

Social support to the families of children with cerebral palsy

Apoio social a famílias de crianças com paralisia cerebral

Ana Paula Dezoti¹

Ana Maria Cosvoski Alexandre¹

Márcia Helena de Souza Freire¹

Nen Nalú Alves das Mercês¹

Verônica de Azevedo Mazza¹

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Corresponding author

Ana Paula Dezoti

XV de Novembro street, 1299, Curitiba,

PR, Brazil. Zip Code: 80060-000

anadezoti@uol.com.br

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Abstract

Objective: To describe the experience of the families of children with cerebral palsy concerning their social support network.

Methods: Qualitative research carried out with 19 families of children with cerebral palsy. Focal group sessions were performed and statements were recorded, thoroughly transcribed and assessed by the thematic analysis technique.

Results: The following thematic categories emerged: Experience of the family in caring for the child with cerebral palsy, and Frail social support concerning family bonds.

Conclusion: The social support network of the families of children with cerebral palsy is basically comprised of family members. Families undergo changes in their daily life and experience unfavorable feelings, seeking in the spiritual realm the hope to cope with adversities.

Resumo

Objetivo: Descrever a experiência da família de criança com paralisia cerebral em relação à rede social de apoio.

Métodos: Pesquisa qualitativa realizada com 19 familiares de criança com paralisia cerebral. Foram realizadas sessões de grupo focal e os depoimentos foram gravados, transcritos na íntegra e analisados pela técnica de análise categorial temática.

Resultados: Emergiram as categorias temáticas: experiência da família no cuidado com a criança com paralisia cerebral e apoio social frágil nos laços familiares.

Conclusão: A rede social de apoio da família da criança com paralisia cerebral é constituída por membros da própria família. Esta passa por mudanças em sua rotina diária vivencia sentimentos adversos e busca na dimensão espiritual o acalento para as adversidades encontradas.

¹Universidade Federal do Paraná, Curitiba, PR, Brazil.

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Introduction

Among the chronic diseases that directly impact children, cerebral palsy cause singular damages to their families by altering several of their lives' axles, such as time, finance, labor, family and social relationships, physical and psychological health.⁽¹⁾

In this adaptation process, and in search for answers to the care demands resulting from such disease, families pursue a set of services, such as medical, rehabilitation, education and community services. On the other hand, these services are challenged to look for and support families, in order to meet the needs of children with cerebral palsy,⁽²⁾ as they call for additional stimuli toward their development.

Caring for a child with cerebral palsy consists of a challenging task, as their physical and emotional demands require effort, dedication and time. Financial, emotional and social distresses are other setbacks experienced by families.⁽³⁾

In order to reorient goals and objectives, family members need to reframe emerging daily feelings regarding the new and unusual experiences with the child with such neuropathy. This reorganization requires responsibilities, fears, anxieties and uncertainties to be shared. In this sense, social support networks, as spaces of intersubjectivity, may support the family in financial, psychological and information aspects, among several others. Therefore, the social forces of these support systems may help in the adaptation process toward the children's care and quality of life.⁽⁴⁾

It is believed that beyond the practical care processes with the child, the family needs a type of support that is able to meet the interdependence needs of individuals.⁽⁴⁾ Such support may originate in the elements that compose the network in which the family seeks help to care for their children. Social support networks are deemed to be the structure of relationships among subjects that are tied by affective bonds, a locus where subjective and objective exchanges take place, turning networks into real entities.⁽⁵⁾

In this sense, the present study addresses how families of children with cerebral palsy experience

the transformations in their realities, which lead them to seek help in social support networks in order to overcome the difficulties they face in the child's development process. The objective of the study, therefore, was to describe the experience of families of children with cerebral palsy concerning their social support network.

Methods

This descriptive, qualitative-based research was carried out in a university located in the state of Paraná, in the southern region of Brazil. Inclusion criteria were as follows: being enrolled in the service; being a steady participant in the service; being a family member of children with cerebral palsy in the 0-12 group age; and being a resident in the city of the project. The study was comprised of 19 families.

Data were collected in a controlled environment between November 2012 and January 2013 by means of three focal group sessions and counting on the support of a thematic guide, which addressed family support issues toward the care for children with cerebral palsy. The statements were fully recorded and transcribed. Data were analyzed by the thematic analysis technique, without software support.

The development of this study complied with national and international ethical guidelines for research involving human subjects.

Results

The data analysis process brought about two thematic categories: Experience of the family in caring for the child with cerebral palsy, and Frail social support concerning family bonds. In the first category, the study approached the changes experienced by the family, their feelings and their search for spiritual help. The second category presented the social support network, which displayed a denser support to the family on the part of the closest family members.

Experience of the family in caring for the child with cerebral palsy

In face of the care demands associated with cerebral palsy, the daily life of families undergo several changes, and family members are more intensely dedicated to the care for the child, especially the mother. The uncertainties generated by the medical diagnosis intensify the family's search for spiritual support.

Such transformations occurring in the heart of the family overloads the child's major caregiver, who in the case of this study was the mother. She adapted her daily agenda in order to care for her child. When asked about her opinion about cerebral palsy, she blamed herself for the diagnosis and showed significant distress when speaking about the future. Aiming at relieving the intensity of the cerebral palsy diagnosis, the family started leaning upon spiritual beliefs toward coping with the uncertain present and future.

Frail social support concerning family bonds

Family support processes are often dependent on the availability of family members, and usually highlight the responsibility of the mother as the major caregiver. Such support is frequently located at the core of the family, and especially expected from older children; whereas other family members, such as grandparents, husband, aunt and mother-in-law, interact only in occasional opportunities in order to provide the necessary care.

Discussion

The limitation of the results of the present research is related to the qualitative methodology, which does not allow for generalizations. On the other hand, the study highlighted the social support network listed by the families, as well as how families sought to adapt to the daily adversities resulting from cerebral palsy. In face of that, the current care process toward such type of family should be rethought. New research, which could provide practical tools to the families experiencing such a chronic

disease, should be produced, so that healthcare professionals may be able to go beyond the biological and individual dimensions and insert not only the child into the care process, but also the whole family, addressing both the healthcare hindrances and the care potentials toward the family and the child's health needs.

The thematic category "Experience of the family in caring for the child with cerebral palsy" showed that, allied to the changes observed in the family's daily life following such chronic diagnosis as cerebral palsy, there was a higher care demand and alterations in the family's social framework related to the development of the child. Moreover, families sometimes do not believe that they will be once again able to dream of a prosperous future anymore.

The present research highlights that due to the excessive care demands toward children with cerebral palsy, the major caregivers are very rarely able to leave them under the responsibility of other people, a fact that disconnects them from their personal lives and prompts them to only care for the children. Such fact is corroborated by another study carried out with caregivers of children with cerebral palsy, who affirmed that they were less willing to leave their children with other people. However, if these caregivers sought for help toward caring for their ill children, they would be able to reap significant benefits.⁽⁶⁾

The transformations that take place in the family's daily life alter their dynamics and, above all, the caregiver's life dynamics. Thus, this study observed that the centralization of responsibilities was strongly connected with the mothers, who implied that the daily care for the child with cerebral palsy necessarily brought about difficulties toward maintaining other activities. Such experience emphasizes the essential anguishes and uncertainties experienced by mothers in the search for answers regarding the future of both her child and her family.⁽⁷⁾

The energetic and almost totally exclusive effort of the mother concerning the child with cerebral palsy may be associated with the guilt feeling resulting from the child's chronic disease, thus mobilizing another type of feeling, the compulsoriness to dedicate one hundred percent of herself to her

child. Such data is corroborated by a study carried out within the Chinese context with mothers of children with cerebral palsy, who also felt guilty and accountable for the child's impairment.⁽⁸⁾

Families in this study expressed ambiguous feelings emerging from their experiences with the children's chronic disease. The mother was the family member that expressed the most diverse types of feelings regarding the chronic condition of the child, ranging from joy to sadness, guilt and questionings about her personal failure during the pregnancy.

This situation generates feelings of sadness, which are justified by the degree of dependence of the child and their life prognosis. The child is expected to present a certain degree of dependence for their entire life, with no chance of getting cured and demanding special care and stimuli toward the promotion of their development, as well as their personal and family quality of life. A study carried out with parents of children with cerebral palsy ratifies the findings of the present study, as the approached family members also experienced a variety of negative emotions ranging from mild anger to exhaustion and frustration.⁽⁹⁾

These data show that, in face of the situations imposed by the chronic condition of their children and most often by the lack of a more effective support, these families may be stimulated in their search for answers, help and/or meanings in realms of life other than the material, cognitive and affective dimensions, thus taking them to the spiritual realm, aiming at encompassing aspects of their experiences that go beyond the objectivity of life. Hence, in face of the loss of the idealized child and the new routine imposed by the child with cerebral palsy, families find in belief/faith a new pillar toward coping with the daily chronic condition experienced by their children.

Another study that corroborates the data of the present research points out that in order to overcome negative feelings and thoughts about the ill children and to face the dark future promoted by cerebral palsy, parents seek to call upon God,⁽⁹⁾ as spirituality, most of the times, becomes a strong support toward accepting the child's chronic condition.

In addition to the spiritual support, the family also looks for other types of support toward caring for the child with cerebral palsy. A steady search for care services that may improve the children's life conditions is often noticed, as it mobilizes families toward seeking multiple resources, so that the children may have a more natural development, in spite of facing such chronic condition.

The "Frail social support concerning family bonds" category points out that due to the intensity of the care imposed by cerebral palsy, the mother takes on the whole care for her child, causing her to carry a heavy burden. The care demanded by this child leads the mother, the child's major caregiver, to seek support in her closest relational system, especially her other children and other women in the family, such as grandmothers and aunts, with whom she shares the care. Mothers believe that family members are more likely to provide support and attention. As such, these members are usually chosen to help major caregivers.

To corroborate these findings, a study showed that families of children who were born with Apgar ≤ 3 in the 5th minute and counting on a diagnosis of severe perinatal asphyxia found their social support network within the family universe⁽⁴⁾, thus indicating that the family is a relevant source of care.

The search of the mother for family members, especially women, to help her out in caring for her child may be related to the fact that society has labeled the female gender as the one responsible for the caring act. Such data is ratified by a study that points out that the care responsibilities of mothers are influenced not only by the sex, but also by the expectation that mothers will carry out such duty as a major function.⁽⁸⁾

Bearing all this in mind, family-centered services should offer social support and develop different strategies to cope with the challenges and needs of caregivers of children with cerebral palsy, with a special attention to mothers.⁽¹⁰⁾

The present study highlighted how important it is for healthcare professionals to be prepared to address social support network strategies for families of children with cerebral palsy, so that they are em-

powered to plan a comprehensive care that values the family's specific challenges. Besides broadening family relationships, the approach of a competent professional may generate a set of support and intervention actions and promote the development of the ill children in their maximum potential.

Another study pointed out that the family-centered care may reduce the family's overloads. Hence, it is important that such type of care be inserted into healthcare policies, aiming at both integrating the care services in all healthcare levels,⁽¹¹⁾ and improving the quality of life of the families and their children.

Conclusion

The social support network of families of children with cerebral palsy is composed of family members, as these are closer to them. These families undergo changes in their daily routine, experience unfavorable feelings and access the spiritual dimension in order to find support to their adversities.

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Collaborations

Dezoti AP; Alexandre AMC; Freire MHS; Mercês NNA and Mazza VA declare that they have contributed to the study conception, analysis, data interpretation, wording, relevant critical review of

the intellectual content, and final approval of the version to be published.

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