

## ORIGINAL ARTICLE

## UNIQUE EXPERIENCES OF HEALTH PROFESSIONALS IN THE SOCIAL SUPPORT NETWORK FOR CHILDREN WITH CEREBRAL PALSY

Meryeli Santos de Araújo Dantas<sup>1</sup>, Egmar Longo<sup>2</sup>, Kátia Suely Queiroz Silva Ribeiro<sup>3</sup>, Maria Adelaide Silva Paredes Moreira<sup>4</sup>, Altamira Pereira da Silva Reichert<sup>5</sup>, Neusa Collet<sup>6</sup>

### ABSTRACT

**Objective:** To gain knowledge on the experiences of health professionals in the social support network of children with cerebral palsy.

**Methodology:** Descriptive study with a qualitative approach with eight mothers and one grandmother in a school clinic and institution for disabled people, from October 2015 to May 2016, through semi-structured interviews. Interpretation was based on thematic analysis and on the concepts of Emmanuel Lévinas.

**Results:** The stress experienced by health professionals often affects the relationship health team-child and family, generating distrust and lack of commitment between them. Trust is placed in rehabilitation professionals and weakness is perceived in the relationship with professionals of the Family Health Strategy (ESF).

**Conclusion:** The experiences of health professionals in the social support network for children with cerebral palsy show that these professionals must respect the situations in which the Other is involved, in order to adjust treatment goals according to the needs of the Other.

**DESCRIPTORS:** Cerebral palsy; Health professionals; Childcare; Family; Social support.

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<sup>1</sup>Physiotherapist. PhD, Nursing. Professor from Centro Universitário de João Pessoa. João Pessoa, PB, Brazil. 

<sup>2</sup>Physiotherapist. PhD, Advances in the Investigation of Disabilities. Professor from Universidade Federal do Rio Grande do Norte. Nova Cruz, RN, Brazil. 

<sup>3</sup>Physiotherapist. PhD, Education. Professor from Universidade Federal da Paraíba. João Pessoa, PB, Brazil. 

<sup>4</sup>Physiotherapist. PhD, Health Sciences. Professor from Universidade Federal da Paraíba. João Pessoa, PB, Brazil. 

<sup>5</sup>Nurse. PhD, Children's and Adolescents' Health. Nursing Professor from Universidade Federal da Paraíba. João Pessoa, PB, Brazil. 

<sup>6</sup>Nurse. PhD, Nursing. Nursing Professor from Universidade Federal da Paraíba. João Pessoa, PB, Brazil. 

## VIVÊNCIAS SINGULARES DE PROFISSIONAIS DE SAÚDE NA REDE E APOIO SOCIAL À CRIANÇA COM PARALISIA CEREBRAL

### RESUMO

*Objetivo:* compreender as vivências dos profissionais de saúde na rede e apoio social à criança com paralisia cerebral.

*Metodologia:* estudo descritivo, qualitativo, realizado com oito mães e uma avó em clínica escola e instituição à pessoa com deficiência, de outubro de 2015 a maio de 2016, por meio de entrevista semiestruturada. Interpretação balizada pela análise temática e fundamentada nos conceitos de Emmanuel Lévinas.

*Resultados:* é comum estresse dos profissionais afetando a relação equipe-criança e família, gerando desconfiança e falta de compromisso entre estes. Deposita-se confiança nos profissionais de reabilitação e há fragilidade na relação com profissionais da Estratégia Saúde da Família.

*Conclusão:* as vivências dos profissionais de saúde na rede e apoio social à criança com paralisia cerebral demonstram que esses devem respeitar as situações em que o Outro está enredado, de modo a ajustar as metas do tratamento de acordo com a necessidade do Outro.

**DESCRIPTORIOS:** Paralisia cerebral; Profissionais de saúde; Cuidado da criança; Família; Apoio social.

## VIVENCIAS RARAS DE PROFESIONAJS DE SALUD EN LA RED Y APOYO SOCIAL AL NIÑO CON PARÁLISIS CEREBRAL

### RESUMEN

*Objetivo:* comprender las vivencias de los profesionales de salud en la red y apoyo social al niño con parálisis cerebral.

*Metodología:* estudio descriptivo, cualitativo, que se realizó con ocho madres y una abuela en clínica escuela e institución para personas con discapacidad, de octubre de 2015 a mayo de 2016, por medio de entrevista semi estructurada. La interpretación fue hecha por análisis temática y fundamentada en los conceptos de Emmanuel Lévinas.

*Resultados:* es común que el estrés de los profesionales afecten la relación equipo-niño y familia, lo que puede generar desconfianza y falta de compromiso entre estos. Hay confianza en los profesionales de rehabilitación y fragilidad en la relación con profesionales de la Estrategia Salud de la Familia.

*Conclusión:* las vivencias de los profesionales de salud en la red y apoyo social al niño con parálisis cerebral muestran que esos deben respetar las situaciones en que el Otro está, de modo a ajustar las metas del tratamiento de acuerdo a la necesidad del Otro.

**DESCRIPTORIOS:** Parálisis cerebral; Profesionales de salud; Cuidado del niño; Familia; Apoyo social.

## INTRODUCTION

Cerebral Palsy (CP) is a disorder of the development of movement and posture, causing activity limitations attributed to non-progressive disturbances of the fetal or infant brain that may also affect sensation, perception, cognition, communication, and behavior skeletal muscle, among others<sup>(1)</sup>.

CP is considered the most common physical disability in childhood, which requires greater adaptation in the family environment, such as the building of a social support network to cope with situations imposed by disability. A study<sup>(2)</sup> with school-age children reported the estimated prevalence of children with CP in 3.6 cases out of 1,000, and thus the condition is a disabling chronic childhood disorder, which generally requires ongoing and routine family care and assistance from health care services.

Several studies are being conducted on social networks, with focus on the benefits of social support provided by the interaction of people in the health care area. Because they have common interests and actions, or due to the imposition of a formalized structure of work, people can act on behalf of others, either because they have common interests and actions, or due to the imposition of a formalized structure or work, providing support to some functions or solving problems. Just as social networks can be associated with health recovery and disease prevention, lack or insufficient support can have negative implications for people's lives<sup>(3)</sup>.

In their care for children with cerebral palsy, families find in the social support network a strong ally to overcome the difficulties that arise in the course of the disease<sup>(4)</sup>. In this process, mothers play a key role in the growth and development of their children<sup>(5)</sup>. Thus, having the support from professionals from health facilities that provide care to children with special needs, religious institutions, and families is important for coping with the disease, family restructuring and easing the physical and emotional burden of caregivers, improving their quality of life<sup>(6)</sup>.

Studies on health professionals regarding the construction of a social support network to the family of children with CP are relevant, as they may contribute to the improvement of the quality of care provided to the families and the children.

Based on this scenario, the following question is posed: how do families of children with cerebral palsy perceive the experiences of health professionals in the social network regarding care to these children? Thus, the present study aims to understand the unique experiences of health professionals in the social network regarding care to children with cerebral palsy.

## METHOD

Descriptive study with a qualitative approach conducted from October 2015 to May 2016 with nine families of children with cerebral palsy assisted in a school clinic and institution that is a center for referral for support to disabled people, in Paraíba. Data was collected through semi-structured interviews.

The following inclusion criteria were defined: being a parent and/or primary caregiver of a child with any type and degree of CP who was assisted at the institutions investigated; child up to 12 years old, since according to Brazil's Child and Adolescent Statute, in its Article 2, a child is considered to be a person less than 12 years of age; and living in the municipality of João Pessoa. Exclusion criteria were being father, mother and/or primary caregiver of a child with CP who had cognitive and communication disorders and children who had not a final diagnosis of CP.

The present study complied with the requirements of Resolution 466/12 of the

National Health Council of the Ministry of Health, and the project was approved by the Ethics Committee of the Federal University of Paraíba, under protocol no 1,157,717. The participants agreed to participate in the study by signing the Informed Consent Form. Data collection (interviews) was discontinued after data saturation to avoid redundancy.

For data collection, a semi-structured interview guide was used. The guiding question was: How do you perceive the experience of health professionals in the health care network for your child with CP? The interviews, which lasted in average 30 minutes, were recorded and transcribed in full. Thematic analysis was used for data interpretation, according to the following steps: pre-analysis, where there is a first contact with the collected material, selection of the material according to its relevance to the goal, free floating reading of the material to be analyzed and organization of this material; exploration of the material, which involves defining the units of analysis, (a word, a paragraph or a theme); classification, processing and interpretation of the results<sup>(7)</sup>. Interpretation was based on the concepts of Otherness and Co-responsibility of the Other, described by Emmanuel Lévinas.

From the perspective of a multidisciplinary team integrated to a network of care to children with cerebral palsy, Lévinas' philosophy addresses the exteriority in the relations with the Other and that is not limited to the Self. In this relation, the Other is perceived in its whole alterity, and presents itself as the Face, exceeding the "idea of the Other in me"<sup>(8)</sup>.

For Lévinas, the Other has a Face and this Face speaks. The Face speaks because the encounter of the Other with the Self occurs through the Face that initiates the discourse, installing a responsibility for the Other in the Self<sup>(9)</sup>.

According to this perspective, taking care of the Other requires that the technical and scientific knowledge of health professionals meets the demands of the Other, and that public policies should always ensure high quality services<sup>(10)</sup>. Some children with CP have a poor prognosis, with difficulty in performing daily living activities, such as self-care, hygiene and social interaction. Therefore, they need special care provided by a special multidisciplinary team, focused on the delivery of care to the children and their families<sup>(11)</sup>.

To ensure the anonymity of the participants, their statements were identified by letter F (for the identification of the participant's family) followed by the interview order number. The institutions cited by the mothers were identified by random letters such as X, Y, Z, W, O, M, B.

## RESULTS

Nine families of children with CP participated in this study, and the relatives interviewed were eight mothers and one grandmother, totaling nine families. The ages of the respondents ranged from 22-42 years, and most of them were married. Among the participants, four completed 9 years of schooling; three had completed 16 years of schooling; one had 14 years of schooling, and one had completed 5 years of schooling.

Seven respondents did not work outside the home, and family income ranged from BRL 880.00 to BRL 4,500.00. Six of these families also received a Federal Government grant usually paid to families who had children with disabilities and/or who benefited from the Bolsa Família (Family Grant) program. Regarding the transportation means to move the children to the health care services, three respondents reported using vehicles provided by the municipal government or help from relatives and/or friends; three used public transportation, e.g. buses, and three used their own cars.

Regarding the characterization of the children investigated in this study, most (8) were classified as spastic quadriplegic CP, corresponding to level V of the Gross Motor Function Classification System (GMFCS), aged six months to 12 years, and who were 2 months to 4 years old when the diagnosis of CP was confirmed.

Health professionals should actively participate in the construction of the social support network for children with CP, as empathy between professional and family facilitates communication, favors the delivery of accurate diagnosis and therapeutic indications. However, the respondents said that these health professionals were often stressed out because they have too many patients to see every day. This affects the team-child and family relationship, and makes the establishment of a bond to integrate this team as a member of the network difficult.

*Well, when we come to the appointment, the doctor is already stressed out. He asks us to be quick because there is a long line of people waiting outside. (F2)*

*The doctor wouldn't even look my boy in the eyes, would not ask us anything and would send us home. The appointments lasted about 15 minutes. It's hard for us to trust such a doctor. (F4)*

Due to the stress experienced during the care delivered in the appointments, the mothers expressed their feelings of distrust towards the health professionals, of dehumanization of health care and lack of commitment to care for the sick children, which caused these mothers to be angry with the health professionals.

*If the patient were her child or a relative, she [doctor] would treat the child differently, would investigate the situation better and, listen to me. You know, since the patient is not their son/daughter, they don't care (F1)*

*I think these inattentive people who are always in a bad mood shouldn't take nursing or medical courses. [...]Some professionals treat everyone badly because they are always stressed out. [...]Obviously, if I take my daughter to see the doctor, it is because she is sick, not healthy (F2)*

Despite the difficulties reported, the families are satisfied and feel safe with the care provided and the conducts of the health care team responsible for the rehabilitation of their children. The families' trust in the health team can facilitate the promotion of the children's development according to their potentialities, and are the most frequent bond perceived in the social network.

*Although I am a layperson, I always share my opinions about the therapy with them [the rehab professionals] and they listen, they do not react unpleasantly, as if I'm intruding. It's just that as I live with him [my son], I know some tricks that can help. (F1)*

*Here, in institution X I feel more supported, I seek help and people are responsive. I can watch my child's therapy sessions, if I want, and thus be able to conduct them at home later (F7)*

In a health service that provides high quality care, where families of children with CP feel welcomed and supported, the respondents explained their expectations regarding health professionals and the care received.

*To pay attention to the patient, to ask questions, to talk to him/her, to know their routine, [...].And I believe their concern shows that they provide a better health service [thinking] that is more considerate toward the patients and their mothers. Consideration toward patients makes all the difference. (F4)*

Since the rehabilitation of a child with a clinical diagnosis of CP takes a long time, and rehabilitation professionals often spend long years caring for these children, it is important that families be included in this therapeutic process. Therefore, a good relationship between family and health professionals is essential to ensure continuous care at home and promote high quality of life for both the children and their families.

However, lack of empathy of health professionals was also reported in one rehabilitation institution. The referred institution does not allow the families to witness

the therapy sessions of their children, and thus, they do not perceive the families as a collaborator and co-participant in the process.

*I am very disappointed with the care provided by institution Z because I am not allowed into the rehabilitation room. I can't see what my daughter does during physical therapy, speech therapy and occupational therapy. No one explains anything to me. [...] And I really want to see what the professionals do, how they manage to make my daughter sit down. (F7)*

The perspective of care for the Other and family participation in the therapeutic process was disregarded. The family excluded from this process does not perceive the health care team as an ally in the building and strengthening of the social network.

As the child grows up after a long period of rehabilitation, it becomes clear that some goals set by the health care team were not achieved due to the child's clinical condition. It is at this very moment that parents face difficulties in pursuing the rehabilitation treatment and fear for the future of their children.

*My son has been receiving care at the medical school for several years, and as we all know, when a child who has been assisted for several years gets older, it is more difficult to pursue the therapy sessions, because the waiting list is long. The professionals prioritize younger children. It is as if my child no longer needs rehabilitation (F4)*

*When my son was younger, there was always someone available for his rehabilitation sessions. Now, it is difficult. [...] they say he is very big, heavy [...] We begin to realize what is happening.. and that there is no hope for our children, because even health professionals no longer have hope in them. (F8)*

The role of the social network, particularly of the professionals involved in the monitoring and rehabilitation process of children with CP is crucial, because the families are not aware of the real clinical status of their children, especially after the passing of several years, and they believe that the goals set at the beginning of the rehabilitation therapy should be maintained throughout the lives of the children. As the children grow, they face different problems and the family must be aware that the goals of the treatment are different from those established in the beginning of the treatment, and there is little possibility of major changes in the health status of the patients.

The statement made by F8 reveals the feeling of hopelessness experienced by the families at this point of the rehabilitation program, because care for their children is no longer a priority. Thus, an effective social network is then more than ever necessary.

In the construction of the network of care for children with CP, some weaknesses in the family's relationship with the professionals of the Family Health Strategy (ESF) emerge, as follows: weak relationships; lack of bond and low resolution of care; lack of integral, comprehensive care.

*In my opinion, an effective ESF service should have a doctor available every day of the week, because if the idea is to have a family doctor, this professional must get in touch with the families, to get to know them. [...]. (F5)*

*I don't know the ESF very well. I only go there to weigh, measure and vaccinate my son. If necessary, I see a neurologist or a hospital doctor. (F6)*

Health professionals must provide comprehensive care to children with CP and their families: social, psychological, emotional and physical care, responding to their needs, especially because the appointments are often focused on the disease, and a more comprehensive care is neglected. We stress that health services should perceive users as agents entitled to choose, valuing their autonomy, feelings and needs.

## DISCUSSION

Lack of interactive dialogue between health professionals and families of children with CP, in which there is no active listening and no exchange of information due to the distance between these professionals and the families is a stressor. It should be mentioned that such distance does not promote confidence and does not allow for alterity in care <sup>(12)</sup>. For Lévinas, consciousness arises from the moral awakening of subjectivity conceived as hospitality and in relation to others <sup>(13)</sup>. A fragile and superficial type of care does not allow hospitality, revealing deterioration at this stage of childcare <sup>(12)</sup>.

According to Lévinas, thinking about hospitality means thinking about the Other. For this hospitality to occur, bonds must be created with the Other and a relationship based on ethics must be established. Such a bond only occurs when the Other feels safe and welcomed through an act of hospitality <sup>(14)</sup>.

The relationship between health professionals and families should be mediated given that they are all human beings who have acquired considerable knowledge and information, and that the knowledge of one of the parties complements the knowledge of the other party <sup>(2)</sup>. Health professionals must understand that the Other is not empty, but filled with stories. Therefore, the Other must have the right to show his/her Face, without preconceptions and pre-judgments <sup>(14)</sup>.

The families explain that the therapeutic care delivered by rehabilitation team professionals is welcoming and meets the expectations of the family. One study <sup>(15)</sup> showed that children with cerebral palsy need prolonged rehabilitation assistance, and a good relationship between professionals, children and families is necessary for the achievement of therapeutic goals.

Since the purpose of the health service is to take care of the Other, the relationship between the Self (health professionals) and the Other (family) should favor the alterity of the Other and not the Self. According to a study <sup>(16)</sup> empathy is essential for ensuring continuous care, since as soon as we are able to feel and show empathy towards the other, a connection is established between the two parties, and exchanges are easier.

During the transition of children with CP to adulthood, their parents become worried about the evolution of their child's clinical condition and prospects. They also experience feelings of sadness and are stressed out because of the situations imposed by the disability, their need for support and coping strategies <sup>(17)</sup>.

Rehabilitation processes for individuals with CP in adulthood are frequently discontinued <sup>(18)</sup>. As it is highlighted in one study <sup>(19)</sup>, health professionals must focus on strategies that promote secondary prevention by developing approaches that help individuals overcome personal and environmental barriers to an active lifestyle.

In order to operationalize the actions of health professionals targeted to the priorities of the families, the actions coordinated by the Family Health Strategy team involve extended family care, so that the interventions may impact the health-disease processes, both individually and collectively <sup>(20)</sup>.

It is important to stress the unequal distribution and the difficulty to retain health professionals in Brazil, especially in primary care, which are perceived as important challenges for improving the quality and access to health care <sup>(21)</sup>.

To ensure compliance with the principles of the Unified Health System (SUS), the Ministry of Health established Primary Care as the preferred entry point to the SUS and as a communication center of the Health Care Network. In Brazil, compliance with the principles of the SUS requires an integrated action of the health care team with the families, communities and the available social facilities <sup>(21)</sup>. Weaknesses were detected in the care for children with chronic diseases in primary care.

A study on care to children with disabilities in Primary Health Care found weaknesses in the actions targeted to these children, where principles and foundations of primary care, such as the coordination of care and the construction of an integrated comprehensive family and community-oriented care are not applied<sup>(22)</sup>.

A study on Family Health Support Centers and their potentials and obstacles proposes the expansion of Family Health teams, operationalization of specialized outpatient services in the SUS, in order to improve care and minimize the suppressed demand in the system<sup>(23)</sup>.

The Brazilian Public Health System (SUS) has undergone major changes over the years, and it is obviously necessary that public managers are aware of the problems to be faced, demonstrate agility and flexibility and are able to plan, structure, organize and evaluate the actions implemented in this process, in order to contribute to the development of new policies and projects capable of intervening on the health status of the population<sup>(24)</sup>.

In the health work process, the subjects of action - health professionals - are the agents responsible for the integration of the constituent elements of this process, mediating the relations between the instruments and the subjects-objects of the intervention and hence developing a project that is mediated by the intersubjectivity of the subjects involved<sup>(25)</sup>.

The referred authors also affirmed that welcoming - a professional-user interaction - is a positive aspect in health care. However, its implementation in the health care system is limited due to the lack of understanding of users and the excessive number of patients, which has a negative impact on the work process of the multidisciplinary team<sup>(25)</sup>.

One limitation of this study is the fact that some mothers did not have enough time for the interviews, as they were only available during the children's therapy sessions. In some cases, the interviews were interrupted sooner than expected and resumed on the subsequent session.

## CONCLUSION

The present study found that the families need to understand what is happening with their children, as well as be informed about the procedures and the clinical status of the patients, because based on this information, the parents and the childcare team can identify any signs of abnormal neuropsychomotor development. When such information is not available, the families face the diagnosis alone and tend to rely on the opinions of individuals in their communities and of people who have been through similar situations.

Gaps were identified in the care of children with CP within the scope of the FHS. These gaps are related to the weak relationships, lack of bond and low resolution, which does not favor the delivery of integral care in this sector.

The strengthening of this care network depends on welcoming attitudes, expressed in words, gestures, behaviors and expressions that come from the Other. Caring for someone involves the creation of bonds, individualization of the Other, taking responsibility for and meeting the needs of the Other. This is only possible if the knowledge of the Other is respected, so that both provide together the care needed by the child, since trust in the health team should be one of the links of the care network, favoring the child's development and family coping.

The present study may contribute to raise awareness among health professionals who assist children with CP and their families of the need to develop in their daily practices welcoming attitudes, bonds, humanization and responsibility towards children with PC, as well as towards their families, contributing to the qualification of care.

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Corresponding author:

Meryeli Santos de Araújo Dantas

Centro Universitário de João Pessoa

R: Anastácio Camilo de Oliveira, 105 - 58037-318 - João Pessoa, PB, Brasil

E-mail: meryeliaraujo@hotmail.com

**Role of Authors:**

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