

VULNERABILITY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: IMPLICATIONS FOR NURSING

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ABSTRACT

This qualitative-based, descriptive, exploratory research aimed to provide an account of the vulnerability of children with special health needs in terms of required care and everyday life support. The subjects were ten family members/caregivers of children who were approached in a pediatric admission unit of a teaching hospital. Data were produced by means of the creative and sensitive method, mediated by creativity and sensitivity group dynamics and submitted to French discourse analysis. Results pointed out that the individual, social and programmatic vulnerability of children was translated into their clinical frailty, difficulty in gaining access to healthcare services, and absence of specific public policies. The study recommends that the referral and counter-referral system, as well as the specific healthcare public programs and policies aimed at this clientele, be restructured. For this purpose, nursing professionals should strive to actively listen to family members/caregivers and subjectively recognize the home-based caregiving process carried out by the families.

Descriptors: Child Health. Pediatric Nursing. Vulnerability. Family.

RESUMO

Trata-se de uma pesquisa qualitativa, descritiva e exploratória que objetivou descrever a vulnerabilidade das crianças com necessidades especiais de saúde para o cuidado e manutenção da vida no cotidiano. Os sujeitos foram 10 familiares/cuidadores de crianças em uma unidade de internação pediátrica de um hospital de ensino. Os dados foram produzidos por meio do método criativo e sensível, mediado pelas dinâmicas de criatividade e sensibilidade e submetidos à análise de discurso francesa. Os resultados apontaram que as crianças possuem vulnerabilidade individual, social e programática traduzidas pela sua fragilidade clínica, a dificuldade de acesso aos serviços de saúde e a inexistência de políticas públicas específicas. Recomenda-se a reestruturação do sistema de referência e contrarreferência, programas e políticas públicas de saúde específicas para essa clientela. Para isso, torna-se relevante que os profissionais de enfermagem proporcionem, aos familiares/cuidadores, momentos de escuta, reconhecendo na subjetividade do cuidado desenvolvido pelo familiar no domicílio.

Descritores: Saúde da criança. Enfermagem pediátrica. Vulnerabilidade. Família.

Título: Vulnerabilidade das crianças com necessidades especiais de saúde: implicações para a enfermagem.

RESUMEN

Estudio cualitativo descriptivo y exploratorio que tuvo como objetivo describir la vulnerabilidad de los niños con necesidades especiales de salud para el cuidado cotidiano. Los sujetos fueron 10 familiares/cuidadores de niños en una unidad de pediatría de un hospital universitario. Los datos se produjeron por medio del método creativo y sensible a través de la dinámica de la creatividad y sensibilidad y sometidos al análisis francés del discurso. Los resultados mostraron que los niños tienen vulnerabilidad individual, social, y programática traducidas por su fragilidad clínica, la dificultad de acceso a los servicios de salud y la falta de políticas específicas. Se recomienda la reestructuración del sistema de referencia y contrarreferencia, los programas y las políticas públicas de salud para que estos niños. Es importante que los profesionales de enfermería proporcionen a los familiares/cuidadores momentos de escucha, reconociendo, en la subjetividad de atención desarrollado por la familia en el hogar.

Descritores: Salud del niño. Enfermería pediátrica. Vulnerabilidad. Familia.

Título: Vulnerabilidad de los niños con necesidades especiales de atención médica: implicaciones para enfermería.

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INTRODUCTION

Child care practices have been changing in recent years. The scientific and technological advancements achieved in the 1990's strongly contributed to the enhancement of the survival of children once deemed to be clinically incurable and/or extremely fragile. Such advancements have resulted in larger numbers of children in need of complex medical care; hence, the indices of children presenting with chronic and/or incapacitating diseases have skyrocketed and many of them are wholly dependent on technology. The so-called "CRIANES" in Brazil were initially named CSHCN, or Children with Special Health Care Needs, in the United States⁽¹⁾. This clientele need home-based care that goes beyond the basic care offered to other children and teenagers.

In Brazil, the growth in the CRIANES group is related to preventable illnesses that evolve to chronic diseases due to successive readmissions of the child and to perinatal afflictions that evolve into complex diseases following intense treatment, in addition to congenital malformations that require health care follow-up for indefinite periods of time⁽²⁾.

In the municipality of Santa Maria, in the State of Rio Grande do Sul, the CRIANES stand out as a significant group of patients in the pediatric unit of a teaching hospital. In 58.5% of children that developed health care special needs, such a profile was a result of perinatal causes, congenital malformations, prematurity and syndrome diseases⁽²⁾. Regardless of their care demands, these children need to be considered as an emerging clientele, due both to the complexity of their cases and the unique circumstances of clinical fragility in which they live⁽³⁾.

These special health care needs (SHCN) can unleash various types of sufferings and expectations in the child and his family that go beyond the disease itself: they can trigger social and emotional repercussions. In this way, families must cope not only with all of the difficulties related to these children's care, but also with all problems arising from the lack of efficiency of the public health system, such as the difficulty in accessing specialized medical care and specific exams⁽⁴⁾.

The legal foundations grounding this issue are the Brazilian Federal Constitution⁽⁵⁾, together with the Statute of the Child and Adolescent (ECA)⁽⁶⁾.

These documents have begun the process of recognizing the citizenship status of infant-juvenile populations, regardless of sex, color, ethnic group, social class and cognitive development. Thus, every child is now deemed to be a citizen. However, a broad gap still exists between what is guaranteed by law and what is practiced by society⁽⁷⁾.

Bearing the above-mentioned considerations in mind, this present study aimed to describe the vulnerability of the CRIANES toward their care and everyday life support. The research also sought to identify the specific vulnerabilities presented by these children.

METHODOLOGY

In this qualitative-based, descriptive, exploratory research, data collection was carried out in a participatory way, stemming from the concept that subjects are actively engaged in the construction of knowledge; in this framework, the research stands out as a tool aimed to create conditions that allow subjects to have their say and let their views be known⁽⁸⁾.

The study opted to make use of the Creative and Sensitive Method (CSM), applied by means of Creativity and Sensitivity Group Dynamics (CSD), which creates a space for discussion and reflection, as do the Freirean Culture Circles, assisting research subjects to problematize their life and experience-related practices. The CSM provides a space for collective critical thinking, based on a dialogical, dialectic, plural understanding in which the group evolves from the condition of being an object to the condition of being a subject in the research⁽⁸⁾.

Two group dynamics were developed in this present research.

First, the *Corpo Saber* (Body Knowledge) CSD aimed to measure the home-based care process; using the metaphor of the body, the purpose of the group dynamic is to awaken the latent memory of participants stemming from the following debate-triggering question: How do you care for your son or daughter with special health care needs at home?

Secondly, the *Costurando Estórias* (Sewing Stories) CSD aimed at providing spaces for subjects to share collective and socially-rooted individual problems and difficulties by applying an activity in which they make comments regarding the following phrase while intertwining a string: Tell me how you learned to care for your son or daughter at home.

The scenario of the study was the Pediatric Admission Unit (PAU) of a teaching hospital in the southern area of Brazil. The subjects were ten family members/caregivers of CRIANES, among them an aunt, two fathers and seven mothers of children with SHCN admitted into the pediatric unit. Family members/caregivers of CRIANES admitted into the PAU during the data collection period who had already developed/provided home-based care to those children were included in the research. Excluded family members/caregivers were those whose children had never undergone home-based care, or who were not adequately prepared or committed to taking part in the study, according to the analysis of the healthcare team.

Data were submitted to the French-based Discourse Analysis (DA) applied to the text's linguistic material⁽⁹⁾. This type of analysis aims to provide the text with expression, thus allowing the reader to comprehend the statements of the subjects. For this purpose, the following orthographic resources were employed: / – short reflexive break; // – long reflexive break; /// – very long reflexive break; ... – incomplete thought; # – interruption of statement; [] – used to insert information and complete the statement; “...” – quote and unquote indicate someone else's words or text reproduced by the interviewee; [...] – points out a break in the subject's statement. Later on, the metaphor, the paraphrase and the polysemy were employed as analytical tools.

It is worth highlighting that the research was initiated only after being approved by the Research Ethics Committee under protocol number 0318.0.243.000-10. Research subjects were presented with the Free and Clarified Consent Form, which communicated the goals of the study, the voluntary character of their participation, and included the information on the total lack of any type of penalty should they decide to quit the study at any time. Their utter anonymity in the process by means of the use of fictitious names under their statements was also secured.

RESULTS

By means of their statements, the family members/caregivers identified that the difficulties they felt concerning the social inclusion of

their children was the major vulnerability of the CRIANES; in other words, the prejudice displayed by people due to their technological dependence, their fragility and the delay in diagnosis, as well as the solitary family-centered care. A few artistic productions clearly show the wide array of home-based caregiving activities carried out by the family members/caregivers, and also the relevance of the presence of the family as a guiding axis toward the development of home-based caregiving practices. These perceptions were reaffirmed by Figures 1 and 2, as well as by the following statements:

Well, /she does not play in school, right?! She stays in the school's office, // she sits down there! / Now, thank God, she already goes to the courtyard and sits there, / when she can participate in a type of play in which she can be seated! (Solange).

[...] // Difficulty in harmonizing the relationship between my son and the others [other children of the couple] because... Ours, too, because, well, if the issue is the loud volume of the music, it has to be even louder for him, because of his auditory problem [...] (Abel).

[...] Because since he was born, several people approached me and asked, "How many days does he have?" [referring to the questions coming from people]. She [a person that addressed Eva] looked me in the eye and asked, "Is he sick?" [...] And I asked myself... is he sick? He said: No! He just lacks growth hormone [...] (Eva).

[...] It's been so hard on us, on our family... because of Clara! She has even quit going to school... In school! About the jokes told about her in school! Her mates quit talking to her... They stopped playing with her... // It's not anymore like it used to be in the past! (Roberto).

[...] My husband is a nursing assistant! He was the one who helped me the most, he was much more prepared than me, you know! [...] We learned almost everything with the medical team! (Rosa).

[...] It's just me and my mother! [Who care for the CRIANES] (Vilma).

For the CRIANES' family members, the social inclusion process of these children is quite a difficult move due to their clinical frailty. Caregivers also brought up the difficulty in accessing a medical diagnosis for the child, as well as the long path they had to travel, showing how hard it was for them to

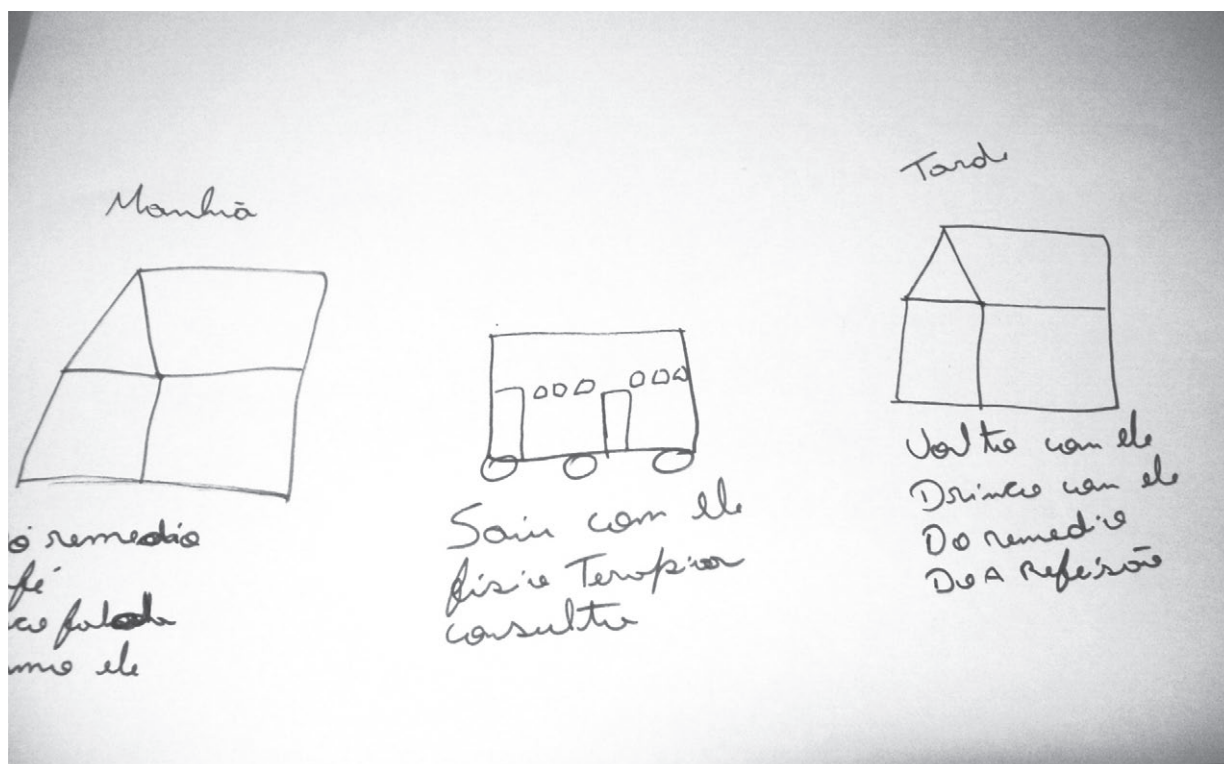


Figure 1 – Eva's artistic production: *Corpo Saber* Group Dynamic. Santa Maria (RS), 2011.

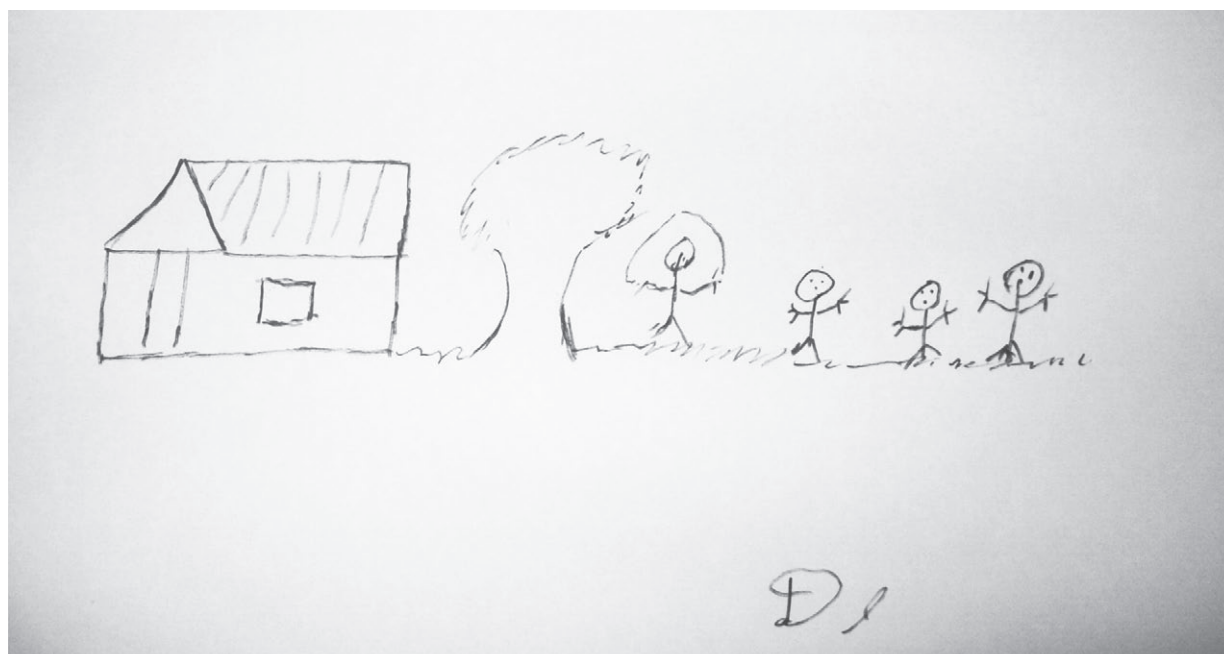


Figure 2 – Roberto's artistic production: *Corpo Saber* Group Dynamic. Santa Maria (RS), 2011.

access the necessary services, thus configuring a social and programmatic vulnerability. The activity of intertwining the string, shown in Figure 3 and

representing the statement of each family member/caregiver, clearly indicated that the challenges in caring for these children were very similar.



Figure 3 – Sewing Stories Group Dynamic. Santa Maria (RS), 2011.

No, at the beginning she always used to attend the prenatal exams [...], but he was a general clinical practitioner and cared for pregnant women... / when he noticed the problem, / he was not able to tell what it was and thus asked her to come here! [...]. Then, she took this private exam / and then she knew of the problem // [...] (Lúcia).

[...] It was very sad, you know! / Because... // Julia's whole prenatal process was so normal and adequate, / Julia was born / in the 38th week, / everything was all right, I was taken back home, you know! [...] And on the third day she started showing those symptoms / I don't know how to explain them... // Her little hands started wriggling / [convulsions]. Wherever I lived, I took her / to six doctors, and they looked at her and said that she just gave me a fright. This other doctor said that it was just a cramp! [...] (Circe).

Can you imagine that... // when I knew about it, she was just seven! And... // she was born in perfect condition! She started getting weak and then I brought her... The doctor there prescribed this syrup, but she couldn't even swallow her saliva! / Then, I told her that she was not able to even swallow her saliva, and the doctor told me to take her back home and administer the syrup. [...] Then, the doctor wanted me to go away... / and she gave me another medication, then I said: I'm not taking her

away! Then the doctor replied, "Then, you take her to the hospital" [a hospital located in another neighborhood municipality] [...] (Solange).

[...] When he was around ten days old, I bathed him as usual, // he slept and then woke up crying very hard! We thought he had cramps, but it was not, it just did not cease, / then, we took him to the emergency unit and they thought it was an earache... As they did not have available resources, they told us to go back home! [...] The doctor told me to go to the clinic / as this pediatrician would come [from another city], that he would examine him, as his case was a serious one. [...] I got there and handed the baby to the doctors [for the medical exam], and then we were kept there up to 7:30, when they gave us the news that the baby had meningitis! (Mara).

The statements of family members/caregivers show that the reference and counter-reference service does not establish a direct connection; that is, it does not work as it should. The primary service is unaware of the true clinical status of the children, resulting in even more significant complications as they are taken to and from the emergency unit and their homes. This profile denotes the utter absence of articulation in the system, as well as

a clear lack of preparation of healthcare professionals to cope with the clinical findings towards properly diagnosing the child.

The statements also indicate the difficult journey undertaken by family members in search for assistance/diagnosis for their sons and daughters. Such a journey oftentimes requires contact with a private service that allows for quality care and/or access to the public healthcare system, besides the family's search for financial support aimed to provide for the child's treatment process.

[...] As soon as Caio was born, we knew of his health problems, we started with his heart... [a protocol requiring medical support due to his cardiac problems]. We applied for [...] sick pay, he got it, / and he will receive it up to the age of 10. / And... and... and.../ syringes, uh... equipment, gauze, micropore, and stuff. I get everything he needs at the health unit! If the medication is available at the office, I get it! If it is not, I buy it! (Eva)

I count on... / his pension! [...] The pump sprays are expensive, and then I brought him and asked whether he could quit them. He was not well then, you know! I even went to the radio stations, but he was not left without the pump sprays [the mother reports that she required the medication even in the means of communication]. Then, I succeeded in getting his pension, that's how I buy his missing medication... / I also bought the inhaler, as he has to use it constantly! (Ana)

Families clearly seem to look for alternative resources in order to provide for the children's care needs, allowing for the acquisition of all necessary materials for their treatment. At times, families even explore other means of communication and appeal to charities/donations, aiming to sensitize society to the situation faced by their CRIANES. Thus, families begin weaving a parallel and solitary network, depending on the demands of their child and the services/institutions they are able to access.

DISCUSSION

The child's chronic disease generates new demands on family members. Whenever they are encouraged to share their feelings with one another, they are given to efficient communication, which helps them cope with their problems in a healthy way⁽¹¹⁾. Family groups conjointly find new paths toward adjusting to the challenging reality caused

by detours provoked by difficult situations within the family context. The care activities carried out by the family are most of the time performed in a lonely and uninterrupted status⁽¹²⁻¹³⁾.

Another aspect is the steady fight for survival and the unceasing search of the CRIANES' family for a better life, constantly coping with the prejudice of the population at large, as society is not prepared to accept these children. Hence, the children's social ties are restricted to the family unit.

Family members/caregivers brought up the limitations experienced while caring for the CRIANES, their restricted social network, and the vulnerabilities of the children with special healthcare needs. As the family member/caregiver is the major provider of assistance for the child with SHCN, the family needs to be held up by the support networks after being released from the hospital. The healthcare field must focus on the core of the care, where children and their families need to be cared for due to their vulnerable condition⁽¹⁰⁾. In this way, nursing practice must act toward planning, organizing, executing and assessing the entire health care and assistance process.

In addition to the social vulnerability these people constantly face, social inclusion stands out as another of their major challenges. While fighting for the survival of their children, these families are frequently left on their own to cope with the child's treatment process after being released from the hospital. Family members also pointed out the need to learn how to balance their personal and social lives with the care of the CRIANES. In this way, it is clearly observable that the family lives mainly for the child's life, taking full and continuous responsibility as caregivers.

Nonetheless, the vulnerability profile of these children does not stem from their inabilities. It lies in the capacity of the CRIANES to be prepared to develop adaptive behaviors toward overcoming risk factors that may stunt their health and quality of life. Social vulnerability is related to access to information and the possibility of turning it into practical changes in the child's life. This status does not depend only on individuals, but also on access to the means of communication, education, material resources, political will and actions toward coping with cultural barriers, among other aspects⁽¹⁴⁾.

The programmatic vulnerability is linked to the social resources individuals require. These resources

are fundamentally programmatic efforts, such as the management and monitoring of national, regional and local prevention and care programs aimed toward the disease, aiming to optimize their application and identify the necessity of other resources⁽¹⁵⁾.

Several vulnerability factors affect the environment of the child and his family, especially those based on social-economic and cultural aspects. Vulnerability is associated with the precariousness in the wide array of goods and services surrounding the disease-centered situation. The healthcare team must take into account the difficulties affecting the child and his family in order to deliver comprehensive health care based on the construction of support networks both at the hospital and home⁽¹⁶⁾.

Bearing all these factors in mind, it is clearly observed that the special health care need of the CRIANES causes these children and their families to fight for their survival and also to find their place in society, which is not yet ready to properly accept them. This status causes this group to become vulnerable regarding their citizenship rights. Legal and public policy mandates are essential in supporting family members/care givers, as this daily care demand is already quite challenging in itself. It should be highlighted that caring for the CRIANES is an exclusively family-focused and isolating process.

In a world of pragmatic behaviors, profit and production, the underlying idea is that children with any type of restriction would be subdued by society⁽¹⁷⁾, causing them and their families to suffer the consequences of their social confinement.

A study carried out in Minas Gerais pointed out that those responsible for these children considered the Family Health Strategy's (FHS) embracement as satisfactory, as well as the attitude of the professionals, approved by over 70% of the participants⁽¹⁸⁾. A research carried out in the capital of Rio Grande do Sul regarding the reference services provided to these children showed that 74.4% of families attended the family healthcare unit, followed by private doctors' offices (11.1%), which denotes the adherence of clients to primary healthcare services⁽¹⁹⁾.

Notwithstanding, the results achieved in this study revealed that whenever family care givers sought out primary healthcare services, they were confronted by a non-resolutive system that frequently sent them back home without providing

them with any effective response to their needs. Most often, caregivers go back to the healthcare service after observing a lack of improvement in the child's clinical condition; others come up with strategies toward solving the problem in private clinics, or attempt to hospitalize the child in referral services located in other municipalities.

It must be highlighted that the FHS is a policy aimed at reorganizing primary health care in Brazil. The strategy proposes to apply the technical care precepts of the Unified Health System (UHS) based on universality, resolutivity, comprehensiveness, equity and social participation⁽²⁰⁾.

However, if on the one hand the service forecasts universal and problem-solving access to health care, on the other hand it cannot be observed in the practical demands presented by the CRIANES. In this study, family members/caregivers pointed out care gaps in terms of obtaining the child's diagnosis, which ended up resulting in more severe repercussions to the children's health.

In this way, the family of children with special health care needs plays quite a relevant role, as opposed to the child's social marginalization, thus providing them with visibility while making their own lonely ways into society and its healthcare services. Consequently, the family network provides the CRIANES with the opportunity to create social bonds, broadening the possibilities of social inclusion in a society that is either ill-prepared or unprepared to meet the demands of clinically fragile children.

FINAL CONSIDERATIONS

The care processes carried out by the family member/caregiver of the child with special healthcare needs is grounded on strategies aimed at the maintenance of his survival and supported by the knowledge resulting from practical experience.

The research pointed out the individual, social and programmatic vulnerability of the CRIANES, verified in the statements of family members/caregivers regarding the clinical fragility of the children, the precariousness of their access to healthcare services and the references to their ill sons and daughters as not being ill at all in their perspectives.

Medical diagnoses that accelerate the beginning of the child's treatment, as well as his/her access to healthcare services are hard to find, leading to a worsening of the child's clinical status.

Family members also indicated that the paths to be covered toward accessing primary healthcare are either unsatisfactorily resolute or non-resolute at all, leading them on a constant, lonely search for adequate treatment - figuratively associated with a pilgrimage to both healthcare referral and counter-referral centers and private clinics.

The study also observed that the symptoms presented by the child and described by family members/caregivers are oftentimes disregarded, causing them to feel oppressed by a system that neither embraces nor listens to them in a sensitive way. Hence, the delayed diagnosis slows the beginning of treatment, which may bring about severe complications to the child's healthcare status. Although the UHS's legislation ensures basic principles such as universality, comprehensiveness, equity and resolvability, family members/caregivers of CRIANES have not enjoyed them fully toward the solution of these children's care demands.

The primary healthcare professionals must be qualified to deal with children with special healthcare needs, addressing the home environment as an extension of the care practice. Nursing professionals must recognize the care practice carried out by family members/caregivers, aiming at allowing children to live a better quality of life. To this purpose, it is important that nursing professionals actively listen to family members/care givers, perceiving the subjectivity of the care carried out by them, thus opening dialogue for a more effective/objective healthcare education and improved home-based care.

It must be highlighted that the CRIANES experience vulnerability situations in their everyday life; however, such vulnerability should not be addressed as being a lack of potential toward their recovery, nor should they be treated with indifference, thus preventing them from gaining a more worthy and qualified treatment aimed at sustaining and improving their lives. For that purpose, healthcare professionals must envision a comprehensive care process, valuing the singularities, limitations and conquests of these children and their families as a potential and emerging clientele.

Bearing the above-mentioned considerations in mind, this study highlights the need for healthcare programs and policies to support family members/caregivers within their communities, so that after being released from the hospital, the

CRIANES and their families may feel sustained by a support network that is able to minimize eventual complications of the disease.

REFERÊNCIAS

- 1 McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newachek PW et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102(1):137-41.
- 2 Vernier ETN, Cabral IE. Caracterização de crianças com necessidades especiais de saúde e seus familiares cuidadores, Santa Maria (RS), 2004-2005: subsídios para intervenções de enfermagem. *Rev Soc Bras Enferm Pediatr*. 2006; 6(1):37-45.
- 3 Silveira A, Neves ET. Cuidado de enfermagem à criança com necessidades especiais de saúde: demandas de educação em saúde de familiares. Dissertação de mestrado. Universidade Federal de Santa Maria. 2011; 89p.
- 4 Gaiva MAM, Neves AQ, Siqueira FMG. O cuidado da criança com espinha bífida pela família no domicílio. *Esc Anna Nery Rev Enferm*. 2009; 13(4):717-25.
- 5 Brasil. Constituição da República Federativa do Brasil: texto constitucional promulgado em 05 de outubro de 1988. Brasília: Senado Federal. 2004.
- 6 Brasil. Ministério da Saúde. Estatuto da Criança e do Adolescente. Lei 8.069 de 13 de Julho de 1990. 2. ed. Atualiz. Brasília, Ministério da Saúde, 2005.
- 7 Milbrath VM, Siqueira HCH, Amestoy SC, Cestari ME. Criança portadora de necessidades especiais: contrapontos entre a legislação e a realidade. *Rev Gaúcha Enferm*. 2009; 30(1):127-30.
- 8 Cabral IE. O método criativo e sensível: alternativa de pesquisa na enfermagem. IN: Gauthier JHM. et al. Pesquisa em enfermagem: novas metodologias aplicadas. Rio de Janeiro: Guanabara Koogan; 1998.
- 9 Orlandi EP. Análise de Discurso: princípios e procedimentos. Campinas: Pontes; 2005.
- 10 Cabral IE. Desafios e perspectivas do cuidar de Enfermagem na saúde da criança. *Esc Anna Nery Rev Enferm*. 2009; 13(4):691-93.
- 11 Paula ES, Nascimento LC, Rocha SMM. A influência do apoio social para o fortalecimento de famílias com crianças com insuficiência renal crônica. *Rev Latino-Am Enfermagem*. 2008; 16(4).

- 12 Decesaro MN, Ferraz CA. Famílias de pessoas dependentes de cuidado: aspectos das mudanças na vivência do cotidiano. Ciênc Cuid Saúde. 2006; (5):149-57.
- 13 Brondani CM, Beuter M, Alvim NAT, Szareski C, Rocha LS. Cuidadores e estratégias no cuidado ao doente na internação domiciliar. Texto Contexto Enferm. 2010; 19(3):504-10.
- 14 Bretãs JRS. Vulnerabilidade e Adolescência. Rev Soc Bras Enferm Pediatr. 2010; 10(2):89-96.
- 15 Ayres JRJM, França-Júnior I, Calazans GJ, Saletti-Filho HC. O conceito de vulnerabilidade e as práticas de Saúde: novas perspectivas e desafios. In: Czeresnia D, Freitas CM, organizadores. Promoção da saúde: conceitos, reflexões, tendências. Rio de Janeiro: Fio-cruz; 2003. p. 117-39.
- 16 Pedroso MLR, Motta MGC. Cotidianos de famílias de crianças convivendo com doenças crônicas: microssistemas em intersecção com vulnerabilidades individuais. Rev Gaúcha Enferm. 2010; 31(4):633-39.
- 17 Falkenbach AP, Drexler G, Werler G. A relação mãe/criança com deficiência: sentimentos e experiências. Ciênc Cuid Saúde. 2008; 13(2):2065-73.
- 18 Ribeiro LCC, Rocha LR, Ramos-Jorge ML. Acolhimento às crianças na atenção primária à saúde: um estudo sobre a postura dos profissionais das equipes de saúde da família. Cad Saúde Pública. 2010; 26(12):2316-22.
- 19 Harzheim E, Starfield B, Rajmil L, Alvarez-Dardet DC, Stein A. Consistência interna e confiabilidade da versão em português do Instrumento de Avaliação da Atenção Primária (PCATool-Brasil) para serviços de saúde infantil. Cad Saúde Pública. 2006; 22(8):1649-59.
- 20 Brasil. Ministério da Saúde. Portaria nº 648, de 28 de março de 2006. Aprova a Política Nacional de Atenção Básica. Diário Oficial da União 2006.

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