

Families' concerns about the care of children with technology-dependent special health care needs

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Objective. To identify concerns of family members of Children with Special Health Care Needs (CSHCN) as far as care related to using technology, and to discuss nurses' performance in the face of these concerns.

Methodology. Qualitative descriptive research, developed through February and March 2014, through semi-structured interviews with six family members, caregivers of technology-dependent CSHCN who are followed at a University Hospital in Rio de Janeiro. The setting chosen was the family members' home. Data were submitted to content analysis. **Results.** Concerns were distributed in a timeframe, divided between those occurring the moment the family members received the information about the technological device needed, then those which arose while accompanying the child during hospitalization, and finally those that remained after the hospital discharge.

Conclusion. The family needs information and support from nurses, because different concerns emerge throughout the treatment and accompaniment of a technology-dependent child

Key words: pediatric nursing; disabled children; health communication.

Dudas de los familiares sobre el cuidado del niño con necesidades especiales de salud con dependencia de la tecnología

Objetivo. Identificar las dudas de los familiares de Niños con Necesidades Especiales de Salud con respecto al uso de las tecnologías relacionadas con su cuidado.

Metodología. Estudio cualitativo descriptivo realizado entre febrero y marzo de 2014. Se realizaron entrevistas

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semiestructuradas en el domicilio a seis cuidadores familiares de Niños con Necesidades Especiales de Salud dependientes de tecnología y que eran acompañados desde un Hospital Federal de Río de Janeiro (Brasil). Los datos se sometieron a análisis de contenido. **Resultados.** Los familiares indicaron dudas que se relacionaban con la trayectoria del cuidado, divididas así: 1º) el momento en el que recibían la información sobre la necesidad del uso de algún dispositivo tecnológico, 2º) el acompañamiento del niño durante la hospitalización, y 3º) después del alta hospitalario, de regreso en el domicilio. **Conclusión.** La familia necesita apoyo del enfermero para el desarrollo de las habilidades y competencias para el cuidado del niño con necesidades especiales de salud con dependencia de la tecnología.

Palabras clave: enfermería pediátrica; niños con discapacidad; la comunicación en salud.

Dúvidas de familiares sobre o cuidado de crianças com necessidades especiais de saúde dependentes de tecnologia

Objetivo. Identificar as dúvidas dos familiares de Crianças com Necessidades Especiais de Saúde (CRIANES) quanto aos cuidados relacionados ao uso de tecnologias; e discutir a atuação do enfermeiro frente a essas dúvidas. **Metodologia.** Pesquisa qualitativa descritiva. O cenário foi o domicílio de seis familiares cuidadores de CRIANES dependentes de tecnologia, acompanhadas em um Hospital Federal do Rio de Janeiro. Coleta de dados em fevereiro e março de 2014, a partir de entrevista semiestructurada. **Resultados.** As dúvidas se distribuíram de forma temporal, sendo divididas entre o momento em que os familiares receberam a informação da necessidade do uso de dispositivo tecnológico, depois, durante o acompanhamento da criança na hospitalização e, por fim, as que permanecem quando saem de alta hospitalar para o domicílio. **Conclusão.** A família necessita receber informações e apoio do Enfermeiro, pois surgem diferentes dúvidas no decorrer do tratamento e acompanhamento da criança dependente de tecnologia.

Palavras chaves: enfermagem pediátrica; criança com deficiência; comunicação em saúde.

Introduction

In the course of their regular pediatric care, some children are observed to need special care, which in turn requires that their family provide different care strategies at home after their discharge from hospital. This type of care demands technical expertise and necessitates changes in household routines. The international literature refers to these children as those with special health care needs (CSHCN). This term is employed in Brazil,^{1,2} and the increase in this group of children is directly related to three factors: preventable diseases that become chronic in children due to hospitalizations and re-hospitalizations, perinatal conditions, and congenital malformations.³

Continuing health care must be provided to CSHCN, whether on a temporary or permanent basis. Such care demands are classified into five groups: developmental (those who need psychomotor and social rehabilitation); technological (children who depend on some form of medical technology in their body to survive); pharmaceutical (drug-dependent children); modified standard (requiring aid for common everyday tasks); and mixed (for those demanding associated care).^{1,2,4} Patients with technological needs are also known as technology-dependent children. The Office of Technology Assessment (OTA) states that the term “technology-dependent children” refers to those who both need

medical devices to compensate for the loss of a substantial vital body function, and require skilled long-term nursing care to avoid death or later deficiencies.^{2,5} In the hospital, care focused on the technological demands is performed by the nursing team; however, when the technological device remains in the child's body after hospital discharge, the care is provided at home by family members. This illustrates the importance of the nurses' role in promoting health education and fostering the training of family members for home care as needed.

Due to the complex type of care that CSHCN demand, professionals are required to have adequate skills, expertise in care coordination, and good communication with family members. Work with the family is needed because the latter is fundamental to the child's care, and plays an important role in its physical, emotional, and social well-being.^{2,6,7} Given the complexity of care provided to technology-dependent children, this study was supported by the theoretical precepts of Collière,⁸ whose works deal with the evolution of care practices and their different natures during mankind's socio-historical changes. Collière distinguishes two types of care with different natures: 1) daily, habitual care, which ensures the continuity of life, relating to nutrition, hydration, elimination, heating, energy, displacement, and the need for affection; and 2) repair care or disease treatment, aimed at limiting the illness. Caring is therefore sustaining life, ensuring the satisfaction of a set of essential needs for living.⁸

The term "caregiver" can apply to any person who helps another to maintain his or her life, and not necessarily a trade or profession. However, there are situations where individuals need professional care to maintain life,⁸ and in the case of technology-dependent children (TDC), care oscillates between the professional and the family. However, family care will differ from that provided to children without special needs, and requires information and guidelines from qualified professionals, including nurses. The scientific literature shows that there are inconsistencies between the instructions given by the health team and the demands of the families, to the extent that they have difficulty in understanding the language used by professionals for preparing home care.^{9,10} It is crucial to note that before planning educational activities directed to the care of the

technological device, families must be given a voice so that they can express their concerns related to this care, since such information underpins the discussion of the nursing practice with the child and its family.

Evidence suggests that when nurses perform educational practices, their bond with the client strengthens, especially when the training is adapted to the family's situation, according to their particularities, to ensure care continuity and completeness.^{2,3,11} To this end, before planning educational activities professionals must listen to the needs of the family, so as to draw strategies that better suit the reality experienced by the subjects. In this sense, the interest in listening to families to better plan care provoked the authors' interest and motivated this research. Based on the above, this work's aim was to study the concerns that family members of children with special health care needs had about the use of technology. Its objectives were: to identify the concerns of parents of children with special health care needs about the care related to the use of technologies, and to discuss the role of the nurse in the face of these concerns.

Methodology

We conducted descriptive qualitative research,¹² carried out in the homes of families of children enrolled in the Home Care Program of a Federal Hospital in Rio de Janeiro, Brazil. Data collection took place in February and March 2014. The criteria for inclusion of participants were: family aged over 18 years participating in the care of CSHCN with technological care demands. Exclusion criteria were: family members of children who failed to use technology during the data collection period. To select the participants, a review was performed of the medical records of all children served by the program. Initially there were nine children eligible, but two were discharged from the program, and in one case the family declined to participate. Therefore the survey was conducted with one relative of each of six children, because in each family only one member was available to participate in the interview.

Each interview was conducted in a single visit in which all the questions were answered, and lasted

approximately 30 minutes. The first author of this work accompanied the home visits conducted by the Home Care Program team and was introduced to the family by the nurse from the Program, who is the third author of this study. The researcher then presented the objectives, the aspects contained in the Informed Consent Form, and subsequently invited the family member to participate, and proceeded to interview those who consented. To collect data we used a semi-structured interview conducted by the first author, who at the time of the survey was a graduate student in nursing, being guided by the second author of the study, an assistant professor, with a bachelor's degree in nursing and a Ph.D. from a Federal University located in Rio de Janeiro. We used a script with open and closed questions. Closed questions were aimed at identifying the characteristics of the participants, such as degree of kinship, age, gender, education, as well as data relating to the children, such as type of pathology and technology used. As for the open-ended questions, they were designed to identify the concerns related to care provided to technology-dependent children. (TDC) These included: "Talk about the care that you perform with the child. Do you have any questions about the care you give? What are they? Do you have any questions about the care with the device (gastrostomy, tracheostomy, venous catheter, colostomy, among others) that the child uses?"

The study was approved by the Ethics and Research Committee of the institution where it was held (CAAE: 23229613.0.0000.5243 / Opinion: 541 806), and respected all aspects contained in Resolution 466/12 of the Brazilian National Council of Health. Survey participants signed the consent form. The anonymity of the participants was ensured, and they were identified with the letter F followed by the sequential numerical order of the interviews. In addition, to guarantee privacy and confidentiality of information at the time of the interview, only the researcher and the family participant were present. With the permission of the respondents, the speeches were recorded with an mp3-type voice recorder, and subsequently fully transcribed for analysis. Data collection was closed when there was theoretical saturation verified by the repetition of family members' concerns about care related to the use of technologies.¹³

Data analysis was carried out by following the three phases of thematic analysis:¹² (a) pre-analysis, floating reading. At this stage, after being fully transcribed the interviews with relatives were read in order to know the content of the generated empirical material; (b) material exploration phase. This consisted of exhaustive reading to delineate units representing meanings, which were then aggregated into pre-set categories that addressed the concerns of technology-dependent CSHCN; (c) treatment phase and result interpretation, when it was possible to make inferences in the light of the scientific literature on the concerns of family members of technology-dependent CSHCN. To operationalize the analysis, the speeches of family members were classified manually, using colors, in which those with the same sense were assigned the same color, thus giving rise to categories. It is noted that the categorization and analysis were made in pairs, initially by the first and second author. Subsequently, the material was subjected to critical analysis by the second pair, consisting of third and fourth author.

Results

Data analysis led to the emergence of three categories of concerns, which respondents identified in a temporal manner, i.e. at three different moments: at the beginning of the care path, when they received the information necessary to be able to use the technological device; concerns resolved during hospitalization and preparation for discharge; and finally, concerns that arose when the children were already at home, and remained there until the end of the data collection period.

Concerns of family members of technology-dependent CSHCN at the onset of the care path

The family noted that initially, when they received the news of the need to use technology, their concerns were related to the pathology itself, the need to perform surgery, and the child's clinical condition. In this initial phase, the technological devices attached to the body of the child did not arouse so many concerns and questions, as seen in these excerpts:

At first she desaturated a lot! I wanted to know about the condition, the heart surgery, the part of the lung [...] They were deeper questions, such as: the role of the heart, why the heart soaked, why it was damaging the lung, about the surgeries (F 4). What worried me most was the part of the disease, much more stuff is coming, cystic fibrosis does not only attack only the intestinal part. It attacks the pancreas, kidneys, and even if knowing that a transplant is possible, we know that it is not the cure, it's just some more lifetime, unless they suddenly they a remedy [...] My worries were about the disease (F 6).

After the initial phase, after obtaining the information regarding the pathology, they began to take an interest in knowing what gastrostomy and tracheostomy were. They reported concerns about the technological device itself, they needed to know about the button used in gastrostomy, to know what volume the bolus can take, the milliliters of medication that can be administered, the size of the tracheostomy tube, and the length of the probe that must be inserted into the cannula to perform aspiration: *At first I had concerns. I did not know what tracheo (tracheostomy) or gastro (gastrostomy) were, I knew nothing of this (F3). My question was to know how it (the button) is inside, right? I wanted to know how many mls (milliliters) fit into the bolus. The maximum and the minimum, got it? I wanted to know the tracheostomy tube, its size inside. As for introducing the probe (aspiration) I wanted to know the cannula number (F 4).*

In addition to the questions related to the devices themselves, family members highlighted those about home care, because when they began providing the care with the device they experienced tension, nervousness, and anxiety. The main concerns were with tracheostomy cannula change and colostomy bag change. It is worth noting that over time and with repeated procedures, respondents began to feel confident while providing this care: *At first I was quite afraid of this tracheo (tracheostomy), because his tracheo it is different, but now he already pulled it out five times. Of course, there is a tension at the time of placing it, right? But now I'm very confident, it is calmer (F 1). I had doubts about how to get the colostomy bag out, place it, wash it, I was nervous ... The gastro (gastrostomy) leaked a lot, I do not know why, he ate, it leaked (F 5). I was*

afraid to hurt him, especially when changing the cannula (tracheostomy). I was afraid to put it wrong (...) you are dealing with life. Now I feel safe (F3).

The care path during hospitalization and preparation for discharge of technology-dependent CSHCN

Family members reported that their anxiety concerning care using technological devices were gradually resolved during hospitalization, insofar as the children spent a long time in hospital. In this sense, during the hospitalization they gained experience using the devices by observing the care being carried out on other children: *In the beginning I had doubts, but today I feel confident to provide care because I stayed in the hospital for over a year (F 4). When I came home I did not have many concerns about taking care of her (CSHCN) because I saw it (care being carried out) in the hospital, right? As we stayed a long time in the hospital, I saw the other mothers performing care, and I kind of knew [...] I knew I have to open and close (gastrostomy) (F 2). I always tried to clarify my doubts, see, observe, so when she started using (gastrostomy treatment), I knew how to use her gastro device, knew already how pass the tube into the gastro because I saw other children using it in the hospital (F 6).*

Family members also reported that they learned to perform care with technological devices so that the child could be discharged. They carried out the procedure a few times to feel safe enough to perform them at home. *The doctor told me that my (CSHCN) would be discharged and I had to learn how to use the tracheo (tracheostomy), my (CSHCN) would only be discharged if I learned. There in the hospital I changed it four times. Until I felt confident. I had doubts about inserting the cannula, but as I was dying to go home I learned very fast (laughs) (F3). I had many doubts even about washing the colostomy bag because it leaked and I had to put adhesive tape and gauze. We were discharged (from the hospital) only after I had learned (F 5).*

Concerns of family members of technology-dependent children about home care

Upon returning home after hospital discharge, family members reported that they felt insecure and

uncertain about how to care for the child in case of possible complications: *I get nervous, not knowing what to do when the light goes out (electricity) and she is on oxygen, then I call power company telling them that I have a special child at home. She uses the oxygen cylinder until the power is restored.* [F6] Another aspect highlighted was their concern about complications with the device, such as the disruption of the button and the need to use another device (probe), to which they are not accustomed. *What if the button (gastrostomy) breaks? What if I do not have another to use? If you have to insert the probe, I will not know [...] Until today I only put the button ... If I have no way to do it at the time or if it happens to burst, do I put the bandage? I have doubts in the case an accident occurs... What to do? (F 4).*

Another situation mentioned that generates concern and nervousness in the family is if the tracheostomy tube is displaced, or when there is a need to change it: *Another thing ... that makes me very nervous is to change the cannula (tracheostomy) when it comes out of place, because she shakes a lot, and becomes very purple (cyanotic). [...] Whenever I need to change the cannula I get anxious, afraid that something will happen (F 4).*

Discussion

The family members of technology-dependent children highlighted that the initial phase of contact with the disease and the special needs of the child generated worries about the disease and clinical picture. The literature indicates that initially the situation is the manifestation of shock and feelings of helplessness. Thus, the way the family is supported at diagnosis and the explanations they receive have an important impact on how they will cope with the child's condition and special needs.¹⁴ A sign of the family's desire for information is the fact that in this diagnostic phase some turn to the internet to get it, a habit that becomes less frequent over time.¹⁵

The concern of the family members about the surgery undergone by the CSHCN, cited in one of the speeches, is justified because this procedure is a stress factor. A study of mothers accompanying children hospitalized for performing elective surgical

procedures stressed that the pre-surgical period involves an emotional overload for the whole family. In addition, it found a high stress level for mothers accompanying hospitalized children, especially when it came to the first experience of surgery on the child.¹⁶ Another aspect highlighted by family members was the concern and anxiety about the course of a chronic disease such as cystic fibrosis. The literature points out that despite the progress of science and technology in relation to the procedures used for diagnosis and treatment of chronic diseases, the child and the family are affected by feelings of fear and uncertainty, and that the care path they take is full of suffering, struggle, and challenges.^{17,18}

According to Collière's theory,⁸ life is marked by a succession of passages from life to death: birth, weaning, first teeth, entering school, puberty, first job, and others. In addition to these expected passages, individuals may run into unexpected and occasional passages like diseases, which lead those involved to seek some kind of preparation for facing them. In this sense, family members were observed to seek information about the child's disease, possible procedures such as surgery, as well as the possible evolution of the disease. It is also clear that family members require understanding and more information about the disease process and the procedures carried out with the child. With regard to the exchange of information between professionals and families, a study showed that parents of technology-dependent children using gastrostomy judged inadequate the information provided by professionals, and reported that they were not heard.¹⁹ Thus, the concerns of the family extend beyond what the team believes necessary to be remedied, and that for the appropriate preparation in order to enhance a more positive coping the families need to be heard.

The difficulties the family faced in performing certain types of care was noticeable, such as changing the tracheostomy tube, replacing the colostomy collection bag, and caring for a child with a gastrostomy. Such difficulties are mainly due to insecurity and fear of hurting the child. This confirms the challenge that family caregivers face while performing care for their loved ones.²⁰ It is in the cultural milieu where the family live and learn to perform daily habitual care, focused on feeding, eliminating, and other processes,

without the use of devices such as gastrostomy probes and colostomy bags. But when faced with a technology-dependent child, the nature of such care also includes disease repair or treatment,⁸ so the families need time to assimilate this new way of caring for the child's life maintenance. In contrast, the survey data indicated that, with the passage of time and repeated procedures, they gain more confidence at providing care. This finding agrees with research that states that some caregivers learn to take care of CSHCN through practice developed over time, through experience.²

Some of the family's questions were addressed during the child's hospitalization. This information confirms that the knowledge and ability to perform home care begin during hospitalization, where some family members acquire knowledge, supported by their observation of health professionals during this time.^{2,20} In this sense, the observation of the care using the technological device by professionals and other families facilitated the learning of respondents who, by close observation gained greater confidence in performing these procedures. In preparation for discharge from hospital, family members showed concern about how to provide home care. Therefore, throughout the hospital stay the family must be prepared for the time when the child leaves the hospital and goes home, thereby reducing the family's anxiety. This study agrees with another which states that the preparation for discharge happens during hospitalization, is consolidated at the end of the admission, and continues in the post-hospital period.²¹

It is important to keep in mind that a child's discharge does not mean a full recovery of health, and that the care developed in the hospital will continue to influence that performed at home by family members.^{7,22} The possibility of occurrence of any complication generates nervousness and anxiety in family, and parents are unsure about how to proceed in these situations. Another study found that the family regards complications in CSHCN as an emergency, giving the same weight to both the severe and the complex.³ Taking care of technology-dependent children at home requires family reorganization to meet the needs of the child, because situations like power outages can be life-threatening when there is dependence on electrical equipment.

Taking into account the various questions presented by family members, it is confirmed that clear information from the professionals addressing their concerns decrease the parents' anxiety, increase acceptance and their involvement in care, and promote the process of coping with the disease.²³ In an attempt to minimize psychological distress, the family should be valued and respected in the relations that permeate the hospital environment.²³ We stress the importance of the nurses' role in guiding these families, so that anxiety and fear is minimized, and the care of children is better. Thus, during the course of care, professionals should encourage autonomy and foster acceptance of and social support for these caregivers so that they feel confident and comfortable in carrying out the child's care and life maintenance.

Given the possible concerns that family members can present at different points along the care trajectory of the technology-dependent child, it is evident that nurses need to guide the family on how to use the technological devices and care for the child during the course of hospitalization, to minimize uncertainty at the time of transitioning to home care. In this regard, the literature points out that nursing is fundamental in the hospitalization process, and can directly contribute to the development of skills and knowledge of the home caregivers if there is a commitment to support them in the transition to the home and later follow-up.²⁰ Thus, in order to not compromise care, the nurses are involved in the discharge process to promote continuity of hospital-level care at a patient's home.

Teaching parents to develop care does not depend solely on theoretical and practical information provided at discharge, since fears and worry arise on a daily basis once they are at home. Previous research has highlighted the challenge of performing care for these children in the home setting, the knowledge and practices of which are not related to the parents' usual daily life but to the context of the hospital.^{2,4} It is important to note that nurses need to be closer to the family so that they can seek strategies together to meet the vital needs: caring is following the difficult passages of life, encouraging, developing skills, and making up for what is not well.⁸ To that end, it is crucial to create spaces for conversing, listening, and learning, which take into account the knowledge

acquired and the possibilities of family care at home.² In addition, nurses need to conduct follow-up care with the families of technology-dependent CSHCN in their homes. It is recommended that the team that caters to technology-dependent children expand its performance space from the hospital to the home, because new concerns arise in the latter scenario, and professionals and family together can seek better solutions to deliver the care needed for the child.

Because no other family members were present on the days scheduled for the interviews, the participation of a single family caregiver per child may translate as a limitation to this study. The conclusion, therefore, is that the role of nurses in the development of skills and competencies of caregivers is very important. Moreover, guidance regarding the child's discharge process must take place throughout the hospitalization, and not only at the moment of discharge. At home, the concerns concern the possibility of complications, either from power outages, the need to use different devices, or accidental displacement of the device. It should therefore be noted that there is a need for nursing follow-up to deal with the concerns specific to daily home care.

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