilization is referred to as *curing* and *controlling*"[17:398].

In the category **experiencing service support of family members**, *reasons for* are related to the support provided by the multidisciplinary team to family members, which happens, according to some participants, only when they seek help or when there is an invitation from the service to take part in some type of activity. However, some family members report the following:

> *A few days ago I went to the psychologist for the first time, and I honestly didn't like the service. The second time we went, we talked to the occupational therapist, and this service I liked, I found it very useful (e).*

> *[...] I think CAPSi is very important [...] mothers who need it should search for it. I think that [...] it is a very good service for us. When he misses an appointment, dear God! (h).*

> *They gave me support when I went there and took part in many activities; they guided us very well (j).*

On the other hand, some family members reported a lack of appropriate care regarding the clients' treatment, psychological support and guidelines regarding the disorder. They reported that they wanted more contact with the multidisciplinary team, with a view to understanding intra-family relationships and the clients' behavior at home, believing that it aids individual care and promotes a more harmonic family atmosphere.

> *I think I must talk to them about the medication she is taking and they must hear from me about her behavior at home [...] (c).*

> *So if there was a [...] I think it is part of. [...] How can I say the word [...] a service provided for the family too, a service [...] (d).*

> *[...] they call us sometimes. This week they called me to invite me for an appointment, in case I wanted to go there and talk. There was going to be a lecture, that type of thing [...]. But if not that [...]. Apart from that, nothing else (k).*

*That's my only complaint, you don't know if you don't ask!!! They are all fine people [...], but it's like that, if you ask, ok, and if you don't ask, it's ok too (i).*

In this category, family members expressed a need for a face- to-face relationship[9], a direct relationship with CAPSi health team professionals, in order that their experiences might be more intimately known and so that they can truly support clients' experiences and expressed needs.

In the psychosocial care model, a participating family member is necessary, determining the scope of the institutional action itself[18]. However, some family members' speeches are corroborated by research results revealing that mental health practices in substitute services, compared to confinement models, are often based on common sense knowledge and the theoretical knowledge supported by the hospital-centered model[19].

For example, the hospital-centered model ignores the multidisciplinary work that includes the family as the primary care unit of its patients and, therefore, sources of important information for the clients' unique therapeutic plans. In addition, they are subjected to mental health care, since they require guidance regarding the mental health-sickness process and the treatment offered to clients of this service.

Moreover it is important to point out that the therapeutic planning process must involve both the individuals with psychiatric disorders and their families, considering their biographic and social situations[20].

## FINAL CONSIDERATIONS

This present study enabled an understanding of the experience lived by Child Psychosocial Care Center clients' family members, who constitute a group of people with unique characteristics. This understanding was reached from the description of social behaviors that convergence with the individuals' intentions.

Therefore, the experience lived by CAPSi clients' family members was built from five concrete categories emerging from *reasons why* and *reasons for*, demonstrated in family members' statements; these are the individuals who experience the client's behavior; accept referrals from other services; wait for treatment; hope for improvement in the medical condition and experience the service support of family members.

The search for CAPSi services by child and adolescent family members occurred due to their experience in situations involving clients' altered behaviors in their social environments, and also as a result of referral from professionals, institutions and diversified services such as schools, Child Protection Services, and the Basic Health Units.

When family members search for care in CAPSi, they seek treatment for their family member-clients, with a view to improving their medical condition, decreasing symptoms and improving social interactions.

Moreover, family members seek professional support so they can understand the situation experienced, acknowledging the mental disorder as well as contributing to clients' treatment, obtaining clear information about their behavior and improving relationships with other family members.

Mental health nursing professionals may encourage this support, helping family members to implement the therapeutic plan for clients and identifying families' needs regarding how to deal with individuals suffering from a psychiatric disorder at home. In addition, nurses also may institute mental health preventive care aimed at clients' family members.

Finally, this present research points out new study foci, such as those involving nursing professionals, clients and family members, which may contribute to mental health nursing care, focusing on mental health substitute services under the social phenomenology perspective and clients' expectations regarding the care received, as well as the motivation of the multidisciplinary team regarding this service.

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