

PREVIOUS KNOWLEDGE OF CAREGIVERS FOR CHILDREN WITH SPECIAL HEALTH NEEDS: A FREIRIAN APPROACH¹

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ABSTRACT

Objective: The objective of this study was to describe the prior knowledge of caregivers of children with special health needs regarding their way of care. **Methods:** Convergent Care Research was used to produce data through participant observation and interviews before and after the health education practice with the participants. The study included five mothers who provided care for children with special health needs who were hospitalized in a school hospital in the south of the country. Special needs presented by children included use of gastrostomy tube, insulin and nasogastric tube. Paulo Freire's reference to empowerment and liberating education was used as guidance of data analysis. **Results:** The caregivers of these children have previous knowledge, especially from observations of care given to their children during hospitalization. This knowledge should be considered for the practice of health education based on a dialogical relationship of exchange with the user. **Conclusion:** The development of a unique care plan that is coherent with the reality of children with special health needs, contributes to the quality of care of these children.

Keywords: Pediatric nursing. Child Health. Health Education. Caregivers.

INTRODUCTION

Children with special health needs are defined as those who are at risk or at a higher risk of developing a chronic, physical, developmental, behavioral or emotional condition and requiring certain health services beyond what is required by children in general. This definition aims to contribute to the elaboration of public policies that meet the social, health and educational demands of these children in favor of their quality of life ⁽¹⁾.

These children have different demands for care that may be related to their development, due to continuous use of medication, to dependence on technological resources, to the need of adapted regular care, or all of them together. Prior to the discharge of a child with special health needs, there is a need to prepare the caregiver (parents, grandparents or others) for the care of the child at home. Caregivers need to manage care using enteral feeding tubes, tracheostomy, supportive respiratory treatments (nebulizers, ventilators, and airway aspiration),

wound care, venous network care, and medication administration ⁽²⁾.

Family members of children with special health needs leave the hospital setting with children who have (super)natural demands for care, that is, care that goes beyond that demanded by another child of the same age and which brings a high burden of demands for part of the caregivers, such as care with medications, search for health services and constant watch at home ⁽²⁾. Family members feel a huge responsibility in the face of the challenge of developing new and unfamiliar skills on which children often need to survive ⁽²⁾. This way, the practice of health education by the nurse professional becomes central for the maintenance of children's quality of life, since their families need support to live with this new reality that begins in hospitalization, but does not end at this moment ⁽³⁾.

Education is understood as the deepening of critical awareness, with the exchange of experiences and the construction of a new understanding through the reflection that starts

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from the reality of the learner⁽⁴⁾. Health education is understood as a social practice and a process that contributes to the formation and development of the critical awareness of people and stimulates the search for solutions and the organization for collective action. The health practice as an educational practice stops being a process of information transference and becomes a process of empowering individuals and groups to modify reality⁽⁵⁾.

In the development of a critical education, the educator understands that teaching is not only transferring knowledge but creating the possibilities for its production and construction. This is in line with the Freirean proposal for education, which is practice based on problematizing pedagogy. This practice seeks to break with the reception of information and the reproduction of techniques. In the pedagogy of problematization, the subject learns from the reality lived and is prepared to modify it⁽⁶⁾.

At home, during care of children with complex diseases, some parents, because they are excluded from the decision process, experience suffering and frustration in their relationships with health professionals. This exclusion causes a gap related to respect and appreciation of parents' knowledge on the child⁽⁷⁾. This way, for an action to be transformative, it must be considered, at first, that the family holds a knowledge, a worldview, constructed by its praxis, in the common sense, that must be valued, considered and respected⁽³⁾.

Based on these considerations, it was questioned: how can health education mobilize family caregivers to change their daily practice of caring for children with special health needs? This work describes the first phase, related to the previous stage to health education, of the study whose general objective was to develop a health education program in a school hospital in the country of Rio Grande do Sul with family caregivers of children with special needs health.

METHODOLOGY

The research was carried out in a pediatric inpatient unit of a medium-sized, public, federal hospital that attends medium and high complexity by the Unified Health System. The study participants were family caregivers of

children with special health needs who were admitted to the unit from March to July 2013. The participants were selected by lottery among the children with special health needs hospitalized during the data collection period. For the selection of the participants, the caregivers were approached from the order of the lottery and ended this stage, totaling five caregiver mothers, including all stages of the Convergent Care Research, constituting in 10 hours of observation and six hours of interviews recorded. For the child, the Statute of the Child and Adolescent was considered, which considers a child with an incomplete age group up to twelve years of age. To preserve the anonymity of the participants, codenames were assigned, being C for the caregiver and CR for the child. The conclusion of the collection occurred when the data collected had enough interpretive density for the proposed objectives of this research to be achieved.

The data were collected in six distinct stages, following the method described by the Convergent Care Survey⁽⁸⁾. In the first stage, the setting and preparation of the scenario for the research was carried out. The second stage was the identification of children with special health needs hospitalized and the sortition for the order of participation in the study. The third step was the pre-health education participant observation, using an observation script that aimed to observe how the caregiver family member cared for the child, in order to reveal the problematic situation. The fourth step was to conduct the pre-intervention interview that had the purpose of describing the situational diagnosis of the caregiver relative to care so as to plan the intervention practice. In the fifth step, which occurred after the interview, the start was given to the health education process, searching through a dialogic relationship, rescue and enhance the common sense of each caregiver if acquainting on their actual condition of teaching and learning. Finally, in the sixth stage, so that the caregivers could take ownership of new knowledge after the completion of the educational activities (which varied according to the uniqueness of each case) was monitored and participant observation, during which was observed how the caregiver was caring for children with special health needs.

Data analysis and interpretation followed the assumptions of Convergent Care Research⁽⁸⁾, including the transcription of interviews in pre- and post-educational digital media and health education. The comparative analysis of the data was performed, comparing the results found with the relevant literature and the theoretical reference. This analysis was carried out in four distinct stages: the apprehension process, where the data were organized and the first reading was carried out in full, seeking to identify the codes in the interviewees' speeches, organizing the information with the chromatic coding feature; process of synthesis, in which the codifications were gathered according to similarities, rising the categories; process of theorization, in which the process of data comparison and theoretical basis of the research occurred; and the transfer phase, which consists of the socialization of the results. The results presented in this article are related to the interviews performed with caregivers prior to the practice of health education. The findings describe the category of previous knowledge reported by caregivers.

The study respected the formal requirements in the norms of Resolution 196/96 of the National Health Council, regulating research involving human beings, and was approved by the ethics committee of the institution under the number of CAAE 12252612.0.0000.5346.

RESULTS

When discussing with the caregivers about their knowledge on the condition and demands of child care, it was perceived that this knowledge originates from experiences coming from different forms. These occur through the experience of hospitalization, when observing care in other children with the same condition or demands similar to that of their child or by observing the work of the nursing team with a relative or someone in the community that has similar demand.

When asked C1 about what demand for care the child needed at the time, she replied:

I think it's just the tube (C1).

And when asked if C1 was aware of the gastric tube's position:

It is, as they informed me, it goes up in the ...

gut[intestine], inside there (C1).

C1 used "gut" to refer to intestine. It is known that the position of the gastric tube should be in the first part of the small intestine. When asked C1 about why the gastric tube had to stay in that position, she added:

Not to return the milk. Yes, and it has the imprints. They have the numbers. You always must take care if it is by the same number (C1).

Although the C1 did not handle the gastric tube, she spoke about details and detailed care related to the numerical mark used to verify the position of gastric tube, possibly resulting from the observation and listening of professionals. This knowledge also comes from her interest in learning about caring for her daughter, which led her to seek new knowledge, until now, unknown to her world.

In the same way, it can be verified that the other caregivers, through their knowledge, seek in a simplified way to demonstrate their knowledge about hydrocephalus and the need to use the Peritoneal Ventricular Derivation (PVD) valve:

Because if it does not fill with liquid, it may even burst, then putting the valve reduces the liquid. (C2).

It goes all to tummy to pee. (C2).

He has[PVD]. He had at the right side, he rejected it and got pus [infection], then he stayed here for two months [hospital]. They took it out, cleaned it well and put it on the left side. Never again. He stayed for a week without a valve, cleaned the rest, took that medicine to decrease the liquid (C5).

It is noticed that both caregivers have knowledge about the aspects that involve the health-disease of their children from their cultural matrices, beliefs and values.

In general, observation and demonstration of care done by the nursing team can be mediators of care, aiming at a learning to do to the detriment of knowledge, in which the reasons that justify the practice are not presented to them:

I have seen them doing this [diet management through nasogastric tube], but in the PICU [pediatric hospitalization unit]. There at the PICU

I saw it. And after feeding milk, you put a little water. Only it was not with her. It was with others that I saw only from afar! Because there you cannot, you know? (C1).

No, the only thing that I saw it was when he was there at the PICU there was a little boy besides him who did [gastrostomy], and I looked. Because even in my imagination it was down here, but it is not. It's here, right? right on top... [on the stomach] (C3)

From the reports of C1 and C3, it is noticed that there is a distance between the nursing team and the caring family member regarding the care of the children. This is expressed by the statement that the family member saw "from far" the care being performed. In this way, family members often feel like mere spectators of the care taken by professionals.

In the following statement in the Pediatric Hospitalization Unit, the relationship between professionals and family caregivers presented deficiencies in communication and educational actions:

Now[referring to having seen a child with gastrostomy], the one on the corner there, that she had thrown to gastro [stomy]. The other one, that her little boy had the gastro, she showed me everything. (C2).

In questioning C2 if she had observed how to handle the diet, it states:

I Saw. They began with water, they gave water for two days. (C2).

This caused C2 to seek knowledge with a mother caring for another child with gastrostomy, even that her daughter already had gastric tube and was hospitalized for gastrostomy.

When C2 was asked about her knowledge about this procedure and handling care, she first mentioned being able to take care of the experiences already lived. However, in the course of the dialogue, the researcher and C2 were un(constructing) knowledge built in an earlier process that occurred with little or no reflexive criticism of the subjects involved, as can also be seen in the case of C5:

Because ... Of course, because how many [times]... Oh! I go there [Porto Alegre] on Wednesday to do this course and on Wednesday there are four patients in the morning and four

patients in the afternoon and the same instruction that they give to me, they give to the other three. The other three staying in the afternoon and the other four staying in the morning. And it is passed on there. Did you see that little book I have? That little book explains everything, proves everything I said. Just wash your hands with soap and water, and do not talk about gloves ever, do not talk. Even the nurse explained if there is anyone coughing near gastric tube, do not stay close, because the moment you opened and moved there could be the risk of any infection. So, it is very important, yes, because there are many mothers who want to learn, are willing to learn and learned the wrong way and are trying to do. For example, a gauze, they gave, is just one, you clean around and later you clean in the middle. With a gauze. It's not with a bag of gauze. It's just a little gauze. And then what happens, suddenly you take them aside and put them in the middle [the dirt]. (C5).

Despite all this explanation of C5, when observing her performing the bladder catheter of relief in CR5, procedure for which she received a training in another institution where she is monitoring, it was detected that she performed it incorrectly. Possibly as a consequence of this, readmissions of CR5 were frequent due to infections caused by multiresistant germs.

Regarding prior knowledge, knowledge has also emerged from the observation of care given to other children with special health needs in the community, such as neighbors, friends, family, and others.

There is a neighbor, who is the same neighbor who had a nasogastric tube. She also had this thing in her belly [gastrostomy], something like that. I only saw it installed once the little girl was a month older, not even a month the little girl was, they were there at home, only she was a little bigger ... It's going to be three or four years this year... And they had this thing like that. Then they fed milk and they put water. Then I stayed watching. (C1).

The degree of family involvement and the willingness to learn and seek new knowledge are decisive factors that can have a positive impact on the child's quality of life. Thus, the experiences lived by the caregiver with the same demands of care can be a stimulus to persevere and to tread new paths. The statement of C5 illustrates this fact:

Yeah, but when he gets older, what he starts talking, it might be that ... You know?! I also

know we do not know how much is compromised, because the doctor told me he would never walk. And that we were going to have to get used to that idea. Who knows when it got bigger, because I met a nineteen-year-old boy he would insert his own tube, but he did not wear diapers. (C5).

Some caregivers already cared for family members with special needs, such as in the case of C4, who has in the family two more cases of people with diabetes mellitus the husband and mother-in-law. Even in the face of this reality, receiving the diagnosis that her daughter also had diabetes, with the need for continued insulin use, she had many doubts and insecurity. When asked if she knew how to inject the insulin into the syringe to administer it, C4 states:

Yes, Yes. I never just administered. No. He [husband] does not know. Just use the...[oral medication]. (C4).

When the knowledge about the importance of the rotation of the regions of insulin application was mentioned, the participant C4 reflected on the consequences of the non-rotation of the applications and expressed the following speech:

Oh yes! My mother-in-law has some balls [nodules caused by hypertrophy of the subcutaneous tissue]. She just does it in the leg. (C4).

When questioning the caregiver if any professional had already done guidance on the procedure to which the child with special health needs would be submitted, and the care demands of this, the following report was obtained:

Not! They only told me about the gastro[stomy]. (C2).

C2 commented that CR2 had many episodes of vomiting, and that the doctor in charge talked about the gastrostomy but did not explain about the narrowing procedure in the proximal part of the stomach performed in some cases, which prevents regurgitation of diet. The other caregiver also commented:

No ... The surgeon was here in the afternoon and talked to his father, I had left, but I did not ... No one yet ... the doctor, one day on the phone when I called her. She told me. So, I... I was, Oh! But she told me: "But it's simple..."that's what she told me. But then ... she spoke endoscopic probe ... and I ... but at the time I did not realize, I just

understood after I stopped to think about what she had told me ... and then I... until I decided to search, me and my sister to see what it was, right? ... and we ended up researching. (C3).

It was noticed in the dialogue with C3 that the only professional who had talked to her about the procedure had been the assistant physician, who gave this information superficially (by telephone), in language based on scientific knowledge, demonstrating the power of a knowledge that makes the subject impossible to think, to reflect, considering the subject as object of the process in which knowledge is deposited. Consequently, C3 resorted to alternative means in the search for information to try to solve her doubts.

DISCUSSION

Based on the analysis of the reports in the interview "Pre-education in Health", it is confirmed the importance of seeking, through dialogue, the prior knowledge of caregivers of children with special health needs. The caregivers who participated in the study demonstrated knowledge from observations and exchange of experiences with other mothers. Another study carried out with relatives of these children pointed out that they develop abilities to perform the care from the observation of health professionals at the time of hospitalization. At home, such care becomes continuous and improved over time by the need to maintain the child's survival⁽⁹⁾.

Putting observation as the basis that guides health education, allows an analysis of the level of knowledge, needs and potential that each caregiver has to the demands of child care. Thus, it was possible to reveal, through the dialogue between the researcher and the participants, previous knowledge of the caregivers, promoting a true sharing of experiences. In this way, one has the possibility of constructing a plan of care congruent with the needs and desires of both, in a convergence of practice with theory. This configuration of educate-caring is only possible when the subjects involved form an interchange between technical-scientific or professional knowledge and popular knowledge coming from common sense, thus building a shared knowledge⁽¹⁰⁾.

As reported in the interviews, when using the observation of the practice of health professionals as a learning mechanism, caregivers focus on doing, that is, reproduce attitudes without any reflection on the practice. With this, it is observed that caregivers remain naive and uncritical. Since there is no other person to share experiences, it is not possible for man to immerse himself in the world of meanings, not to deepen himself in the stream of language, without elevating his psychic functions and formation of critical consciousness, not constituting himself as subject⁽¹¹⁾. Thus, it is the responsibility of health professionals to mediate practices that account for the demands of care that family caregivers face during the hospitalization of children with special health needs.

Usually, the practice of health education in the hospital context is based on a traditional tendency in the way knowledge is transmitted, focused on the verticality and hegemony of scientific knowledge⁽¹²⁾. In addition, there is an invisibility about health education in the hospital context by nursing professionals⁽¹²⁾.

Family caregivers expect health professionals, specifically nursing, to meet their real needs. For this to happen, it is necessary that all situations of encounter are viewed as opportunities to dialogue and exchange experiences, observing the way of caring and demonstrating an attitude of understanding and approximation with the reality of family members. Thus, an intersubjective relationship can be established between those seeking services and professionals, so that the needs of the children are met⁽¹³⁾. This requires nurses to have a pedagogical conception that dialogue and respect for the other is fundamental for educational actions to be effective and relevant. Dialogue is an existential necessity; it is the basic condition for knowledge. The act of knowing occurs in a social process and dialogue is precisely a mediation of this process⁽¹¹⁾.

Therefore, it is understood that, without dialogue, there is no communication and interaction. True dialogue is based on a critical thinking that perceives reality as a process⁽¹⁴⁾. For this to happen, it is necessary to establish a dialogical relationship with the subjects, in order to establish a true empathy, making them critical

through communication⁽¹⁵⁾. Thus, the nurse has the possibility of reaching the universe of family caregivers, exchanging experiences and experiences, making them receptive to the particularities of each individual and able to plan health education for autonomy⁽¹⁶⁾.

However, it is often observed that nurses perform health education in a vertical, traditional, hierarchical way, directed toward a depositary education. This practice consists of actions developed for the subject and not the subject, resulting in hegemonic care, based on scientific knowledge⁽⁶⁾.

Following this proposal of dialogic and problematizing education, the change in the relation of the nurse's care takes on the understanding of the subjects as potentially active, that are inserted in a singular reality, whose experiences accumulate, are re-created and modified during its existential trajectory. In this situation, the subject participates in the care, decides, opts and chooses the best for himself what constitutes a condition in which he behaves as someone who is far from being a mere receiver of knowledge. This generates a real autonomy of the subject, so that the latter starts to organize and implement care in their spaces of daily life⁽¹⁷⁾.

FINAL CONSIDERATIONS

The prior knowledge of caregivers about the demands of care of their children who have special health needs, originates from several experiences in the course of their trajectory. These experiences are related to observations of caring for other mothers or health professionals in previous hospitalizations. In their statements, the caregivers exposed detailed and scientific knowledge from observations and curiosity about the health status of their children. This knowledge must be respected and considered by the nursing professional at the time of health education.

The use of the Freirean approach for the interview "Pre-education in Health" allowed the listening committed to the caregivers and (re)cognition of their previous knowledge. Thus, it was possible to develop a true dialogue between the health professional and the subject that became part of the process of knowledge

construction. It is believed that this approach allows expanding the possibilities of the practice of health education, which considers values and respects the prior knowledge of caregivers in the elaboration of a coherent care plan, which corroborates for the improvement of the quality of care provided to these children.

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CONHECIMENTO PRÉVIO DE CUIDADORAS DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE: UMA ABORDAGEM FREIRIANA

RESUMO

Objetivo: o objetivo deste estudo foi descrever o conhecimento prévio de cuidadoras de crianças com necessidades especiais de saúde sobre os cuidados com seus filhos. **Métodos:** utilizou-se a Pesquisa Convergente Assistencial para a produção de dados por meio de observação participante e entrevistas antes e após a realização da prática de educação em saúde com as participantes. Participaram do estudo cinco mães cuidadoras de crianças com necessidades especiais de saúde, hospitalizadas num hospital escola do sul do país. As necessidades especiais apresentadas pelas crianças incluíram uso de sonda de gastrostomia, insulina e sonda nasogástrica. Utilizou-se o referencial de empoderamento e educação libertadora de Paulo Freire como condutor da análise dos dados. **Resultados:** as cuidadoras destas crianças possuem um conhecimento prévio oriundo, especialmente, de observações da realização de cuidados com seus filhos durante a hospitalização. Esses conhecimentos devem ser considerados para a realização da prática da educação em saúde pautada em relação dialógica de troca com o usuário. **Conclusão:** sugere-se a elaboração de um plano de cuidados singular e coerente com a realidade das crianças com necessidades especiais de saúde, contribuindo para a qualidade do cuidado dessas crianças.

Palavras-chave: Enfermagem pediátrica. Saúde da Criança. Educação em saúde. Cuidadores

CONOCIMIENTO PREVIO DE CUIDADORAS DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD: UN ENFOQUE FREIRIANO

RESUMEN

Objetivo: describir el conocimiento previo de cuidadoras de niños con necesidades especiales de salud respecto a los cuidados con sus hijos. **Métodos:** se utilizó la Investigación Convergente Asistencial para la producción de datos por medio de observación participante y entrevistas antes y después de la realización de la práctica de educación en salud con las participantes. Participaron del estudio cinco madres cuidadoras de niños con necesidades especiales de salud hospitalizados en un hospital escuela del sur de Brasil. Las necesidades especiales presentadas por los niños incluyeron uso de sonda de gastrostomía, insulina y sonda nasogástrica. Se utilizó el referencial de empoderamiento y educación libertadora de Paulo Freire como conductor del análisis de los datos. **Resultados:** las cuidadoras de estos niños poseen un conocimiento previo originario, especialmente, de observaciones de la realización de cuidados con sus hijos durante la hospitalización. Estos conocimientos deben ser considerados para la realización de la práctica de la educación en salud basada en una relación dialógica de intercambio con el usuario. **Conclusión:** se sugiere la elaboración de un plan de cuidados singular y coherente con la realidad de los niños con necesidades especiales de salud, contribuyendo para la calidad del cuidado de estos niños.

Palabras clave: Enfermería pediátrica. Salud del Niño. Educación en Salud. Cuidadores.

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