

Mental disorder in childhood: family structure and their social relations

Transtorno mental na infância: configurações familiares e suas relações sociais
Trastorno mental en la infancia: configuraciones familiares y sus relaciones sociales

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ABSTRACT

Objective: This study aimed to assess the social network and social support from the perspective of the family of a child with mental disorder. **Methods:** This is a descriptive, exploratory qualitative study with 14 families of children with mental disorders treated at CAPS-i Maringá - PR. Data collection took place from January to April 2013, through semi-structured interviews and construction of genograms and Eco maps of families. **Results:** Data were analyzed using content thematic analysis, creating two categories: "Network and social support: assisting the family living with a child with mental disorder" and "Family Structure: outlining linkages". **Conclusion:** The support network and social support are necessary to cope with the difficulties arising from mental illness, and it is the nurses' responsibility to know these sources of support and the types of bonds to provide family-centered care.

Keywords: Mental Health; Health of the child; Family; Social Support.

RESUMO

Objetivo: Este estudo teve como objetivo conhecer a rede social e o apoio social na perspectiva da família de criança com transtorno mental. **Métodos:** Foi uma pesquisa descritiva-exploratória de abordagem qualitativa, com 14 familiares de crianças com transtornos mentais atendidas no CAPS-i de Maringá - PR. A coleta de dados aconteceu de janeiro a abril de 2013, por meio de entrevistas semiestruturadas e construção de genogramas e ecomapas das famílias. **Resultados:** Os dados foram analisados a partir da Análise de Conteúdo, modalidade temática, originando duas categorias: "Rede e apoio social: auxiliando a convivência da família com a criança com transtorno mental" e "Configuração familiar: delineando vínculos". **Conclusão:** A rede de apoio e o apoio social são elementos necessários para o enfrentamento das dificuldades advindas da doença mental, cabendo ao enfermeiro conhecer essas fontes de apoio e os tipos de vínculos existentes para prestar um cuidado centrado na família.

Palavras-chave: Saúde mental; Saúde da criança; Família; Apoio social.

RESUMEN

Objetivo: Conocer la red y el apoyo social en la perspectiva de la familia de niños con trastorno mental. **Métodos:** Investigación descriptiva-exploratoria de abordaje cualitativo, con 14 familiares de niños con trastornos mentales atendidos en el CAPS-i de Maringá/PR. La recolección de datos ocurrió entre enero y abril de 2013, por medio de entrevistas semiestructuradas y construcción de genogramas y ecomapas de las familias. **Resultados:** Los datos fueron analizados a partir del Análisis de Contenido, modalidad temática, originando dos categorías: "Red y apoyo social: auxiliando la convivencia de la familia con el niño con trastorno mental" y "Configuración familiar: delineando vínculos". **Conclusión:** La red de apoyo y el apoyo social son elementos necesarios para el enfrentamiento de las dificultades advinidas de la enfermedad mental, compitiendo al enfermero conocer esas fuentes de apoyo y los tipos de vínculos existentes para prestar un cuidado centrado en la familia.

Palabras-clave: Salud Mental; Salud del Niño; Familia; Apoyo Social.

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Submitted on 02/05/2014.

Accepted on 08/28/2014.

DOI: 10.5935/1414-8145.20150015

INTRODUCTION

It is estimated that among the child population, 10% to 20% suffer from mental disorders and of that total, 3% to 4% require full mental health treatment¹.

In Brazil, the recognition by government authorities, that the mental health of children is a public health issue is recent, given that historically, the actions related to this issue have been delegated to educational and social care sectors.

Regarding the particular impacts of this problem, it is known that the establishment of a chronic condition in childhood interferes with the functioning of the child's body in the long term, limits daily activities, affects the growth and development and directly affects the daily lives of all family members who need assistance from health professionals².

In these contexts, it is common for families to start to feel responsible for mitigating the effects of the disease, seeking to promote the development and satisfactory growth of the child. These families need to learn to live with the disease, facing the difficulties and adapting to the new situation in order to maintain balance within the family³.

Mental illness, particularly, unquestionably undermines the family structure, because even after psychiatric reform, a posture riddled with stigma and prejudice related to mental illness persists in society in general⁴. The family struggles to help the child, facing difficulties such as: time investment; economic dependency, deprivation of the needs of other family members, lack of social activities and reduction of relations with the outside world⁴.

Moreover, the family member that lives more directly with children with mental disorder is deprived of his/her life, in order to provide adequate care, suffering physical and emotional distress. This caregiver then starts to deal daily with child's unpredictable behaviors, which slaughter social expectations and generates uncertainties and difficulties in the family and society⁴.

Caring for a child with chronic illness is complex and painful, since many questions, anxieties and fears arise in this every day, demanding a range of support needs, whether financial, emotional, intelligence, emotional or social exchange. To supply this demand, it becomes essential in these contexts to build social networks and the provision of social support³.

The social network refers to structural or institutional dimension, connected to an individual. Social support is in the personal dimension, consisting of members of this social network, effectively important to families. Social network is a web of relationships linking the various individuals who have social ties, providing support resources to flow through these links^{5:325}.

The social network aims to provide better living conditions to the population; this includes interpersonal, family and school

relationships, health systems and sectors that offer support and protection. These networks are linked and enable exchange of experiences and knowledge in order to improve social, economic, cultural and health conditions⁶.

A study with a family of a child with chronic conditions showed that social networking helps to face adversities and promotes adaptation, reflecting positively on family balance and quality of life for family members³.

Regarding mental health care, it is currently emphasized the treatment of patients with mental disorder in the family scope, in community-based services. In this perspective, and with the psychiatric reform, the family is now considered an essential ally in the therapeutic process in order to contribute to the rehabilitation of its being⁷.

Considering the importance of this partnership, to identify the social support networks, the nurse increases its resources to develop a plan of care that encompasses the needs of families and the person with mental disorder, contemplating the proposal of psychosocial care model for mental health⁷.

Given the scarcity of studies addressing the support network for families of children with mental illness and nursing practice, the interest and need for the development of this research emerged, which is based on the theoretical framework of Wright and Leahey⁸, of assessment and interventions with families.

Ultimately, the study is warranted in order to provide elements that can contribute to the work of nurses in these health care settings, always considering the prospect of family involvement.

It is highlighted the need for nurses and other health professionals know the social network and social support from families to whom they provide care, as these constitute indispensable allies in care. Given the above, this study aims to evaluate the social network and social support from the perspective of families of children with mental disorders.

METHOD

Descriptive qualitative study that consists in part of a research project of dissertation, whose general objective was to understand family experiences in the presence of mental disorder in childhood. The field research was conducted with families of children in care at the Center for Psychosocial Care for Children and Adolescents (CAPS-i) of Maringá - PR.

For selection of respondents, it was adopted as selection criteria: resident on the city of study, be preferred family member and caregiver of children served by CAPS-i, whose diagnosis and monitoring has been conducted for more than a year, given that the diagnosis or recent monitoring could interfere with reaching the goal of the study. We used the definition of childhood established by the Statute of Children and Adolescents (ECA), which considers it until 12 years old⁹.

The field research was conducted in two stages. In the first stage, researcher participated of therapeutic groups in CAPS-i as listener, with prior approval of the service and the participants of these groups in order to know the families and establish links. Survey participants were nominated by the health team, who intermediated the first contact with them. At the appropriate time, subjects were then informed about the objectives of the study and invited to participate. According with acceptance, home visits were then scheduled to conduct interviews, constituting the second stage of data collection.

The home was chosen as the research location, believing that in this environment the family would feel more at ease to tell her story. The study included 11 families, totaling 14 respondents, because it was not established any hindrance to the participation of more than one helper per family.

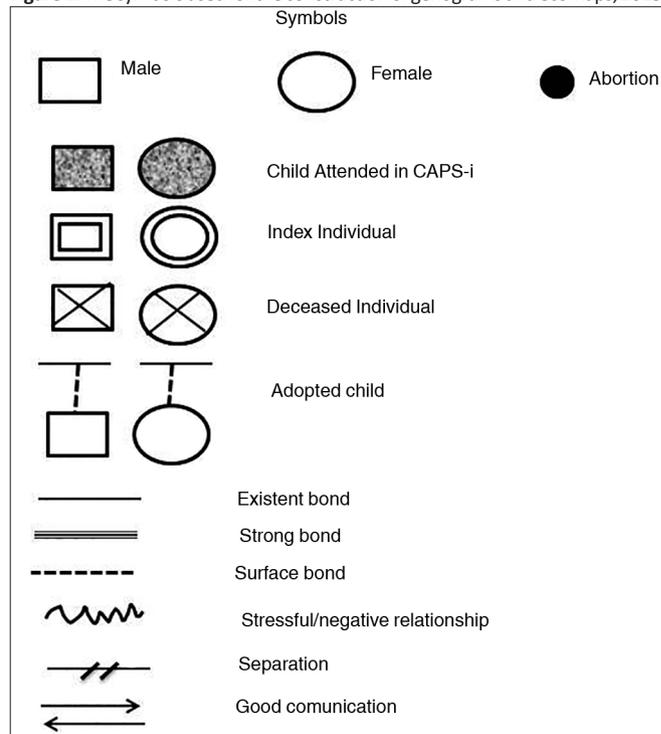
Data were collected from January to April 2013, through open interviews. The interviews lasted on average 40 minutes through the use of a data collection instrument consisted of two parts: the first aimed to characterize the respondents and to record data on children with mental disorders. The second part focused on addressing the central theme of the study, containing the following question: tell us about the condition of your family member (child's name), from diagnosis/start of monitoring until today. From this broader question, issues of support that encouraged the respondent to verbalize their experiences with greater detail were inserted over the reports, always observing the necessary precautions not to interfere with the answers. Among the topics covered by the script of support regarding the social support issue, are: changes in family life after diagnosis/start of monitoring, child/interviewed relationship with extended family, school, friends, health care unit, church, work.

The interviews were recorded and supplemented by the use of a Field Journal, to record the researcher's observations regarding aspects not captured in the recording, such as nonverbal language, gestures, facial expressions, etc.

At the end of each interview, manual construction of the genogram and ecomap occurred; its purpose and the meaning of each symbol were explained so that respondents could correct possible errors (Figure 1).

These tools are very useful for delineating the internal and external family structure. They are simple to use, since only paper and pen is needed. "The genogram is a diagram of the family group. The ecomap, on the other hand, is a diagram of family contact with other individuals outside the immediate family. It represents the important links between the family and the world"^{8:77}. These tools are devices that allow performing assessment, planning and intervention with family and also illustrate the relationships and links between individuals⁹.

Figure 1. The symbols used for the construction of genograms and ecomaps, 2013.



For analysis of data concerning the characterization of the sample, we used descriptive statistics. Data from genograms and ecomaps were analyzed descriptively, while depositions were subjected to content thematic analysis. The interviews were transcribed verbatim for analysis, which occurred in three phases: pre-analysis, the exploration of material and data processing¹⁰.

In pre-analysis it was established the initial contact with the documents that were analyzed, allowing the emergence of impressions that guided the selection of the most significant segments, the formulation of hypotheses and the development of indicators that substantiate the final interpretation. At the exploration of the material phase, groups and associations that responded to the study objectives were found, thus originating the categories. At the stage of processing of the results, inferences and interpretation of results were performed¹⁰.

The development of the study followed the guidelines governed by Resolution 466/12 of the National Health Council. Therefore, we obtained approval from the Secretary of Health of Maringa and the Standing Research Ethics Committee involving Human Beings, of the State University of Maringa (opinion N^o. 162 598/2012). All participants signed an informed consent form in two copies and to ensure their anonymity, the names of interviewees have been replaced by names of flowers, in allusion to the delicacy and beauty of the reported stories.

RESULTS AND DISCUSSION

Study participants were 11 families, totaling 14 respondents, considering that in three of the participating families, there was the contribution of two individuals. Of the participants, ten were mothers of children with mental disorders, three grandparents and one father. The ages of the respondents varied from 25 to 74 years old (mean 39 years old). Six respondents were married, six divorced and two widowed.

With respect to educational level, four respondents had attended high school education, two had incomplete secondary high school education, one attended elementary school and six did not complete primary schooling. Only one respondent was illiterate.

The monthly household income ranged from R\$300.00 to R\$3,000.00 (average of R\$1,255.00), with one of the families having no income, relying only on the help of extended family (grandfather, grandmother and uncles). In eight families, only one person contributed to the income; and in the others there were two contributors. Six respondents left their jobs to devote themselves exclusively to caring for the child.

Regarding the profession, it was cited: housekeeper (4), seamstress (1), house maid (3), retired (2), caretaker (1), administrative assistant (1) snacks maker (1), self-employed (1).

Families had one to four children (average of 3 children), and the age of children in care at CAPS-i ranged from five to 12 years old (mean 8 years old). Treatment/monitoring time ranged from one to four years (average of 1 year and 7 months), and only three of these children had the definitive medical diagnosis (Hyperactivity, Attention Deficit, Bipolar Disorder). It is noteworthy the fact that there was a family history of mental disorder in eight of the families participating in the study.

There is great difficulty in concluding a diagnosis of child mental disorder, due to the limitation of current classificatory systems in child psychiatry, which do not cover the complexity of clinical findings observed in clinical practice¹¹. The prevalence of mental disorder in children has increased, but the difficulty in diagnosis remains, arising from the way these individuals are approached and judged by the people who surround them⁴.

With regard to the thematic approach of the study, according to the steps of content thematic analysis¹⁰, two categories emerged: "Network and social support: assisting the family living with a child with mental disorder" and "Family Structure: outlining links".

"Network and social support: assisting the family living with a child with mental disorder"

Living with a child with a mental disorder requires of the family an effort to adapt to the new situation, permeated by innumerable feelings and needs related to daily care. Such a condition drives these families to seek support in their social network, to face the difficulties and the new demands that mental illness imposes on their lives.

Families showed the CAPS-i and the church as constituents of their social networks. These institutions aim to fill the need that people have to relate, involving physical and emotional aspects, and providing a sense of comfort in belonging to a group and to be loved, raising self-esteem⁷.

Religious institutions were cited as an important element of the social network, greatly helping to address the difficulties, as pointed testimony:

But then, I only have God's support. God, my husband and my willpower to fight for it, because in this walk, during his life, I found many doors closed. So it was with much prayer, clinging too much with God and asking God to open the doors, so I could care for him the best way possible, right?! [...] (Daisy, mother).

[...] There is the support of the church, so there is a whole support, thanks to God there is a whole support. (Sunflower, mother).

Our Lady! Sometimes I lay in bed to sleep and thank God... I say: Our Lord, thank you so much I could get here [...] (Tulip, mother).

I'm in the Catholic church, I used to talk to priests, I used to go in the gospel churches... So I guess that is why I have this more open-minded. I would listen, would ask for support, I have always asked assistance from God. (Dahlia, grandmother).

Families, when they experience chronic illness, face great suffering and feel helpless when faced with difficulties of daily life, seeking in God and spirituality the necessary support to rise again each day, finding the strength to continue in their struggle. It is evident in the statements that religiosity is a source of hope for these families, giving vent to all the pain and distress that mark their daily lives and alleviating the fears arising from the disease.

Study on this subject reveals that households believe that God is the source of healing, which means that they seek in these spiritual forces feelings of comfort to face such situations¹². The authors also point out that scientific knowledge is not the sole source of explanation to justify what they experience with the child. Facing this, family members seek new ways and models of support as spirituality¹².

Religious practice allows individuals to form bonds of friendship, building a chain of mutual aid. The social support received in this context will not by itself solve the problems, but it is of great help easing the pain and suffering, and promoting the development of skills to cope and understand the disease⁷.

CAPS-i has been highlighted as an important element of the social network of all families and service professionals cited

this as a source of social support. Families showed that the information, clarifications, therapeutic groups offered by the assisted in understanding, coping and acceptance of mental illness, facilitating interaction with the child and helping the balance of family dynamics.

I have support now, but I did not have it before, it was just suffering... now we have a support of CAPS-i to talk, to understand what it is and what it is not. (Sunflower, mother).

CAPS actually helped a lot. I was looking for a place for him to stay a shift, and I always talk with the social worker about everything. Any problem I have, if I need something for him, I always talk to her and she gives guidance, a phone to call... then she calls there, she always helps (Chrysanthemum, mother).

So, we start to lose patience... and there (CAPS-i) they teach, you learn a lot! For example... I hit, I have no patience, I tell everyone that I hit, and they say this is violence. And as I hit, he will put in his mind that if his grandmother hits, he can also hit. And so, I just cannot explain everything I learn there (CAPS-i), but I learn many things: how to cope, as in his case, he is very stressed, he assaults us and the kids, so we learn a lot [...] and our Lady! They talk a lot with us; we can settle down with them, it is very, very good. The family needs support, just because we do not know how to handle [...]. (Iris, grandmother).

The mental health services prioritize the knowledge and strength of family and community and the professionals who work there need skills to work in a team with the family and the community, learning to listen and understand the needs of each individual and family¹³.

Another source of social support highlighted by respondents was represented by extended family members, perceived as important allies of the main caregivers, not only for the financial contribution made by these family members as well as the emotional support offered. Moreover, the aid of these people in the daily care of the child does much to minimize the physical and emotional burden of the caregiver.

For these families, the extended family represents the largest and most constant source of support in tackling this kind of health problem, which corroborates the findings of other studies^{3,7,14,15}. When the child is affected by a disease, the family plays a role in providing physical and emotional resources, forming a support system to maintain health at the time of difficulty¹⁴.

My family gives greater strength to us, right? Related to rent, water, electricity... they help us a lot! Now we are counting on them to help and we take staple food from the

church as well, because it is the only way! I do not have conditions to work. (Carnation, father).

I have my aunt who supports me, in the absence of my mother (deceased). She helps me a lot, when I have to go in CAPS, pick up the kids at school, daycare... There she goes and gives me a hand. There are times when I need something, then she comes here and help me. (Tulip, mother).

Unlike the reports presented, other families reported not finding expected support from members of the extended family, which led to the feeling of helplessness. It was noticed in the testimonies, and the facial expressions were recorded by means of a field journal, sadness and frustration before the removal of the extended family. It is possible to infer that the lack of support by other family members undermines the primary caregiver, whose expectations were based on the idea that blood ties were synonyms of love and unity.

Only I take care of him... I have my mother and my siblings here in Maringa, but no one helps! And my husband's family lives nearby but we do not have much contact. (Azalea, mother).

I always had this difficulty, because my mom, she is always far! My parents pretty much only criticize [...] This begins at home: the way you act, the way you think and talk... Even a father or a mother talking to a child, or a relative talking to the person who has this kind of problem, give a friendly word... we feel in heaven, is the best thing. Because I often, in my walking, I just wanted a word, I had to get alone, to face alone. Search for God, for people I never saw in my life, and I found much love, much support. But when we are in trouble, we want this from family, father, mother, or a mother-in-law, an uncle [...] my family moved away, it is a broken home, each thinking itself, they do not think in the neighbor, in helping. (Daisy, mother).

I have nobody to help me, it is just me [...] his father lives with another family... this is why I do not ask for help to his dad for that! And his father does not know how to handle with his problem. (Hortense, mother).

A childhood disease can weaken family ties and destabilize the family. Even with the degree of consanguinity, the links do not settle evenly, since the ability to cope with illness is different for each individual¹⁴.

The support network and social support is essential for the family in coping with the difficulties arising from living with a child with mental disorder. In this perspective, studies claim that knowing the "social network and social support available

can contribute to the care for the family, because it constitutes possibilities of expanding strategies to relieve stress and share responsibilities, and social support is a strong element in family assistance in addressing the difficulties^{15:17}.

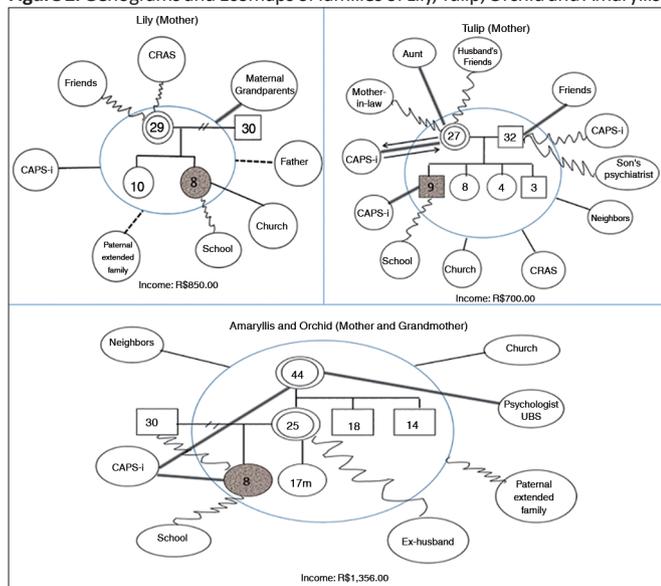
Family structure: outlining links

The presence of a child with chronic illness in the family can cause several changes in the family routine. Among these changes, both strengthening, as the weakening of the bonds between family, friends, neighborhood, health services, church can occur; causing in some situations, a change in the configuration of these families own.

By building Genograms and Ecomaps, it was possible to identify that families had a varied structure and global dynamics: five were of the nuclear type (consisting of a union between adults and children), one was a single parent (made by mother and two daughters), five were extensive type (that extends beyond the unit formed by parents and children, even including close relatives).

In Figure 2, family relationships are presented from the perspective of caregivers Lily, Tulip, Orchid and Amaryllis, showing the three types of family structure (nuclear family, single parent and extensive type) found in the study, and their support networks. In constructing the genogram, we proceeded to the elaboration of relationship lines from the family generation of the index subject (helper).

Figure 2. Genograms and Ecomaps of families of Lily, Tulip, Orchid and Amaryllis.



Through Genograms and Ecomaps it was possible to check the links and relationships of households with extended family and other support networks. It was noticed that some links were strengthened with the discovery of the child's illness. In these cases, the family strengthened their bonds, in seeking to meet

the challenges and changes in daily life, seeking a way to adapt. We observed also the support of the other children, assisting in the care of children with mental disorders and their monitoring, during activities with the CAPS-i.

Regarding ties with extended family father-related (of total respondents), one caregiver reported the presence of linkage, one reported the existence of strong relationships, five mentioned the presence of shallow relationships and four alleged the existence of conflicting relationships. Regarding maternal extended family mother-related, seven caregivers reported relating with these families, three reported having strong ties and one reported having superficial bond. Three caregivers assigned the surface linkages to the separation/divorce process or motivated by geographic remoteness. Two said to have stressful relationships due to previously existing family conflicts, and prior to the onset of the disease; and two mentioned that stressful relationships are a result of not understanding and acceptance of mental illness in children by extended family. Only one family reported the replacement of ties, formerly superficial, with strong ties in relation to maternal and paternal extended family, motivated by the discovery of the presence of mental disorder in the family.

By experiencing the disease, the family comes closer and mobilizes to maintain its operation and create a new structure to adapt to reality¹⁴. It is critical that nurses observe the family structure and the links between the members, and work to build and strengthen these ties, which are essential to maintain the balance and health of the family.

The interviewed relatives also mentioned the existence of links with neighbors (6) and friends (4). The fragility of relationships beyond their immediate family, as evidenced in the study, was attributed by caregivers to demand of total dedication to child care, and an arduous routine of tasks related to this care, including trips to CAPS-i. Because all households in the study reside in neighborhoods away from this service, they also reported difficulties related to the shift to the CAPS-i, since they depend exclusively on public transport to reach the institution. Thus, delays for consultations were common, which in turn generated delays in fulfilling other commitments, impacting the available time for these families to engage in recreation and leisure time with friends or neighbors.

The fragile ties with friends and neighbors is detrimental to the health of the caregiver who gives himself entirely to the care of the child, while he fails in looking at himself, his needs for socialization, recreation, distraction. Thus, although family members are the main source of support for these caregivers, friends also play a major role, especially in the support offered through difficult times¹⁴.

The majority of respondents (10) reported maintaining strong ties with the CAPS-i, which was observed during various times in the interviews, highlighting in particular the role of service

in offering support and information, generating in the caregivers, feelings of gratitude and appreciation.

The positive evaluation of these users to the service provided by the CAPS-i confirms the importance of it in the scene of attention to child/youth with mental illness at the same time it seals the fulfillment of its goal which is "besides to serve children and adolescents with mental disorders, giving psychological support for the family"¹⁶.

The author points out that to care and live with a child with chronic illness, the family needs to acquire skills, knowledge of the disease, and when the information is provided in a superficial or technique way, this process is difficult¹⁷. Thus, it is critical that healthcare professionals understand the importance of providing family-centered care, providing guidance, clarification of the pathology, and helping the family develop strategies to adapt to the new reality.

With regard to religion, three families mentioned having surface bond; four reported having bond and four referred having strong bond. These findings corroborate the results of other studies that link religion and the church as a strong element in the social support network of families^{7,12,14}. Chronic illness changes the family dynamics, strengthens and/or weakens bonds and brings suffering to the family as a whole, making them need care. In this context, it is up to the nursing to enter the reality care that is unfolding before it, and raise awareness by providing a care that focuses on the family. "Under this approach, attention to family health should not be limited to scientific and technical knowledge, since the care of children and their families within a systemic context requires a comprehensive, unique and special action"^{18:526}.

CONCLUSION

This study showed the importance of the support network and social support for families living with a child with a mental disorder. Mental disorder have brought a lot of conflict within the family, by the changes imposed by the disease and, in this very difficult environment, the family needs support sources to redress the balance and not getting sick.

In the present study and considering the scenario of family facing child mental illness, the social network has been viewed as a set of services, formal and informal institutions, with which the family had some kind of relationship; and social support was understood in terms of people or elements of society, significant and important in the process of coping with family. CAPS-i and the church emerged as social support networks; and extended family members as sources of social support.

Ties with friends and neighbors were considered superficial or non-existent, which shows the fragility of the relationships of these families, with external elements or people. Such a stance was attributed by caregivers for time, because of the demands of

caring for a child with mental disorder. Nor leisure activities were cited, revealing their total dedication to the child that characterizes the reality of these families and the physical and emotional burden generated on caregivers.

It is critical that health professionals, especially nurses, seek to deepen their understanding of these very particular realities. In this perspective, we must seek to uncover daily life and the dynamics of these families, recognizing their health problems, thus tracing its networks and social support. Only through this sensitive look, it becomes possible to plan actions that take into account the strengths and weaknesses of each reality, in search of an individualized nursing care, focused on family, and able to promote the quality of life of all its members.

By using a qualitative approach in this study, it is understood not to be possible to draw generalizations from the results and conclusions of it, or transpose such considerations in a linear way to other realities and care contexts. However, it is hoped that it will stimulate further reflection on the topic, encourage further research in the area, and subsidize nursing practice in working with families.

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