

Family caregivers articulating the social network of a child with special health care needs

Familiares cuidadores articulando rede social de criança com necessidades especiais de saúde
Cuidadores familiares articulan red social de niño con necesidades de asistencia especiales de salud

Ivone Evangelista Cabral¹, Juliana Rezende Montenegro Medeiros de Moraes¹

¹ Universidade Federal do Rio de Janeiro, School of Nursing Anna Nery,
Maternal and Child Nursing Department. Rio de Janeiro, Brazil.

How to cite this article:

Cabral IE, Moraes JRMM. Family caregivers articulating the social network of a child with special health care needs.
Rev Bras Enferm. 2015;68(6):769-76. DOI: <http://dx.doi.org/10.1590/0034-7167.2015680612i>

Submission: 04-01-2014 Approval: 08-04-2015

ABSTRACT

In Brazil, studies rarely address the social network of a child with special health care needs (CSHCN). **Objective:** the study sought to characterize the social network of the child and analyze the role of the family in its creation. **Method:** a qualitative approach was developed through five dynamics (Speaking Map) based on the creative sensitive method, with five groups of families (12 participants) in their homes. **Results:** the critical discourse analysis of the caregivers (grandparents, siblings and neighbors) showed that the mother plays the main role in articulating the social network, with its points being linked by the hospital, primary and rehabilitation care, household, school, etc. Familial care becomes more visible at home and within the community. **Conclusion:** with the insufficient public policy that articulating healthcare facilities for CSHCN in the community, family members shape a social network characterized by a dense and fluid mesh.

Key words: Child Health; Social Network; Nursing Care.

RESUMO

A rede de atenção à criança com necessidades especiais de saúde é restrita e pouco abordada no Brasil. **Objetivos:** caracterizar a rede social de criança com essa condição de saúde e analisar o papel da família na sua constituição. **Método:** abordagem qualitativa desenvolvida com cinco dinâmicas Mapa Falante do método criativo sensível, com cinco grupos familiares (12 participantes), realizadas em seus domicílios. **Resultados:** a análise crítica do discurso de cuidadores (avós, irmãos e vizinhos) apontou a mãe como a principal articuladora da rede social cujos pontos eram unidos pelo hospital, Programa Médico de Família, reabilitação, domicílio, escola etc. O cuidado familiar adquire maior visibilidade no domicílio e na comunidade. **Conclusão:** na ausência de políticas articuladoras dos cuidados em saúde na comunidade, os familiares conformam uma rede social de malha densa e fluida.

Descritores: Saúde da Criança; Rede Social; Cuidado de Enfermagem.

RESUMEN

En Brasil, rara vez estudios abordan la red de atención al niño con necesidades de asistencia especiales de salud. **Objetivo:** caracterizar la red social y analizar el rol de la familia en su constitución. **Método:** enfoque cualitativo desarrollado con cinco dinámicas (Mapa que Habla) del método creativo sensible, con cinco grupos familiares (12 participantes), en el hogar de los grupos de familias. **Resultados:** el análisis crítico del discurso de abuelos, hermanos y vecinos señaló la madre como el articulador principal de la red cuyos puntos fueron el hospital, atención primaria, rehabilitación; hogar, escuela etc. **Conclusión:** el cuidado de la familia fue mas visible en el hogar y comunidad. En la ausencia de políticas que articulan la atención de la salud comunitaria, miembros de la familia configuran una red social de malla densa y fluida.

Palabras clave: Salud del Niño; Red Social; Cuidado de Enfermería.

CORRESPONDING AUTHOR Ivone Evangelista Cabral E-mail: icabral44@hotmail.com

INTRODUCTION

Children with special health care needs (CSHCN) encompass those with a higher risk of presenting a physical, behavioral, emotional, chronic or development condition and of needing a network of specialized health services, more than other children in general⁽¹⁻²⁾.

Child health indicators in Brazil reveal a decrease of infant mortality rate and a 3.1-year increase in life expectancy over a decade. In 2011, Brazil achieved a target 4 of the Millennium Development Goal related to childhood with 15.3‰ child mortality rate. In spite of the decrease tendency due to the rate of 13.4 per 1,000 live births⁽³⁻⁵⁾ in 2013, the infant mortality rate in Brazil is still challenging in comparison with other countries of the Americas with universal health care systems, such as Cuba (4.6 deaths per 1,000 live births) and Canada (5 deaths per 1,000 live births).

Many factors in the health sector contributed to this decrease, such as the improvement of life and nutritional conditions of Brazil's child population, income transfer programs, the expansion of primary health care with the implementation of programs and strategies to prevent avoidable deaths (National Immunization Program, National Breastfeeding Program, strategies for the integrated management of neonatal and childhood illnesses, Family Health Strategies, etc.) and the incorporation of prenatal and neonatal new technologies into the Brazilian Unified Health System (Sistema Único de Saúde/SUS) to manage acquired and congenital conditions, among other initiatives⁽⁶⁻⁷⁾.

On the other hand, among the children who survive, there was an increase in the number of those who started living with special health needs, demanding more healthcare network and more life-sustaining supplies. As a result, health services face more challenges to integrate the social network of the child⁽⁸⁻¹¹⁾.

Nowadays, CSHCN account for almost a quarter of Brazil's child population. In the last population census carried out by the Brazilian Institute of Geography and Statistics, the percentage of children under 14 years old with at least one type of handicap was 21.68%. A higher number of handicap children with was observed in regions with low-income families, revealing a strong correlation with life conditions⁽¹²⁾.

Brazilian studies have classified the health care demands of children with special health care needs (CSHCN) into five categories: developmental, technological, medication, modified daily life activities and mixed demands. The first category includes children with neuromuscular dysfunctions that require psychomotor and social rehabilitation; the second, children dependent on technology (semi-implantable catheters, with stomas, use of life-sustaining devices, etc.); the third, a pharmacological dependent (antiretrovirals, cardiotonics, neuroleptics, etc.); the fourth, those who depend on modifications on daily life care; and the fifth, children with a combination of one or more demands. The complexity of the care demands of the CSHCN entails the establishment of a social network composed of health services, family and community^(2,8-11,13-15).

The anthropological perspective of a network characterizes it as some social units or all social units (individuals or groups) with which a particular individual or group is in contact. When a social network is studied, it is necessary to understand a new organization principle of society, with the emergence of a collective value, not limiting the network to the family, but instead moving from it to the social collective level⁽¹⁶⁾.

Social networks are collective structures capable of making its subjects autonomous, empowered, reflective and caring in their actions and relationships, conscious of their behavior. Awareness is only obtained within a social health care network when the individual chooses and decides, with freedom instead of submission, becoming a subject. The network is constituted of relationships characterized by strong, weak, dependence or autonomous bonds^(14,17-19).

Nevertheless, studies in Brazil focused on children with special health care needs rarely analyze the social network that provides comprehensive care for them. In this sense, this study sought to characterize the social network and analyze the role of the family in its creation in order to meet the demands for comprehensive care of the children with special health care needs, inside the health care network.

METHOD

A qualitative descriptive study was developed with the creative sensitive method that has been applied repeatedly since 1998 to studies about families with children with special health needs^(2,14-15,17-21). The epistemological basis is the critical reflection of participant research, the group dynamics of social psychology and the artistic creation of the art-based research. The foundation of the method is the dynamics of creativity and sensibility that combines artistic production with group discussion and participant observation⁽²⁰⁻²²⁾. During group research practices, that aim for alterity in the singular individual experience, this method favors the interaction of the researcher with participants that do not have enough vocabulary to express complex ideas. During the group meeting, the participant produces, attributes meaning to what they produce and gives new meaning to their statements, conveying internalized experiences from their social life and praxis. Gradually, subjective data emerge as something objective from the analysis of the artistic production.

The Creativity and Sensitivity Dynamics Speaking Map was selected due to the possibility of the participants singling out, in their artistic production, the locations and people that were part of the path of their experience. The socio-space dimension of the experience becomes visible on the drawings of the locations where people circulate⁽²⁰⁻²³⁾.

In the dynamics, each family member used colored pens and white cardboard sheets to draw their artistic production representing the network of relationships that is established within the community, guided by two questions that generate debate: Who are the people which take care of (your child) at home? To which places do you turn to when he or she needs care (health care, spiritual care, school care, etc.)? Then, the

production was presented, singling out the places and people that participated in the process of adapting the social network for the child with the special health care needs.

The research came to an end in 2012, and the field work stage was comprised of five group meetings, with the household of five groups of families of the city of Niterói (RJ) as research scenario, in a total of 12 participants (five mothers, one aunt, four grandmothers, one brother and one father), and they all were indicated by the families themselves. To select the participants, the inclusion criteria was being a family caregiver to a child with special health needs due to an acquired condition (epilepsy, cerebral palsy) or a congenital one (hydrocephaly, sickle-cell disease, cardiopathy), experienced in meeting their care demands (medication demands, modified usual demands, technological demands, development demands and mixed demands) and residing in the municipality of Niterói, in an area included in the Family Doctor Program (PMF- Programa Médico de Família). Participants under 18 years old were excluded.

The study was approved by the Ethics and Research Committee of the São Francisco Teaching Hospital/Anna Nery Nursing School (HESFA/EEAN). All participants signed the Informed Consent after learning the aims of the study and before the operationalization of the creativity and sensitivity dynamics. The meetings carried out in the households of the families were previously scheduled in a convenient date and time for the family members that accepted to take part in the dynamics. Each meeting lasted from 45 to 60 minutes, was audio-recorded in MP3 format with the previous consent of the group members and then transcribed word for word.

The conclusion of the field research was guided by the criteria of internal and external validity⁽²⁴⁾. For internal validity, theoretical saturation was attained with the homogeneity and scarcity of new types of statements, as each narrative was transcribed after the end of each CSD. As for external validity, the quantitative of participants in previous studies of qualitative approach was compared in order to determine the minimum of six participants and the maximum of 12^(2,14-15,18-19).

The data were analyzed through Critical Discourse Analysis since they presented discourse markers that reflected power relations, the dominant ideology and the macro-structural context, influencing the statements of research participants. Based on the three-dimensional analysis framework proposed by Fairclough, the textually oriented discourse analysis was carried out: text analysis, discourse practice analysis and, posteriorly, social practice analysis. The particular ways and specific social contexts of discourse production determine the discursive practice dimension. Social practice, in its turn, implies understanding how and why ideology determines the way a person speaks and which are the hegemonic power relations that sustain this discourse⁽²⁵⁾.

The data were organized into a pictogram (Figure 1) that presents the points (initial, central, secondary, intermediate, support and final) of the social health care network of the CSHCN with its ties (strong, weak and dependence) and how they relate to each other (links between one point, link between two points).

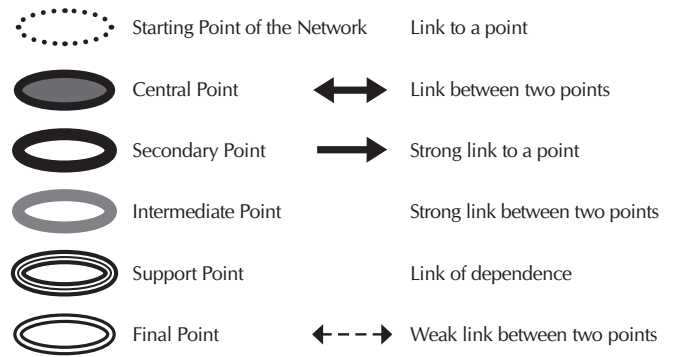


Figure 1 - Caption of the pictogram of the social network of the child with special health care needs structured by family caregivers, Niterói, Rio de Janeiro, Brazil, 2012

The result of the analysis identified two categories: the places within the social network and the people of hospitals, households and communities in the social network.

RESULTS

Places in the social network

The pictogram of the social network of the CSHCN structured by family caregivers (Figure 2) shows the fluid and dense mesh of the network, with their home representing the central unit and institutions constituting the starting, intermediate, support, final and secondary points of the network.

The starting point (:.....:) of the network is a high complexity public pediatric hospital part of the Brazilian Unified Health System and located in the municipality of Niterói (denominated as Hospital G). All five families maintain a strong permanent bond between the child and the hospital institution. In this hospital, families count on the following provided services for the continuous care of their children: a) emergency services and intensive care during periods of acute crises of the condition; b) beds in pediatric nursing units for frequent rehospitalization; c) complex and high cost therapeutics for the most diverse disorders; and d) offer of high technology diagnostic investigation.

The strong link (↔) between Hospital G and the other specialized tertiary hospitals of Rio de Janeiro reinforces the maintenance of the strong bond created by the family between the CSHCN and the hospital institution. For any intercurrent in the health and disease condition of the hospitalized CSHCN, the family has a guaranteed referral and counter-referral system organized by the institution itself.

Hospital G admits children from other hospitals of Niterói's healthcare network, but if a specialized and highly complex surgical procedure is required, they are sent from that hospital to other specialized hospitals from the health care networks of high or medium complexity of the SUS, in the city of Rio de Janeiro. Hospital G organizes the social network of the CSHCN in high complexity cases, sending them from one hospital to another and vice versa, and once the medical care demand is met, the child returns to it.

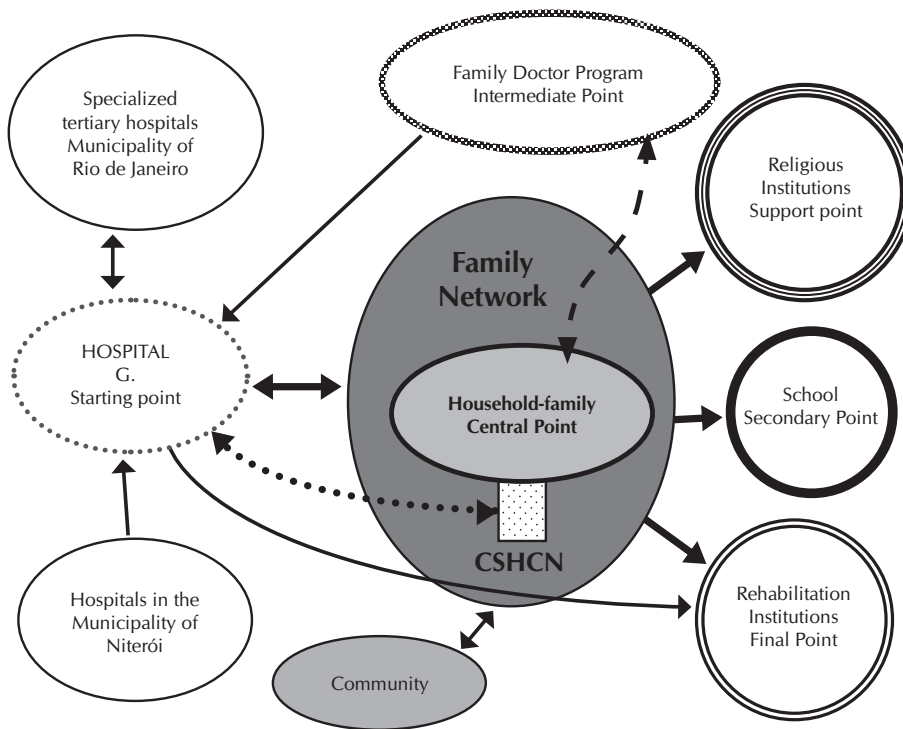


Figure 2 - Pictogram of the social network of children with special health care needs structured by the family caregivers, Niterói, Rio de Janeiro, Brazil, 2012

Yes, he (the son) was operated in the hospital in Rio de Janeiro (a high complexity pediatric surgery). Then, he had the surgery and came back to (hospital G). (Mother of CSHCN T.)

... the doctors explained that he (the son) needed to be operated in a hospital in Rio de Janeiro (cardiology hospital) because no public hospital in Niterói performed that surgery. (Mother of CSHCN C.)

These specialized services are located in the city of Rio de Janeiro, 25 km away from Niterói, outside the area subject to SUS. In Hospital G, the health personnel articulate the referral and counter-referral system by integrating it to the social system of the CSHCN in high complexity situations. Hence, both the family and the CSHCN are protected by the Health System when in the context of the hospital.

F. (the daughter) was always sick, always sick. I always took her to the doctor covered by her (health) insurance; but the sickle-cell disease was never discovered. Then, the doctor of (hospital) G (was) the one who discovered the sickle-cell disease. [...] After that, I did not treat her anymore through the insurance. I always preferred to hospitalize and treat her at hospital G. (Mother of CSHCN F.)

Sometimes, at night. J. (the daughter) had a fever, was coughing a lot, with phlegm, I took her directly to hospital G. I didn't wait [...]. I went directly to their emergency room. (Mother of CSHCN J.)

hospitalization. The bond developed from the medical diagnosis is the foundation for the strong link between the two points of the network, creating a link of dependence (↔) between the CSHCN and the hospital.

In the contexts of home care and community care, the household is the central point (●) in the social network of the CSHCN.


When at home, it is me who takes care of (the daughter). I bathe her, accompany her to physiotherapy and speech therapy, feed her, wash her clothes, play with her. I do everything, I really take care of her. (Mother of CSHCN J.)

In the social network of care of the CSHCN, the household is the place where family members take over the care of the child, performing all their daily life activities for them, regardless of their age. In the context of the household, the mother assumes the role of main caregiver, bathing the child, preparing their food, playing with them and washing their clothes. In addition to household activities, there are also daily life activities of the children and the intense schedule of continuous care with rehabilitation services (physiotherapy and speech therapy). Of the five CSHCN involved in the study, three were enrolled in rehabilitation programs (T., C. and J.) – the final points (○) of the social network structured by the families.

Now she is only doing physiotherapy and speech therapy, at Sociedade Pestalozzi, twice a week (Mother of CSHCN J.)


[...] *From the Associação Fluminense de Reabilitação, where he does physiotherapy and speech therapy* (Grandmother of CSHCN T.)

Rehabilitation encompasses physiotherapy and speech therapy services for the CSHCN, which have care demands related to the development of psychomotor skills, language and education. The programs are carried out in philanthropic institutions (Sociedade Pestalozzi do Brasil and Associação Fluminense de Reabilitação/AFR) that are part of the supplementary network of the Brazilian Unified Health System (SUS), through the sale of services and the offer of inclusive education.

All families of CSHCNs lived in areas subject to the Family Doctor Program (Program Médico de Família - PMF) of Niterói, which is the intermediate point of the social network () structured by the family.


When (daughter) left the hospital, (...) she came here... for home visits. Now she is fine and it is I that (accompany her to the) Family Doctor. (Mother of CSHCN J.)

Home visits are one of the intervention strategies of the PMF that brings the CSHCN and their family closer to the health surveillance actions concerning the child. Within the community, the Family Health Unit of the PMF is the first option for child care when the family caregiver needs it.

For the CSHCN within school-age (A. – 13 years old and F. – 12 years old), the family structures the school as a secondary point of the social network ().

[...] *Due to the disease and to her many hospitalizations, she ended up missing a lot of school years* (Mother of CSHCN F.)


She is one year behind in school [...]. When she was in the third year of Kindergarten, she started having seizures and when she came back to school, her class had moved forward. (Mother of CSHCN A.)

Disease and hospitalizations made these two children (A. and F.) miss school for long periods, affecting negatively their school performances and leaving them without any chance of accompanying the regular school class. The school has a strong link () in the social network of the child, but its mesh is loose owing to the discontinuity in the schooling process and to the lack of school classes in the household.

In the social network of the CSHCN of two families, religious institutions were structured as supporting points ().

[...] *on Sundays, she (the daughter) goes to church with me [...]. My entire family is Christian.* (Aunt of CSHCN F.)

She (daughter) has also been coming with me occasionally to the Spiritist Center on Saturdays (Mother of CSHCN A.)

Families go to church and to the Spiritist Center on weekends or on occasion to express their faiths and religions, bringing their children along. In this sense, these places fit into the social network of the CSHCN and have a strong link with it ().

People from hospitals, households and community in the social network

In the hospital context, the health personnel structure the hospital care in the social network of the CSHCN. Within this scenario, physicians give explanations and the nursing personnel shares child care with the family.


On the other hand, in the community context, family members play the main role in articulating the points of the social network, which are represented by the household, the Family Doctor Program and the neighborhood, in order to meet these children demands.

She (aunt of T.) lives right behind us; so sometimes she comes here and helps me bathe T. (CSHCN). Sometimes, [...] she watches T., helps change a diaper, things like that (Grandmother of CSHCN T.)

[...] *During the week, she (the daughter) stays at the work of her stepmom because she is studying in Niterói.* (Mother of CSHCN F.)

In the beginning, my neighbor L. helped me because my mother works outside the home (Grandmother of CSHCN J.)

What I really do is remember about her medicine, and sometimes I even give it to her before bedtime. (Brother of CSHCN A.)

In the household, the mother plays the main role in articulating the social network, taking the place of the health personnel of the PMF. She fits primary care (PMF) into the social network of the child, but paradoxically the link established with the health personnel (doctor and nursing assistant) who provide the service is weak (), indicating an intermediate point of the network. Women (mothers and grandmothers) were identified as the main caregivers of the CSHCN at home, but other family members (brothers, fathers, aunts, grandmothers) also participate in the care as helpers. At home, interdiscursivity between people from the family and the community influences child care. A multiplicity of voices reflects ideologically different life experiences, constituted by family and community knowledge. Therefore, in the household, the guiding ideology belongs to the family, and the dominant discourse belongs to the household (local) and the community.

Family caregivers articulate the social network since, in addition to being responsible for modifying the usual care of the CSHCN in the household, they take them to the hospital for emergency and first aid care, accompany them throughout hospitalization and take them to rehabilitation treatment. Moreover, they articulate care in the most diverse points of the social network (such as hospital, household, rehabilitation services, the PMF, churches, spiritism centers and school).

The members of the PMF personnel (nursing assistant and doctor) were included in the social care network of the CSHCN after the child returns home from the hospital (hospital discharge) since they worry about how the child is doing.

When... at home, she (nursing assistant) came here with the doctor... She always worried if everything was okay. Now

she is fine, and when I need something, I am the one who takes her to the PMF. (Mother of CSHCN J.)

In the neighborhood, people from the community, generally women (stepmother and neighbor), were occasionally included in the social network as caregivers at the request of mothers and grandmothers.

DISCUSSION

The clinical frailty of the CSHCN is the reason behind their dependence on the hospital of SUS, as they need emergency services, frequent rehospitalization, complex and intensive clinical interventions and outpatient follow-up⁽⁹⁾. Hence, the hospital is the first choice when mothers seek a health service, the starting point of the social network. Referral to other hospitals from the high-complexity health care network followed the principles of the Agreed and Integrated Programming of SUS, in accordance with its hierarchies, municipal divisions and the location of specialized hospitals in large urban centers for the care of referred patients^(6-7,12).

The comprehensive social network of the CSHCN can be studied under two approaches. The first is based on the many health services provided due to the commitment of professionals who listen to patients intently and carefully in order to identify their health needs⁽²⁾. This relationship needs to promote a higher empowerment of family members who seek autonomy in the care, with no dependence and a possibility to reconstruct their life meanings. Their way of life will undergo a significant transformation, encompassing the struggle to satisfy their needs in the most comprehensive way possible⁽⁹⁾. A second dimension of this idea is the extended comprehensiveness, which stems from linking each service with a complex network composed of other services and institutions in all social contexts (hospital and community) where the CSHCN belongs, not just hospitals.

Comprehensiveness is the aim of the network, therefore it should not be restricted to the individual efforts of the families of the CSHCNs, which reveals insufficient public policies and the lack of coordination among them. The SUS' hospitals play a decisive role in the life of these children when they go through an acute crisis of chronic conditions. Health services need to be committed to coordinate the network with the purpose of meeting the health demands of the CSHCN, with the user seeking comprehensive care to reduce health damages⁽¹⁸⁾.

In the context of the community, CSHCNs have stronger bonds with the hospital, the school, rehabilitation and religious services than with the PMF – with which they have a weak bond.

Discontinuity in the schooling process stems from the difficulty of harmonizing the long hospitalization periods of the child with school attendance. Paradoxically, the lack of an educational pedagogical care at home and at the hospital is observed, as is the exclusion of these children from the schooling process. In this modality, pedagogical care of hospitalized children and teenagers reaches hospitals, care homes

and residencies⁽²⁶⁾. It is a legal obligation, therefore not ensuring access to education is to not in compliance with a fundamental right of the child defined by the Child and Adolescent Statute (Law No.8,069, 1990). The quality of health care also involves meeting educational needs within comprehensive care, one of the organization guidelines of the Brazilian Unified Health System, defined by the organic law of health (Law No. 8,080, 1990). The paradigm of social inclusion assumes that, if school attendance is impossible during health treatment periods, alternative ways of teaching need to be organized and offered to the child.

Within the community, people from the neighborhood are caregivers together with the family members, and most of them are women. The social network of the CSHCN allows concrete reality to be met, encouraging the vocation of people to actively act⁽¹⁰⁾ and their capacity of relating to other people in the network. As such, the family keeps seeking comprehensive care for the CSHCN and answers to the challenges related to it.

The mother assumed most responsibilities related to child and household care. However, the amount of care demanded by the CSHCN may require a lot of time from the mothers, leaving them without any free time for other activities, including personal care, and possibly causing social isolation and less participation in the community. This reality may cause the need to rearrange family life and the implementation of an extended care centered on the family, and not just the mother. In other words, a coordination that favors the participation of the woman-mother in her social and family lives should be sought between the hospital and the social networks^(2,11,18). Kinship and friendship are the most important types of primary social relationships, and their importance stems from three factors. Firstly, relatives tend to know each other, and the kinship area of the network tends to have a narrower mesh than other sectors. Secondly, relationships with and between family members are relatively permanent. Lastly, relatives play an important role of financial support in the social network. Relatives usually assume a role of mutual assistance⁽⁶⁾.

Family caregivers pointed out that the family mesh is denser than the institutional mesh in the social network of the CSHCN. Although family relatives and neighbors provide support to the demands of continuous and complex care within the community context, there is still the challenge of expanding the social network in order to reduce dependence on the hospital and strengthen the competencies of the family and primary care⁽¹⁴⁾.

The support received through the social network is fundamental to maintain mental health, to face situations that are physically or mentally stressful and to promote health and wellness of family members⁽¹⁵⁾. Families with CSHCN may go through crisis situations and difficulties to provide care, in addition to the lack of psychological, social and economical support⁽⁴⁾. It occurs during the process of adjustment to live with the CSHCN, possibly causing family conflicts and changes in the roles and individual functions of internal family members. A holistic approach to care is especially important for families with CSHCN in the context of these challenges.

Receiving support from the nursing personnel may help the family regarding proper child care and increase the capacity of caregivers of dealing with care difficulties, particularly in the context of the community, which had a disperse and not much visible role in the social network of the CSHCN⁽¹⁵⁾. Nursing maintains a closer relationship with the individual, the family and the community; it is also more accessible than other health disciplines⁽⁴⁾. Under this perspective, it should be pointed out as well that the caring dimension of nursing should not be lost, for even when the family provides care to the child in the context of the hospital, care responsibility belongs to Nursing⁽¹²⁾. For primary care, however, child care practices are based on relational technologies, interaction, receptivity, bonding, accountability and life respect.

Nursing assistance needs to focus on the family owing to its importance for the survival and especially the care with the special health needs of the child⁽¹³⁾. This social group depends entirely on the medium and high complexity health network of the Brazilian Unified Health System, externally connected to the family when it seeks hospital services. The void left behind by the implementation of SUS on the other networks, especially primary care in the daily life care, is filled by the effort of the family to link them to the social network of the child with the rehabilitation services provided by philanthropic entities and non-governmental organizations. In this sense, in the discursive practice of family members, the social network presents a fluid and dense mesh, requiring additional efforts from families.

FINAL CONSIDERATIONS

In the social network of care for a child with special needs, the hospital stood out as starting point, the household as central point, the PMF as an intermediate point, the school as a secondary point, places for religious expression as support point and rehabilitation institutions as final point. The link between these points is constructed by the health personnel from the hospital every time there is need for hospital referral and counter-referral, as part of the comprehensive care of the social network. In the community context (household, Family Doctor Program of Niterói and neighborhood), the points are linked by the family caregivers who take the CSHCN to school, rehabilitation care, religious services, specialty clinics and emergency care at the hospital.

The mesh of the social network is composed of articulating and disarticulating movements between people and locations. In the context of the hospital, the referral and counter-referral to and from specialized hospital occurs, but there is no relationship between the hospital and the Family Doctor Program, and no articulation between the level of primary care and the levels of medium and high complexity care. Articulating the social network is part of the intense, complex and continuous care required by the special health needs of a child, such as the challenge of keeping them in school. The social practice of family care in the contexts of the hospital and the community has consequences for professional practice that can be classified into three topics.

The first is the expansion of the social network of the hospital in a way that includes different people from the family other than the mother, since excessive demands on the woman-mother may lead to physical and emotional fatigue. We know that, in the household, other members of the family and the community will participate in the care. The second topic is to promote the empowerment of caregivers in order to decrease their dependence on health services and strengthen competencies of families, asking authorities to comply with the fundamental rights of the child as defined on the regulatory marks of childhood and adolescence protection. We understand as competencies of families the set of knowledge, practices and abilities necessary to promote the survival, development, protection and participation of the children in the care process. The third is to expand visibility of nursing care within the care demand required by the CSHCN, strengthening the role of Nursing in the social network of the child.

It is necessary to contribute to the elaboration of public policies specifically aimed at the CSHCN that place Nursing within their social care network, offering care within the household together with families. Regarding assisting, it is necessary to rethink the hegemonic power of the nurse and break away from the biomedical model of hospital, creating space for an emerging model of care that values family and community as central and permanent elements of the life of the child. It is essential as well to incorporate CSHCN care to the teaching of Pediatric Nursing, increasing the visibility of their care demands and connecting them to the contexts in which they are inserted. It is imperative to overcome the curative and short-term oriented health model that follows oppressive care standards for family caregivers. A limitation of the study was not listening to the children with special health care needs.

REFERENCES

1. McPherson M, Arango P, Fox H, Lauer C, McManus M, Newacheck PW, et al. A new definition of children with special health care needs. *Pediatrics* [Internet]. 1998[cited 2014 Mar 17];102(1):137-39. Available from: <http://pediatrics.aappublications.org/content/102/1/137.long>
2. Neves ET, Cabral IE. A fragilidade clínica e a vulnerabilidade social das crianças com necessidades especiais de saúde. *Rev Gaúcha Enferm* [Internet]. 2008[cited 2014 Mar 17];29(2):182-90. Available from: <http://seer.ufrgs.br/RevistaGauchadeEnfermagem/article/view/5533>
3. Ministério do Planejamento Orçamento e Gestão (BR). Censo demográfico 2010. Características da população e dos domicílios: resultados do universo. Rio de Janeiro: IBGE; 2011.
4. Ministério da Saúde (BR). Rede Intergerencial de Informações para a Saúde-RIPSA. Indicadores de Mortalidade.

- C.1 Taxa de Mortalidade Infantil [Internet]. Brasília (DF): Ministério da Saúde; 2012.[cited 2014 Mar 17]; Available from: <http://tabnet.datasus.gov.br/cgi/idb2012/c01b.htm>
5. Ministério da Saúde (BR). Paineis de monitoramento da mortalidade infantil [Internet]. Brasília (DF): Ministério da Saúde; 2014[cited 2014 Mar 17]; Available from: <http://svs.aids.gov.br/dashboard/mortalidade/infantil.show.mtw>
 6. Paim J, Travassos C, Almeida C, Bahia L, Macinko J. The Brazilian health system: history, advances, and challenges. *The Lancet* [Internet]. 2011 May[cited 2012 May 20];377(9779):1778–97 Available from: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60054-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60054-8/fulltext).
 7. Barros FC, Matijasevich A, Requejo JH, Giugliani E, Maranhão AG, Monteiro CA, et al. Recent trends in maternal, newborn, and child health in Brazil: progress toward Millennium Development Goals 4 and 5. *Am J Public Health* [Internet]. 2010[cited 2014 Mar 17];100(10):1877-89. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2936973/pdf/1877.pdf>
 8. Perrin JM1, Romm D, Bloom SR, Homer CJ, Kuhlthau KA, Cooley C, Duncan P, Roberts R, Sloyer P, Wells N, Newacheck P. A family-centered, community-based system of services for children and youth with special health care needs. *Arch Pediatr Adolesc Med* [Internet]. 2007[cited 2014 Mar 17];161(10):933-6. Available from: <http://archpedi.jamanetwork.com/article.aspx?articleid=571226>
 9. Góes FGB, Cabral IE. Crianças com necessidades especiais de saúde e suas demandas de cuidado. *Rev pesq cuid fundam* [Internet]. 2010[cited 2014 Mar 17];2(2):889-01. Available from: http://www.seer.unirio.br/index.php/cuidado_fundamental/article/view/579/pdf_22
 10. Leite NSL, Cunha SR. [The Family of the Technology-Dependent Child: fundamental aspects for hospital nursing practices]. *Esc. Anna Nery* [Internet]. 2007[cited 2014 Mar 17];11(1):92-7. Available from: <http://www.scielo.br/pdf/ean/v11n1/v11n1a13.pdf> Portuguese.
 11. Marques E, Bichir R. Redes de apoio social no Rio de Janeiro e em São Paulo. *Novos estud. – CEBRAP* [Internet]. 2011[cited 2014 Mar 17];90:65-83. Available from: <http://www.scielo.br/pdf/nec/n90/06.pdf>
 12. Secretaria de Direitos Humanos da Presidência da República (BR). Características da População Brasileira [Internet]. Brasília (DF): Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência Censo 2010. 2009[cited 2014 Mar 17]; Available from: <http://www.pessoacomdeficiencia.gov.br/app/node/766>
 13. Rezende JMM, Cabral IE. As condições de vida das crianças com necessidades especiais de saúde: determinantes da vulnerabilidade social na rede de cuidados em saúde as crianças com necessidades especiais de saúde. *Rev Pesq Cuid Fundam* [Internet]. 2010[cited 2014 Mar 17];2(Supl.):22-5. Available from: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/773/pdf_68
 14. Moraes JRMM, Cabral IE. The social network of children with special healthcare needs in the (in)visibility of nursing care. *Rev Latino-Am Enfermagem* [Internet]. 2012[cited 2014 Mar 17];20(2):282-8. Available from: <http://www.scielo.br/pdf/rlae/v20n2/10.pdf>
 15. Hayakawa LY, Marcon SS, Higarashi IH, Waidman MAP. [Support network to the families of children admitted in a pediatric intensive care unit]. *Rev Bras Enferm* [Internet]. 2010[cited 2014 Mar 17];63(3):440-5 Available from: <http://www.scielo.br/pdf/reben/v63n3/a15v63n3.pdf> Portuguese.
 16. Both E. *Família e Rede Social*. 2a. ed. Marcio Guerreiro, Tradução: Rio de Janeiro: Francisco Alves; 1976. 318p.
 17. Leite NSL, Cunha SR, Tavares MFL. Empowerment das famílias de crianças dependentes de tecnologia: desafios conceituais e a educação crítico reflexiva freireana. *Rev Enferm UERJ* [Internet]. 2011[cited 2014 Mar 17];19(1):152-6. Available from: <http://www.facenf.uerj.br/v19n1/v19n1a25.pdf>
 18. Neves ET, Cabral IE, Silveira A. Family network of children with special health needs: implications for nursing. *Rev Latino-Am Enfermagem* [Internet]. 2013[cited 2014 Mar 17];21(2):562-70. Available from: <http://www.scielo.br/pdf/rlae/v21n2/0104-1169-rlae-21-02-0562.pdf>
 19. Neves ET, Andres B, Silveira A, Arrué AM. A rede social de cuidados de uma criança com necessidade especial de saúde. *Rev Eletrônica Enf* [Internet]. 2013[cited 2014 Mar 17];15(2):533-40. Available from: http://www.fen.ufg.br/fen_revista/v15n2/pdf/v15n2a28.pdf
 20. Gauthier JHM, Cabral IE, Santos I, Tavares CMM. *Pesquisa em Enfermagem: novas metodologias aplicadas*. Rio de Janeiro: Guanabara Koogan; 1998.
 21. Groleau D, Cabral IE. Reconfiguring insufficient breastmilk as a sociosomatic problem: mothers of premature babies using the kangaroo method in Brazil. *Matern Child Nutr* [Internet]. 2009[cited 2014 Mar 17];5(1):10-24. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1740-8709.2008.00151.x/epdf>
 22. McNiff S. An Introduction to the ideas and methods of arts-based research. *The Journal of Pedagogy, Pluralism and Practice* [Internet]. 2004[cited 2014 Mar 17];III(1):(about 10 pages). Available from: <http://www.lesley.edu/journal-pedagogy-pluralism-practice/shaun-mcniff/research-new-keys/>.
 23. Ferreira AL, Pereira MFW. O mapa falante como instrumento do processo ensino-aprendizado do aluno de medicina. *Revista de Pediatria SOPERJ* [Internet]. 2013[cited 2013 Jun 12];14(1): 29-32. Available from: http://revistadepediatria.soperj.org.br/detalhe_artigo.asp?id=631
 24. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. *Cad Saúde Pública* [Internet]. 2011[cited 2013 Jun 12];27(2):389-394. Available from: <http://www.scielo.br/pdf/csp/v27n2/20.pdf>
 25. Fairclough N. *Discourse and Social Change*. 2nd ed 6th Reprinted. Cambridge: Polity Press. 2006, 259p.
 26. Barros ASS, Gueudeville RS, Vieira SC. [Profile of Brazilian scientific publications on the subject of hospital schooling]. *Rev bras educ esp* [Internet]. 2011[cited 2014 Jul 09];17(2),335-354. Available from: <http://www.scielo.br/pdf/rbee/v17n2/a11rbee17n2.pdf> Portuguese.