

## Social Support Network for the Family of Cerebral Palsy Bearing Children

Rede De Apoio Social À Família Da Criança Com Paralisia Cerebral

Red de Apoyo Social a la Familia del Niño con Paralisia Cerebral

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### ABSTRACT

**Objective:** The study's goal has been to gain further understanding about the social support networks of families with cerebral palsy bearing children. **Methods:** It is a descriptive-exploratory study with a qualitative approach, which was carried out in the *Associação de Pais e Amigos dos Excepcionais (APAE)* [Special Person's Parents and Friends Association in Brazil], from a municipality located in the South of Brazil, with mothers and fathers of cerebral palsy bearing children. Data were collected through interviews from April to May 2017, according to the ethical precepts established by the Resolution No. 466/12. **Results:** It was verified that the social network is composed by the family and, mainly, by health professionals and social assistance in referral institutions, such as the *APAE*. **Conclusion:** The support networks are essential for the families of children bearing cerebral palsy to adequately take care of their children. Furthermore, health professionals can provide guidance on the child's needs and support for family care.

**Descriptors:** Cerebral Palsy, Social Support, Family, Child, Nursing.

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## RESUMO

**Objetivo:** Conhecer as redes de apoio social das famílias de crianças com paralisia cerebral. **Métodos:** Estudo qualitativo, exploratório e descritivo, realizado na Associação de Pais e Amigos dos Excepcionais, de um município situado no sul do Brasil, com mães e pais de crianças com paralisia cerebral. A coleta das informações ocorreu entre abril e maio/2017, por meio de entrevistas. Foram respeitados todos os preceitos éticos estabelecidos pela resolução nº. 466/12. **Resultados:** Constatou-se que a rede social é composta pela família e, principalmente, pelos profissionais de saúde e de assistência social em instituições de referência como a Associação de Pais e Amigos dos Excepcionais. **Conclusão:** As redes de apoio são imprescindíveis para que as famílias de crianças com paralisia cerebral possam cuidar adequadamente de seus filhos. Os profissionais de saúde podem prestar orientações sobre as necessidades da criança e suporte para o cuidado familiar.

**Descritores:** Paralisia cerebral, apoio social, família, criança, enfermagem.

## RESUMEN

**Objetivo:** Conocer las redes de apoyo social de las familias de niños con parálisis cerebral. **Métodos:** Estudio cualitativo, exploratorio y descriptivo, realizado en la Asociación de Padres y Amigos de los Excepcionales, de municipio situado en el sur de Brasil, con madres y padres de niños con parálisis cerebral. La recolección de informaciones ocurrió entre abril y mayo/ 2017, por medio de entrevistas. Se respetaron todos preceptos éticos establecidos por la resolución nº. 466/12. **Resultados:** Se constató que la red social está compuesta por la familia y, principalmente, por los profesionales de salud y de asistencia social en instituciones de referencia como la Asociación de Padres y Amigos de los Excepcionales. **Conclusión:** Las redes de apoyo son imprescindibles para las familias de niños con parálisis cerebral puedan cuidar adecuadamente de sus hijos. Los profesionales de salud pueden proporcionar orientación sobre las necesidades del niño y el apoyo al cuidado familiar.

**Descriptores:** Parálisis Cerebral, Apoyo Social, Familia, Niño, Enfermería.

## INTRODUCTION

The birth of a child impacts both the life of the parents and the family, as there are many expectations about the new family member.<sup>1</sup> When the child is diagnosed with a chronic illness, the impacts become even greater for the child family, and when the diagnosis is cerebral palsy, a family disruption occurs, and a reorganization is necessary to provide care for this child.<sup>2</sup>

The changes in the organization of life are most evident in the daily lives of families living with a cerebral palsy bearing child. The existence of a childhood illness, in this context cerebral palsy, demands care that can be influenced according to the availability of the social and psychological resources that the family possesses, causing to its members some situations in which they feel vulnerable, mainly in the social component. This concerns the acquisition of information, the ability of people to synthesize such information and incorporate it into their daily activities, not only depending on individuals, but also access to the media, schooling, living conditions, health services, material resources, confrontation of cultural barriers, among others.<sup>3</sup>

In this regard, there is a need for the family to have a

social support network that will support the coping of this transition.<sup>4</sup> Considering that one of the greatest social problems in situations in which society conceptualizes cerebral palsy as an incapacity, defining the child as synonymous with limitations, in which, frequently, the conception is more serious than the problems that the child actually presents.<sup>5</sup>

Nonetheless, social support networks are important for the guidance and behavior that family members need to adopt. Yet, it is necessary to differentiate the concepts of network and social support. Social support is defined as the personal dimension, which consists of the resources provided by members of the social support network, which bring physical, emotional and behavioral benefits. The design of a network of social support is attributed to structures or institutions linked to the individual or to families in which interpersonal exchanges have been declared important to family members.<sup>6,7</sup> So, they constitute care that contributes to the maintenance of the health in times of stress, helping to overcome the experienced events.<sup>5</sup>

Hence, the presence of the family is fundamental so that the child with cerebral palsy can develop properly, however, this family needs an organized social network. This social support network can be understood as any assistance that provides support at home, school, institutional, among others.<sup>8</sup>

Therefore, the social support network is indispensable so that it is possible to promote family support at different times, and health professionals must be vigilant in order to be able to work together with the family on strategies to strengthen coping methods.<sup>4</sup> A study about the social support network for the families of children bearing cerebral palsy reports that the support provided by the health team is important in the routine of care that the family provides to the child, as it alleviates the burden of family members by giving them emotional support. Furthermore, it reduces the doubts that arise concerning cerebral palsy, allowing the reception and generating a sense of security, which contributes to the improvement of life of the main caregiver.<sup>9</sup>

It is necessary for families to have an understanding of the social support networks they have, since such conditions interfere with the health of the child. By having the social support, families can express the difficulties they encounter in caring for a child with cerebral palsy, thereby facing such difficulties, since, without the support, feelings of helplessness, anguish, and distress arise.<sup>7</sup>

Considering the aforementioned, the study's purpose was to know the social support networks of families of children bearing cerebral palsy.

## METHODS

The birth of a child impacts both the life of the parents and the family, as there are many expectations about the new family member.<sup>1</sup> When the child is diagnosed with a

chronic illness, the impacts become even greater for the child family, and when the diagnosis is cerebral palsy, a family disruption occurs, and a reorganization is necessary to provide care for this child.<sup>2</sup>

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In this regard, there is a need for the family to have a social support network that will support the coping of this transition.<sup>4</sup> Considering that one of the greatest social problems in situations in which society conceptualizes cerebral palsy as an incapacity, defining the child as synonymous with limitations, in which, frequently, the conception is more serious than the problems that the child actually presents.<sup>5</sup>

Nonetheless, social support networks are important for the guidance and behavior that family members need to adopt. Yet, it is necessary to differentiate the concepts of network and social support. Social support is defined as the personal dimension, which consists of the resources provided by members of the social support network, which bring physical, emotional and behavioral benefits. The design of a network of social support is attributed to structures or institutions linked to the individual or to families in which interpersonal exchanges have been declared important to family members.<sup>6,7</sup> So, they constitute care that contributes to the maintenance of the health in times of stress, helping to overcome the experienced events.<sup>5</sup>

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Therefore, the social support network is indispensable so that it is possible to promote family support at different times, and health professionals must be vigilant in order to be able to work together with the family on strategies to strengthen coping methods.<sup>4</sup> A study about the social support network for the families of children bearing cerebral palsy reports that the support provided by the health team is important in the routine of care that the family provides to the child, as it alleviates the burden of family members by giving them emotional support. Furthermore, it reduces the doubts that arise concerning cerebral palsy, allowing

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## RESULTS AND DISCUSSION

The ten participants were within the age group from 27 to 49 years old, seven of them aged 41 to 49 years old and three from 27 to 32 years old. Regarding the number of children, one of the participants had a child; five had two children and three had three children, six of whom were children and three were adolescents. The predominant religion was Catholic, with three participants; two were Spiritists, two Umbandists, two Evangelicals and one said that they had no religion. In terms of family income, five participants have an income of up to one minimum wage (R\$ 937.00), one has two minimum wages (R\$ 1,874.00) and three have three minimum wages (R\$ 2,811.00). Three participants were married, one had a common-law marriage, one was divorced, and three were single. Considering the schooling, one participant had not completed the elementary school, three had completed elementary school, one had incomplete high school and five had completed high school.

In analyzing the support networks used by the family of the child bearing cerebral palsy, it was verified that the social network is composed by the family and, mainly, by health professionals and social workers in institutions of reference such as the APAE in question, which is composed by a team with physiotherapist, doctor, social worker, and pedagogue, as can be seen in the following statements:

*We look for resources, a health plan for her, but I prefer APAE [...] it was where I saw evolution (F1)*

*I've been using APAE since he was 2 years old, he's got everything from speech therapists, physiotherapy, pedagogy, equine therapy [...] since he came in, he's always gotten better (M2)*

*As soon as I knew I went to the APAE, here it has everything (M4)*

*Here at APAE they explain everything, they were very attentive (M5)*

*With 2,5 years old I brought to APAE, and we are here today [...] it's a great place (M6)*

*I only use the APAE, she does everything here [...] is very well assisted, I owe my daughter's evolution to APAE (M7)*

*In the APAE they provide the possible and the impossible (M8)*

Participants refer to *APAE* as a place that provides comprehensive child and family care, since there is full support from the institution, helping build trust between families and the professionals who work there. Families in this study understand the *APAE* as a social support network, a place where they find help in the rehabilitation and care of children with special needs.

Other researches have also described *APAE* as social support centers, where there is prevention, treatment, and promotion of the quality of life of children bearing cerebral palsy and their family. These support networks can be easily accessed and help the family by minimizing care overload.<sup>9,13</sup>

Families also find instrumental assistance in the service, which refers to practical services such as transportation, housing, among others; information, which provides assistance in solving problems, communication, and information; and emotional, which seeks care, such as attention, love, empathy, and trust.<sup>14</sup> This network is so significant that it makes a difference in the way the family will cope with the chronic condition of the child.<sup>8</sup> Given that quality of children bearing cerebral palsy and their families is not always directly related to the severity of the disease but also to the physical well-being of the parents, social welfare, freedom and independence, family well-being and financial stability.<sup>15</sup>

Children attending institutions of reference to treat and monitor cerebral palsy receive all the support necessary to stimulate cognitive and physical development. This type of assistance is the responsibility of health professionals, since they are trained to carry out these activities.<sup>7</sup> In addition to helping to develop the potential and skills of the child with cerebral palsy, the professionals of these institutions also welcome families, by creating bonds with them.<sup>9</sup> Support networks are a care mechanism that can facilitate and adapt the responses of families throughout the time care for the child bearing cerebral palsy is provided.<sup>15</sup>

During the interviews, it was possible to perceive that the participants have the institution as a reference, with regard to the care given to themselves, as well as the children with special needs. This relationship is only possible through the dedication of *APAE* professionals, who mobilized to meet the demands of anxieties, fears, sorrows, and fears. In addition to keeping parents informed and informed about how certain situations should be handled,

the care of health professionals can contribute positively to reducing the impact caused by the child's diagnosis, as they favor a broader view, showing not only the fragilities and the limitations, but highlighting the potential that this child can develop, and this interaction contributes to the formation of the bond between family and child.<sup>9</sup>

The strengthening of family relationships can help at this moment, making everyone have a commitment to care, so that there is such involvement, the family must be prepared to face the condition of the child. Therefore, it is important that everyone searches for information in order to contribute positively to coping with the chronic condition of the child.<sup>5</sup> In order to make it a reality, continuous learning is necessary, both in relation to the pathology and situations of vulnerability, so that it is possible to identify these situations by acting effectively against them.

Throughout the interviews, it was possible to understand the importance of family support in the care of the child bearing cerebral palsy, because when the family members help, the parents can rest and reduce the overload.

*We keep going, we do whatever we can [...] everyone helps, the family helps a lot (M1)*

*My family is very supportive; everyone helps a little (M2)*

*Help me a lot; I've always had a lot of support from my family (M3)*

*Total support, my son, my husband, everyone helping together (M7)*

In those reports, there is a commitment on the part of the family in relation to the care of the child with cerebral palsy, in which each member has a fundamental role, such commitment helps to have a balance in the responsibilities. The family is indispensable for overcoming problems, as it is one of the most important networks of social support, especially in difficult times, helping, providing emotional, instrumental and spiritual support.<sup>8</sup>

Bearing the aforementioned in mind, family support is so significant because this support can make all the difference in the way the family meets the special needs of the child.<sup>8</sup> This is one of the most positive aspects when it comes to a child with cerebral palsy because having support among family members helps with acceptance and daily care. It is known that the focus of care should be the child, but for this to happen, the needs of the family must appear as an investment in this care, showing the importance of family involvement.<sup>14</sup>

Caring for a child with a chronic disease, especially with cerebral palsy, can generate demands on the family, requiring a redefinition of roles so that there is no overload of the main caregiver. So, all family members need to reorganize

in order to be able to help, often this reorganization is to support the primary caregiver so that he can devote himself to the care of the child.<sup>16</sup> The family of the child bearing cerebral palsy may show signs of depression and dissatisfaction with life.<sup>17</sup>

The main social support network is family, since it is the social unit closest to the parents and the child, and it is from this that support is expected to face difficulties.<sup>18</sup> The family cares for its members, not only to provide or to reestablish the health condition, but also of his life. This occurs through affective interactions for mental and personality development, daily learning with the body and surrounding environment, as well as care in the circumstance of illness,<sup>19</sup> nurturing with affection and security and showing that suffering and overload can be shared, by sharing of tasks.<sup>9</sup>

All times when the family is assisted by relatives who are in a family relationship are using family social support to deal with temporary difficulties.<sup>4</sup> The families of children bearing cerebral palsy find family protection personal protection, thus the importance of this network is strengthened. Despite this, some of the participants reported not having a close family support network, as can be seen in the lines:

*No, I do not have family assistance, [...] it was complicated (M5)*

*The family helped a bit, but not much, I do most of the things (M6)*

*Nobody helped me a lot, people think they help, but in the end, it's all up to you (M8)*

*I went alone, 99.9% alone, even my husband he supported me morally let's say, because I went alone with her (M9)*

The reports show that care is usually focused on the mother, who takes responsibility for primary care and is often the only one the child will have. Thus, the person who is usually more demanding and more involved in the role of caregiver is the mother, since care is understood as something natural and integrated with her tasks. Although the social support network is fundamental to the primary caregiver, this mother rarely has someone with whom she can share this care, being the only person to develop it with the child.<sup>9,20</sup>

Accordingly, the process of caring for the child bearing cerebral palsy requires caregiver concern, responsibility, and affective involvement. There are women who, even without support, are able to cope with the situation by creating care strategies. However, caregivers are not always able to provide effective care, so they end up giving up their own lives for their children because they can not reconcile all their tasks with this specialized care, once their activities

begin to diminish and/or are completely suppressed, due to the impediments determined by care.<sup>9</sup>

Given the aforesaid, the lack of support causes the caregiver to go through difficult moments that can lead to a very high level of stress and exhaustion, leading to physical and emotional shocks.<sup>21</sup>

In this framework, social support can facilitate the life of these people, enabling them to have a good quality of life and provide well-being to the child bearing cerebral palsy. Another point worth mentioning is that, in some cases, the support of the child's father has diminished over time, as can be seen in the following statements:

*He was present until she was 4 years old, helping me, [...] then he left (M3)*

*Until about 5 years old he brought her and so on, 8 years ago he is no longer coming (M6)*

*He stayed with me, sought resources, after a while, we separated [...] and he has abandoned us (M8)*

## CONCLUSIONS

Herein, it was possible to identify the social support networks of the families of the children bearing cerebral palsy, being composed by relatives and professionals of the APAE. This Association prioritizes the care of children bearing cerebral palsy and their families, based on their needs, allowing the establishment of effective links, valuing the uniqueness and the historicity of families and, thus, either reducing or minimizing the situations in which families feel vulnerable. It is underlined that this relationship assists from the revelation and understanding of the diagnosis to the acceptance and care of this child.

It is hoped that this study will make health professionals ponder a bit more, especially nurses, in order to rethink the care provided to families of cerebral palsy bearing children. From this, it can identify the fragilities that permeate the social support network, rethinking its commitment as a member of an institution that serves the health of the population. Hence, collaborating with a process of behavioral development, especially regarding the dialogue between health professionals and the family of the child bearing cerebral palsy, so that they understand the whole process that involves the care of this child, aiming for a comprehensive care and a humane care to all involved.

It is possible to consider as a limitation of the study the non-insertion of all the family members, therefore, it is recommended to carry out research that gives voice to the other members of the family of the child bearing cerebral palsy, as well as to the members of the network of social support, stimulating reflections to rethink the care given to the family of the child with cerebral palsy. Having in mind that it is a qualitative study, it does not claim generalizations;

however, despite analyzing a specific reality, it might be useful for the elaboration of support strategies in other contexts of care for the families of cerebral palsy bearing children.

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