

THE FAMILY CARE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN THE COMMUNITY CONTEXT¹

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ABSTRACT

It is a qualitative research with a participatory approach that aimed at describing the social network of a child with special health care needs (CRIANES) in the community context. The subjects were the parents of a CRIANES drawn from the database of a research. We adopted the Creative Sensitive Method (CSM), through the development of a dynamics of creativity and sensitivity, Speaking Map, in May 2011. The data were subjected to Discourse Analysis in its French strand. The results showed that the CRIANES has an institutional social network and a family social network. The primary care services were considered by the subjects as difficult to be accessed and, therefore, were not used by the child at stake. We concluded that there is an invisibility of CRIANES in the primary care services. We recommend that the nursing staff encourages the family-centered care, considering it as a Nursing's client, in order to give continuity to the care shares in the home environment.

Keywords: Caregivers. Pediatric Nursing. Health Care. Children's Health.

INTRODUCTION

With technological and medical advances arising from a quick industrial evolution, an increase in the survival of children affected by perinatal hazards, chronic diseases or traumas started to take place ⁽¹⁾. This change led to a significant decline in the infant mortality rate, which fallen down from 45,19 for each thousand live births, in 1991, to 24,32, in 2007, which corresponds to a reduction of over 46% in 16 years ⁽²⁾.

The technological innovations in the area of neonatal and pediatric intensive care have triggered the appearance of a new group of clinically fragile children that, in many cases, rely on technological devices for their survival. In Brazil, they were called children with special health care needs (known as CRIANES) ⁽³⁻⁵⁾.

Results of a survey conducted in the period from 2002 to 2006, which took place at the institution that is study scenario, showed that the admissions average of CRIANES in the

Neonatal Intensive Care Unit (NICU) was of 9,3% of admissions. As to the year 2006, in which the family that was subject of this study was drawn, the number of admitted children was of 346, being that 31 of them were CRIANES, accounting for 8.9% ⁽⁵⁾.

The CRIANES temporarily or permanently present a chronic physical, developmental, behavioral or emotional condition, and they need of health care services of any sort, besides the normal procedures for children of the same age. Their demands are classified, according to a typology of care, in five segments: development, technological, medical, modified customary and mixed ⁽⁶⁾.

After hospital discharge, there is no data about the monitoring of CRIANES in the community in which they reside. Usually, one realizes the lack of reference and counter-reference, which hinders the trajectory of family members/caregivers, making them create their own network in quest for care actions.

In this study, social network refers to structural or institutional dimension associated

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with an individual, such as: neighborhood, religious organizations, health care system and school ⁽⁷⁾. Thus, the social network has its importance in building the personality of the individual, reflecting in the way in which he deals with the disease. Accordingly, when having knowledge of these demands, the healthcare professionals might incorporate them in their daily work, pursuing for an effective intervention, both for the children and for their family members/caregivers.

Given the above, we questioned: how is the social network of children with special health care needs for the practice of family care in the community context? Therefore, this study aimed at describing the social network of children with special health care needs in the in the community context.

METHODOLOGY

It is a qualitative research of descriptive and exploratory nature, with a participatory approach. This is a subproject of the research entitled “Children coming from neonatal intensive care: characterization of special health care needs and of access to follow-up services in health at the city of Santa Maria – RS”, developed with funding from the ARD Notice 003/2009 FAPERGS. The data were collected by means of a proper form in the medical charts of children coming from the Neonatal Intensive Care Unit (NICU) of a teaching hospital. From these data, a database was formed through which CRIANES were selected to participate in the dynamics of creativity and sensitivity (DCS), Speaking Map and Sensitive Creative Method (qualitative phase of the study), during home visits.

The DCS create spaces for discussion and reflection, leading the subjects to socialize their living and existential practices ⁽⁸⁾. The Creative Sensitive Method (CSM) adds consolidated techniques of data production in qualitative research, such as the Paulo Freire’s Cultural Circles ⁽⁸⁾.

The study subjects were the parents of a CRIANES randomly drawn from the database of children born in 2006, discharged from a NICU. We conducted a previous contact with its family members by telephone, in order to inform and

invite them to participate in the research. The data production took place in May 2011. The setting chosen by them was the work environment. At the collection time, firstly, we presented the Free and Informed Consent Form to the participants; after it, we applied a questionnaire to know the social position of the respondents, which is an essential assumption of Discourse Analysis. The Speaking Map had the following of discussion-generating question: “Subsequent to the hospital discharge, what are networks that comprise the care shares of Manoela in the community?”.

At the end of the DCS, the obtained audio was transcribed and subjected to Discourse Analysis ⁽⁹⁾ in its French strand. The first step, called superficial analysis, presupposes a horizontal analysis that gives linguistic materiality to the text. This analysis serves to give motion and speech to the text, allowing the reader to understand the subjects’ speech. For this purpose, we made use of signaling resources: /: short reflective pause //: long reflective pause ///: too long reflective pause; ...: incomplete thought; #: interruption of the person’s enunciation; ##: interruption of the enunciation of two people; *{italics}*: to complete the verbal thinking enunciated in the same speech; ‘.’: single quotes indicate speech or text of someone quoted inside the enunciation of another one; [...] indicates that there was a cutting in the subjects’ speech.

The second step of analysis, called vertical reading, is used to search for clues in the text that might lead to the discursive processes. We applied the following analytical tools: metaphor, paraphrase and polysemy. The research project was approved by the Research Ethics Committee from the UFSM (CEP), under the CAAE n° 0003.0.243.000-08. All names presented here to refer to the CRIANES and its family members/caregivers are fictitious, with sights to ensure the anonymity of the subjects.

RESULTS AND DISCUSSION

From the data analysis, two categories have emerged: the institutional social network and the family social network. The institutional network refers to the secondary social network, in which there are the relationships and bonds with the

health services and their professionals. The family network refers to the primary social network, in which the family is included. Thus, networks might be understood as systems composed of various social objects, such as people, functions and situations that provide instrumental and emotional support to people in their different needs⁽¹⁰⁾.

For describing these networks, firstly, it becomes relevant to contextualize the social place of the research participants: Manoela five years old, she had demand for drug-related and developmental care, because this girl showed psychomotor delay since her birth, besides recurrent seizures. She had weekly systematic outpatient monitoring with pediatrician, neurologist and physiotherapist.

The girl's parents were teachers at a dance school, being that her mother, in some periods, was in college. The care of this CRIANES was mainly developed by her father, who played the role of major caregiver. Accordingly, during the morning shift, it was the father who performed the child care procedures, however, in the afternoon, she went to school. When they needed to leave her alone, counted with the help of her grandmother, who remained with the couple's three daughters. Furthermore, the family had the support of an aunt and a godmother of the child, who were regarded as moderate bonds in her social network.

The institutional social network

From the discussion-generating question, we build an Artistic Production (AP), as provided in CSM, in which the parents drew a map of the networks that were part of the care of Manoela in the community context. This drawing has mediated the group discussion.

The following discourses point out to the locals of support social network that the child at stake attended:

The school! She loves it! Today, we ended up delaying .../ [...] "Where we go [,] mother?" {mother reporting the CRIANES' speech} Let's go to school! "Êêê!!" {mother reporting the CRIANES' speech}. [...] and she .../ had no classes and her sisters went to school and she got crying, cause she wanted to go to class, she likes it; because she plays there, there are playmates, everything [...] there are not playmates at home,

then she stands alone at home, no one to play with her, so .../ she got sad! (Marina)

It's! Because we work like this: on vacations, every day she comes with us to get here {referring to the dance school}. [...] All the others were grown up inside the school! (Marina)

We forgot to say she goes to see the mass!! I'll put the church here! [...] She goes to the church and stands in front... # (André)

There in front of! (Marina)

[...] the musicians all the time there, looking at them [...] (André)

The mother quoted the school environment as one of the places that Manoela (CRIANES) most liked to attend. She illustrated this fact through a speech of the child at stake in which the girl celebrated by knowing that she was going to the school. She reported that her daughter loved the school, since it was a place where she played, had colleagues, i.e., had a social network of friends of the same age. The mother spoke that, when the Manoela's sisters were not at home, the little girl stayed with no companion during the jokes, which made her sad for having to play alone.

Regarding the dance school, the parents reported that it was an institutional network very frequented by Manoela, mainly during vacations. Metaphorically, the Manoela's mother showed the relevance of the dance academy as a reference for the family, by saying that the girls "were grown up in the academy"; in her speech, one can see that the academy represented a second home for them.

The Manoela's father highlighted that she went to church, which was part of her institutional support network. He still stressed that the CRIANES liked music and that she remained just watching the musicians who played during the ceremony in the church.

The practices of leisure and culture contribute to the building of social networks, strengthening bonds, thereby providing an improvement in the ability to deal with problems⁽¹¹⁾. For people who are going through situations of illness, religion ends up playing the role of emotional support, strengthening hope, renewing forces, helping them to live and cope with the difficulties of a different way of people who do not seek religion⁽¹²⁾.

The father reported the presence of the physician who cared of Manoela in the health monitoring at the hospital, besides the relationship between Manoela and her pediatrician:

Doctor. {doctor's name}/ here ///. She has medical follow-up there in the UFSM / HUSM, right! (André)

It's the doctor. { doctor's name}. Yes, it is .../ this is not so often. (Marina)

When there is need, because .../ {laughter}. Indeed, sometimes we will take because he himself says: "Look [,] she has not been there". You know we take her [...] but it is about twice, three times a year [,] now. Three times. (André)

In relation to the CRIANES' pediatrician, André and Marina described that he was occasionally sought, when necessary, or even when requested by the physician, at that time it was approximately three times a year.

Accordingly, health care procedures were seen as crucial to the daily life of this family, given that the relatives assigned the achievements related to the CRIANES' improvement to the physician. This contrasts with other studies on CRIANES, which emphasized the need for them to be monitored by a set of multidisciplinary services, with sights to help in the rehabilitation process. In this sense, they need a social support network that provides assistance to helper family members, since this support network should go beyond the medical and nursing shares^(14,3).

The complexity of CRIANES' diagnoses makes these children require services in a weekly frequency, from various specialties, geographically separated, thus demonstrating the intense dedication and the level of exclusivity that this type of child imposes on its life and on the lives of its caregivers. Thus, caregivers need to organize a complex and decentralized schedule of attendances, involving multiple services and places⁽¹⁴⁾.

We asked the parents about the place in which they took their daughter to be examined by the physician:

We take her to the medical office. It's. Because, then, when we need it, such as...// It was through the doctor {doctor's name} we could achieve her first resonance, but talking to him in the medical

office. Because there at the CH {College Hospital} they {doctors} ... put it in the her folder that we didn't want to have the resonance, and I told to the resident that, at the time, we had no financial conditions, so we would make that through the SUS {...} It did not take a month, Manoela was doing that, and she could have done that much before, you know!?! {mother in tone of indignation} (...) (Marina)

Marina polysemically expressed that it was through the help of the physician that they could achieve the first magnetic resonance to Manoela. At one of these consultations, the parents found that the physicians had said that they did not want to perform the exam. Nonetheless, they did not have the financial resources at that time, and the exam was performed by the SUS because of the intervention of the family's pediatrician.

The CRIANES' rights are ensured by means of current public policies, however, it was realized that there is a gap that separates these children's rights and their implementation in practice⁽¹⁵⁾. In the USA, the CRIANES have the right to health, education and social assistance in a specific way, through public health policies targeted to this clientele. Nevertheless, in Brazil, the health legislation of children and teenagers sustains this group, although there is a growing recognition of their rights⁽⁶⁾.

Regarding monitoring of the child and the location of basic health unit, the caregivers stated:

It has, yes it has. But we ... # [...] live near the EC [Municipal Emergency Care] we go straight there. [...] (André)

Because the reality of these Basic Health Units is [,] you have to go in advance, so you can early get a ticket. Sometimes, you go there, but cannot. Then, we end up giving up. (Marina)

Thus, they reported not using the primary care network because of the difficulty of access. A study on access to primary health services found that users complained about the lack of professionals, as well as the instability of the team on the workplace, which ended up breaking the bonds that were formed during the attendances, besides having a change in the treatment that already was being conducted⁽¹⁶⁾.

As to the Guidelines on the care that the CRIANES would need at home, the following speech was obtained:

Here, in this process, ok, you indicate health professionals, even different places .../ has someone guided the care process at the time in which the discharge was given, something like that, you consider relevant? (Researcher)

In physiotherapy, we receive enough guidance, in the first treatments, first exercises, even to buy accessories, those little cushions, those things, do .../ pushing, lifting. [...] (André)

Within the HUSM, when she was hospitalized, I think the doctor came {referring to the physiotherapist}, physiotherapist from .../ [...] "Not, take care during the first three months, each stage has its development; being aware for not let it pass by, right, then stimulating and everything else [...]. " (Marina)

The parents highlighted the physiotherapists and the pediatrician as responsible for the guidelines at the time of hospital discharge. The physiotherapist from the Neonatal Intensive Care Unit (NICU) was the one who guided them about the treatments, first exercises, technological devices that the CRIANES would initially require, as well as on the importance of observing the development and of stimulating the child at home.

Some caregivers of CRIANES seek information by means of the health team, in order to help them in coping with the situation. Usually, the belief in healing becomes evident and the caregivers end up putting their expectations in the health professionals, such as physiotherapists, since they transmit a possibility of improvement, with the hope that the child acquires some autonomy of locomotion ⁽¹⁴⁾.

Nonetheless, others seek this support in the closer family network. Thus, networks of family and institutional care for CRIANES start to be formed, based on the sociocultural matrices and their legacies ⁽¹⁾.

Concerning the issue of guidelines and care related to the Manoela's motor function, the mother quoted one of the students of the dance academy as a strong point of network:

Then, as our student was ... she is physiotherapist [...] there, so we had a close contact, Manoela were always together {in dance classes}, so there we'd talk and detect [...] Then we always have a lot of contact with people, that's why I guess it also facilitates. (Marina)

Marina reported that managed to put Manoela in physiotherapeutic classes at her six months of age because of the mediation of one of her pupils who was a physiotherapist. The mother assigned to the environment in which they worked and the knowledge of key people the fact of getting some facilities relating to the care of Manoela. Accordingly, there is a weaving of the network through the contacts of caregivers, who are people outside of the family group that provide support for the caregivers, thereby establishing interdependent and affective relationships ⁽¹²⁾.

The family social network

The main strengths of the Manoela's family network included her godmother and her aunt.

Dinda! Dinda comes here, right? (André)

Dinda lives in Porto Alegre. [...] And her dinda is deaf-mute, ok. Then, she .../ 'Mom, doesn't dinda Carla speak?' {repeating the CRIANES' speech} No! How does dinda Carla speak, Manoela? 'It's like this ohh!!' {mother makes gestures imitating CRIANES } [...] The dinda love her too much, loves! [...] Then she gets there and Manoela goes to her lap, and now she began to understand, she wants to start imitating dinda and talkin. (Marina)

And aunt Débora? Is she Sister? (Assistant Researcher)

It's ... she is dinda of another. She's the sister ... my sister, in this case. (André)

And she comes at a frequency like this .../ # (Assistant Researcher)

Weekend, sometimes ... yesterday she was there too! Throughout this week, she has already been there twice. // It's because she lives a little longer, so we have to go across town to go there ... (Marina)

Or at parties, right... // birthday. (André)

The godmother, even having hearing and speech impairment, held a natural relationship with the child, without that the little girl showed any different reaction in relation to such a fact. Aunt Débora was another family reference in the Manoela's family map, but she was not visited as often, but on holidays or weekends.

The family plays an important role in child care, as it holds responsibility for the physical, emotional and social welfare of its members. In fact, the stronghold family offers the child the major portion of its referential ⁽¹⁷⁾. In their day

lives, the CRIANES need this support provided by the family, because, due to their dependence, whether it is drug-related, technological or developmental, undergoes prolonged treatments, or for periodical consultations, which ends up being a disruption in daily lives of such children.

In relation to the family context:

It's... near {the child's home} that's the Grandma's house. [...] maternal {this is the maternal grandmother}. [...] I can cite the female cousin {at grandma's house}. (Marina)

The Manoela's nuclear family emerged as the first point in the family network presented by the subjects, being that it was comprised of her father, her mother, the CRIANES itself and her two sisters. The residence of the maternal grandmother was identified as a second reference family network, due to the nearness between the family's home and the grandmother's home, where the Manoela's female cousin lived, who was part of this family core.

In this research, the extensive family network was found, denoted by the presence of the grandmother and other family members, and was highlighted by the CRIANES' parents as something essential. The extended or branched family network is considered as one that adds different generations⁽¹⁸⁾.

The grandmother emerged as a support for the care of Manoela. The parents indicated the fondness through which the family members approached the CRIANES, demonstrating the level of relevance that it was for her daughter the fact of having this affection on the part of the family. It is known that the presence of the family member is a source of safety and affection, besides benefitting the child and its recovery⁽¹⁹⁾.

FINAL CONSIDERATIONS

The social support network of the CRIANES, study subject, was shaped by an institutional network and a family network. In the institutional network, it should be highlighted the points that provided professional support to the CRIANES through activities of leisure and culture, such as: the school, the dance academy and the church. The main finding of this study is related to the inclusion of this child in a dance

school, providing an environment in which she had contact with music and dance, which contributed to her development and treatment.

As to the family bonds, there was a maternal grandmother, who assisted in the care when the parents needed to leave the child alone. In addition to the grandmother, other family members belonging to this network with weaker bonds were identified. In this sense, it should be demonstrated the relevance of the family context for CRIANES, given that it is essential for their healthy development, by providing the emotional support that these children need at all times. We emphasize the role of the father as the major caregiver of the child at stake. This is an unprecedented ascertainment, when compared with other surveys held on this topic.

As to the follow-up network in health within the community context provided by the Brazilian public health system (SUS), we found the non-compliance with the principles and guidelines with regard to the universality and equity of access. This was denoted when the child's access to the service and exams was assigned to the bond between the physician and the health service. By considering that, regardless of the professional who accompanies the CRIANES, he/she has the right to have his/her health exams, as well as the hospital admission and a quality care. We found the lack of guidance towards the parents regarding the health rights of the daughter and that the CRIANES' family went through several locations in pursuit for an appropriate treatment.

The primary care services were considered by the respondents as difficult to be accessed and, therefore, were not used by the child at stake. This demonstrates the lack of monitoring of this child in the community where she lived, as well as the non-operation of the service of reference and counter-reference. Furthermore, this invisibility of the CRIANES in primary care services hinders their integration in the existing public policies, since the parents end up looking for other health services, such as, for example, the emergence care services.

Moreover, it is noteworthy to highlight the invisibility of the nursing professional in the parents' speeches. At no time Nursing was mentioned, even when asked about the guidance that they received during the admission period or

at the time of hospital discharge, which makes clear the weakness of the bond of the nursing staff with the family in question.

We recommend that the nursing staff encourage and develop the family-centered care, considering the family of a chronic child as a Nursing's client, giving continuity to the care shares at home, when the child returns to the community. Through the knowledge of this

social network, it is possible to intervene in the implementation of therapeutic plans designed for these children in the post-discharge period. Furthermore, we should stimulate the children's participation in other activities that enable their social inclusion, as well as providing entertainment for these infants and their families, resulting in a better life quality.

O CUIDADO FAMILIAL À CRIANÇA COM NECESSIDADES ESPECIAIS DE SAÚDE NO CONTEXTO DA COMUNIDADE

RESUMO

Pesquisa qualitativa com abordagem participativa que objetivou descrever a rede social de uma criança com necessidades especiais de saúde (CRIANES) no contexto da comunidade. Os sujeitos foram os pais de uma CRIANES sorteada do banco de dados de uma pesquisa. Adotou-se o Método Criativo Sensível (MCS), com o desenvolvimento de uma dinâmica de criatividade e sensibilidade, Mapa Falante, no mês de maio de 2011. Os dados foram submetidos à análise de discurso em sua corrente francesa. Os resultados apontaram que a CRIANES possui uma rede social institucional e uma rede social familiar. Os serviços de atenção primária foram considerados pelos sujeitos como de difícil acesso e, por esse motivo, não eram utilizados pela criança. Conclui-se que há uma invisibilidade da CRIANES nos serviços de atenção básica. Recomenda-se que a equipe de enfermagem incentive o cuidado centrado na família, considerando-a como cliente de Enfermagem, a fim de dar continuidade dos cuidados no âmbito domiciliar.

Palavras-chave: Cuidadores. Enfermagem Pediátrica. Assistência à Saúde. Saúde da Criança.

EL CUIDADO FAMILIAR AL NIÑO CON NECESIDADES ESPECIALES DE SALUD EN EL CONTEXTO DE LA COMUNIDAD

RESUMEN

Investigación cualitativa con abordaje participativo que objetivó describir la red social de un niño con necesidades especiales de salud (CRIANES) en el contexto de la comunidad. Los sujetos fueron los padres de una CRIANES sorteada del banco de datos de una investigación. Se adoptó el Método Creativo Sensible (MCS) con el desarrollo de la dinámica de creatividad y sensibilidad Mapa Hablante en el mes de mayo de 2011. Los datos fueron sometidos al análisis de discurso en su corriente francesa. Los resultados apuntaron que la CRIANES posee una red social institucional y una red social familiar. Los servicios de atención primarios fueron considerados por los sujetos como de difícil acceso, y por este motivo no son utilizados por el niño. Se concluye que hay una invisibilidad de la CRIANES en los servicios de atención básica. Se recomienda que la Enfermería incentive el cuidado centrado en la familia, considerándola como cliente de enfermería, para continuidad de los cuidados en el ámbito domiciliar.

Palabras clave: Cuidadores. Enfermería Pediátrica. Asistencia a la Salud. Salud del Niño.

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