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Social support network of the family for the care of children with cerebral palsy

Rede de apoio social da família para o cuidado da criança com paralisia cerebral

Red de apoyo social de la familia para el cuidado del niño con parálisis cerebral

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ABSTRACT
Objective: to know the social support network used by the family to care for children with cerebral palsy. **Method:** this qualitative and descriptive research was conducted with twelve mothers of children with cerebral palsy assisted at a pediatric unit of a University Hospital in Rio Grande. Data were collected in August and September 2018 through semi-structured interviews and submitted to thematic analysis. **Results:** we identified the social support network consisting of family, friends, neighbors, health professionals, and faith in God. Mothers were protagonists of care and some received no support for childcare. **Conclusion:** the social support network contributed to overcome family difficulties and childcare, being a source of emotional, financial support, help with transportation, medicine, and guidance from health/nursing professionals.

Descriptors: Family; cerebral palsy; child; social support.

RESUMO
Objetivo: analisar a rede de apoio social utilizada pela família para cuidar a criança com paralisia cerebral. **Método:** pesquisa qualitativa, descritiva, realizada com 12 mães de crianças com paralisia cerebral atendidas em unidade de pediatria do Hospital Universitário de Rio Grande. Os dados foram coletados nos meses de agosto e setembro de 2018, por meio de entrevista semiestruturada, e submetidos à análise temática. **Resultados:** identificou-se a rede de apoio social formada pelos familiares, amigos, vizinhos, profissionais de saúde e ancorada pela fé em Deus. As mães foram protagonistas do cuidado e algumas não receberam nenhum tipo de apoio para os cuidados dos filhos. **Conclusão:** a rede de apoio social contribuiu para a superação de dificuldades da família e para o cuidado da criança, sendo fonte de apoio emocional, financeiro, ajuda com o transporte, remédios e orientação dos profissionais de saúde/enfermagem.

Descritores: Família; paralisia cerebral; criança; apoio social.

RESUMEN
Objetivo: conocer la red de apoyo social utilizada por la familia para cuidar a niños con parálisis cerebral. **Método:** investigación cualitativa, descriptiva, realizada con doce madres de niños con parálisis cerebral atendidas en una unidad de pediatría de un Hospital Universitario de Río Grande. Los datos se recopilaron en agosto y septiembre de 2018 a través de entrevistas semiestructuradas y se sometieron a análisis temáticos. **Resultados:** identificamos que la red de apoyo social estaba formada por familiares, amigos, vecinos, profesionales de la salud y fe en Dios. Las madres fueron protagonistas de la atención y algunas no recibieron apoyo para el cuidado de los niños. **Conclusión:** la red de apoyo social contribuyó a superar las dificultades familiares y el cuidado de los niños, siendo una fuente de apoyo emocional y financiero, ayuda con el transporte, medicamentos y orientación de profesionales de la salud/enfermeros.

Descriptores: Familia; parálisis cerebral; niño; apoyo social.

INTRODUCTION

Cerebral Palsy (CP) or chronic non-progressive encephalopathy is characterized by a special psychomotor condition due to central nervous system injury, still in the maturation phase, manifesting in early childhood, commonly before 18 months of age. This condition influences the context of family life because it requires the need for special care for the child and is permeated with doubts, fears, conflicts and uncertainties[1,2].

Epidemiological data indicate variable prevalence in developed countries from 1.5 to 2.5 per 1000 live births with CP. In Brazil, it is estimated the approximate emergence of 30,000 to 40,000 new cases per year. Faced with this situation, families need to reorganize and seek effective forms of care[3,4].

For families and children with special needs, the social support network means protection to cope with the new living conditions presented. The social network concerns the aspects related to the individual, structurally or institutionally, their various relationships and social links, with supporting resources, which may include churches and health institutions[5].

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Support network means the process of interaction between people or groups that establish friendship and information bonds, receives material, emotional, affective support, contributing to reciprocal well-being, building positive factors in the prevention and maintenance of health[5]. Given the demand for care presented by children with CP, it is necessary to involve a social support network, integrated by health/nursing services and teams, family and community, able to assist caregivers in decision making, transforming them. in autonomous subjects. Thus, the research aimed to analyze the social support network used by the family to care for the child with CP.

LITERATURE REVIEW

CP is a disabling chronic disease with varying degrees of dependence that imposes a constant need for family care and is the most common cause of severe physical disability affecting children.[2] Characterized by disorders of tone, posture and movement and secondary musculoskeletal problems. It is a heterogeneous condition with multiple causes, various patterns of brain imaging neuropathology, various clinical types, and associated developmental disorders such as autism, mental impairment, perceptual, communication and behavioral disorders, epilepsy, and visual impairment.[6,7]

A study that aimed to analyze caregiver satisfaction with social support available to children with CP identified high satisfaction with the support received and indicated a high overall satisfaction level in parents of children with greater impairment, through material, affective, emotional support, information, and positive social interaction[8].

Research has identified that the network is not always strengthened and able to offer the necessary support for the adequate coping of the disease. However, at some points in life the child received different types of support offered by strengthened bonds. Thus, it is emphasized that health professionals need to direct their gaze to the child, listening to their uniqueness, helping to identify links in their social network that can provide the support they need to face chronic disease[9].

A study highlighted that mothers of children reported the importance of the support received to overcome adversity and readaptation to child care. Data demonstrated various sources of stress and resource scarcity, as well as the influence of lack of support on participants' physical and emotional health[10].

The social network in the care of children with chronic disease favored the sharing of information and experiences, moments of relaxation and assistance in the acquisition of treatment inputs, with positive repercussions in the family context[11]. Women, in general, are primarily responsible for taking care of their children and are thus exposed to high demands and overload.

METHODOLOGY

This is a qualitative descriptive study conducted at the pediatric unit of a university hospital located in the city of Rio Grande, Rio Grande do Sul/Brazil. Twelve caregivers of children diagnosed with CP who met the following inclusion criteria participated in the research: being the main family caregiver of the child, being 18 years old or older and providing them with direct care at home. Caregivers who, even being present during the child's hospitalization, eventually promoted their care were excluded.

The caregivers were contacted at their own pediatric unit and invited to participate in the study. They were explained the purpose, methodology and method of data collection. Data collection was initiated after the participants signed the Informed Consent Form. Data were collected between August and September 2018, in an environment attached to the pediatric unit, using semi-structured interviews, which had an average duration of 40 minutes. They were asked about the social support received for child care.

Data were processed by the content analysis process[12] which was divided into three stages: in the pre-analysis, fluctuating reading and hypothesis formulation were performed; the second stage consisted in the exploration of the material with data coding and classification into categories; and the last one included the treatment of the obtained results, inference, interpretation and reflection. The Social Support Network category and the subcategories were discussed: Protagonist mothers of care; Support from family members; Support from friends and neighbors; Support from health professionals; and Support in faith in God, which emerged from the content analysis of the testimonials.

The ethical principles of research involving human beings were respected, according to Resolution No. 466/12. The anonymity of the participants was guaranteed and their speeches identified by the letter F (Family member), followed by the number corresponding to the interview. The research project was approved by the Health Research Ethics Committee, having received favorable opinion No. 197/2018 and CAAE 94590218.7.0000.5324.

RESULTS AND DISCUSSION

Twelve family caregivers participated in the study, 10 mothers of the child with CP, one father and one institutional caregiver. Their ages ranged from 23 to 53 years old. Eight have incomplete elementary school, two incomplete high school and two complete high school. Regarding family income, one could not inform, one receives half a minimum wage, four a minimum wage, one about R$ 1,400.00, three about R$ 1,800.00, one about R$ 2,000.00 and another about R$ 2,500.00.

The contents of the interviews with the family caregivers were included in the social support network category and divided into five subcategories, which are dealt with below.

Protagonist mothers of care

Mothers were protagonists of the integral care of children with CP due to the importance their children assume in their lives. However, some mentioned not having a social support network, impacting on physical and emotional overload.

> *How am I going to explain to you, family in quotes, because I assumed the whole scolding on my own. (F5)*
>
> *Practically I turn around a little, because he [his father] also has his tasks. (F9)*
>
> *Nobody, only I take care of her. (F8)*
>
> *Right now I needed someone to be with him. No one volunteered. It's hard (F4)*
>
> *His father doesn't help or offer himself. It could very well help me, say like this: I'll pay someone off to give you strength. I go out and my sisters stay in five minutes calling me: Will you take too long? (F5)*

Mothers were the protagonists of child care with CP, dedicating themselves integrally, assuming the demands determined by the needs of their children. A study showed the significantly poor quality of life of the caregiving mother of a child with CP, who presented more physical and emotional fragility[13].

The data from this study demonstrated the lack of the social support network of certain mothers who exclusively took care of their children, without receiving help from those close to them. As facilitators of family support, research has shown friends and society to carry out activities and improve the living conditions of children and families[14].

Mothers mentioned the emotional and physical overload caused by the continuous care given to the child. Research aimed at understanding the family's difficulties and difficulties in caring for children with CP revealed that the difficulties are more evident compared to the facilities and have repercussions on daily life activities such as eating, bathing and locomotion, as children stay every day. more dependent on carers[9].

Family support

Mothers mentioned family support in the child care routine. There was help in the care of the general and younger siblings, exchanges with the mother during hospitalization, financial aid for transportation and medicines.

> *Only from my daughter I have help. It's me and her and sometimes my mother's. We are the three we face, day and night, in this case 24 hours, but only me, direct with him (F5).*
>
> *They help me with the care we need, like medication and everything he needs. (F3)*
>
> *Dad quit his job so he could help me. (F6)*
>
> *While he's here in the hospital, they come so we can go home and have a shower, take care of the other kids. (F1)*
>
> *There is always someone around to help. If I need a car or I need money. (F2)*

The social support network is necessary to face the complexity imposed by the constant needs in all dimensions of child care. The findings of the study corroborate the importance of the family support network, which provided social, emotional, cognitive guidance, material help, alleviating the limitations imposed by disability[15].

Most mothers mentioned the existence of family support as a fortress for coping with the circumstances imposed by the child's condition. Research has shown similar data, showing that the family nucleus contributes to the strengthening of the emotional, instrumental, informational and cognitive dimensions[16].

Study has shown the importance of the support of husband and other family members for the adaptation and reorganization of life. These are resources used by women to facilitate maternal role play, meet challenges, and minimize stress[10].

Support from friends and neighbors

In this study, the social support network was configured beyond the family, the support of friends and neighbors was essential to face the difficulties. The support involved the dimension of offering help for the child's transportation, medicine purchase and also meant the emotional support.

> *I received support from my neighbor and boss, they are great people and Neneca. (F3)*
>
> *Friends came a lot closer. I know if I call, if I need anything, I always have someone who comes to help me. Sometimes the difficulty is with the medicine I have to buy, but all I need I always have. Sometimes when the situation is difficult with his own health, he always has a hug. (F7)*
>
> *And friends who also have a car, sometimes I need to call when my husband can't go and ask: Can you take me to such a place tomorrow morning? (F2)*

Study has shown that families have a restricted support network and for the care demand only the support of husband, grandparents, children and godparents[5]. In the present research, the mothers who pointed to the existence of the social support network mentioned the support of friends and neighbors.

Research has pointed to the social network formed by friends as an essential family support resource to help them through difficult times[4,16]. In this study, mothers sought the necessary support from friends and neighbors to overcome obstacles.

Support from health professionals

For mothers, health/nursing professionals were important sources of emotional and physical support, as they felt calmer and were able to rest. They also received appropriate information about child care and clarified doubts.

> *They are always explaining. Yesterday I even asked him why he was drooling, why he had never put so much drool and they said it's normal mom. You do not worry. Reassure. (F1)*
>
> *Doctors have always been helpful to me, always accompanying him. They treat the best they can. (F4)*
>
> *The nurses do everything and explain, but I forget. When I am in the hospital I do nothing. Rest. I just watch them do it. (F8)*
>
> *The aspiration part, the gastrostomy, this is all the care of the nurses. So while he is in the hospital we get this help because the nurses are helping. (F6)*
>
> *Everything I know to take care of him I learned here, inside the hospital. I get guidance from the nurse on how you do this, how you do that. (F7)*

The performance of health/nursing professionals in the treatment process of these children was relevant for providing comprehensive care to the child and family. In this sense, it is recognized the importance of extended professional care that can deal not only with children with CP, but with interventions with family members, ensuring their well-being, quality of life and continuous support[9,17].

In this study, the data pointed to the positive relevance of professional/nursing support in improving mothers' quality of life and psychosocial well-being. Thus, the professionals contribute to the reduction of stress and to cushion the burden of care, as they strengthen the social support network, with the correspondence and empowerment of the family for child care[17].

Thus, health/nursing professionals were essential to support the family in times of difficulty, transmitting security and tranquility, as well as enabling scientific knowledge about care. Thus, the behavior and information provided by professionals contribute to the understanding of the disease process and coping with the child's condition16.

Support in faith in God

Another important source of family support is faith in God. This faith gives the family strength and hope to fight for the child and to believe in their recovery, with the possibility of developing and acquiring a better quality of life.

> *Thank God, with God's grace, she's there. (F9)*
>
> *We see her battle every day. We fight because it will be good, for sure. We have faith in God that she will get better. (F3)*
>
> *I pray to God every day to see him improve, to have a better quality of life. God is giving me strength and I'm holding on. (F5)*

> *Everything I need, thank God, I get, everything he has needed so far I've always gotten. I started taking him to church, I have a lot of faith and he started to develop. (F4)*

Belief and faith were decisive for mothers to compose themselves and seek to face the condition of their children. Thus, faith/spirituality appears as emotional support, which influences the family's acceptance, adaptation and comfort in relation to the disease, as well as the security and ability to experience this situation[16].

A study has pointed out that families seek the spiritual dimension for comfort in the face of the adversities encountered. They see belief/faith as a support for their daily coping with their children's chronic condition[18]. The family is often driven to seek answers, help and/or meanings in other dimensions of life, not only material, cognitive and affective, reaching the spiritual.

The new routine imposed on family members by the condition of children with CP, permeated by daily difficulties, makes families look for belief/faith strengths to face obstacles. Research has shown that parents have called upon God to overcome negative feelings and thoughts about their children and to face the hazy future in the face of CP, as spirituality often becomes a support for the acceptance of the chronicity of the child's life condition[19].

Although difficulties permeate the families' context, they were able to find support and help in the social support network, such a network intertwines so that the needs of family caregivers and the child are best met[17].

CONCLUSION

When researching the social support network of caregivers of children with CP in a pediatric hospital unit in the city of Rio Grande, mothers perceived themselves as protagonists of the care given to their children and also by the difficulties that some of them had due to lack of support.

In general, the support network was broadened and strengthened, consisting of friends, neighbors, health professionals and anchored in faith in God. It was identified, through the results, that these forms of support meant having help from people living with the child care, guidance and clarification by health/nursing professionals. Faith in God presents itself as a bulwark for overcoming family difficulties.

In conclusion, although there is a social support network for child care, the mother has emotional and physical overload. It is noteworthy that the families underwent changes that led to the readaptation of their routines, needing to face daily challenges and difficulties that surrounded the care of the child.

As a limitation of the research, it is pointed out the restriction of the field of study in only one pediatric unit, because despite its relevance, it is not possible to generalize the results to other municipalities, as it constitutes a local sample not representative of the universe. However, the research deals with a worldwide reality, serving as subsidy for further investigations on the subject.

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