HEALTH EDUCATION: KNOWLEDGE OF THE FAMILIES OF CHILDREN WITH SPECIAL HEALTH NEEDS

ABSTRACT

Objective: to describe how family caregivers have learned to develop home care required by children with special health needs at home. Method: qualitative research involving 10 family caregivers of children with special health needs who were admitted to an inpatient pediatric unit. The data were constructed through the creative sensitive method, mediated by the dynamics of creativity and sensitivity, and submitted to French speech analysis. The research project had the approval of the Research Ethics Committee, under the opinion paragraph nº 0318024300010. Results: it was discovered that the family caregivers develop a continuous care, relying on the experience made. Conclusion: the knowledge and skill necessary to meet the demands of children with special needs arise from health practice experience of family members. It is recommended that health care professionals are prepared to work with these families, visualizing the context home care as an extension to the practice of care. Descriptors: Health Education; Family; Caregivers; Child Health; Pediatric Nursing.

RESUMEN

Objetivo: describir como familias cuidadoras aprendieron a desenvolver cuidados domiciliarios requeridos por niños con necesidades especiales de salud en el ámbito domiciliar. Método: pesquisa qualitativa com 10 familiares cuidadores de crianças com necessidades especiais de saúde que estavam internadas em uma unidade de internação pediátrica. Os dados foram construídos por meio do método criativo sensível, mediado pelas dinâmicas de criatividade e sensibilidade, e submetidos à análise de discurso francesa. O projeto da pesquisa teve aprovação do Comitê de Ética em Pesquisa, nº 0318024300010. Resultados: descobriu-se que os familiares cuidadores desenvolvem um cuidado contínuo, apoiando-se no saber da experiência feita. Conclusión: o conocimiento e a habilidade necesários para atender as demandas das crianças com necesidades especiais de saúde decorrem da experiencia práctica dos familiares. Recomenda-se que os profissionais de saúde estejam preparados para trabalhar com esses familiares, visualizando o âmbito domiciliar como uma extensão para a prática de cuidado. Descritores: Educação em Saúde; Família; Cuidadores; Saúde da Criança; Enfermagem Pediátrica.
Children with Special Health Needs (CRIANES) correspond to an emergent clientele, which stands out for its diversity and uniqueness of care required. This complex nature care extends beyond the performed care to other children due to the fragility of this clientele that requires care for the preservation of life. Added to this, the presence of social, individual and programmatic vulnerability of this group.  

Healthcare of CRIANES must include the process of health education for families to broaden knowledge and specific skills in order to improve the quality of life of CRIANES. Health promotion actions should put in action strategies that involve the family, as holder of a knowledge that cannot be discarded, but improved scientific knowledge. So, family-centered care requires the awareness of professionals that the experiences, knowledge and practices of individuals should be considered for planning educational activities in the specific context of life. Based on that assumption, the health education aims to develop the sense of empowerment of the family, with the aim of reducing the dependency of the health services and strengthen the powers of the subjects. Such competences refer to the body of knowledge, practice and skills essential to the survival, development and protection of CRIANES.

It is believed that health education must be extended beyond the hospital context, whereas the children live in a society full of social diversities. Thereby, it is essential to enable people, in order to prepare them for the various phases of existence, including the fight against disease. For that, the educational activities should be carried out in a perspective of action-reflection-action dialogical and consciousness raiser, in which the nurse develops activities as an educator, assisting in the transformation, emancipation and autonomy of the family.

This idea meets the liberating pedagogy and problematizing of Paulo Freire, in which the exchange of knowledge beyond the specific field of education only, turning it into education for the world and the world to education, a possibility of transformation through conscious action. In this way, it becomes essential to meet the social context of the family, their prior knowledge about the way of caring, respecting the family culture, understanding the changes that occur through the process of awareness. In the case of CRIANES, it is necessary to consider the wonder of family caregivers that requires treatment and ongoing care of both the caregiver and the family nursing.

On this issue, it is believed that the educational process with family caregivers of CRIANES must resound the way of vertical and traditional education. Therefore, it is considered that the alliance of knowledge is an important strategy for the process of health education with family caregivers of CRIANES, to the empowerment of these subjects.

In front of the exposed, this study aims to:

- To describe how family caregivers have learned to develop home care required by children with special health needs at home.

**METHOD**

Article elaborated from the Dissertation Nursing care to children with special health care needs: health education demands of relatives presented at Post-Graduation Program in Nursing, of Health Sciences Centre, of the Federal University of Santa Maria/UFSM, Santa Maria-RS, Brazil. 2011.

The present research is descriptive and exploratory in nature, with a qualitative approach. For the production of data, we used the Creative Method and Sensitivities (CMS), through the Dynamics of Creativity and Sensitivity (DCS) that, as Freire Cultural Circles, provide spaces for discussion and reflection. The CMS provides a space of collective discussion, in a dialectical and plural, dialogic understanding, in which the group assumes the position of subject in research.

The data were produced in a participative manner, starting from the conception that subjects act in the process of knowledge construction, in which the research implies the creation of conditions for individuals to have their voices recognized.

Developed two dynamics, DCS Body Know, in order to scale the process of care in the home space, from the realization of a design, seeking to awaken the hidden memory of the participants, the issue of generating debate: How do you take care of your son or daughter with special health needs at home? And the DCS Sewing Stories, so that the subject could socialize with the group problems and difficulties with social and collective roots, based on interlace of line one skein. The subjects answered the following question: tell me how you learned to take care of your son or daughter at home?

The study scenario was the Inpatient Pediatric Unit (IPU) of Santa Maria University Hospital (HUSM), which is characterized for...
being a teaching hospital of reference in southern Brazil, in the second half of 2011. The research subjects were 10 family caregivers of CRIANES (seven mothers, two parents and an aunt). For the selection of subjects, it was applied the criterion of inclusion: be familiar and/or caregiver of CRIANES institutionalized in IPU which has developed home care to CRIANES. And as exclusion criteria: family caregivers whose CRIANES was never under domiciliary care or that they were not in conditions to participate in the study by orientation of the health team.

The data obtained in the DCS were submitted to Analysis of Speech (AS), in its current French. The first moment of AS corresponds to the materiality of language text, in which the researcher uses spelling resources in order to provide movement to the text allowing the reader understand the lines of the subject. For this, we used the following spelling resources: /: short reflective pause; //: long reflective pause; ///: reflective pause very long; ....: incomplete thought; #: interruption of the enunciation of a person; [ ] - complete verbal thinking really mean; ‘ ‘ ‘ ‘ ‘ ‘: single quotation marks indicate speech or text from someone quoted within the enunciation of others; [...] indicates that there was a cut out in the speech of the subjects.

The second time, were applied analytical tools: metaphor, paraphrase and polysemy. On the third time, occurred the interpretation with the identification of themes and sub-themes that originated the analytical categories.

The study subjects were clear about the purpose of the research, the voluntary character of their participation, without any kind of penalty if they wanted to give up at any stage of the study, as well as anonymity, using fictitious names in their enunciations. The search began after the approval by the Research Ethics Committee of the Federal University of Santa Maria (UFSM), under the protocol number 0318.0.243.000-10. Participants signed an Free and Clarified Consent Term (FCCT), in two copies, receiving a copy with the signature of the researchers.

RESULTS

The family caregivers of CRIANES develop continuous care, in order to maintain the survival of the child at home. Some learn to care for the practice of care developed with the child over the years, through the wonder of the experience gained over time, according to the following enunciations:

I learned from the studies that I had, / and then with my own experience I’ve had with Pedro. It’s like he had a telepathy, / knowing, / learning with him day by day, because when I get home / I look at Pedro and I see if he’s OK. / [...] And then, sometimes, he leaves or otherwise give the injections, and I make it myself at home, / and then she [Basic Health Unit nurse] will be there overhauled at home! (Mara)

# 1 // and some things the doctors. [Crying] am so lonely... But I’m fortified, / very brave / how to take care of Julia during the convulsion [convulsions], how to take care of her at home ... // all alone! Her father came at noon, / also terribly nervous. But ... // always me! [Referring to the exclusive care of her daughter]. [...] Then I stayed 33 days with her at home [went home], with convulsion, / and then I say ..., // now I know that my daughter had a convulsion. / That’s why I say, // so, that I went through all alone! // (Circe)

I taught myself, huh?! / Me... / Seeing her way, huh?! (Solange)

In the morning I take his diaper ... / Then... / [...] Around noon I give him a bath... Then at four [hours] I give medicine again, of pressure! (Vilma)

 [...] On placement of the probe, the doctor asked us to put the probe and we thought: what a shock, huh?! How will it be ... Will it come out of his belly? [Mother demonstrates fear facing the need of the child using the probe]. [...] Like Caio’s state, when he ripped out the probe, the first time, I was in shock, I was watching him, and I thought, this is done here? But this [probe] had to be somewhere. You know, it’s not easy! Even when he has a convulsion, I’m terrified! My heart in my mouth [metaphorically] I get ... (Eva)

Through the speech of the family caregivers, it is obvious that knowledge about domiciliary care was being perfected by the caregiver within its own possibilities and everyday experiences. Some family caregivers have acquired the knowledge through observation they did to health professionals during the hospitalization of the child.

Other caregivers resorted to familiar with professional preparation to assist them, as it can see:

[...] My husband has a nurse’s aide! He was the one who helped me, he knew a lot more than me, huh?! [...] We learned almost everything with the medical team. (Rosa)

Here! Here in [Pediatrics] / and with the godmother that is pharmaceutical here [in the teaching hospital where the child was committed], because she knows a lot and she is my brother’s mother-in-law. / Because...
we're not from here. /And she's always giving assistance to Joice, she is her godmother [CRIANES], is always helping. (Lucia)

Caregivers who have relatives or acquaintances who work in the health area feel safer to develop caution practices because they have this care aid at home. The process of taking care of the CRIANES requires special family attention/caregiver on the medical condition of the child, the primary caregiver learns what to do and to recognize the habits and routines of the child:

[...] Because he doesn't know how to vomit! If he has nausea he doesn't vomit! So, food is just me and my husband that we give by the probe. So, people are scared ... or he will pull it [probe] .../is what I do with him throughout the week/I wake up, give medicine, give his food by the probe that he uses/ah! change the diaper, put his clothes, get out of the bus with him, or sometimes, I go out in my car with my husband. Go out with him... And when I see, four o'clock it's time to take the medicine, his lunch, and time for his medicine! (Eva)

Then I took her home, when I gave the syrup she threw herself backwards, so I almost lost my daughter! There, / I took a cab and took her on duty of the same doctor and said: I'm not taking her away because he's having convulsion! // But I didn't know [what is a convulsion] the mother explained to me [referring to the child's grandmother who realized what was happening with her granddaughter]. (Solange)

Because she gave me everything [learning], everything she [mother of CRIANES] learned in here [hospital], she gave it to me! The dad is always around too! Whenever she needs / he's coming over. Of course, / that he has his job out there, and there is more difficult for him to sleep and stay ... / but thank God, she has a confidence in leave her to me! But she calls directly, to see how she is, / how she went, huh!? / (Lucia)

There are also caregivers seeking to improve that care, as in the case of Mara, who went on to study nursing in order to deepen her knowledge about the care required by his son, fact can be observed in the following lines:

//Yesterday the doctor said to me: "You know the name of all the medicine!" [doctor impressed with the knowledge of the mother]. But off what he has, he only takes another medication if he's sick! So I decorated name, / dosage and give everything for him. The injections, when he has to take, the doctor released me to do / due I'm doing nursing course, right?! So I don't have to take him out of the house. Aspire ... so / I aspire but only the mouth.

But not the nose and trachea because at home is too dangerous. (Mara)

Before the enunciations of family caregivers, it is possible to understand that they develop a process of care based on the experience made, knowing that is built and perfected over time. Although it is necessary to know the essential management to the development care, for these families, the science is linked to feelings. To realize that children face various situations and still survive, the family members are motivated to fight for maintaining the life of CRIANES.

DISCUSSION

Despite numerous technological advances in health, increasingly highlights the need for guidance and support to family caregivers. In this sense, it should be recognized the nuclear family and home as locus ideal to return and/or maintaining the quality of life and health of the child with a chronic disease.11

Family care to a CRIANES at home is challenging and generates definitive changes in family life. The care consists of transpersonal efforts of human being to human being, in order to protect, promote and preserve a unique and exclusive care, helping people find meaning in situation of disease, suffering and pain as well as in the knowledge of their daily practices.12

Also, the process of caring by the family requires health professionals to create a sympathetic relationship with the family caregiver, understanding their unique demands, respect of their limitations and the stimulation of their potential child care under domiciliary.13 Nursing is fundamental to strengthen and support the family, through the educational approach, emotional care and social support, in an integrated and cooperative, favoring spaces of participation and autonomy for the caregiver.14 It should be noted that the family caregivers of CRIANES seek creative alternatives to the practice of domiciliary care, by harnessing the popular knowledge with the notions of careful observed within hospitals.

Nursing support should be promoted, taking into account the needs of family caregivers, seeking to recognize the possibilities of helping these families, encouraging so that they enjoy a network of support.15 In this context, nursing has an important function to the consolidation of a fairer and more democratic society through health education, which makes it possible to become independent.16

The exchange of experiences and the construction of knowledge between the
technical and popular knowledge imply that the various knowledge are only different and not hierarchical, and that experience is worth as much as the theory. Therefore, family care aims to keep the child alive and integrate into society. In counterpoint, nursing care is based on scientific theories, consolidated health techniques for survival with quality of life. However, the process of care often is related to which dominate the technique and knowledge, and those who perform without knowledge of what this is about, passively and repetitively, deleting spaces for dialogue.

Studies show that when the family caregivers of children with chronic disease or disabling are properly instructed and empowered, parents not only enable the quality of care offered, but also contribute to improving the quality of life of the child, so domiciliary care becomes strengthened. The health team, while interacting with the familiar caregiver of the child during the hospitalization, assists the family be part of care with more naturalness and share expectations and doubts, building a system of cooperation.

Indeed, it is necessary to help professionals in the implementation of the family care, within its possibilities. Health education and care must be integrated and extensive for the home care and health education to be effective and simultaneous, glimpsing the promotion of child health. It is understandable that professionals can contribute in various ways with family caregivers, reducing their fears and doubts about the care and promoting the comfort of nurses and the compliment in their positive attempts of care.

Child care, in an integrative perspective, implies the inseparability of the curative, preventive actions and promotion of health, establishing family care spaces to the child in the home context. The pediatric nursing can act with the technical and educational success of care, seeking growth and development monitoring and interventions that are based on improving the care offered at CRIANES.

Therefore, it is essential that nursing professionals have an attentive eye to the daily lives of families of CRIANES, understanding the challenge of caring for the maintenance of life, acting in the practice of health education in the families, providing them guidelines and instituting strategies of approach with the reality of family caregivers.

CONCLUSION

Faced with the reality of the process of care required by CRIANES, singular and complex in nature at home, family members are acquiring knowledge and skills, from their own experiences of everyday practice. Commonly, the observation of attitudes of health professionals, during hospitalization, also subsidizes and supports the family in performing everyday care at home.

As a source of security and support, to incorporate and assist in the care, and in decision-making related to diagnosis and pathology of the CRIANES, the family caregivers also resort to other members of the family who have scientific knowledge in the area of health. This occurs for both domiciliary care as for issues related to the hospitalization of the child. In this perspective, some caregivers feel the need to pursue and enhance the technical and scientific knowledge that the child requires, in front of the clinical complexity developed through technical courses or even in higher education linked to healthcare.

From these assumptions, the actions that pervade the daily lives of CRIANES care under the care of the experience gained by family caregivers who carry out these actions in order to meet the needs of the CRIANES, or the presentation of different signs and symptoms of their usual routine. The attitudes are acquired and perfected over time, after the daily contact with the child and domiciliary care demands required.

It should be pay attention to the development of an educational practice from the time of admission of the child to the hospital post discharge, so that caregivers can be empowered to carry out the care demanded by the CRIANES at home. Health education strategies serve as support for these caregivers, minimizing the anguish generated by accountability of care at home.

It is recommended that health care professionals, especially those who work in primary care services are prepared to work towards and support for family caregivers instrumentalization of CRIANES, visualizing the context home care as an extension to the practice of care.

REFERENCE


