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Network and social support to families of children with cerebral palsy

Rede e apoio social às famílias de crianças com paralisia cerebral

Red y apoyo social a las familias de niños con parálisis cerebral

Naiara Barros Polita[1]
Mauren Teresa Grubisich Mendes Tacla[1]

1. Universidade Estadual de Londrina.
Londrina - PR, Brazil.

Corresponding Author:
Naiara Barros Polita.
E-mail: naiarapolita@hotmail.com

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Abstract

Objective: To analyze the structure and composition of families with children with cerebral palsy and to identify the presence of support and social network they have. **Methods:** This is a descriptive and qualitative study conducted in a University Hospital in Londrina-PR. Data was collected with ten families at the hospital and the participants' residences, from October 2011 to March 2012 using field diary entry, genogram, ecomap and semi-structured interview. Data was analyzed using The Interpretation of Meaning Method. **Results:** The families were in most of the nuclear type. Their social network was composed by the maternal family, health professionals and religious institutions, highlighting the lack of the professionals of the Family Health Strategy. They received emotional, instrumental, informational and cognitive support, which were not sufficient and generated negative feelings. **Conclusion:** The nurse should detect frailties in the network and help families to look for and obtain the support needed.

Keywords: Cerebral palsy; Family; Social Suport; Family Relations.

Resumo

Este estudo objetivou analisar a estrutura e composição das famílias com crianças com paralisia cerebral e identificar a existência de apoio e rede social que elas dispõem. **Métodos:** Trata-se de uma pesquisa descritiva, qualitativa, desenvolvida em um hospital universitário em Londrina-PR. Os dados foram coletados com dez famílias, no hospital e em domicílio, no período de outubro de 2011 a março de 2012, por meio de diário de campo, genograma, ecomapa e entrevista semiestruturada. Foram analisados mediante o Método de Interpretação dos Sentidos. **Resultados:** As famílias foram, na maioria,do tipo nuclear. Sua rede social foi composta pela família materna, profissionais de saúde e instituições religiosas, destacando a ausência dos profissionais da Estratégia Saúde da Família. Receberam apoio emocional, instrumental, informacional e cognitivo, os quais não foram suficientes e geraram sentimentos negativos. **Conclusão:** Cabe ao enfermeiro detectar as fragilidades na rede e auxiliar as famílias na busca e obtenção do suporte necessário.

Palavras-chave: Paralisia cerebral; Família; Apoio social; Relações familiares.

Resumen

Objetivo: Analizar la estructura y la composición de familias con niños con parálisis cerebral e identificar la existencia de apoyo y de red social. **Métodos:** Estudio descriptivo, cualitativo, desarrollado en un hospital universitario en Londrina/PR. Los datos fueron recogidos con diez familias, de octubre/2011 a marzo/2012, a través de diario de campo, genograma, ecomapa y encuesta semiestructurada y analizados mediante el Método de Interpretación de los Sentidos. **Resultados:** Las familias eran, en su mayoría, del tipo nuclear. Su red social fue compuesta por la familia materna, profesionales de salud e instituciones religiosas, destacando la ausencia de los profesionales de la Estrategia Salud de la Familia. Las familias recibieron apoyo emocional, instrumental, informacional y cognitivo, los cuales fueron insuficientes y resultaron en sentimientos negativos. **Conclusión:** Cabe al enfermero detectar los puntos débiles en la red y auxiliar a las familias en la búsqueda y obtención del soporte necesario.

Palabras-clave: Parálisis Cerebral; Familia; Apoyo Social; Relaciones Familiares.

INTRODUCTION

Cerebral palsy (CP) consists of a set of motors and postural disorders that cause functional impairment to the child. Is considered a non-progressive condition, resulting from injury or abnormalities that occur in the brain in fetal or child development, until the second year of postnatal life. Disabling character, CP cause great impact on family, and may destabilize it, requiring sudden changes in family dynamics, causing conflicts and changes of routines and functions[1].

The experience of living with cerebral palsy is usually stressful and generates suffering, beyond the immediate search for assign meanings for both the life of the child as for the whole family. The sense that the man finds in the events in which he lives is socially constructed, strictly historical, shaped in the flow of events and arises from a concrete social interaction[2].

In the process of living, the family builds a world of symbols, practices and knowledge that are built, shared and redefined in social interactions intra and extra family[3].

In addition, it is well known that the availability of certain features social and psychological influences on care to the chronic sick and contributes to improving the quality of life of families[4]. In this way, the social support networks become important to guide the feelings and conduct adopted by relatives.

In a study that analyzed various concepts of network and social support, it was adopted as a definition of social network structural or institutional dimension linked to an individual. The social support as the personal dimension, which consists of the resources provided by the network members that generate physical, emotional and behavioral benefits[5].

Given the above, the question arose: How are comprised the families of children with CP and what social support they receive?

Thus, this study aims to analyze the structure and composition of these families and identify the presence or absence of support and social network available to them. It is believed that the knowledge of these aspects will provide subsidies for a best performance of nurses in these cases, targeting not only the child with cerebral palsy, but the family in its entirety.

THEORETICAL AND METHODOLOGICAL TRAJECTORY

This study is part of a master's thesis in Nursing, entitled "Experiences of families of children with cerebral palsy".

This is a descriptive study of qualitative approach, carried out with ten families of children with definitive diagnosis of cerebral palsy, aged between two and 12 years, hospitalized in the Pediatric Unit at the University Hospital of Londrina (HUL), of the State University of Londrina (UEL). We opted for this age group because we believe that from two years old the family has lived through the diagnosis and its implications, and by 12 years old to be the end of the age met in this unit of hospitalization.

The data were collected in the period from October 2011 to March 2012, in a reserved place of HUL and domicile located in the city of Londrina, until they were sufficient for the apprehension of the phenomenon. The total were ten families, represented by ten mothers and two fathers. The instruments have been applied to the main family caregiver, but when other family members were present, these also participated. It was used: field journal, genogram, ecomap and semi-structured interview.

In the field journal were noted during the two stages of collection, data obtained from non-verbal communication such as gestures, expressions and tone of voice.

The first contact occurred during the hospitalization of the child. At that time, it was applied the genogram (Figure 1), which graphically represents the data from the family by symbols and standardized codes[6], allowing the visualization of history, of culture, of the dynamics and relative relations[7]. Its development has enabled rapprochement, the knowledge and the immersion of the researcher in the field of study, for require social interaction with the subject of pesquisa[6].

Then it was formulated the ecomap (Figure 2), which consists in the diagram of the relationships between family and community, employed to assess the support and supports available and its use by the family[8].

Then it was scheduled the second date at home or in the hospital according the discharge prevision and family's availability. On this visit, was held the semi-structured interview containing questions relating to the composition of the network and social support that families have.

As theoretical opted for Interpretive Anthropology of Clifford Geertz, for understanding that building social networks and the support provided are influenced by culture and refer to the meanings constructed by groups. Geertz[9] proposes that to learn about people, their thoughts, their actions and why they do the way they do it is necessary to interpret the social discourse, translating the meanings socio-culturally built by the subject. These meanings are built, shared and redefined in social interactions and intra and extra family[3]. For the anthropology[9], culture is understood as the set of interlocking systems of symbols interpretable suffering extrinsic influence and influences the attitudes and behaviors of human beings, within the social and psychological processes. Culture influences and is influenced by social interactions.

The data analysis was performed according to the Method of Interpretation of the Senses, because it is based on the hermeneutic-dialectic perspective and cultural interpretation described by Clifford Geertz. This approach seeks the interpretation of context, of the reasons and the logics of speeches and actions, relating the data to the interrelationship and conjunctures, among others analytic bodies[10]. For this, general categories were prepared beforehand, during the formulation of the instruments, which were: composition and family relationships, social support received and social support non-received. For the analysis was followed the steps proposed by the method, which are: a) the comprehensive reading of selected material, to get an idea of the set of the particularities of the material. At that stage, specific categories were elaborated

Figure 1. Representation of the genogram

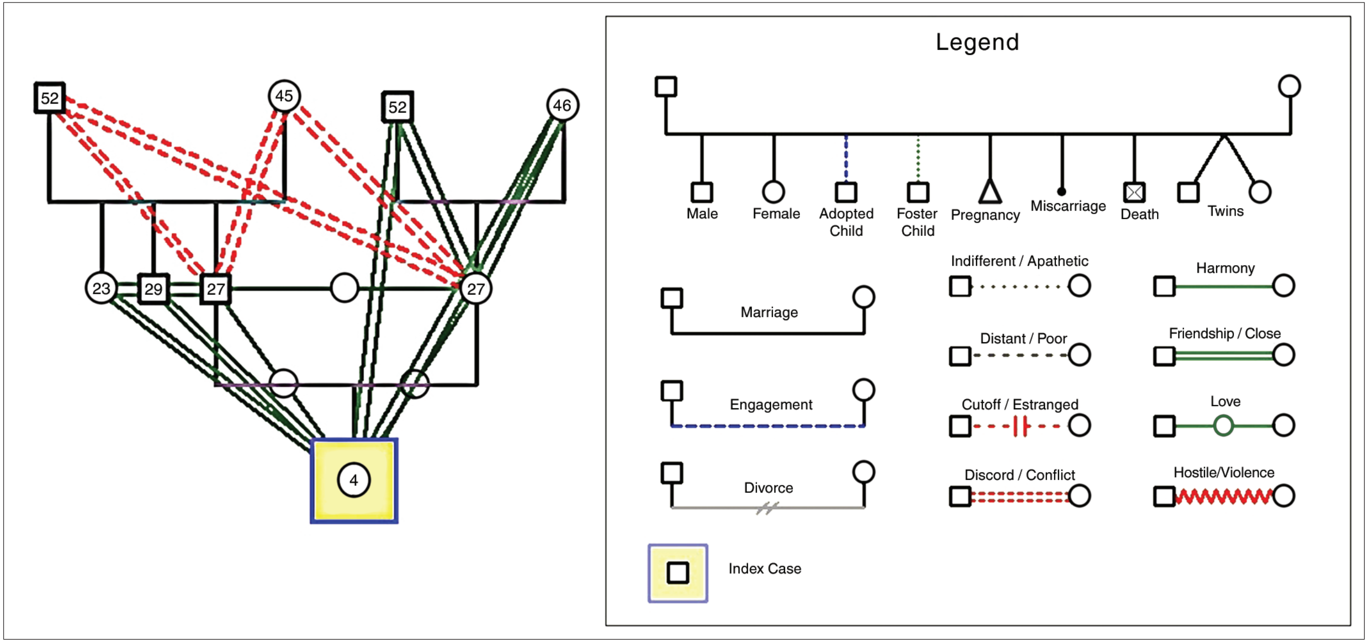
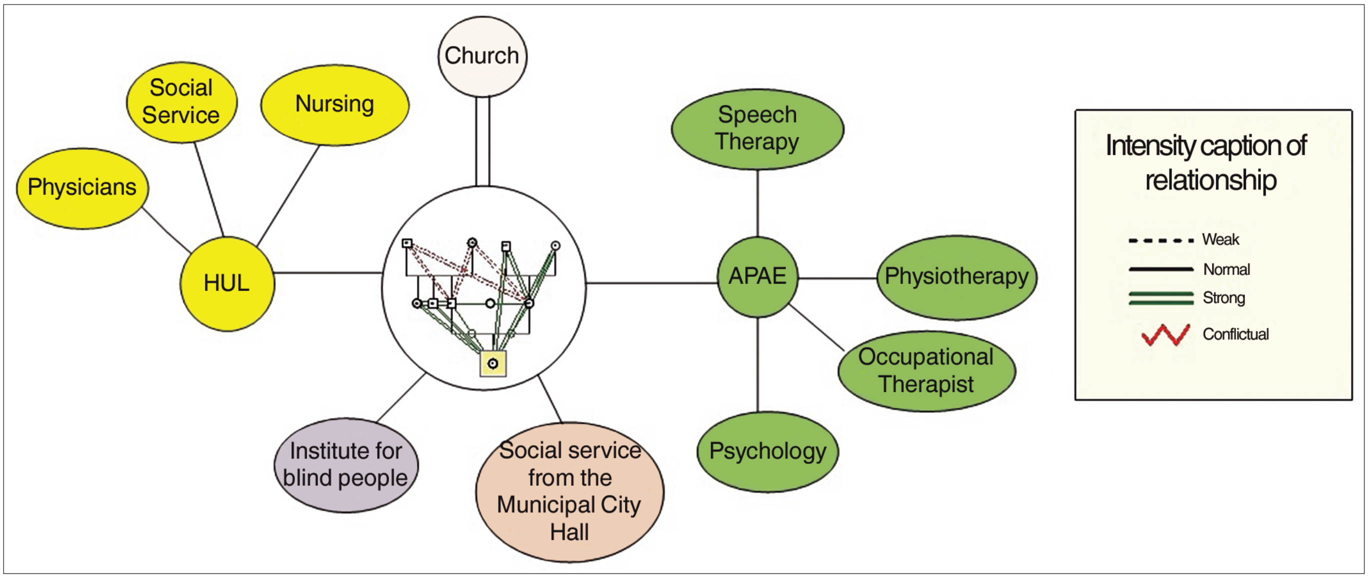


Figure 2. Representation of the ecomap



that emerged from the data, which were: family structure, sources of social support and social network composition, dimensions of social support received and feelings by the absence of social support expected. These were compared with the general categories and settled more concrete categories[11]; b) exploration of the material, seeking the broadest sense by identifying and questioning of the ideas taken from material; c) preparation of interpretive synthesis through the articulation of the data with the theoretical framework and the research objective[10].

This research was approved by the Committee of Ethics in Research Involving Humans of the State University of Londrina (CEP/UEL), in 9/6/2011, Protocol nº 195/2011, CAAE 0160.0.268.268-11. To preserve the anonymity of the subjects of the research, in the presentation of the results was used the letter M for mother and F for father, accompanied by ordinal numbers relating to families. Fictitious names were assigned to children.

RESULTS AND DISCUSSION

With the analysis of the data were established the following specific categories: structure and family composition; social network composition and sources of support; dimensions of social support received and perceptions regarding the need for social support not supplied.

Structure and Family composition

Through the genogram, we found that all children live with their biological mothers. Of the families studied, six are of the nuclear type, because most parents remain married and live in the same house. There are two cases of separation. Three children are only children. Of the remainder, only four live with their brothers. There is a case in which the brothers, minors, living with their maternal grandparents, separated from the nuclear family. There are two homes with extended family, in which reside the maternal grandparents.

Parents are an important source of social support, but the mothers are the main caregivers. In one case the father assumes this role. The maternal grandparents offer aid, but not centralize the special child care. Similar results were found in a study carried out in Rio Grande do Sul, in 2008, with mothers of children with CP, in which only a father abandoned the family and others in conjunction with the maternal grandparents are main source of support[12].

Also, it should be noted that the biological parents prioritize the child with cerebral palsy, to the detriment of other children, sometimes under the responsibility of the care and education of those grandparents. In addition to the high financial cost related to child care with CP, there is a need for full 24 hours a day care, making it difficult to pay attention to the other children.

The paternal family in three cases has no relation and in two cases it is conflicted with the families studied. Sometimes the paternal family does not accept the way of taking care of mothers, interfering in family relationships. When it comes to chronic disease, this disagreement cause conflicts and could rupture relations.

In a study conducted with family caregivers in Fortaleza - CE stands out the existence of conflicts with the other members of the family by dissatisfaction with the way the patient is being careful and financial issues[13].

Another causative factor of conflict and disruption of relations is the non-acceptance of the disease by the family members. It is associated with the meaning attributed to the disease, which are built from symbols partly from the family of origin and socio-cultural context in which they are inserted and partly originated from their experiences and social interactions. In this way, the family culture bases care developed by families, which changes according to the experiences and interpretations of the family and the members of the network[3]. The culture models individuals as single species, but also as separated individuals[9]. Thus, the beliefs, the values, the ideals, customs and religion of the families who live with the child with cerebral palsy and components of their social network define them as a group and influence their actions and their behavior. However, these cultural aspects also shape every actor of the group, enabling each subject has a different attitude to illness.

Social network Composition and sources of support

With the completion of the interviews and the construction of ecomaps, it was evidenced that the social network is mainly composed by professionals of health and social assistance of reference institutions such as the Association of Parents and Friends of Excepcional (APAE), Association for Assistance to Disabled Children (AACD) and Association of Disabled People from Londrina (ADEFIL), besides the high complexity hospitals in the city of Londrina. Also, the maternal family, highlighting the maternal grandparents and siblings of the child, are part of this network. Religious institutions appear as an important source of support for coping and overcoming adversity.

It should be noted the presence bit highlighted of Domiciliary Hospitalization system (SID), and the absence of medium complexity hospitals and Family Health Strategy (ESF), which were not perceived by the families as components of their support network.

It is known that the against reference, is typically made from the hospital for Basic Health Units (UBS) and teams of ESF and not to special institutions. The need for effective communication between the professionals really involved in care and follow-up of these children and families, whether intra or extra hospital.

In addition, these institutions do not absorb all the families and children with cerebral palsy. Thus, the ESF should be part of this support network. The ESF aims to the reorientation of the assistance model, aiming at quality, completeness, fairness and social participation. For that, the Family Health teams work with actions of promotion, prevention, recovery, rehabilitation and maintenance of health of the comunity[14].

To ensure the structuring of the network of services and support the insertion of the ESF in it, the Ministry of health created the Core of Support to Family Health (NASF), by Ordinance GM No. 154, January 24, 2008, republished in March 4 2008[14].

The NASF is formed by teams of professionals from different areas of knowledge, which operate in partnership with Family Health teams, focusing on health practices in the territories under the responsibility of the teams and has as its main guideline the integrality[14].

Thus, the main purpose of the NASF is to ensure, in conjunction with the ESF, the integral approach of the individual considering their social, family and cultural context, the integration of actions of promotion, prevention, cure and rehabilitation and the organization of the health system so that the population has access to networks of attention, as their necesities[14]. Thus, the ESF supported by NASF, consists of valuable service to the care of the population of the study.

Also, secondary-level hospitals and the SID could strengthen that network as though they were children with difficult management of disease, complications such as pneumonia and urinary tract infections could be treated at home or in hospitals, avoiding exposure to multidrug-resistant agents and unnecessary occupation of beds.

However, this result may be related to greater appreciation of the specialized services by the families, to the detriment of other services. However, the meanings are constructed and molded from the socio-cultural context, social relations and experience[9].

Thus it arises the need for evaluation of public services of primary and secondary attention with regard not only to accessibility, but also the structure and the quality of assistance provided.

In a study conducted with mothers of children with mental disease[15] also appear as major sources of support professionals in health and education institutions and as family helpers, spouses and friends. However, in the current study, the friends were only cited as components of the support structure for a family.

The success of the home care of children with special needs is directly related to their network of support. The lack of family and community support is the main cause of failure in the care of these children at home. The community offers families an incentive as education services, culture and recreation opportunities[16].

Dimensions of social support received

The dimensions identified of social support received were: emotional support, informational and cognitive instrumental[17].

The emotional support understands the perception be cared for, supported and valued by someone affectively available[17]. In this sense, family members have significant importance for the family unit and are valued by them.

> *Her older brother [the child] cares so much about her. He always calls for her to know about her and us as well (M4).*

The extended family was cited as the main source of emotional support, particularly the maternal grandparents, which are available to listen and comfort.

> *I have my mother's shoulder to cry on (M8).*

That kind of family support is important to avoid the disruption of relations between its members. In this context, the nurse can guide them to obtain their own strengths and resources to support each other, to promote opportunities to express their experience[18].

Emotional support is also through religious institutions. By faith/spirituality, coping ways are sought less painful and consolation. Also, the relatives that have faith feel more secure and able to experience this situation.

> *My intimacy with God is very great. He is the one who gives me strength (crying). [...] Where I won't go, He follows me (M8). We put God in front of everything. All mothers when they have a son with problem, I think God is empowering. Since the first day, preparing, directing (M7).*

In another study conducted with families of children with chronic diseases, in Rio de Janeiro, faith/spirituality also appears as emotional support, which helps in acceptance, adaptation and solace of family in relation to the disease[15].

It is understood as instrumental support or practical assistance and direct material in carrying out concrete activities or problem-solving, including financial aid[17]. It was noticed that children who attend referral institutions for treatment and follow-up of cerebral palsy and its complications, have a strong instrumental support of professionals of these services.

> *He was going to the APAE [...], after he did tracheotomy, they prefer to attend at home (M5). Feeding him is with a nutritionist of the AACD. I always come with the menu ready. It is a blessing to his bowel (M7).*

In a study conducted with mothers of children with CP, in an institution for treatment of children with special needs in Rio Grande do Sul, the professionals of the institution itself were not cited[12]. This difference may be related to the fact that, in the current study, families have found it difficult to get space in these reference institutions, resulting in greater appreciation of the professionals who work in them.

Despite the main caregiver of the child being the mother, fathers, uncles and maternal grandparents offer support instrumental.

> *My husband helps a lot when he's home. He is always present in the query, on hospitalization. He knows to use the vacuum, help in the bath (M5).*

This type of support is critical to not overburden financially or physically a particular family member and preserve health.

However, in this study, mothers feel overloaded:

> *I am the only one staying with him. [...]. My mother and my younger sister help me. [...]. I feel overwhelmed, but I ask God to give me the strength, because I only have myself (M2).*

Support received from friends only appears in the following talks:

> *I have a friend that when something is missing or need something borrowed, she lends me. But she works, she doesn't have much time. (M2).*

In other surveys conducted with families of children with chronic diseases, also showed that family members offer more instrumental support that friends, which are few cited. However, this support is insufficient, because mothers feel overwhelmed and undergo financial difficulties[7,12].

Another dimension of social support is the informational support, related to information and useful tips for dealing with situations or to solve problems[17]. The analysis of the data shows that this type of support is sought exclusively with the health team and, even so, it is not always satisfactory.

> *The phase of learning to handle I had it at the hospital (M8). In the hospital Physiotherapist gave me a lesson and taught me to aspirate, because I was afraid. Everybody helps me. The doctors give me information (M5).*

The relationship with health professionals persists for the whole family history, contributing to the formation of strong links. Thus, these professionals become references to the family, giving them security. This interaction enables the family to acquire and incorporate the knowledge and practices of the group of health professionals in its culture[9]. Thus, the behavior and the information provided by the professionals contribute to the significance of the disease and the confrontation of the condition. Meet the meaning attributed to the disease is essential for efficient communication and assistance focused on the family[7].

Another dimension of social support cognitive was identified, which refers to an active posture of encouragement, listening and positive reinforcement given by someone[17]. As a source of this type of support the nursing staff, religious group and other families of children with chronic diseases are highlighted.

> *One day I took him to the orthopedist and had a boy of about 2 years old, I had the same problem of Angel. Talking to his mother I saw that we are on the right track (M1). The nursing staff says that she is only alive because of the family she has (M8).*

Families who face chronic problems, most of the time, feeling losing hope or frustrated with their efforts to overcome or live with this condition. Thus, the cognitive support becomes tool of nurses to promote coping. The encouragement and praise allow family members change their perception of themselves and see the problem differently and, as a result, they seek solutions more effective[18].

Religious groups can be strategies for the strengthening of the family. The religion possesses cultural, social and psychological function. It serves both for individuals or groups, for the construction of meaning and understanding of the world and of him, and to promote arrangements and motivation for taking action, in addition to defining the feeling and emotion in order to support los[9]. Thus, besides the social interaction promoted by religious groups, is the motivation and support of practices and sentiments adopted by the family.

The groups of families of children with CP can also be helpful for the encouragement of the family, because the exchange of experience can be beneficial and contribute to face the situation.

Perceptions regarding the need for social support not supplied.

In this category, the family expressed their perception in relation to social support expected and greeted by family, friends, professionals and health services. Highlight the feelings of abandonment, anger, sadness and guilt.

> *My mother started to reject. She spokes like: 'I don't want handicapped grandson'. I expected a force from her, what I saw was she walk away (crying) (M7). They never told me anything about Gardenal when discharged from the ICU. He had marks on the face and my father insists to take to the doctor. With 9 months he did the EKG and CT. I heard that she could not walk, not talk, not to fix, not catching the little things by hand (crying). Only in this initial phase, the hospital failed me. Who knows if I knew she had that anoxia, why Gardenal [...], and if I were to become more vigilant, maybe today, she'd be looking at me (M8).*

Families of children with chronic diseases receive less support than those with healthy children and feel lack of support from family and health team[7], generating feelings of abandonment, anger, sadness and guilt. These feelings reflect the impact of the disease on the family, which will influence the whole family experience, along the path of the disease.

The families realized the stigma of CP, when not received the expected support of friends and family. It is determined in part by the cultural patterns and can be defined as a situation in which the individual has no social acceptance[8]. This acceptance differs between social groups. At the same time, the child with cerebral palsy can be accepted by certain family and rejected by others, because no culture models only the group, but each member, providing that each have a different attitude to illness[2].

In this context, family-centered care models are ideal to promote support, because they consider the impact of cerebral palsy in the family and respect the individuality of the child and family. Also, include the family in care planning, assisting in the provision of physical resources, spiritual, financial, social and biological, necessary for the fight against disease.

CONCLUSION

The networks of social support to families of children with cerebral palsy are composed mostly by professionals from institutions of treatment of children with special needs, the maternal family and religious institutions. The support received by this network is of type emotional, instrumental, informational and cognitive. Social support was important to the fight against disease and family restructuring. When not supplied, it resulted in feelings instrumental in the meaning of illness and the search for solutions to the situations.

Thus, it is the responsibility of the nurse to recognize the weaknesses in the network of support and, from there, to encourage and guide the family in search of needed support, promote the social support among relatives and friends and the relationship between health services, in addition to the evaluation of public services available, in order that the family receives all the resources necessary for coping and adapting to situations experienced.

This research was limited to hear only moms and dads. However, the experience of CP is experienced and shared by all involved. Thus, it is suggested that studies with other family members and social network are carried out.

This study does not exhaust the subject, but stimulates reflections about the need of social support to families of children with cerebral palsy and the use of interpretative anthropology as a reference for evaluation and familiar approach.

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