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RESEARCH

CARE TO CHILDREN REQUIRING CONTINUOUS AND COMPLEX ASSISTANCE: NURSING PERCEPTION

ATENÇÃO À CRIANÇA COM NECESSIDADES ESPECIAIS DE CUIDADOS CONTÍNUOS E COMPLEXOS: PERCEPÇÃO DA ENFERMAGEM

ATENCIÓN DE NIÑOS CON NECESIDADES ESPECIALES QUE REQUIEREN CUIDADOS CONTINUOS Y COMPLEJOS: PERCEPCIÓN DE LOS ENFERMEROS

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ABSTRACT

The objective of this study was to describe the perception of nursing professionals about children with continuous complex care needs. This is an exploratory, descriptive study with qualitative approach developed with 13 participants in a pediatric hospitalization unit in southern Brazil. Data was produced through the Creative Sensitive Method from April to June 2013 and submitted to thematic content analysis. The results showed that the nursing team creates a strong bond with these children, recognizes the importance of the family in this care and identifies the mothers as the main caregivers. We concluded that the team establishes a bond with these children and their families, and at the same time feels physical and emotional exhaustion due to the care demands of these children. Support to the teams that work with this clientele is suggested, considering not only the technical-scientific knowledge, but also, self-knowledge, ethical and aesthetic Nursing care aspects.

Keywords: Nursing Team; Child; Child Health; Child Care; Chronic Disease.

RESUMO

Objetivou-se descrever a percepção de profissionais de enfermagem acerca da atenção à criança com necessidades especiais de cuidados contínuos e complexos. Trata-se de estudo descritivo exploratório com abordagem qualitativa desenvolvida com 13 participantes atuantes em unidade de internação pediátrica no Sul do Brasil. Os dados, produzidos a partir do método criativo sensível de abril a junho de 2013, foram submetidos à análise temática de conteúdo. Os resultados revelaram que a equipe de enfermagem constrói um vínculo maior com essas crianças, reconhece a importância da família nesse cuidado e identifica a mãe como a principal cuidadora. Concluiu-se que a equipe estabelece vínculo com essas crianças e suas famílias, ao mesmo tempo em que sente desgaste físico e emocional pelas demandas de cuidado apresentadas pelas crianças. Sugere-se dar suporte às equipes que atuam com essa clientela, considerando não só os saberes técnico-científicos, mas também autoconhecimento, ético e estético do cuidar em enfermagem.

Palavras-chave: *Equipe de Enfermagem; Criança; Saúde da Criança; Cuidado da Criança; Doença Crônica.*

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RESUMEN

Este estudio tuvo como objetivo describir la percepción de los profesionales de enfermería sobre la atención de niños con necesidades especiales que requieren cuidados continuos y complejos. Se trata de un estudio descriptivo exploratorio con enfoque cualitativo desarrollado con 13 participantes activos en una unidad de internación pediátrica del sur de Brasil. Los datos, producidos a partir del método creativo sensible entre abril y junio de 2013, fueron analizados según su contenido temático. Los resultados mostraron que el equipo de enfermería construye vínculos más estrechos con los niños, reconoce la importancia de la familia en el cuidado e identifica a la madre como el cuidador principal. Se llegó a la concusión que los enfermeros establecen lazos con estos pacientes y sus familias y que, al mismo tiempo, sienten cansancio físico y emocional por las exigencias de la tarea de cuidar a dichos niños. Se sugiere dar apoyo a los equipos que trabajan con esta población, teniendo en cuenta no sólo el conocimiento técnico y científico, sino también el auto-conocimiento, ético y estético, de los cuidados de enfermería.

***Palabras clave**: Grupo de Enfermería; Niño; Salud del Niño; Cuidado del Niño; Enfermedad Crónica.*

INTRODUCTION

Child care has found space for extensive debate in the health area. In this scenario, the Program for Integral Attention to Child Health (PIACC) was published in 1984 with a view to promote a more specific attention to the health of children. The actions developed by this program aimed at guaranteeing comprehensive child care, contemplating the children's process of growth and development, beyond the disease.[1]

Then, in 1990, the Statute of the Child and Adolescent (SCA) determined that children and adolescents must have the guarantee of care, universal and equal access to actions and services for promotion, protection and recovery of health through the Unified Health System (SUS).[2] These and other actions aimed at the health of children made it possible to develop a differentiated attention, directed to their singularities.

Brazil had a 73% reduction in childhood deaths comparing 2012 to 1990. The rate indicated that, for every thousand children born alive, 58 died before completing five years of life. In 2011, the international body reported that the index had fallen to 16/1,000.[3]

However, this reduction caused a change in the epidemiological profile of children worldwide. Technological advances and improvements in the living conditions of the population have led to a decline in infant mortality rates and, on the other hand, have contributed to the increase in childhood chronicity.[4]

The increase of chronic diseases in childhood is related to the survival of high-risk newborns in neonatal intensive care units (NICU), a place with a high concentration of technology and professional specialization.[5] Children who need some kind of follow-up or have some differentiated demand of care, technology or drug, whether of temporary or permanent nature, are called the *Crianças com Necessidades Especiais de Saúde (CRIANES)* in Brazil and Children with Special Health Care Needs (CSHCN) in the United States. These, in general, have a plurality of diagnoses, continuous dependence on multiprofessional care, and need for types and amount of health care services beyond that required by other children.[6,7]

Authors also present names for CSHCN in subgroups such as: medically fragile children, technology-dependent children, medically complex children, children with chronic conditions or children with continuous complex care needs who, despite multiple dependencies and cognitive and/or developmental problems, are assisted by family members at the home setting.[5,8]

This represents a challenge for nursing, to provide care for these children and their families in different health care settings. Caring involves interaction, bonding, counseling and, above all, support to the caregiver.[9] The role of professionals goes beyond the ability of carrying out specialized technical procedures for CSHCN; it must also be based on the process of health education to family members.[10] In this sense, nurses should enhance the family's ability to promote and elaborate care, enabling them to develop the necessary skills for this practice.

Thus, considering the constant presence of CSHCN in hospital admission units and, especially those classified as children with special needs for continuous and complex care, we ask: what is the perception of nursing professionals about the care provided to these children? Based on this question, this study aimed to describe the perception of nursing professionals about the care provided to children with special need for continuous and complex care.

METHOD

Exploratory, descriptive study with qualitative approach carried out from a re-reading of the database of a master's thesis. In respect to Resolution 466/2012, an amendment was submitted to the Research Ethics Committee and approved under CAAE 12142612.8.0000.5346.

The participants of the research were professionals of the nursing team who worked in the pediatric hospitalization unit (PHU) of a teaching hospital from April to June 2013, totaling 13 participants. The teaching hospital studied is large and of high complexity and provides assistance exclusively to the Unified Health System. The choice for the PHU as the research site is justified by the significant number of CSHCN with prolonged hospital stay.

The nursing professionals of both work shifts were invited to participate in the research. At the moment of invitation, the

objective of the study was presented and the Free and Informed Consent Term (FICT) was presented. Professionals on leave for health reasons or vacations during the period of data collection were excluded from the study. Data was produced in three meetings through the creative sensitive method (CSM), developed by the research master student and qualified research assistants. CSM is a form of data production that aggregates consolidated qualitative research techniques into group meetings called creativity and sensitivity dynamics (CSD), such as: group discussion, press conference and participant observation. CSD have the operating group of Pichon Rivière, and the focus groups and the circles of culture of Paulo Freire as theoretical base.[6]

CSD were developed in five moments. Initially, group presentation and interaction took place, which made participants and the researcher to familiarize with each other. In addition, the objectives of the research and of the meeting were introduced. In the second moment, the materials were distributed to the participants and the question generating of the debate was triggered. From this moment on, the participants carried out their collective or individual artistic productions, depending on the type of dynamics. In the third moment, there was the socialization of the productions for the group, when the generating themes were codified. Then, the participants presented and commented their productions, decoding the data. Finally, in the fifth moment, the synthesis and validation of the data were carried out.

The database consisted of the transcripts of three CSDs: the first, called creative brainstorm, based on the question: "what ideas come to your mind when you think of children with special health needs in your daily care?"; the second is called weaving stories, based on the instruction: "Tell me about your experience of providing care for CSHCN and their families in your daily activities in the pediatric hospitalization unit". Finally, the dynamic called almanac, based on the question: "what difficulties/facilities do you identify in your care practice to CSHCN and their families in the pediatric hospital?".

Data were submitted to thematic content analysis, organized in three stages.[11] In the first stage, the pre-analysis, a overview was carried out to identify the material collected, and a framework separating the emerging themes was organized. In the second stage, the analytical reading was performed. In this moment, the chromatic technique was used, grouping similar speeches in equal colors. In the third stage, categories were created to meet the proposed objective.

In order to maintain the anonymity of the participants, alphanumeric codes consisting of the letter P of participant and the order of enunciation in the group were used during the production of data. Yet, in this study, the terminology 'children with continuous complex care needs' was adopted, considering the denomination used by the study participants, about this clientele.

It should be noted that the financial expenses and materials used for the development of this research were entirely assumed by the authors.

RESULTS AND DISCUSSION

During the analysis, two aspects clearly draw the attention of the nursing team when dealing with children with continuous complex care needs: the issue of the wear of the team to provide the care that these children demand, and the emotional involvement that arises from the long-term nature of the treatment and conviviality, and the issue of the mother as the main caregiver, almost entirely assuming the care of the child. Thus, considering these aspects, two categories emerged, as presented below.

AFFECTIVE BOND, EMOTIONAL AND PHYSICAL WEAR OF PROFESSIONALS PROVIDING CARE FOR CHILDREN WITH CONTINUOUS COMPLEX CARE NEEDS

The health team reported establishing attachment with these children who have a history of recurrent hospitalizations in the unit, the study scenario. The conviviality turns out to be periodic, depending on the need of each child, and, professionals are present in this cycle, knowing the uniqueness of the children and their relatives.

> *[...] They are children with whom we end up creating a closer bond! When compared to children who are more transient [who are not hospitalized frequently and for long periods]. Because they are children who are more often here with us, and stay for longer times. So you already treat... You already know the mother, you know the family [...] (P1)*

> *[...] A child who... needs help getting around, a child who needs help to feed, whether by catheter, or gastro (gastrostomy), whether it's a wheelchair or not, right? But they are children who need... depend on us for something (P3).*

> *[...] Yes! Because you end up... Then, the more time... see the child, she goes and then comes back, right?! Because it is a child who goes [is discharged]// and she will return! She is going to be hospitalized in a few days! (P2).*

> *[...] Then you have more affinity with them, for the family! You already know mother, you know father, you know the family, the aunt... Sometimes the grandparents [...] (P3).*

Because they are children who need continuous and complex care, professionals recognize the difficult trajectory of these families and they develop empathy through the daily interaction with their families and caregivers, who, although lacking training in the health area, for the most part, perform activities and help in the demands of daily childcare. This is important because the team's work with the family is critical to promoting adequate training to deal with the complexity of the care required.[10]

Besides the empathy, the professional is sensitized by the situations experienced and feels committed to provide a quality nursing care:

> *[...] Because they do not know how to speak, they do not know... If they will communicate through crying... knowing the patient, knowing the... There you have this... In order to protect him... Or do your work, the care, as a nurse [...] (P4).*

> *[...] I feel sorry for the child because sometimes they are in pain, they are not being correctly medicated, they have stiffness, and they feel pain. I feel sorry for this (P2).*

The participants also emphasized that the way how these children face the delicate situations and the adversities imposed by the clinical situation often surprises the health team:

> *[...] They are warriors really! Because, how many times they go to the ICU, they go bad. [...] They surprise us because... How many times have they come bad and go home and get well. So it's a daily fight, I use to say they put up a daily fight for life (P5).*

> *[...] Yes! But then I think that you feel more this "life by a thread" by... Because of the problems they face (P6).*

The need for continuous and complex care experienced by these children culminates in coping with chronic illness as a daily battle for life. They present a health situation that can subsequently progress into a serious picture, leading to the need for intensive care.

The team can collaborate with the way the children face the hospitalization and the illness, promoting interaction with the hospital environment and its routines, playful practices, activities and games that may make them feel more comfortable.[12]

Still in this category, professionals report how this continuous and complex care can affect them, both in the way they work and in terms of physical and emotional exhaustion.

> *[...] I consider that, many times, we say that it is a burden for the team and often for the family as well. [...] So... and we get very much involved, because they are mothers who are all the time here with the children, and the ... when ... they have us [nursing staff] as a reference too! [...] Because it requires a lot [...] (P5).*

> *[...] It becomes heavy for the infirmary! (P1).*

From the enunciations, one can see how providing care is a hard and tiring task in the professionals' view, considering that these children and their families demand more attention than the usual. In an infirmary with many CSHCN, care becomes exhausting, because it demands not only technical-scientific knowledge from the professionals, but also articulation of ethical, aesthetic and self-knowledge of the science of Nursing.[13]

The severity of clinical conditions and the complex demand for care required by these children demand skills, combining the practice of care and scientific knowledge necessary for preventing or minimizing diseases, identifying clinical changes, as well as intervening in timely moments, when necessary.[14]

Therefore, caring is an attitude of consideration, knowledge, feelings, solidarity and concern.[15] Care requires a comprehensive vision, as it is necessary to encompass and respect all the issues that permeate the process, which include, besides the person, who is the focus of the assistance, also their families.[16]

In the following statements, it is possible to identify the emotional involvement of professionals with these children, despite the difficulties encountered by them. They are patients differentiated by their daily struggles, and the team emphasizes good humor as an important work tool:

> *[...] Here one of the difficulties that I put is how to deal with the emotions, that little eye here [...] So we end up clinging to those "little patients" who are more often here, sometimes, than at home (P5).*

> *[...] And here in the facilities I put the good mood is everything! I mean, our good mood, the team, the family, too. And here I put... the love, from the mother to her child [...] (P7).*

Nursing professionals can help families to face the difficulties related to the complexity of providing childcare:

> *[...] I think that for us to work with these children, we have to renew our courage every day, no matter how hard it may be, we have to renew our courage every day, the hope. We have to pass on this courage, this strength to these relatives [...] (P5).*

> *[...] What is the impact of this on a family, right? [...] And what that means: that in the first place is the care,*

second is the care and third is the care! Physical, emotional and psychological. [...] And from there, in the drop, I put the professionals, the whole team, right? More care and more love! I think that's what it means... our daily life like this... that we need to have... we need it! (P8).

[...] I think it's up to us to give them strength, not to tell a lie! She knows what it's there! But we must try to make it lighter, a little. Teaching what we have to teach [...] (P2).

We can see how much necessary is to strengthen the humanist side, so that the professional become sensitive and able to encourage families and caregivers to have the courage and hope to move forward, one day at a time, soothing the suffering.

In the speech of the participant P1, it is possible to identify the difficulties found in the slowness of the health system in relation to these children:

[...] And we feel this anguish, because sometimes the system, I will call the system, it does not work. So, you have slowness in the medical evaluation, you have slowness in the examination... It seems that everything is difficult and that child, she may destabilize very fast and you start to get distressed (P1).

Because they are children under a fragile and unstable clinical situation, they may have their health status quickly modified; it is imperative that they have a health team and services ready to mitigate and overcome any intercurrence.

However, the Brazilian health system is still flawed with respect to the provision of adequate care for these children who need continuous and multiprofessional care at all levels of health care. This reality is due to the fact that there is no adequate flow of care, and the children and their families suffer mainly from the difficulties of accessing health services. In the US, this reality is also experienced, since 48.8% of the CSHCN' relatives have reported difficulties in accessing medical services and 31% reported having difficulties in accessing other services.[17]

Thus, health system managers should plan specific strategies as well as create public policies aimed at addressing the needs of this population who require specialized care.

Mothers as the main caregivers of children with continuous complex care needs

The participants of the research, when talking about the family, highlighted the role of mothers as main caregivers, reporting that they are at the forefront of care and show an exclusive dedication to these children.

[...] It's usually the mother, so... It becomes a heavy task, to provide care. Many times she forgets everything, forgets about herself, forgets about the other children in order to take care of that child, then... It may become a burden! (P5).

[...] They look like this because they... really, they wear out! Who takes the children to everything, thus, whatever they have to improve their quality of life. They get exhausted, for sure! (P8).

[...] And these neurological children [children diagnosed with cerebral palsy] that we are talking about, most mothers aspire to [aspiration of the upper airways] [...] There are some mothers that check the signs [vital signs]! (P2).

In general, mothers are the ones who take on the care not only of this child, but also of other family members. This all results in physical, psychological and affective overload for the mother or responsible caregiver.[16]

These statements clearly show how important is the role played by the mothers in this process. They become the main responsible for the care and often suffer physical and emotional overload due to the heavy demands of these children. This ends up affecting the quality of life of these women.[18,19]

The care demanded by CSHCN requires full time dedication from the family/caregiver. The child becomes a priority, making the family/caregiver to display a personal self-denial and renounce of social life because of the child's needs. Care is often solitary; the primary caregiver shares this responsibility only with the closest people, such as aunts and grandparents.[20] In this perspective, it is important to highlight that the health team considers maternal feelings and expectations as a facilitating strategy for the practice of humanized care, emphasizing the needs not only of the child, but also of the family.[9]

In this context, the professionals brought up considerations about the importance of other family members in the care of these children:

[...] And what I think is very important is having a good relationship with the relatives of these children that are here (P7).

[...] So, what happens very often, due to the situation, is that the family ends up giving in to divisions, there is a difficulty in the family relationships. Thus, it is important that these families become united, more and more close to each other, in order to have the strength to face this situation together. The importance of family unity (P5).

[...] Otherwise only one person will get exhausted! (P4).

[...] It is always good to have more people around! (P3).

[...] And I put this to the family too, that's heavy, because... your care sometimes... that the relative stays 24 hours right there; and it is usually one of the relatives that carries the burden (P5).

They emphasized that the interpersonal relationship between the team and family caregivers facilitates the assistance, because it is necessary to work together. It is possible to identify in the speeches the importance of shared care among family members in order to avoid overloading only one person.

A study that evaluated how parents perceive family-centered care evidenced that family members feel empowered and establish a trusting relationship with the health team when this provides guidance, child-care actions and encourages the autonomy of the parents in the care of the child.[21]

During hospitalization, the family becomes an active participant in the care and may experience destabilizing situations. The team needs to be prepared to provide support and help, so that complicity and willingness may take place, as well as any aid that the nursing team may offer, so that family members feel strong and confident while facing the child's situation in such an atypical state of health.[16]

CONCLUSION

Based on the findings of this study, we conclude that, in the perception of nursing staff, they play an essential role in the daily life of children with continuous complex care needs. To this end, they establish bonds with the children and their families, generating a sum of efforts and a combination of knowledge that contributes to the qualification of care based on empathy and on the precepts of humanization.

The participants emphasized how much the mother is indispensable in the care, positioning herself in the very forefront of the situation and dedicating exclusively to their children, in detriment of their own lives. However, they recognize that establishing a family care network is extremely significant. Families need to be structured when facing the illness, and need to organize itself so as to avoid overloading only one individual. It is noticed that the professionals are able to help in this sense, stimulating the participation of other family members in the pediatric hospitalization. The implementation of outreach activities with groups of family members is suggested to enable the expansion of the space for interaction and exchanges between teams and families for the constitution of this network.

For the nursing team, working with children with continuous complex care needs represents a great challenge because their demands for care in the pediatric hospitalization area require a lot from the professionals, not only in terms of technical and scientific knowledge, but also in physical and emotional aspects, causing great wear of the team. Therefore, we recommend that health services invest both in the permanent education of their professionals, to offer subsidies and constant updating on the technical and scientific aspects necessary to act with this differentiated clientele, and also labor and recreational activities aiming to support the teams in emotional, ethical and aesthetic aspects of nursing care.

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