INSTITUTIONAL CARE NETWORK OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

REDE INSTITUCIONAL DE CUIDADOS À CRIANÇA COM NECESIDADES ESPECIAIS DE SAÚDE

ABSTRACT

Objective: to describe the institutional network of children with special health care needs (CSHCN) in the community. Method: qualitative research of the descriptive exploratory kind with a participatory approach. For data collection, the Creative and Sensitive Method was used with a family that take care of CSHCN who was the subject of the study. Data were submitted to Discourse Analysis in its French approach. We obtained approval by the Research Ethics Committee under number 0003.243.000-08. Results: CSHCN has an institutional network constituted by a pediatrician, a physiotherapist and a teaching hospital. Conclusion: the family of this child seek strategies to provide the institutional network of care in which public primary care services are not included due to the difficulty of access. It is recommended that nursing acts in this process, allowing the bonding of the child and the access to the network of institutional care. Descriptors: social support; pediatric nursing; family; child health.

RESUMEN

Objetivo: describir el acceso a la red institucional de cuidados de la niñez con necesidad especial de salud (CRIANES) en la comunidad. Método: investigación cualitativa, de tipo exploratorio-descriptiva, con abordaje participativo. Para la recolección de los datos, se desarrolló la dinámica de la creatividad y sensibilidad Mapa Hablante del Método Creativo Sensible con una familia cuidadora de un CSHCN que fue el sujeto de la investigación. Para la realización de la Dinámica de Creatividad y Sensibilidad (DSC) Mapa Hablante, fue formulada la siguiente Questão Geradora de Debate (QGD): “Posterior à alta hospitalar, quais são os serviços e/ou instituições que fazem parte do cuidado da (nome da CRIANES) na comunidade?” Os dados foram submetidos à Análise de Discurs. O proyecto de pesquisa foi aprobado pelo Comité de ética em Pesquisa sob número 0003.243.000-08. Resultados: a CRIANES possui uma rede institucional constituída pelo médico pediatra, o fisioterapeuta e um hospital escola. Conclusión: los familiares de la CRIANES buscan estrategias para constituir a rede institucional de cuidados en que los servicios públicos de atención primaria no están incluidos por la dificultad de acceso. Se recomienda que la enfermería actúe en este proceso, posibilitando a formación de vínculo e o acesso da CRIANES à rede institucional de cuidados. Detrscritores: apoio social; enfermagem pediátrica; família; saúde da criança.

RESUMEN

Objetivo: describir el acceso a la red institucional de cuidados del niño con necesidades especiales de salud (CSHCN, sigla en inglés) en la comunidad. Método: investigación cualitativa, de tipo exploratorio-descriptiva, con abordaje participativo. Para la recolección de los datos, se desarrolló la dinámica de la creatividad y sensibilidad Mapa Hablante del Método Creativo Sensible con una familia cuidadora de un CSHCN, la que fue el sujeto de la investigación. Para la realización de la Dinámica de Creatividad y Sensibilidad (DSC) Mapa Hablante, se plantearon las siguientes Cuestiones Generadoras de Discusión (QGD): “Posteriormente al alta hospitalaria, ¿cuáles son los servicios e/ o instituciones que hacen parte del cuidado del (nombre del CSHCN) en la comunidad?” Se obtuvieron los datos para el Análisis del Discurs. El proyecto de investigación fue aprobado por el Comité de ética en Investigación bajo el número 0003.243.000-08. Resultados: el CSHCN posee una red institucional compuesta por el médico pediatra, el fisioterapeuta y un hospital escola. Conclusión: los familiares del CSHCN buscan estrategias para constituir la red de cuidados, en que los servicios públicos de atención primaria no se incluyen por la dificultad de acceso. Se recomienda que la enfermería actúe en este proceso, posibilitando a formación de vínculo e o acceso da CRIANES à rede institucional de cuidados. Detrscritores: apoio social; enfermagem pediátrica; família; saúde do niño.

1Nurse. Master’s student of Graduate Program in Nursing of Federal University of Santa Maria/UFSM. Member of Research Group: Health Care for People, Families and Society from Federal University of Santa Maria/UFSM. Santa Maria (RS), Brazil. E-mail: kelrenchiz@hotmail.com; 2Pediatric Nurse. Doctoral in Nursing. Associate Professor, Department of Nursing and the Graduate Program in Nursing of Federal University of Santa Maria/UFSM. Member of Research Group: Health Care for People, Families and Society. Santa Maria (RS), Brazil. E-mail: elianeves03@gmail.com; 3Nurse. Especialist in Public Health. Master in Nursing in Federal University of Santa Maria/UFSM. Professor of Undergraduate Program in Nursing of University of Cruz Alta/RS. Member of Research Group: Health Care for People, Families and Society. Santa Maria (RS), Brazil. E-mail: andressaasilveira@gmail.com

Study developed with financial aid from “Fundação de Amparo à Pesquisa do Estado do Rio Grande do Sul” - FAPERGS.

Article elaborated as Final Undergrad Paper << Child with special health needs: a social network for care in the community >> presented to the Nursing Undergrad Program of Health Sciences Centre of Federal University of Santa Maria/UFSM. Santa Maria/RS, Brazil, 2011.
INTRODUCTION

Technological advances in the field of neonatal and pediatric intensive care have contributed to the appearance of a new group of medically fragile children, dependent on technological devices for their survival. Named in the United States as children with special health care needs (CSHCN)\(^1\), this group of children is studied since the 80s. In Brazil, since the 90’s, are named and studied as *crianças com necessidades especiais de saúde* (CRIANES).\(^2,4\)

CRIANES are a representative clientele in the health services and emerging due to different factors that may or may not be related to each other. Among these factors, there are: children who survive preventable diseases that turned into a chronic health state due to repeated hospitalizations or readmissions; children with sequels of perinatal diseases and children with congenital malformations who end up needing health assistance for an indeterminate period of time.\(^5\)

CRIANES are classified according to care needs, and these are classified as: developmental care (children in need of motor rehabilitation), technological (children in need of any device on their body such as gastrostomy, for example), medication (children who rely on some type of medication) and modified usual care (those who need help for the common activities of everyday life).\(^4,6\)

Faced with the plurality of CRIANES specific care, the post discharged becomes a challenge for family caregivers, considering that they are confronted with numerous challenges due to the different care required by the child.\(^7\) Thus, these families must rely on the presence of a social network that fosters interpersonal relationships and involves interactions between different types of both professional and family caregivers.

The social network is defined as the set of significant relationships for the individual, including family members, work relationships, friendships, relationships and community health services.\(^7\) Institutional network is part of the child with special needs social universe because of the need to monitor health services and one’s diagnostic complexity.

Consulting the literature on the subject, it was found that the practice of family care for CRIANES has been lonely and exhausting and that family members seek strategies to minimize health risks in the health services. Thus, the family ends up sacrificing social contact, often needs to quit their job to devote themselves full time to child care.\(^4\)

In view of the rights of these children, it is emphasized that due to the difficulty of identifying the epidemiological CRIANES rates, and not having an official estimates on the number and health needs, there aren’t specific public policies aimed at them. Although the country laws in force as the law 8080/90 or the Child and Adolescent Statute (ECA)\(^8\) determine the full access to all citizens in general, CRIANES’ caregivers are unaware of those rights and don’t have access guaranteed to health services\(^9\), determining their social vulnerability.\(^5\) Added to this, the lack of connection between services and professionals that make up the institutional framework that supports the family and contributes to the practice of child care at home.

It is essential that care contemplates not only the biological aspects, but also their needs for leisure, learning and social interaction. By knowing these aspects, nursing can incorporate them in daily work, seeking an effective intervention for both the child and the family caregiver.

Based on these, it was asked: What is the institutional setup of the children with special health care needs network for the practice of family care. This study aimed to describe the access to institutional care network by children with special health needs in the community.

METHOD

Qualitative research with descriptive exploratory nature, with a participatory approach. The research subject, a CRIANES family, was randomly selected from a database search, “Children discharged from neonatal intensive care: characterizing the special health needs and access to health services follow-up - Santa Maria - RS.”\(^10\)

We included families who had already developed CRIANES home care. We excluded data on families whose records did not allow the location. The data production was chosen by the subjects, their working environment, because this environment is where they spend most of their time as part of their daily CRIANES care.

For the data production we choose the Creative Sensitive Method (MCS)\(^12\), through the creativity and sensitivity dynamics (DCS) Map speaker. The MCS uses consolidated technical production data in qualitative research, such as collective interview, group discussion and observation. In addition, the
participants expose their artistic production to the collective and, through the meaning of what has been produced, it generates issues that are discussed by the group. The produced data validation is made by the group that will confirm what is common (collective) and particularizing the unusual (singular).12

To perform the DCS, it was used the following debate generating question (QGD): "Back to the hospital, which services and/or institutions were part of the (name of CRIANES) care in the community?"

Data were submitted to discourse analysis (DA) in its French stream.13 The AD is to assess the units of text beyond the sentence, allowing the inter-discourse reading, valuing the relationship of meaning in interaction with others, considering their history.

The first step of the analytical procedure consisted in the allocation of linguistic materiality to the subjects discourse, so that in reading the text, the reader can move up to the moment of its enunciation and understand their conditions of production. We attributed some spelling resources, to materialize the object of discourse, such as – /: short reflective pause; ///: long reflective pause; ///: really long reflective pause; ...: unfinished thought; #: interruption of a person’s enunciation; ##: interruption of two persons’ enunciation; [...] interruption of an enunciation and subsequent continuation of the interrupted utterance; [italic] [text] – complete the thought in the same verbal statement saying; ‘‘...’: single quotation marks indicate someone’s speech mentioned in the statement; (…) indicates that there was a part which was cut from the subjects’ speech.

In the second stage of analysis is the explicit object of discourse, after successive processes of reading and rereading the empirical material. At this stage, it was identified the language resources used by enunciators to make sense of its said. They are the analytical tools of the field of AD - the metaphor, the inter-discourse, paraphrased processes and polysemy13 - essential to reveal the effects of direction of said and unsaid of the study participants.

The research project was approved by the Institution Ethics Research Committee (CEP) in number of Appreciation Presentation to Ethics Certificate (CAAE): 0003.0.243.000-08. We followed all the provisions of the Resolution 196/96.14 Consent form (CF) was presented to the family and fictitious names were assigned to all subjects mentioned to protect their identity.

RESULTS

● CRIANES Characterization, subject of study and its care demands

The subjects of the research were the Manuela’s parents, Andrew and Marina (all fictitious names), whereas the father is the primary Manuela’s caregiver. The couple has three daughters, and Manuela is the youngest, she was born in 2006 in a medium-sized hospital. She has care demands related to her psychomotor developmental delay, that is why she performs physical therapy, and medication care, making continuous use of anticonvulsants.

The results showed a configuration of two care networks for Manuela: family and institutional network, and this article will address the institutional care network.

● Institutional care network

The following is the Artistic Production (PA) conducted by Manuela’s parents from QGD (Figure 1):
From the QGD, the parents presented the institutional network of health care. The mother pointed the physical therapy as a regular service that Manoela attends once a week:

"No, it's in APAE. Before when it was here at the university [the University Center where the child was being monitored] was bad because there was no bus to come here, I thought it was too far... So I took her from there and had to go all the way downtown to catch another bus and then... [now] we do it in APAE (...), not I get a bus that stops right in front, then I go back (...)(Marina)

Physical therapy is indicated as a referral service used by Manuela. At the beginning of treatment, the mother reported difficulties due to the physical therapy’s location, it was far from home. Currently, due to the Association of Parents and Friends of Exceptional Children (APAE), where she conducts therapy, staying close to Manuela’s house, the displacement is easier.

The CRIANES’ father also brings the medical monitoring and a teaching hospital as referral centers for Manuela’s, as can be seen below:

Doctor [doctor’s name]: here///. She makes her medical monitoring there in [name of the hospital bound to the university], right! (Andrew)

Manuela has an institutional network constituted by the pediatrician that monitors her in his office and the Hospital linked to a University for the demands of more complex health.

The parents are asked about Manuela’s relationship with her pediatrician:

Is the Doctor [doctor’s name]. Well ... is / is not so often! (Marina)

When there is need for that ... / [laughs] In fact, sometimes we will take her because he himself says, “look, she is not going there” [the doctor’s office] knows that we take (...) (Andrew)

Returning, the drawing, the question of the institutional network connected to the CRIANES’ pediatrician, parents describe that he is consulted occasionally, when necessary, or even when asked by the doctor.

Parents were asked about where to take her daughter to consult:

We take her to the doctor’s office. It was through Dr. [pediatrician’s name] we’ve been able to do the first resonance, by talking to him in his office. Because there in the University Hospital they [doctors], in her file, put that we did not want to make the resonance, and what I put to the resident is that, at the time, we did not have conditions and if was able to do it through the free health system (...) it didn’t took a month and Manuela was able to do the exam, and she could have done it a long time ago, you know!? [mother with a tone of indignation] (...) (Marina)

The parents reported that they took their daughter to the pediatrician in private practice. In her statement, Marina says, as polysemy, it was through “medical help” that they achieved the first MRI for Manuela. However, this conversation happened in his private office and not in an outpatient care at the hospital. In one of these consultations, the parents found out that doctors had noted in Manuela’s record that the parents did not want to take the exam, while the situation...
posed by them was that they did not have the financial resources at the time, questioning whether the examination could be conducted by the SUS. So with the pediatrician’s help in private practice, Manuela could take the exam in no time.

Regarding the CRIANES monitoring in the basic unit health caregivers expose:

It has! But we ... # [Pointing to the University Hospital in the drawing] (...) Because they always say: “ah! When you have issues bring her directly. That other time ... # [we took her]. ... we were here at first ... / / ... in PA [Municipal Emergency Services], and then ... # [...] They did not know how to proceed. (Andrew)

(…) Then the pediatrician who was there said: “No, take her directly in the University Hospital that they are aware of [record] it all ... # (…) and we do not know where to take her. (Marina)

The subjects seek, often, the service of the University Hospital Emergency Department because they already know Manuela’s case, in addition to already know how to act in situations of seizures suffered by the child.

In relation to the guidelines on the care that the CRIANES needs and who oriented the parents was detached:

In physical therapy we receive enough guidance, in the first treatment, the first exercises until buying accessories, those pads, those things, do ... / pushing, lifting (...). Also the Doctor [doctor's name], as well, right? ... # (Andrew)

Inside the University Hospital when she was hospitalized, came (…) I think the doctor [referring to the physiotherapist] (...) “No, looks after the first three months, each phase has its own development, observe to not let it pass, right? So, stimulating and everything”(…). (Marina)

When asked if anyone had passed them some sort of guidance at the time of discharge in relation to specific care that Manuela would require, the subjects highlighted the physical therapists and pediatricians. The physiotherapist's neonatal intensive care unit was the one who guided them on the first exercises as well as the technological devices. In addition, he guided on the importance of observing the development and stimulation in each step of the treatment.

On the issue of the guidelines and care related to Manuela’s motor part, the mother quotes one of the students of the dance studio:

Then, as our student was... is a physiotherapist (...) there, there was close contact. Manuela was always together [in the dance class], then there we'd be talking and detecting (...). So, we always have a lot of contact with people, so I guess it also facilitates. (Marina)

Marina adds that because one of her students is a physiotherapist and keeping in touch with Manuela during classes, achieved through it an evaluation of the child, and at six months old began physical therapy. Marina points out as an aspect that facilitates Manuela’s treatment, the environment where she works that provides contacts and knowing several people.

I think that our environment really helped her because she can be in contact with different people! [mother noted with enthusiasm] (Marina)

In their speech, the subjects again highlights the fact that they are known and have many contacts, it becomes easier to get appropriate treatment and guidance to health care that they need for Manuela. Moreover, by being in contact with the dance, Manuela became a stimulated child, especially in motor development.

During the dynamic, it emerged network locations that provide institutional care for CRIANES with leisure and culture, such as: the school, the dance studio where her parents work and the church.

The school! She loves it! Today we got late, and it... / then it took her sisters first to school and I always take her … [Manuela] / / "Where are we going mom?" [mother quoting CRIANES] At school! "EEEE!" [mother's speech brings CRIANES]. (…)

Because there she plays, has playmates, everything… So she stays like this, and not at home … # (…) at home she does not, there she is alone, has no one to play with … (…) (Marina)

The mother says that school is one of the places Manuela (CRIANES) most like to go. She illustrates with a child's speech that she “celebrates” when she knows that she is going to school. And yet, says that her daughter loves the school because it is a place where
Institutional care network of children with...

Zamberlan KC, Neves ET, Silveira A.

she plays, has colleagues, or has a social network of friends the same age. Marina reports that, at home, when the sisters are not there, Manuela ends up having to play alone without company.

The dance school is identified by parents as another place where the CRIANES attends assiduously, as can be seen in the following utterances:

Yeah! Because it is like this: On vacation she comes every day with us here [referring to the school dance] (Marina)

(...) The others were raised inside the school! (Andrew)

Metaphorically, the mother emphasizes the importance of the dance academy in the family life, saying that the girls “were created in the gym.” In her speech it may be noted that the academy represents a second home for family members.

We forgot to say that she goes to church! I'll put the church here! (...) She goes to church and stays in front: # of the musicians all the time, looking at them (...) (Andrew)

Manuela’s father points out that the Church is part of her institutional network of support. He stresses also that the CRIANES likes music and that at the church she stands watching the musicians.

**DISCUSSION**

When it comes to health institutions, it was observed that there are several places that parents and children must travel to get care and effective treatment. However, due to the complex needs and demands required by CRIANES, the care network ends up being fragmented and dispersed. Thus, the care given to CRIANES is accomplished by several different professional and social settings, which means being careful in structuring a social network.15

In the results presented, the pediatrician is quoted as a facilitator for the exams, as well as being a key person for the CRIANES treatment. However, as the laws in the country, people have rights in relation to health. The Brazilian legislation16 provides health as a universal right and duty of the State, as well as the universality and equality in access to health services, and effectiveness of public policies on the health of children and adolescents, to ensure the birth, healthy and harmonious development in dignified conditions of existence.3

The laws guarantee the rights of CRIANES through existing policies, but lack proper implementation to ensure access for all without distinction. It was noticed in this study that there is a wide gap between these children’s rights guaranteed by the laws and their enforcement in practice.16

Thus, health care prove to be important for this family life, and the achievements related to improvement of CRIANES are assigned to this work. Studies show that the CRIANES need a set of services that work in the rehabilitation process, in this sense, they need a social support network that provides support to family caregivers. This network of support should go beyond the medical and nursing services, covering the needs of children and family caregivers everyday.4,17

When talking about the conditions of the Basic Health Unit (BHU), parents report that they do not use it because there is a difficulty in accessing services, queues, and a few calls per shift. Another study reported in the speech of the subjects that there are few professionals to meet the demands of all users who rely on these services associated with the lack of organization of primary care services.18

Due to poor service on offer, it has been common for users seeking an emergency department (ED) to resolve issues that could have in solving BHU. The users end up seeking the ED to treat acute cases like emergencies.18 This is due to immediate resolution of the case.

When asked if someone gave them guidance in the post hospital discharge, only two professionals were reminded: the physiotherapist and the doctor. Thus, some caregivers seeking information on the health care team to help them in coping with the situation. However, other caregivers seek this support network family closer. Thus networks of care for CRIANES begin to be formed, based on the sociocultural matrix and its legacy.3

The CRIANES School along with the dance academy and the church, were appointed as tools for local recreation and culture. Chronic illness requires changes in the life of the child/adolescent, since the beginning of treatment, a new routine emerges in children’s lives, especially when she needs long hospitalization.19 In the case of data obtained in this study, the CRIANES despite having a large dependence on care, has a network of structured leisure and entertainment.

When reporting the presence of children in church, it is observed that in this location, the family receives comfort. The sense of feeling welcomed and better because of spiritual support, causes people to be filled with feelings of hope, comfort, and inner peace that they can’t otherwise.20 For those people
who are going through situations of illness, religion ends up playing the role of emotional support, strengthening the hope, renewing forces helping them to live and cope with difficulties in a different way of people who do not seek religion.\textsuperscript{21,22}

The Manuela’s institutional network is characterized by being wide, and it assists the family in meeting their health needs, opening doors for the treatment of the CRIANES. The network includes not only family members but also people who believe that they offer them support in daily life, such as dance students, friends. This statement is consistent with data obtained from a survey of chronic patients, in which subjects mention people outside the family as a support group for caregivers, establishing interdependent relationships and affectivity.\textsuperscript{23}

In home care, there are several factors that burden the family caregivers such as disruptive and problematic patient, repeated hospitalizations, lack of freedom due to the caregiver’s responsibility to the individual.\textsuperscript{24} Thus, the formation of a broad social network and strengthened helps the caregiver, because it is a very difficult time for him and of great changes in family structure and in their daily routine.

\section*{CONCLUSION}

These research findings point to the existence of a large and complex network in relation to the demands for care and treatment provided to CRIANES. The child’s family runs several locations in search of treatment. Due to the social invisibility of child care to CRIANES often depends on the articulation of family support networks that seek to parallel that may support the CRIANES’ care.

In this study, the care of this CRIANES are restricted to a pediatrician and a physiotherapist. The hospital appears as a reference center for other care demands, followed by APAE where the physical therapy is placed and the city’s ED.

It was noticed that there is a special valuation of the pediatrician in the statements of the CRIANES’ parents in the case of care and treatment. As regards the follow-up on the child’s health, and their evolution, although it does require special care, due to a solitary quest of the family, who from the beginning appealed to various institutions for the treatment of children without aid services reference and cross-referencing of public health services.

The services of care provided by BHU, the primary care services were cited by subjects as difficult to access, and, therefore, are not used by the child. This fact demonstrates that there is a lack of monitoring of CRIANES in the community where she resides and dislocation of the service reference and cross-referencing.

It should be noted, though, the invisibility of nurses in the parents’ discourse. At no time is cited nursing, even when asked about the guidance they received during the hospital admission and discharge, indicating the fragility of the link with this family nursing.

There is a particular focus on the child’s participation in the dance school, it provides an environment where the child is stimulated, and she has a contact with music and dancing which contributes to her development and treatment. Moreover, it constitutes a source of fun and entertainment, not limited only to this child live around its premises health.

It should be noted, the father’s role as primary caregiver of the child. This constitutes a new finding when compared with other studies conducted on this topic.

It is recommended that nursing acts in this process, allowing the formation of bonding and access to the CRIANES institutional network care. Develop a care focused on children and their families, considering the family as a child’s chronic nursing care unit, which provides continuity of care at home. Thus, it is intended that nursing can takes that space, contributing to the welfare of the children and their families.

\section*{REFERENCES}


Zamberlan KC, Neves ET, Silveira A.

2.2.2/index.php/reufsm/article/view/2484/1630


Sources of funding: FAPERGS
Conflict of interest: No
Date of first submission: 2011/12/19
Last received: 2012/04/13
Accepted: 2012/04/14
Publishing: 2012/05/01

Corresponding Address
Kellen Cervo Zamberlan
Edif. Solar Oriente
Rua Aureliano de Figueiredo Pinto, 01, Ap. 505
Bairro Nossa Senhora de Lourdes
CEP: 97050-060 — Santa Maria (RS), Brazil