
FAMILY CARE OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS: A PROCESS OF (SUPER)NATURAL CARE AND (OVER)PROTECTION

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ABSTRACT: The aim of this descriptive exploratory study was to describe the care process developed by family members/caregivers of children with special healthcare needs at home. Study subjects were ten family members/caregivers of children in a pediatric unit. Data production occurred by means of the dynamics of creativity and sensitivity and submitted to the discourse analysis. Results showed a (super)natural care and (super)protection, linked to the child's deprivation of common daily living activities in order to protect him/her from possible health complications. The study revealed the personal selflessness of the family member in favor of the care required by the child, and the presence of the father as primary caregiver. The authors recommend the development of extension activities specific to these families, the creation of programs aimed at the home care of the child and activities that benefit the improvement of the care practice at home.

DESCRIPTORS: Family. Caregivers. Pediatric nursing. Child health.

CUIDADO FAMILIAR DAS CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE: UM PROCESSO (SOBRE)NATURAL E DE (SUPER)PROTEÇÃO

RESUMO: Pesquisa descritiva e exploratória que objetivou descrever o processo de cuidado desenvolvido pelos familiares/cuidadores das crianças com necessidades especiais de saúde. Os sujeitos foram 10 familiares/cuidadores de criança em uma unidade pediátrica. A produção de dados ocorreu por meio do método criativo e sensível mediado pelas dinâmicas de criatividade e sensibilidade e submetidos à análise de discurso. Os resultados apontaram um cuidado (sobre)natural e de (super)proteção, atrelado à privação da criança às atividades comuns do dia a dia, a fim de protegê-la dos agravos à saúde. Constatou-se a abnegação pessoal do familiar em prol do cuidado requerido pela criança e a presença do pai como cuidador principal. Recomenda-se o desenvolvimento de atividades de extensão específicas para esses familiares, a criação de programas voltados para assistência domiciliar da criança e atividades que beneficiem o aprimoramento da prática de cuidar no domicílio.

DESCRIPTORIOS: Família. Cuidadores. Enfermagem pediátrica. Saúde da criança.

CUIDADO FAMILIAR DE NIÑOS CON NECESIDADES ESPECIALES EN SALUD: UN PROCESO (SOBRE)NATURAL E DE (SUPER)PROTECCIÓN

RESUMEN: Estudio descriptivo, exploratorio, tuvo como objetivo describir el proceso de atención desarrollado por la familia y cuidadores de niños con necesidades especiales de salud. Los sujetos fueron 10 cuidadores de niños en una unidad pediátrica, producido a través del método creativo y sensible mediada por la dinámica de la creatividad y la sensibilidad, sometidos al análisis del discurso. Los resultados mostraron una atención (sobre)natural y (super)privación de la actividades comunes de la vida diaria con el fin de protegerlo de posibles problemas de salud. El estudio encontró que la negativa del personal de lo familiar a favor de la atención requerida por el niño, y también la presencia del padre como cuidador. Se recomienda el desarrollo de actividades de divulgación específicas para estas familias, la creación de programas para la atención en el hogar del niño y actividades que beneficien a la mejora de la práctica domiciliar.

DESCRIPTORIOS: Familia. Cuidadores. Enfermería pediátrica. Salud del niño.

INTRODUCTION

Healthcare practices towards children have been changing, and, since the 1990s, scientific and technological advances have contributed to increase the survival rate of children with highly complex ailments, usually considered untreatable.¹ Healthcare has evolved with the introduction of more effective therapeutic resources, besides the technological evolution and specialized human resources.²

These children form an emerging group in the social context, and providing attention and care to them demands forms of knowledge so far unknown to common sense.³ Thus, there is an increase in life expectancy in the neonatal and pediatric areas and, resulting from this, the appearance of a group of children with specific healthcare needs, called Children with Special Healthcare Needs (CSHN).⁴ These children need healthcare follow-up, which range from medical to nursing services, including rehabilitation, educational, social and family support.⁵

CSHN have been classified into five segments, according to the healthcare demand: development care (children who need psychomotor and social rehabilitation), technological care (children who depend on some kind of technology in their body to survive), medication care (children who are dependent on pharmaceuticals), modified habitual care (children who need help for common daily living activities) and mixed care (for those who have associated healthcare demands).⁵⁻⁸ It is essential that the family member/caregiver be qualified to proceed with the care of this child at home, so that he/she may survive with quality of life.⁴

It is important to emphasize that illness and hospitalization change the family dynamics and stress affects interpersonal relationships, and may even cause a crisis among family members. An initial de-structuring process takes place, ending with the later acceptance and structuring of an adapted family routine after the birth of a child with chronic disease.⁹

The family plays an important role in the child's healthcare, because it is responsible for the child's physical and emotional well-being, and it is in the family that the child finds his or her referential.¹⁰ The family members/caregivers are people who coexist with the child, who maintain an affective link and develop healthcare at the home of the child.

Regardless of the healthcare demands presented by CSHN, it is necessary to consider them an emerging class, due to the complexity of the healthcare required, as well as the singularity, clinical frailty and social and programmatic vulnerability these children experience.⁴ All of these aspects present several challenges not only to the healthcare team, especially the nursing team, but also to the family member/caregiver. Therefore, to foster the integration between family and team, the team must recognize the family's participation in the healthcare of CSHN.

Given the aforementioned, the aim of this study was to describe the healthcare process developed by the family members/caregivers of CSHN at home.

METHOD

This is a qualitative, descriptive and exploratory study. The production of data took place in a participative manner, based on the conception that the subjects work in the knowledge construction process, in which the research implies the creation of conditions for the subjects to have their own voices recognized.¹¹

Data were produced using the Creative and Sensitive Method (CSM), by means of Dynamics of Creativity and Sensitivity (DCS) which, just like the Culture Circles of Gilberto Freire, provide moments of discussion and reflection, leading the study subjects to pose the problems affecting their daily life and existential practices, based on an artistic production or symbol. The CSM gives the co-participating subjects of the study a place for collective discussion, a dialogic, dialectic and plural understanding, by means of which the group transcends its condition as an object and becomes the subject of the study.¹¹

In this study, two dynamics were used, the DCS Body-Knowledge, to learn the care process at home, using the drawing of a body as symbol, aimed to awaken the dormant memories of the participants. A debate was performed, starting with the question: how do you take care of your child with special needs at home? And the second dynamics was the DCS Weaving Stories, in which subjects share problems and individual difficulties that may have collective social roots, intertwining lines. Thus, the family members/caregivers answered the following question: how did you learn to take care of this child at home?

The study was performed at the Pediatric Hospitalization Unit (PHU) of a teaching hospital in Southern Brazil, in the second half of 2011. Study subjects were ten family members/caregivers of CSHN, including seven mothers, two fathers and one aunt of a CSHN hospitalized at the pediatric unit. Inclusion criteria were: being a family member/caregiver of CSHN hospitalized at the PHU during the period of data collection, who had already delivered home care to the CSHN; and the exclusion criteria were: being the family member/caregiver of a CSHN who had never been under home care, or who could not take part in the study due to the frailty of the child, as indicated by the health team.

The statements were submitted to the French version of the Discourse Analysis (DA), in which linguistic materiality is applied to the text. The units of texts were analyzed beyond the sentences, allowing a reading of inter-discourses, the valuation of the senses in the interaction with each other and its historicity.¹² This analysis serves to give the text motion, allowing the reader to understand speech. For that purpose, orthographical resources were used in the discourses of the study subjects, in order to enhance comprehension of the statements, namely: /: short reflexive pause; //: long reflexive pause; ///: very long reflexive pause; ...: incomplete thought; #: interruption in a person's statement; [...]: completing verbal thought stated in the same saying; '...': simple quotation marks indicate the speech or text of someone quoted in someone else's statement; [...]: indicates that there was a cut in the subjects' speech. Analytical tools were then applied, with the statements being allocated to a board where the author analyzed their discursive motion, observing whether the statements matched the metaphor, paraphrase or polysemy, in an authentic discourse analysis.

The study was initiated once its proposal was approved by the Research Ethics Committee, under protocol number CAAE 0318.0.243.000-10. The study subjects were presented with a Free and Informed Consent Form, stating the objectives of the study, the voluntary character of their participation, without any type of penalty in case they wanted to quit at any stage of the study, as well as the assurance of the anonymity of both the family member/caregiver and the CSHN by using fictitious names in their statements.

RESULTS

By means of their artistic productions, the family members/caregivers revealed the (super) natural care and (super)protection performed in the household. Although this healthcare is part of the routine of child and family, it is a (super) natural care, since it differs from any other type of care by maintaining the survival of the CSHN, as demonstrated in the statements and in the artistic production that follows:

[...] *I play with him, I give him medication, attention, I give him his meals [...]. He will be five in May, but he is a child that depends fully on me, on my husband. / because he doesn't speak, // he does not eat through the mouth, // he doesn't walk // [cries] [...]. So... I try to do that for him, because he can't do things himself... and he wants to!* (Eva).

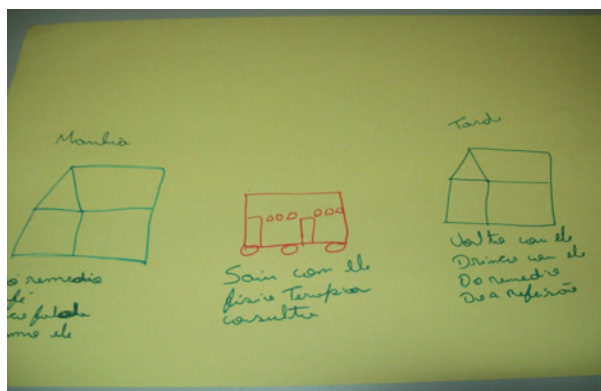


Figure 1 - Eva's artistic production: body-knowledge dynamics. Santa Maria-RS, 2011

[...] *then I got 33 days with her at home [they went home], convulsing, / and then I say, // that's when I learned that my daughter had convulsions. / that's why I say, // I went through everything by myself! // I fed her. When she had convulsions // I always left her lying on her side, / she started developing... / developing, gaining weight / one big beautiful baby!* (Circe).

As to (over)protection, the family of the CSHN, besides protecting him/her against possible health complications, believes that (over)protecting the child can keep him/her healthy, avoiding possible new hospitalizations, as observed in Abel's speech and in his artistic production:

[...] *when it's hot, for example, and he goes to bed [CSHN], we don't place the fan directly towards him! We turn it to the wall, to the roof, but not di-*

rectly towards him! Then, the care in a rainy day, with the coat, umbrella, protecting him with shoes... [...]. I have attempted to say everything we try to prevent him to do! (Abel).



Figure 2 - Abel's artistic production: body-knowledge dynamics. Santa Maria-RS, 2011

To Abel, the father, who in this case is the main caregiver of the CSHN, the care given to the child is seen as everything that must be avoided due to the child's illness, by means of a health-preserving care.

[...] So that he does not run too much ... or get tired, right? He cannot run neither play ball too much. Because otherwise we have to go running to perform nebulization in him! Only that I am more careful about with him... in doing... running ... playing ball too much, he can't do it! Those are the things I care the most for! He has attacks [referring to apneas] and he can't breath well [due to the repeated pneumonia that compromises his lungs]. (Ana).



Figure 3 - Ana's artistic production: body-knowledge dynamics. Santa Maria-RS, 2011

That's why I tell Marcos [CSHN]: don't run in the square! Don't go up there, you can't! I explain to him that what he can and cannot do! (Vilma).

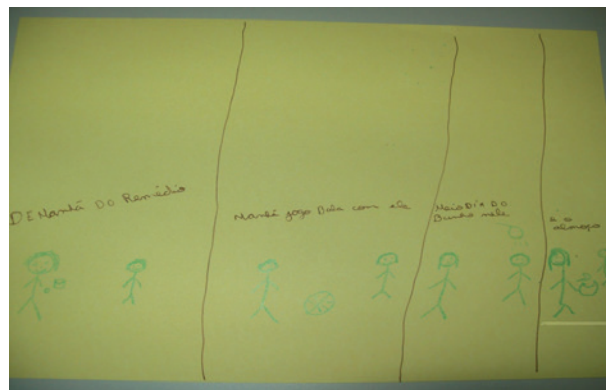


Figure 4 - Vilma's artistic production: body-knowledge dynamics. Santa Maria-RS, 2011

As observed, the child is deprived of common daily living activities. Thus, from a young age, the CSHN is kept from certain activities that demand greater physical effort. The family members additionally reported the understanding and participation of the CSHN in their self-care.

[...] Explain the consequences, trying to be clear, adapting it to his reality. He is six, seven years old. Don't run! OK, but he is a kid, why not run? Because he can't... you can't run, because of this, that, get it? Not hiding everything, but not revealing too much either/ you have to know how to play the game... [metaphorically]. (Abel).

He asked me why he couldn't run. Then I told him once and for all. And now he knows it! In that case, if he insists, plays [soccer], or runs, he comes himself and asks for nebulization. / He knew that he came to the hospital to remove his little lung... [the CSHN was going to undergo a lobectomy] So, he already knows that he's coming to get better, for his own sake! Yes, they understand, they are little, but they understand! (Ana).

As to the child's understanding regarding the pathology, the father of Luís emphasizes how important it is for the child to know why it is impossible to perform the activities that the seven-year old child would like to practice. Explaining the consequences to the child is a strategy to make the child understand his or her limitation. Ana's report shows the understanding of the CSHN regarding his diagnosis. Ana says that her son knows what he has, and every time he feels sick, the child himself asks to get a nebulization. Thus, it is possible to consider that the family and the CSHN resort to the devices they have at home as a strategy to minimize the symptoms of the illness.

As to the care provided, it must be pointed out that they are exclusively provided by the family, and, sometimes, shared with people close to the family, as demonstrated in the following speeches.

My husband! I, / and in fact the person who helped me a lot is dead / it was his grandmother, my mother-in-law! (Rosa).

I have learned this by myself, right?! / I... / seeing the way she was, right?! Because my relatives [CSHN mother's family] / they are all from here [from Santa Maria, but the CSHN and her mother live in São Francisco de Assis] / but it is only me for her, because she doesn't want to be with her father. / [...] Yes, it's only me! // Only me and God! (Solange).

In the case of my sister, who is Joice's mother, / there was plenty of support [family support]. Those who did not volunteer, / it's not because they didn't want to come here / [to Santa Maria, since the family is from another city] but my mother / trusts me to take care of the child! (Lúcia).

Because I have to be with him! I know him... / I have to be there, because he misses me! Sometimes I go out / and then they say 'you left and Pedro complained', and when his father gets home, he gets calm. // At home, his father and I take turns / then I get enough sleep! (Mara).

Polysemically, the family members/caregivers signify this selflessness in their speeches, the care restricted to the parents, thus, revealing the fear of people outside the family towards the child healthcare process, what makes the family share the care only with close people, such as aunts and grandmothers.

[...] It's me and my mother! [who take care of the CSHN] (Vilma).

[...] the care as for medication, right? That depends more on the mother, the father does not participate! I forget the medication, I even give it, but not like the mother! (Abel).

I have seven children! This family is a family of everyone! In this moment when Clara is here, union is the most important thing. Taking care of Clara is everything to us! (Roberto).

[...] We noticed she was very tired / and with depression issues... and you get depressed, right? Then she trusted me to stay / and I stayed! It is tiresome / but we make an effort! (Lúcia).

He came here yesterday [referring to the father of the CSHN]. [...] but I said she doesn't want to stay [CSHN], it's only me! (Solange).

Given the continuous nature of these children's healthcare, the healthcare process of the CSHN is found to be very complex and demands full time from the family member/ caregiver. Thus, taking care of a child with special needs is a priority to family members/caregivers, who renounce their social life, work, and even leisure, in favor of the care process.

Yes / I used to work! But / after she was born, no / It's / it's impossible! She occupies all of our time! / If a normal baby demands care from the mother, the father, whoever ... a baby like her / demands far more! (Circe).

I like taking care of him / and he gives us a lot of joy. I usually say that I know Pedro more than I know myself. That's how I am here! / It's been 15 days, I don't know anyone, I am alone! But I am always happy / and the people admire each other, in spite of my child... [...] I learned that it's no use to despair and cry... (Mara).

Nevertheless, taking care of these children becomes a challenge to the family members/caregivers, given the impossibility of life expectancy of the CSHN, generating suffering in the family responsible for the survival of the child.

The doctor threw me a bucket [of cold water] [...] said that she could die at any moment. / And that, to begin with, she could make it to one year, and right on that day Julia was nine months. /// Because, you see... // all of my family was already living in mourning / and it got to the point that, on Tuesday, my husband came... // talked to the doctor / and returned home. And the measures he took on Saturday and Sunday... // he built a grave, out of desperation... (Circe).

[...] but we know that Joice, because of this Edwards Syndrome / that she has, // she, at any moment /// as the other mothers said... / she can survive a month, or two. And then the third month they spoke... the doctors said, from the first day // that she was born ... they said there was little hope! Then /// we learn with her, because she is already one year and five months now! (Lúcia).

The doctor said it when we went to the ICU // 'mother, call her father' [paraphrasing the doctor during the child's stay in the ICU]. Then I despaired... / and I said: why? And they told me 'we will do everything, she is not reacting and has pneumonia in both lungs' [...] [mother reports possibility of losing daughter]. (Solange).

In the first few days, instead of improving, she would only get worse. Then the doctor told me they increased the doses of antibiotics: 'if he reacts with these antibiotics, he will be saved, if not...' (Mara).

My greatest fear is to lose him in my arms! / In any situation he goes through, I know today that my role at the moment is to take care of him. I know one day God will take him away from me, but I want him to be satisfied! (Eva).

There is always the fear that a fatality can happen... (Ana).

The fear of losing the CSHN and the fact that the child is 'hopeless' have a strong impact on the family member/caregiver, which grows even stronger when they know the child exceeds the life expectancy given by the medical team. On the other hand, thinking of the possibility of death generates suffering in the family members/caregivers of the CSHN.

DISCUSSION

The results obtained show that the family of the CSHN develops a (super)natural care by (over)protecting the child to survive. This care is associated with the fact that the child is deprived of common daily living activities. Give the healthcare needs of the CSHN, the family members/caregivers develop a care dedicated to the protection of the child.

Taking care of oneself and of others is not an easy task, it requires articulation between people and places in a social network, especially when the other is a CSHN, who depends entirely on the family member's care to survive and having his or her voice heard in the world.¹³

When a child gets sick, the entire family is involved in the process. It does not matter if the disease is acute or chronic, neither whether care is required, the child and the family are affected by it.¹⁴ Thus, the family starts living the child's disease, and associating the child's survival to family care.

Family care aims at the well-being, personal realization and development, by means of the interaction of the members of this family, according to the comprehension of the existential situation.¹⁵ In this sense, it is necessary to understand that the family group is made by people with distinct personalities, and it is essential to respect cultural differences, values and beliefs of the family.¹⁶

The care provided to the CSHN is exclusively familial, developed by the parents of the child and, sometimes, with the help of close people, such as aunts, grandmothers and god-mothers.

Hence, care is poorly shared with people outside the family, due to its complexity and the constant surveillance to the child needs. The family is the caregiver, as well as the entity responsible for the survival of the CSHN.

Several types of care required by CSHN involve nursing procedures, which the family must incorporate in their daily lives, beyond those belonging to children in general. The nursing knowledge and practices have to be diluted in the family care network, given that the care abilities that the family members bring with themselves are not sufficient to deal with the complexity of these activities in the family environment.¹⁷

Taking care of the CSHN at home requires full-time dedication, usually causing the caregiver to abandon his or her job to dedicate to the child, revealing the abnegation experienced in the family routine.¹⁸ The family members are recognized as promoters of care and they develop healthcare strategies in the community based on their past experiences.¹⁹ Thus, the care ends up being carried out by the family member/caregiver according to his or her concept of care, previous knowledge or even the knowledge acquired during practice.¹⁷

Chronic illness and the complications resulting from them demand constant control and care from the family, given the possible damages that may take place.²⁰ Thus, the main caregiver becomes occupied exclusively with taking care of the child.

Unlike other studies performed with CSHN, the father figure appears in this study as taking up the role of main caregiver, and, even, helping the mothers in the healthcare process in the household. The father has to share the intimacy of his child; children who grow up without the father's presence have a greater chance of developing emotional problems, lower levels of cognitive development, tendency to drug abuse, behavioral disorders, among other problems.²¹ Thus, the participation of the fatherly figure becomes important in the process of care and development of the child.

Care should foster the capacity to integrate order and disorder, derived from a change in context, environment and other factors that are a part of the child's daily life. It is fundamental to consider that, besides the care involving the illness, children need emotional care, love and empathy.²²

The family members/caregivers also revealed the uncertainty of the CSHN prognosis,

the fear of loss and the certainty they always want to do the best to make their children survive. The family goes through several stages in responding to the disease, and the period after learning the diagnosis is a critical moment. The parents express feelings of guilt for thinking they were not competent enough having a child with limitations.⁹

In addition, the study showed that the chronic illness and the clinical frailty of these children are considered a mission for the family member/caregiver, who is dedicated exclusively to taking care of his or her child. The families of CSHN have a social support network, with decentralized resources. Social support can be seen as an interaction between people or groups of people who establish links, receiving material and emotional support, building positive factors in preventing/maintaining health.²³

Families feel fear in their role as caregivers, and they do not know how to proceed in that care for not feeling prepared to face such clinical condition. Considering that the family members/caregivers of CSHN develop a committed and comprehensive care to keep the child's quality of life, health professionals must be prepared to offer support to the families, promoting spaces for listening and dialogue, answering questions, being receptive and understanding so that families do not lose hope.⁹ In this sense, the caregiver, by viewing childhood only in the absence of disease, limits the child in his or her potential, and thus the nursing care must go beyond the limitations of the sick child.²⁴

FINAL CONSIDERATIONS

In conclusion, the family member/caregiver of the CSHN believes that by developing home care, he/she performs more than a procedure, keeps the child alive. In this context, the care developed is based on the (pre)occupation of these family members with the health conditions of the children and with the feelings of the family who provides healthcare and preservation.

Thus, the healthcare process developed by the family members/caregiver of the CSHN is based on strategies to maintain their survival, validated by the knowledge acquired with the experience gained in practice.

The (super)natural care comes from the sum of efforts by these family members, who perform a routine and life-maintenance care, abdicating

from professional activities and personal desires to keep the child alive. This care, which is predominantly provided by the family, is developed in a solitary manner, and is seldom shared with closer people, such as father, grandparents, aunts and god-mothers.

The father appears in this study playing the role of main caregiver of the CSHN, which denotes a different configuration from other studies on this subject, in which care is associated with the woman.

It is also worth highlighting the lack of studies approaching the care developed by the family members/caregivers of CSHN at home, as a space for education in health and continuity of care practices in favor of the survival of the CSHN after discharge from the hospital, as well as studies revealing the existence of this population and the difficulties to get access to reference services for the necessary treatment. The insertion of public healthcare policies for children considering epidemiological data of this population with some sort of special healthcare need is emerging, given the recognition of CSHN as nursing clients who need healthcare practices and exclusive policies for their singularities.

The authors suggest, thus, the development of extension activities specifically for these family members; the creation of programs for child home care; tracking this population in the community by means of research; and the development of activities that benefit family members/caregivers in enhancing the practice of healthcare in the household.

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