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FAMILY CARE FOR CHILDREN EXPERIECING PSYCHIC SUFFERING: HEALTH PROMOTION ROUTINES

Gisele Cristina Manfrini Fernandes*
Merlange JN Baptiste**
Rosane Gonçalves Nitscke***
Ivonete Teresinha Schulter Buss Heidemann****
Lilian Pagliuca*****
Carolina Gabriele Gomes da Rocha******

ABSTRACT

The objective of this study was to know the care actions for health promotion developed by families with children with mental disorders assisted daily in a Psychosocial Care Center for Children and Adolescents. Exploratory, descriptive and qualitative study carried out with five family caregivers of schoolchildren assisted at a Psychosocial Care Center for Children and Adolescents. The study included observation of the group of caregivers of the service and semi-structured interviews with the mothers. Content analysis was adopted for data analysis, giving rise to four categories: The care provided by families to children in the face of difficulties; Strategies to promote child and family health in daily life; Family routines of care for children experiencing psychic suffering; Social support for families providing care for children in times of crisis. The results revealed that the families do not feel prepared to care for children experiencing psychic suffering, but when faced with this situation, they developed actions and strategies of care to cope with daily challenges. We conclude that caring for a family member experiencing psychic suffering requires a new organization of the family routine and acquisition of new strategies to face the difficulties that emerge in daily life.

Keywords: Mental health. Family Health. Health promotion. Nursing. Daily Activities.

INTRODUCTION

The family environment is considered the first place of socialization of children because it is within the family that persons acquire the conception of themselves, develop their beliefs and values about the world and prepare to face life[1]. The family can be considered a tangle of deep social and affective relationships that connect the lives of the people involved, sharing beliefs, experiences, and understanding the world in a unique way[2].

The family is fundamental when one of its members is in psychic distress. The family is co-responsible with health professionals, since the planning to the implementation of care actions[3]. As a care system that produces health and unity for its members, the family aims at care actions to improve the well-being, provide adequate living conditions and favor the development of the potential of each individual and of the group[2,4]. It is important to emphasize that promoting family health has implications related to the right of comprehensive health care for the healthy growth and development of children. However, care for the mental health of children is still a challenge in the daily routine of health care services, and in cases of psychic suffering, these challenges are extended to family care.

According to the international literature, the average prevalence of mental disorders is approximately 15.8% in children and adolescents in general; approximately 10.2% among preschool children; and 16.5% among adolescents. In Brazil, studies have shown prevalence rates from seven to 12.7%. According to estimates, one of among four to five children and adolescents in the world presents a mental disorder[5].

In Brazil, the Psychosocial Care Centers for Children and Adolescents (CAPSi) are services specialized for the care of children and adolescents (up to 18 years of age) with severe mental disorders and are characterized as one of the points of the Psychosocial Care Network (PSCN) of Unified Health

*Nurse. Doctor in Nursing, Teacher from the Department of Nursing at the Federal University of Santa Catarina. Florianópolis, SC, Brazil. E-mail: gisele.manfrini@ufsc.br
**Nurse. Master Student from the Professional Master Course in Mental Health and Psychosocial Care at the Department of Public Health, Federal University of Santa Catarina. Florianópolis, SC, Brazil. E-mail: merlux.j@gmail.com
***Nurse. Doctor in Nursing, Teacher from the Department of Nursing and Graduate Program in Nursing at the Federal University of Santa Catarina. Florianópolis, SC, Brazil. E-mail: rosanenitschke@gmail.com
****Nurse. Doctor in Nursing, Teacher from the Department of Nursing and Graduate Program in Nursing at the Federal University of Santa Catarina. Florianópolis, SC, Brazil. E-mail: ivonete.heideman@ufsc.br
*****Nurse. Master in Nursing, Municipal Secretariat of Health. Florianópolis, SC, Brazil. E-mail: lilianpagliuca@hotmail.com
******Nurse. Master Student from the Graduate Program in Nursing at the Federal University of Santa Catarina. Florianópolis, SC, Brazil. E-mail: carolinagabriele.r@gmail.com

System (SUS). The Psychosocial Care Network is part of the Line for Comprehensive Health Care for Children, Adolescents and Their Families in Situation of Violence in several points of attention as they receive cases and continue the care and/or follow-up in the network according to its demands[6]. The treatment of children in psychic suffering in the CAPSi is done in partnership with families, who are co-responsible for the care of their family members[6]. Families with a member experiencing psychic suffering goes through significant changes in their structure, such as changes in routine, habits and customs, as they adapt to this new situation in their daily lives[3].

It is understood that there is a singularity in the way people live in their families, expressed by their interactions, beliefs, values, symbols, meanings, images and imaginery, factors that outline their process of living in the movement between being healthy or ill, and their life cycle[7]. This journey through the life cycle has a certain cadence that characterizes the way of living, influenced by both the duty of being, and the needs and desires of everyday life, which is called the rhythm of life and living[7].

In this sense, the guiding question of this study was: How do families of schoolchildren experiencing psychic suffering and assisted in the daily routine of a CAPSi carry out health promotion actions in their daily life? Thus, the outlined goal was to know the care actions to promote health developed by families with children experiencing psychic suffering assisted in a CAPSi.

METHODOLOGY

This is a qualitative, exploratory and descriptive research. The research site was the Psychosocial Care Centers for Children and Adolescents (CAPSi) of a capital city in southern Brazil. The CAPSi is a service of the Municipal Health Network that provides care for children and adolescents between the ages of 3 and 18 years. This service was created by the Ministry of Health through decree nº 1947/2003 and implemented in 2004. It offers outpatient psychosocial support in the form of individual care, family therapy, individual psychotherapy and therapeutic workshops, through follow up with professionals of nursing, social work, psychology, neurology, psychiatry and nursing technicians, with a total of 12 professionals. During the period of the survey, the CAPSi provided care for a total of 208 children. Considering the average of four people per household, approximately 832 users were assisted.

The study participants consisted of five families, represented by biological mothers, fathers and grandparents. The inclusion criteria were: family caregivers of schoolchildren under the age of 13; from the household space; participants in the Therapeutic Workshops of Caregivers and/or who were present in consultations in the CAPSi. At first, it was estimated that 10 family members should be included in the study. However, among the eight participants in the Therapeutic Workshops, five family members were enrolled in the study. These respondents were linked to children aged 8 to 12 years.

Data collection took place during the months of April to July 2016 in the CAPSi through the use of semi-structured interview techniques recorded on digital media and later transcribed, as well as participant observation during the Therapeutic Workshops of Caregivers carried out in weekly basis, in which the families of children were present, being mediated by nurses. The observations were recorded in field diaries and were used to contextualize the data produced in the interviews.

The analysis of data was based on the Bardin's content analysis method[8], including the steps: pre-analysis, analytical description, interpretation and inference.

Pre-analysis consisted in choosing the documents to be analyzed. In this way, the recorded interviews were first transcribed verbatim, and then the material collected was read and re-read and the data was organized. These documents included the speeches of the interviewees collected in the research field, as well as the duration, time and place of the interview. After the exhaustive reading of the transcribed material, the central ideas of the matter in question were captured. The central themes were formed based on the main sense of the questions asked by the researchers. Four categories emerged in this analysis. In a third moment, the data were interpreted and inferences were developed based on the construction of the four central themes that were analyzed and discussed in the light of the literature on Health Promotion and Family Care.

The research was approved by the Committee of Ethics in Research with Human Beings of the Federal University of Santa Catarina (CEPSH/UFSC) under Opinion nº 1,538,931.

RESULTS

Characterization of families and children assisted at the CAPSi

The families of schoolchildren assisted at the CAPSi have diversified and complex structures. Regarding the family members interviewees, the data showed a predominance of females represented by mothers and grandmothers, but there was one biological father among the participants. Regarding the sufficiency of income, two family members reported having enough to cover their daily needs.

The hildren followed up at the CAPSi whose families shared in this study were aged between eight and 12 years. The time of follow-up of these children in the service ranged from six to 18 months. They were received through referrals from primary care, tertiary care and/or school institutions. The type of follow-up and care received in the CAPSi varies according to the demands of each individual, from the construction of a Unique Therapeutic Project (UTP) that comprises a multiprofessional and family approach.

The following are the four categories that resulted from the analysis: The care provided by families to children in the face of difficulties; Strategies to promote child and family health in daily life; Family routines of care for children experiencing psychic suffering; Social support for families providing care for children in times of crisis.

Difficulties of families in the care for children experiencing psychic suffering

One of the central difficulties revealed by families is not to know how to deal with a child who has a mental disorder, especially when it comes to aggressive behavior or agitation. It is noticed that when the parents mention the preoccupation with the psychic suffering of their children, especially with relations in other social spaces, they demonstrate their suffering also. Although behaviors or possibilities of help/support to handle the problem were mentioned, the speeches did not identify an efficient support from the school, teachers and other relatives. This denotes the difficulty of others in dealing with mental disorders.

> It's complicated; we often don't know what to do. The school calls me a lot, they demand from me a lot, because he is extremely aggressive and the parents complain that he attacks the other kids. Now he also attacks the teachers and this is making me very worried (F2).

Families go through varied therapeutic itineraries in search of help to deal with their children, seeking to attend to referrals to different professionals or specialists, homeopathy and allopathy, as well as other popular and cultural care measures such as access to healing rituals and prayers. These are important resources for the management of mental disorders.

> In has one year that we were here at CAPSi, but before that, I was going after at the neurologist, pediatricians and many people said: - "put him to practice sports, he needs to use this energy" - then I would go there and do it, but two weeks later the teacher said; "it is enough! He disturbs the class. Maybe one year from now, when he is calmer"; - but he's never calmer [...] it's complicated. I've been told to take him to everything, to healing rituals, to leave him to the church, to try homeopathy, I take him. Who knows that helps? We're always trying, trying, running after (F2).

In the same way, it is perceived that there is a constant demand for health services and for the elaboration of adequate strategies for coping with the difficulties encountered in the care of children experiencing psychic distress. Caring for these persons is complex, as there are many doubts, concerns and the need to deal with everyday behavior.

In this context, families seek the help of health professionals, and the CAPSi is an important reference. The CAPSi is mentioned as a place where both families and children learn to understand and mediate difficulties, clarify doubts and act before difficult behaviors such as irritability and aggression.

> What we do is to bring him here to the CAPSi. Here we learn a lot about how to deal with her, [...] how to address her questions. The difficulties are a bit different from a normal child [...]. We make her think more, now she started to realize that her classmates may mock her, they can laugh at her attitude. What we have learned is that if she gets nervous, that will not solve anything, insisting or quarreling won't help [...]. So we try to calm her down, first, let her calm down, and then go and I talk with her (F4).

Understanding and coping with the difficulties of children requires families to recognize their own difficulties in carrying out this role. Being open to change is essential, either regarding the way of talking to the children or in choosing the best moment to solve some situations. In this sense, the sharing of experiences of other families is beneficial, as well as the exchange of knowledge and practices with health professionals, in order to qualify the look and approach to children experiencing psychic distress.

Strategies to promote child and family health in daily life

One of the strategies most used by families to promote health and well-being is to provide leisure time, such as walks in the beach and the park, and going to places that provide leisure in different ways, through the contemplation of nature and interaction with the family.

Another strategy identified as a health promoter by families are family gatherings on weekends, for lunch and for sharing moments. These actions stimulate the children's social interaction with other family members. In addition, knowing new places and valuing the nature are important resources for children experiencing psychic suffering. Parents seek to awaken in children a sense of responsibility and care for things, animals, as well as people.

> In summer, we stay at the beach house. My mother lives in another neighborhood and we go there on weekends for lunch [...]. We walk a lot with him, go hiking, we visit the project of preservation of the sea turtles. I tried to have a pet so he had that contact with care, responsibility too [...] he would give food and water to the pet. We have a home garden and he helps planting something (F2).

> I take him for a walk on some beaches. He loves it! I encourage and make him value small things. I think the good of life, the happiness of life is in the little things. And I'm trying to pass this on to him [...] we always seek to bring him closer to nature (F5).

For other families, socialization is the key to promoting children's mental health. It is imperative to bring the children in the CAPSi for psychic care, especially to workshops where they meet other children, becoming colleagues and friends. The Therapeutic Workshops provide moments to play together, to make art, helping to overcome the difficulties related to social interaction, as well as participation in theatrical and religious activities, as expressed in the following speech.

> Today she comes to the CAPSi on Mondays and Tuesdays [...] on Tuesdays and Thursdays after school in our neighborhood she has theater and she participates on it, and on Friday she does evangelism [...] We look for these things to change her environment and have more relationships with other children, to socialize (F4

Considering the psychosocial condition of the children, socialization was evidenced as a strategy of becoming closer to others, knowing, interacting, playing and learning. Therefore, socialization makes it possible to exchange knowledge, experiences and to leave the state of isolation.

Family routines of care for children experiencing psychic suffering

The daily care routines of the families of children experiencing psychic suffering are extensive and complex. Besides household chores and work commitments, which are part of the daily life of the family, there is the school routine of the children and weekly consultations to follow up the health/disease process, not to mention the distance between the home, school and work places, implying a considerable time-consuming displacement, outlining the rhythm of living.

> My life is such a rush now [...] I take her to school and I come to the service, or I have to take her to the speech therapist here and then go to the work [...] I leave from work to pick her up at school and go home [...]. On days when I'm very tired I'll come home, take my shower, I shower her, and we eat something [...]. I lie with her to watch television. She sleeps fast [...]. The next day is the same, everything is very fast (F1)..

The routines change according to the moment they experience. Several situations can bring changes to the family. In the face of events, changes can be positive and bring about something good that promotes health, or not. Some families report the stress present in their routines and the transformations that take place for them to cope with mental disorders.

> Sometimes, when I feel too much stressed I do not clean the house, I go and spend time with my mother, I drink coffee, I go to the beach to walk, to fish, because I love to walk on the beach, you know?(F1)

Families are responsible for educating and teaching children through daily routines; this is not an easy task. One interviewee reported that she established rules in the child's educational process regarding body hygiene, house cleaning and other tasks. On the other hand, families express the difficulties encountered even to make or encourage the children to make simple activities such as dressing. The interviewees faced challenges on a daily basis and needed to stimulate their children through different strategies.

> I have a rule, she gets up in the morning, she has to make her bed, brush her teeth, straighten her hair [...] she goes watching television. I ask her, have you made that bed already? Go do it! Then she goes there and does it in anyway, and I ask her to go there and make the bed well [...]. Have you brushed your teeth? You did not brush your teeth, you go to the bathroom. She

> lies a lot, then she brushes her teeth, the hair she does not do, I have to do it (F1).

Family routines are built giving priority to the needs of children. This often requires much effort from parents; it is essential to seek the support of others in the group.

> Since I work at night and stay home during the day, I can be with him in the morning. In the afternoon he goes to school and at night some days he stays with my mother, on other days with my mother-in-law, or he goes with me to work [...]. Because he demands a lot from us [...] because I always have to be in the school and, twice a week, I have to come here and it's far for us, but it's ok, we can do it (F2).

Other families make reference to a care routine throughout the day, setting times for meals, medications, hygiene and games. At the same time, they report the difficulties encountered in dealing with the children's behavior in daily activities.

> Ah yes! At mealtime he has to stop to eat; we have these routines at bath time, I have to be with him always. Go to class, eat at the right time [...] it is difficult, [...]. He gets dispersed, sometimes he does not stay focused [...]. You know, it's complicated because I don't know how to help; you have to be patient (F3).

It is noted in some cases that the care routine is exhausting, especially when the children present aggressive behaviors, difficult to deal with. Such cases demand patience from the caregivers.

Social support at the time of crisis

The family not always knows how to deal with the suffering of the child. In such cases, families need help and assistance, especially in situations of crisis. They use various social resources as support, since conversations with close people, to professional follow up such as psychotherapy. Spirituality is present; especially when they do not know how to act, they pray for help.

> At the times of crisis, I keep holding on and I open up with my boss. On the day of the psychologist I tell her [...]. Sometimes you get with the thing hurting you, it hurts, you have to be strong [...] then I ask God for help, I kneel down and say - Lord I do not know how to do this, I do not know how to act, but Lord help me [...], you know, that brings me comfort (F1).

The family members outside the household also support those who care for children experiencing psychic distress when difficulties arise on a daily basis, often being the first strategy of embracement and listening. Health professionals are also sought in extreme situations of mental imbalance, and they help the family to cope with crises. Moreover, caregiving mothers, when faced with this problem, get in contact with the fathers as a reference of respect and authority for the child, which mediates the context based on dialogue.

> Usually, my mother is the first to help. Depending on the crisis, when things are very difficult, we ask for professional help. I call here {CAPSi} to see what we can do, we advance the consultation (F2).

> His father, because he's the only person who { name of the child} respects; if I'm on the street, I'll get him a phone call, [...] he hears what the father is saying, asking him to stop or he'll take the bus and come. Then he gets better (F5).

The mother is a reference in family care. Mothers are the ones who dispose more time for children and their demands. Mothers are the ones who often suffer the most with the problems faced every day. These women take care of children in partnership with health services and need support to overcome physical, emotional and psychic distress.

DISCUSSION

It was identified that the families of schoolchildren with psychic suffering face this situation with many difficulties, but they seek health care in their routines with the support of CAPSi professionals. Caring for these families is complex, with the need to face unknown situations and face challenges in their daily lives. As they do not know how to act, these families need to reorganize their structure, seek help and develop strategies for the affective and effective care of children. In this sense, the importance of an expanded view of teamwork stands out, as well as the importance of the care provided by the interdisciplinary team, promoting health by rescuing the autonomy of individuals involved in the treatment, especially the family[9].

The care provided by families to children experiencing psychic suffering becomes a daily need to deal with unpredictable behaviors in the process of psychic suffering. It consists of the constant urgency to seek actions and strategies that can improve the behavior of children[3,10]. Caring for a child with psychic distress is not an easy task, since it requires the care of family members with patience, dedication, financial efforts and time, openness to modify their

routine and introduce something new whenever needed.

Care in psychic suffering is complex and many doubts may arise from parents or other family members involved. There is also concern for the future and the need to deal with the children's behaviors in their daily lives. Relatives who live and care more directly for the children experiencing psychic suffering deprive themselves of their own life so as to provide adequate care; thus, they wear down and suffer physical and emotional overload[3,10].

On the other hand, families make it clear that it takes positive thinking to believe in their children's improvement, to accept the unexpected events and to seek strategies to deal with them. Thus, despite of having to deal with suffering, there is a movement towards healthy life, despite the situation of illness. This movement is identified in the small acts of daily life, such as contemplation of nature and good moments lived in the family. Another study corroborates the concern of mothers caring for children with mental disorders about the future of their children, and how the children will carry on in their absence. They also mention that they look for positive feelings in the perspective of coping with difficulties[11].

Thus, families show a way of living and interacting permeated by values where the small things of daily life are appreciated, signaling the re-enchantment of life and the world[12]. In this sense, happiness intertwined with health and promotion of a healthy life stand out. The current National Policy for Health Promotion (PNPS) has happiness as its fundamental value of implementation, which is understood as self-perception of socially constructed satisfaction, contributing for individuals to decide how to enjoy their life in the best way, in their participation/construction of projects that intervene or assist in overcoming and recognizing their difficulties and potentialities[13].

It is important to highlight the importance of leisure, pleasure, relaxation and nature to promote healthy individuals and families. Relaxation refers to the respiratory movement that oxygenates the life and the living together of people and families. Small pauses, great reinforcements, is an expression that emerged when creating spaces of care for individuals and families to reflect on their daily life and reflect about caring for self and for others to promote health[14].

In this study, the means used by families are: going to the beach, walking, taking the children to know something new, walking in natural areas, going hiking, and taking the children to the park. The literature draws attention to the connection of human beings with nature, with a naturalization of culture and a culturalization of nature, in contemporaneity[12]. Families also already have this clear as a possibility to promote healthy people and families.

Enabling and encouraging the children to share in theater, in the church and other spaces where they can meet new people, and in workshops conducted in the therapeutic space; hygiene care; meeting with family members for lunch, and eating at the right time were mentioned as strategies for routine care for children that promote healthy development and psychosocial well-being. Studies have pointed to the benefits of regular family meals for the children's physical and emotional health[15,16]. The consistency of daily household routines such as mealtime and bedtime brings regularity and is a protective factor against the development of aggressive, oppositional or disruptive behaviors in children[16].

To promote the well-being of children in the daily life and maintain a healthy lifestyle, families establish daily care routines. Routines are, therefore, organizers of family life. In other words, it is through the routine structures that the day-to-day care actions of the families take place and are established.

The activities performed by the families in their daily routines are varied and promote health in different ways. Those relating to food and hygiene, for example, help not only the biological maturation of the body, but also enable well-being, by facilitating social interactions and promoting health in general[17].

Leisure, recreation and social activities, such as games are extremely important because they promote reflective knowledge. These activities provide children with freedom, propagation of emotions and thoughts, as well as a space for interaction with self and with others. The importance of encouraging being together and feeling or an ethic of aesthetics that nourishes the power is evident, the strength that comes from within each one[12], translating into an empowerment of these families for the promotion of their own health and the health of the children[18].

Families are allies, partners of health professionals in the process of care and integration of children into society. However, these families, translated into bonds of affection, go through difficult times and need support to deal with these situations that unfold in everyday life. These difficulties include emotional overload, work overload and excessive activities,

constant contemporary challenges such as busy schedules and urban immobility which shrink and absorb their available time in the age of anxiety. The families need to be embraced, heard and supported; it is necessary to separate time for the self and for the other. In the daily life, the families of the children experiencing psychic suffering provide care, but they also need to be cared for[2,7,14].

FINAL CONSIDERATIONS

This research allowed knowing the care actions of families of schoolchildren experiencing psychic distress assisted at the daily work routine of a CAPSi for the promotion of health in their daily routines.

The routine of the families of children with psychic suffering involves concerns and difficulties, and daily strategies to promote well-being and care for them. It is therefore understood that the relatives develop actions to assist them in biological maturation and in the encouragement of a sense of responsibility, as well as care actions to promote their health in general.

The family's ability to cope with and adapt to such a situation directly influences the children's ability to deal with the disease. It is important that health professionals working in this area, especially nurses, be aware of the difficulties encountered by families in the care and be also able to provide them with care, offering support for coping and decision-making for the care of their children, strengthening relationships that produce health.

In the end of this trajectory, it is hoped to contribute to the production of nursing knowledge in this area, since the focus is to take care of subjects and their families in a comprehensive manner, considering the human beings in their multidimensionality and complexity. It is important to emphasize the need for this theme to be addressed in future studies, as well as the position of the caregiving family before schools and institutions attended by their children so as to defend their right to dignity, when this right is not respected.

CUIDADO FAMILIAR A CRIANÇAS EM SOFRIMENTO PSÍQUICO: ROTINAS PARA PROMOÇÃO DA SAÚDE

RESUMO

Objetivou-se conhecer as ações de cuidado para promoção da saúde desenvolvidas por famílias com crianças em sofrimento psíquico, atendidas no cotidiano de um Centro de Atenção Psicossocial Infantojuvenil. Pesquisa exploratória, descritiva, de abordagem qualitativa, realizada com cinco familiares cuidadores de crianças em idade escolar, atendidas em um Centro de Atenção psicossocial infantojuvenil, por meio de observação ao grupo de cuidadores do serviço e de entrevista semiestruturada com as mães das crianças. Adotou-se a análise de conteúdo, da qual emergiram quatro categorias: O cuidado das famílias às crianças frente suas dificuldades; Estratégias para promover a saúde da criança e da família no cotidiano; Rotinas familiares de cuidado às crianças em sofrimento psíquico; Apoio social destinado às famílias no cuidado da criança em momento de crise. Os resultados revelaram que as famílias não se sentem preparadas para cuidar de crianças em sofrimento psíquico, mas ao se depararem com esta situação, desenvolveram ações e estratégias de cuidado para enfrentar os desafios diários. Conclui-se que cuidar de um familiar em sofrimento psíquico requer nova organização da rotina familiar e aquisição de novos estratagemas para enfrentar as dificuldades que emergem no cotidiano.

Palvras-chave: Saúde mental. Saúde da Família. Promoção da saúde. Enfermagem. Atividades Cotidianas.

CUIDADO FAMILIAR A NIÑOS EN SUFRIMIENTO PSÍQUICO: RUTINAS PARA LA PROMOCIÓN DE LA SALUD

RESUMEN

El objetivo fue conocer las acciones de cuidado para la promoción de la salud desarrolladas por familias con niños en sufrimiento psíquico, atendidos en el cotidiano de un Centro de Atención Psicosocial Infantojuvenil. Investigación exploratoria, descriptiva, de abordaje cualitativo, realizada con cinco familiares cuidadores de niños en edad escolar, atendidos en un Centro de Atención psicosocial infantojuvenil, por medio de observación al grupo de cuidadores del servicio y de entrevista semiestructurada con las madres de los niños. Se utilizó el análisis de contenido, del cual surgieron cuatro categorías: El cuidado de las familias a los niños frente sus dificultades; Estrategias para promover la salud del niño y de la familia en el cotidiano; Rutinas familiares de cuidado a los niños en sufrimiento psíquico; Apoyo social destinado a las familias en el cuidado del niño en momento de crisis. Los resultados revelaron que las familias no se sienten preparadas para cuidar a niños en sufrimiento psíquico, pero al enfrentar esta situación, desarrollaron acciones y estrategias de cuidado para hacer frente a los desafíos diarios. Se concluye que cuidar a un familiar en sufrimiento psíquico requiere nueva organización de la rutina familiar y adquisición de nuevas planificaciones para enfrentar las dificultades que surgen en el cotidiano.

Palabras clave: Salud mental. Salud de la Familia. Promoción de la salud. Enfermería. Actividades Cotidianas.

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Corresponding author: Gisele Cristina Manfrini Fernandes. Rodovia Amaro Antônio Vieira, 2371, apto 818. CEP 88034-102. Bairro Itacorubi. Florianópolis, Santa Catarina, Brasil. E-mail: gisele.manfrini@ufsc.br

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