

<http://dx.doi.org/10.1590/0104-070720180005720016>

## EDUCATIONAL ENCOUNTER OF NURSING AND THE RELATIVES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

*Izabella da Silva Viana<sup>1</sup>, Liliane Faria da Silva<sup>2</sup>, Emília Gallindo Cursino<sup>3</sup>, Daniele Santos da Conceição<sup>4</sup>,  
Fernanda Garcia Bezerra Goes<sup>5</sup>, Juliana Rezende Montenegro Medeiros de Moraes<sup>6</sup>*

<sup>1</sup> Nurse Resident, *Instituto Fernandes Figueira, Fundação Oswaldo Cruz (FIOCRUZ)*. Rio de Janeiro, Rio de Janeiro, Brazil. E-mail: izabellaviana@hotmail.com

<sup>2</sup> Ph.D. in Nursing. Professor of the Department of Maternal Child and Psychiatric Nursing, *Escola de Enfermagem Aurora de Afonso Costa (EEAAC), Universidade Federal Fluminense (UFF)*. Niterói, Rio de Janeiro, Brazil. E-mail: lili.05@hotmail.com

<sup>3</sup> Ph.D. in Nursing. Professor, Department of Maternal Child and Psychiatric Nursing, *EEAAC/UFF*. Niterói, Rio de Janeiro, Brazil. E-mail: egcursino@globo.com

<sup>4</sup> M.Sc. in Nursing. Nurse, *Instituto Fernandes Figueira, FIOCRUZ*. Rio de Janeiro, Rio de Janeiro, Brazil. E-mail: danisancon@gmail.com

<sup>5</sup> Ph.D. in Nursing. Professor, Nursing Department, *Instituto de Humanidades e Saúde, UFF*. E-mail: ferbezerra@gmail.com

<sup>6</sup> Ph.D. in Nursing. Professor, Department of Maternal and Child Nursing, *Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro*. Rio de Janeiro, Rio de Janeiro, Brazil. E-mail: jumoraes@ig.com.br

### ABSTRACT

**Objective:** to know the doubts of the relatives of children with special health care needs regarding home care related to technological devices; and to analyze the use of the conversation circle as a strategy of health education in the preparation for the hospital discharge of the relatives of children with technological devices.

**Method:** descriptive and exploratory research, with a qualitative approach, performed in the pediatric hospitalization sector of a federal hospital in Rio de Janeiro between May and June 2014. Six family members participated in semi-structured interviews and conversation circles. The data were submitted to thematic analysis.

**Results:** the relatives highlighted doubts in the learning and adaptation to the technology during the transition from the hospital to the home environment, and in possible emergency situations after the hospital discharge. These doubts were mainly about procedural care with tracheostomy and gastrostomy. However, the strategy of the conversation circle with the use of a doll with technological devices coupled was well-accepted by the relatives, as it favored the dialogue and the exchange of knowledge and experiences among the participants, as well as promoting safety in care.

**Conclusion:** the conversation circle is a strategy of health education that can be used by Nursing in the preparation of the hospital discharge of children with special health care needs, who are dependent on technology. However, this preparation must happen procedurally during the hospitalization.

**DESCRIPTORS:** Children with disabilities. Health education. Family. Pediatric nursing. Chronic disease.

## ENCONTRO EDUCATIVO DA ENFERMAGEM E DA FAMÍLIA DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE

### RESUMO

**Objetivo:** conhecer as dúvidas dos familiares de crianças com necessidades especiais de saúde quanto aos cuidados domiciliares relacionados aos dispositivos tecnológicos; e analisar o uso da roda de conversa como estratégia de educação em saúde no preparo de alta hospitalar dos familiares de crianças com dispositivos tecnológicos.

**Método:** pesquisa descritiva e exploratória, com abordagem qualitativa, realizada no setor de internação pediátrica de um hospital federal no Rio de Janeiro entre maio e junho de 2014. Seis familiares participaram de entrevistas semiestruturadas e rodas de conversa. Os dados foram submetidos à análise temática.

**Resultados:** os familiares destacaram dúvidas no aprendizado e na adaptação à tecnologia durante a transição do hospital para o domicílio e em possíveis situações de emergência após a alta hospitalar. Essas dúvidas versaram, principalmente, sobre os cuidados procedimentais com a traqueostomia e a gastrostomia. Entretanto, a estratégia da roda de conversa com uso de um boneco com dispositivos tecnológicos acoplados foi bem aceita pelos familiares, pois favoreceu o diálogo e a troca de conhecimentos e experiências entre os participantes, além da promoção da segurança no cuidado.

**Conclusão:** a roda de conversa é uma estratégia de educação em saúde, que pode ser utilizada pela Enfermagem no preparo de alta hospitalar de crianças com necessidades especiais de saúde, dependentes de tecnologia. Todavia, esse preparo deve acontecer de forma processual durante a hospitalização.

**DESCRIPTORIOS:** Crianças com deficiência. Educação em saúde. Família. Enfermagem pediátrica. Doença crônica.

## ENCUENTRO EDUCATIVO DE LA ENFERMERÍA Y LA FAMILIA DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD

### RESUMEN

**Objetivos:** conocer las dudas de los familiares de niños con necesidades especiales de salud sobre los cuidados domiciliarios relacionados con los dispositivos tecnológicos y analizar el uso de la rueda de conversación como estrategia de educación en salud en la preparación para el alta hospitalario de los familiares de niños con dispositivos tecnológicos.

**Método:** investigación descriptiva-exploratoria y con un abordaje cualitativo realizada en el sector de internación pediátrica de un hospital federal de Rio de Janeiro, entre Mayo y Junio del 2014. Seis familiares participaron de las entrevistas semiestructuradas y ruedas de conversación. Los datos fueron sometidos al análisis temático.

**Resultados:** los familiares mencionaron sus dudas en el aprendizaje y adaptación a la tecnología durante la transición entre el hospital y el domicilio, y también, en posibles situaciones de emergencia después del alta hospitalaria. Esas dudas eran, principalmente, sobre los cuidados en los procedimientos con la traqueotomía y gastrostomía. Así, la estrategia de la rueda de conversación con el uso de un muñeco con dispositivos tecnológicos acoplados fue bien aceptada por los familiares porque favoreció el diálogo e intercambio de conocimientos y experiencias entre los participantes, además de la promoción de la seguridad en el cuidado.

**Conclusión:** la rueda de conversación es una estrategia de educación en salud que puede ser utilizada por la Enfermería en la preparación del alta hospitalaria de niños con necesidades especiales de salud y dependientes de la tecnología. Además, esa preparación debe darse como un proceso durante la hospitalización.

**DESCRIPTORES:** Niños con deficiencia. Educación en salud. Familia. Enfermería pediátrica. Enfermedad crónica.

### INTRODUCTION

In Brazil, Children with Special Health Care Needs (CSHCN) are defined as those that require continuous, special, temporary or permanent, sometimes complex, care for the maintenance of their lives. Therefore, they require different strategies from their relatives for home care after the hospital discharge.

A study published in 2014 estimated that 15% to 20% of American children between 0 and 17 years old had a special health need.<sup>2</sup> In Brazil, there is no national estimate of the number of CSHCNs, only studies with isolated incidence records in certain localities, such as Rio de Janeiro/RJ and Santa Maria/RS.<sup>3</sup>

CSHCNs were classified, according to the demands of care, into five segments: development care, related to those in need of psychomotor and social rehabilitation; technological, which include the dependents of some type of technology in their body to survive; medication, including drug-dependent children; children who need help with ordinary day-to-day tasks; and mixed, for those with associated care demands.<sup>4</sup>

In this study, the technological demands, which include procedural care with tracheostomy, gastrostomy, vesicostomy, colostomy, semi-fully implantable catheters, among others should be highlighted. Such care is performed by the relatives at home after the hospital discharge, who sometimes do not have adequate knowledge to perform such care, which may entail complications in the clinical condition of the child and their subsequent return to hospital.

In a study carried out with 102 children dependent on technology, the use of technological devices was considered a protective factor that avoided the non-elective hospitalization. However, the authors emphasized the need to implement educational actions aimed at the family, related to the handling and specific care of each device.<sup>5</sup> Thus, the guiding of the family caregiver of people with special needs should be part of the educational strategies developed by health professionals, among them nurses, as a way to improve the quality of the care provided.<sup>6</sup>

Therefore, the health care of CSHCN should include the health education process, in preparation for hospital discharge, so that relatives learn new knowledge and specific skills in order to improve the quality of life of these children in the socio-family context. Pediatric units should create spaces for dialogue, listening and learning, considering the knowledge learned and the possibilities of maintaining the child care at home.<sup>7</sup>

As a possible strategy for the health education in the preparation of CSHCN relatives for child care at home, the conversation circle emerges as a democratic space for learning. It has the potential to favor and stimulate dialogue, as well as seek the complementarity of knowledge and expertise of its participants. The dialogue exchange, which is the basis of this strategy, favors an individual to apprehend new knowledge, at the same time as sharing a knowledge that is within their own domain.<sup>8</sup> From this perspective, it favors the horizontality in the relations between professionals and families, and the dialogue in the search for overcoming difficulties, encouraging the autonomy for decision-making and identification of problems.

In this sense, this study was based on the theoretical conceptions of problematizing education defended by Paulo Freire, which is concretized as a practice of freedom by breaking with the verticality of the banking practice and proposing, through dialogue, a transversal and dialogical relationship between the subjects. The problematizing education has the essentially reflective character and implies a constant critical questioning of the reality.<sup>9</sup>

A study indicates that the adequate discharge of family members of children with special care health needs, using health education strategies throughout the hospitalization period, reduces the family anxiety and increases the confidence in care. Thus, it facilitates the continuity of care at home, increases the rate of outpatient follow-up and decreases the frequency of unnecessary readmissions.<sup>10</sup>

Therefore, during the hospital discharge process, which includes the preparation of the discharge through educational actions with the relatives of children with the technological device, it is necessary to give voice to the family members to express their doubts related to this care.<sup>1</sup> Although the studies point out the importance of preparing families for home care,<sup>1,5,7,10</sup> they do not indicate possible health education strategies for the families of these children.

In this context, this research seeks to answer the following guiding question: what doubts of relatives of children with technological devices do emerge during the hospital discharge mediated by the conversation circle?

In order to answer this question, this study has as objectives: to know the doubts of relatives of children with special health needs regarding home care related to technological devices; and to analyze the use of the conversation circle as a strategy of health education in the preparation for the hospital discharge of the relatives of children with technological devices.

## METHOD

Descriptive and exploratory research, with a qualitative approach,<sup>11</sup> carried out from May to June 2014, in the pediatric hospitalization sector of a federal hospital in the state of Rio de Janeiro, which has 18 hospitalization beds and cares for children and adolescents in the age group from 28 days to 18 incomplete years old.

The participants of the research were six family caregivers of five children with special health

care needs with demand for technological care, who met the following inclusion criteria: to be a relative with an age equal to or over 18 years old, to take care of a child with special health care needs with demand for technological care and who is expected to be discharged from hospital within the next 30 days. Family members of adolescents with special health care needs were excluded. It should be highlighted that children were considered those whose age range was of 0 to 12 years old.<sup>12</sup>

For the selection of the participants, a consultation was carried out in the medical records, and the application of a form was performed in order to characterize the children who presented demands of technological care. Afterwards, the researcher introduced herself to the family members, explained the research objectives, the aspects contained in the Free and Informed Consent Term (FICT) and then invited the family member to participate. All the invited family members accepted to participate in the study and there was no withdrawal during the generation of data.

To guarantee the anonymity, the participants were identified with the degree of kinship regarding the child, followed by a number, which respected the order of participation of the relative in the research.

In the first stage of the data collection, a semi-structured interview was conducted by the first author, containing open and closed questions. In order to ensure privacy, the interviews were carried out in the pediatric ward, each family member being interviewed individually near the child's bed, without anyone being able to hear what was being said and, at the same time, the relatives did not distance themselves from the children. The duration was approximately 9 minutes.

The closed questions were focused on the characterization of the participants, such as kinship, age, gender, schooling, as well as data regarding the children, such as the pathology and type of technology used. The open questions that identified the doubts were: talk about the care you will provide to the child at home; do you have any doubts about the care regarding the device (gastrostomy, tracheostomy, etc.) that the child uses?

In the second stage, the conversation was held as a health education strategy with the families of CSHCN. In order to do so, a script was used based on the doubts identified in the first stage of the research, which was important to guide the

discussion. As an educational resource, a doll was used; it had technological devices such as tracheostomy cannula, gastrostomy catheter, nasogastric catheter, nasal catheter for oxygen therapy and a colostomy bag coupled in its body, on the doll it was demonstrated, from the doubts of the relatives, the procedural care referring to the devices. In addition, the research participants were able to manipulate the doll and the technological devices inserted in it.

Three conversation circles were made. The first one lasted 40 minutes, with the participation of two family members and three researchers. The second, with a duration of 26 minutes, involved two family members and three researchers. The third lasted 25 minutes and two family members and three researchers participated. Them all happened in the ward, in the afternoon shift, since there was little movement of professionals and silence was guaranteed.

As for the training of the researchers to conduct the conversation circle, it is important to highlight that two of them had already had previous experience in conducting a group research, which was acquired during the master's and doctorate, as well as expertise in child care with a technological device.

For the operation of the conversation circle, initially, it was explained that it was intended to talk about home care to be performed by family members. From this direction, on all circles, the researchers did not have to stimulate the conversation, because people interacted well with each other, exchanging experiences about the care that each one performed to their children. The interventions of the researchers happened to clarify some knowledge that was not of the domain of the relatives.

After the completion of each conversation circle, the third step of data generation was carried out in order to validate the information provided and discussed in the previous step. A new interview was conducted with each relative individually, close to the child's bed, without anyone being able to hear what was being said. Each interview lasted approximately 6 minutes. In it, the use of the interview script tool was continued with the following open question: talk about what you think about the conversation circle to guide the care that the relatives will perform at home.

For a complete and accurate record of the relatives' speeches, all the interviews and conversation

circles were recorded with the help of a digital media, with previous authorization of the participants. Subsequently, the speeches were transcribed in full and the data was analyzed through the thematic analysis method, using the following steps of this analytical method: floating reading; exploitation of the material; treatment and interpretation of the results obtained.<sup>11</sup>

In order to make the analysis process operational, after the transcription of the interviews and conversation circles, the relatives' statements were classified manually, from colors, in which those with the same meaning were colored of the same color, thus giving rise to the categories: doubts about home care related to the use of technology; and the conversation circle as a health education strategy. It should be highlighted that the categorization and analysis were done in pairs, initially by the first and second author. Subsequently, the material was subjected to critical analysis by the second pair, composed by the third and fourth author.

For the criterion of closure of the field work, the theoretical saturation of the data that corresponds to the moment of recurrence of the response patterns was used.<sup>11</sup>

The research followed the proposed determinations of Resolution 466/12 of the National Health Council, being approved by the Research Ethics Committee of the Hospital set of the study under opinion No. 604.695-0 and CAAE 23229613.0.3001.5269.

The participants signed the FICT, which included the title of the project, the identification of those responsible for the project, the objectives of the research, the necessary procedures for its realization, and the risks and benefits that can be obtained. All the material generated in this research will be filed under the researcher's custody for 5 years after the study closure.

## RESULTS

The family members were between 20 and 40 years old, five were mothers and one father. The level of schooling ranged from incomplete elementary school (1) to complete high school (5). To a better understanding of the characterization of children, age, pathology and the use of technological devices are presented in Table 1, along with the information about their relatives.

**Table 1 - Characterization of children dependent on technology according to age, pathology, use of technological devices and family profile of the child. RJ, Brazil, 2014**

Child	Age	Pathology	Use of technological devices	Child's relative
1	2 years old	Larynx atresia, neurogenic bladder, pulmonary hypoplasia and Prune-Belly syndrome	Tracheostomy, gastrostomy and macronebulization mask coupled to tracheostomy	Mother, 40 years old, complete high school
2	9 years old	Bronchospasm and mucopolysaccharidosis	Gastrostomy, tracheostomy and macronebulization mask coupled to the tracheostomy	Mother, 29 years old, complete high school
3	2 years old	Respiratory insufficiency and Prune-Belly syndrome	Tracheostomy	Mother, 28 years old, complete high school Father, 29 years old, complete high school
4	4 years old	Pneumonia and Prune-Belly Syndrome	Gastrostomy, tracheostomy and BPAP (positive non-invasive pressure ventilation) in the 24 hours	Mother, 33 years old, complete high school
5	1 year old	Cystic fibrosis	Nasoenteric catheter and nasal catheter.	Mother, 20, incomplete elementary school

As for the classification by demand of care, all children presented demand for technological care. In addition, all of them required medical care, customary care, and had a demand for developmental care. Thus, they presented mixed care demands.

From the analysis of data, interviews and conversation circles, the following thematic units emerged: 1) Doubts about home care related to the use of technologies; and, 2) The conversation circle as a health education strategy.

### Doubts about home care related to the use of technologies

During the interviews and the conversation circles, the relatives talked about the doubts that arose at the beginning of their adaptation to technology, such as the use of gloves and aspiration of the tracheostomy cannula: *at the first time, I could not even put my glove on, in the beginning, God, it did not fit at all. It is very difficult, especially since it is sterile, right?* (Mother 3). *Oh, at the beginning [to aspire the tracheostomy] was terrifying, right? I felt like I was catching the lungs, right?* But then they [professionals] explained to me that we have to measure the probe [of tracheal aspiration]. *Now I have already memorized* (Mother 1).

The relatives stated that during the hospitalization they observe the care provided, in the change of the tracheostomy cannula, that are necessary for the child, and they expect to learn with the proximity of hospital discharge: *I still do not change the cannula [tracheostomy]. Here [hospital] we only*

*learn when we are about to go away [hospital discharge] (Mother 3). I have not had experience of changing the tracheostomy cannula yet. When it came out [exteriorized the cannula], I automatically in my head started to program myself in case it happens to me at home, I want to learn. Because it may happen* (Mother 1).

The relatives showed anxiety about learning and performing procedural care prior to discharge: *I have not had experience of changing the tracheostomy cannula yet. But I am crazy for the doctors to say: let's learn how to change the cannula* (Mother 1). *We have even learned to do some things, but I wanted to learn more before [the discharge], got it? Then, the will to leave is so big, but we understand that it is part of it. Important thing is that she is well* (Father 1).

One participant revealed anxiety to aspire to tracheostomy and another was unaware of the amount of water the gastrostomy tube cuff supports: *no, not afraid [of aspiring the tracheostomy] it is just the practice, right, time to get more, you know? And then we get anxious. But that is only practicing* (Father 1). *This thing about the water [amount of water needed to fill the cuff of the gastrostomy catheter] I do not know. But can it be any amount of water?* (Mother 6).

Another participant revealed safety in relation to the hospital environment, because at home she will not be as safe as she is in the hospital: *here [at the hospital] I feel safe, at home I do not know, right? Here I have no doubts, but at home we become more fearful because it is just us, right? Because here in the hospital you have all the support of the staff, right?* (Father 1).

The accompanying persons often estimate that they do not have the necessary resources for

quality home care: *my worries become happen more at home. I wanted to have mastery over the use of the stetho [stethoscope] to know when he has secretions [pulmonary]. Suddenly learn to do the respiratory maneuvers to eliminate the secretions. So these things mess with my head... At home I will not have the use of the monitor, so how will his heart rate be?* (Mother 1).

The participants of the survey have expressed doubts and concerns regarding emergency situations that may occur: *so let's suppose: if there is an emergency and I need to quickly put it there [tracheostomy cannula after externalization]. And I do not know how to do it! [...] I have already seen it come out from another child, I saw the girls [professionals] put it back. I wanted to learn because I do not like it when it comes to times of despair! I like to have things programmed in my head* (Mother 1).

### The conversation circle as a health education strategy

The relatives gave prominence, in the conversation circle, to the use of a doll that had technological devices coupled to its the body, being understood as a facilitator of learning new knowledge and skills: *I found the doll cool. Because sometimes we want to pass on to another mother what she should do with her son, but the other cannot touch. And it is kind of crazy for you to explain: the "botton" is like that, and you do not run your hand around the "botton". It's strange, without you showing the "botton". Here you have the contact, and with this contact it is much easier for the staff to understand* (Mother 2).

It was evident in the conversation circle that family members used to talk to each other, most of the time minimizing each other's doubts and fears. One accompanying person taught another, using the doll, how to administer the diet by gastrostomy: *here [showing the gastrostomy catheter] it is closed, here is a clamp. I put the syringe and I open it. It is going to make a little noise, some air come out. After you see that no more noise comes out, you lower it a little so the diet does not run very fast and put the milk* (Mother 5).

During the conversation circles, the relative who was more familiar with the technological device always sought, through dialogue, to demonstrate the way they handled the device. One of the accompanying persons clarified for another one the filling of the gastrostomy catheter cuff and the volume of water it held: *- we must have a sense of how much was put [volume of water in the cuff of the gastrostomy catheter] because if we feel that it [gastrostomy catheter cuff] starts to move, we have to*

*empty it to see how much it has, if it had 5 [5ml of water] and I saw it has 3 [3ml of water], so there is something wrong... (Mother 2). - Then if it is missing, it is because there is something wrong, right? (Mother 1). -Yeah, it's because it's pierced. [gastrostomy catheter cuff] (Mother 2). - I got it, got it! (Mother 1).*

The conversation circle was emphasized by participants as being a facilitator in the pursuit of safety for caring. The presence of the professional was also highlighted as being fundamental: *we exchange ideas. For example, your idea ends up helping me improve my strategy. Or better, to improve even more and to seek safety, got it? (Mother 1). It is very good when you professionals come here to talk to us, which gives us more security* (Father 1).

## DISCUSSION

The relatives expressed doubts about performing procedural care with technological devices such as the tracheostomy aspiration, tracheostomy cannula replacement, gastrostomy diet administration, and volume of water needed to inflate the cuff of the gastrostomy tube. This knowledge is fundamental for children dependent on technology, but it is the domain of health professionals. The literature indicates that the challenges of caring for a CSHCN at home go through the need to learn about practices that are not part of the daily routine of relative caregivers.<sup>3</sup> In the current society, families provide more and more complex care at home to the person with special needs.<sup>6</sup>

The results showed that, in the beginning, the care of the child with a demand for technological care was seen as difficult and frightening, but with time its performance became easier. These data corroborate with the research that pointed out that the care carried out by CSHCN caregivers is delimited by attempts that are subject to errors and correctness, and that the care of the child who is dependent on technology is permeated by doubts, insecurities and fears.<sup>7</sup>

Unknowing about your child's condition is a stress-generating factor on the part of the mothers. This problem is perpetuated as the non-dialogue service is configured, due to the lack of a professional guidance that involves listening and dialogue.<sup>13</sup>

It should be highlighted the importance of the health professional, especially the nurse, as an educator, with the role of guiding the family in the care so that they learn how to handle the technology incorporated to the body of their children, besides contributing to overcome stressor moments.<sup>14</sup> Thus,

the family caregiver should receive special attention in order to respond to their needs, largely related to the provision of care.<sup>6</sup>

It was seen that the hospital discharge preparation happens close to the child leaving the hospital moment, not during the hospitalization. Thus, relatives become apprehensive, wondering how to proceed in a certain situation with which they are not yet familiar. Since hospital discharges occur momentarily, the family member may have doubts or be unprepared for home care, such as for the aspiration of the tracheostomy, replacement of the tracheostomy cannula, and handling of the cuff of the catheter of gastrostomy and administration of the diet by gastrostomy, which may make it difficult to learn and perform care in the transition from the hospital to the home.

However, the hospital discharge must be conceived as a process that includes planning and preparation of the families, to be initiated from the admission of the child, and not just as a moment, so that they are problematized with the family, during the entire hospitalization, the demands of care for the maintenance of the child's life at home. Otherwise, there will be no room for the adequate preparation of the CSHCN relatives during the hospitalization, which will compromise the safety and quality of care when returning home.<sup>15</sup>

Therefore, the discharge should occur during the course of hospitalization, being strengthened at the final moment of hospitalization and remaining in the post-hospitalization period, since many doubts arise after returning to the home.<sup>16</sup> It is added that feeling anxious before performing the first care happens quite frequently, but that the learning process contributes to decrease that anxiety, thus enabling the improvement of self-confidence and the skills for care.<sup>17</sup>

It was highlighted, during the conversation, that the stage of preparation for the hospital discharge generates a lot of anxiety on the part of the relatives. This finding agrees with research that stated that caregivers learn to care for CSHCN through the practice developed over time through experience,<sup>7</sup> which reinforces the need for the hospital discharge preparation to occur during hospitalization and to remain after the child leaves the hospital, even considering the safety that the relatives have on the hospital's health team regarding the assistance in the care of their children.

In order to strengthen the autonomy of the CSHCN family members dependent on technology, the scientific literature showed that nursing is deci-

sive in the hospitalization process, which can contribute to the development of knowledge and skills in home care, and these professionals are fundamental in the transition process from the hospital to the home.<sup>18</sup> Thus, it is necessary to think of educational actions as inherent and inseparable from the hospital care, from a perspective of action-reflection-action, a dialogic action that is conscientious.<sup>9</sup>

With the analysis of the testimonies, it was noticed that home care is sometimes more complex than hospital care. Another research has also revealed that in caring for their children at home, parents end up taking responsibility for performing highly technical procedures, which should be formally performed only by qualified professionals.<sup>18</sup>

Evidence indicates that many families, despite receiving guidelines regarding the tracheostomy care, return with the children in search of care to the reference service. This is due to the fact that they cannot remain safe in the development of care for these children due to the difficulty in assimilating and adapting to the new situation in the home environment.<sup>10</sup>

In the same sense, the American literature points out that as family members experience the daily care of the child using tracheostomy and are developing the skills to care for this device, the search for care and re-hospitalization may become less frequent.<sup>19</sup>

The CSHCNs require specific care even after the hospital discharge, so it is imperative that health professionals attend to the needs of CSHCNs and their families in order to ensure the continuity of home-based care. In this sense, it is necessary to consider the knowledge of family caregivers of this demand, which requires continuous treatment and care of both the family caregiver and the nursing.<sup>7</sup>

It is also necessary to consider the acquisition of supplies and equipment for the maintenance of home care, as well as the evaluation of housing for possible adaptations that are necessary for the care of the child.<sup>15</sup> Thus, the contents to be included in the development of educational technologies together with the family caregivers of dependent persons should cover the domains of knowledge, instrumental and the resources available in the community, aiming at a guidance adapted to the needs of family caregivers.<sup>6</sup>

It was also seen that the relative has doubts about emergency situations that may happen at home. These doubts were also highlighted in a study that interviewed CSHCN family members after the hospital discharge when they were at home,

and they reported insecurity in case of possible complications with the device, such as the rupture of the gastrostomy valve or displacement of the tracheostomy cannula.<sup>1</sup>

These data meet the need for high-level planning to include an understanding of the local community and the available health-related services, including emergency services and a thorough assessment of the family and home environment to ensure that emotional and physical resources are enough to manage the tasks of home care.<sup>15</sup> It is advisable, therefore, that the team that cares for the child to expand their spaces of action, from the hospital to the home, because professionals and families together can seek solutions to take care of these children.<sup>1</sup>

During the conversation circles, relatives indicated that the use of a doll to instrumentalize them in the handling of technological devices was a facilitator of learning. Such strategy was inspired by realistic simulation, which consists of a technique to replace or extend real experiences, used as a training tool.

The simulation technique has been used with professionals and academics in the health area,<sup>20</sup> especially in nursing, but it can be adapted and used for the preparation of relatives, since the care they perform requires training of technical procedures. Since making use of the doll, the relative is provided with an improvement of their techniques, before contacting the care that your child demands.

It is added that in the conversation circle the use of the doll provided the relatives to experience situations of care that their children needed and to exchange information among themselves. With the doll, they were able to perform procedures such as changing the fixation of the tracheostomy, handling the catheter and the "botton" of the gastrostomy. Given this, the scientific literature says that simulation allows trainees to play roles in real life, adjusting their behavior according to the scenario.<sup>20</sup>

When using the doll on the conversation circle as a means of health education, the idea of sharing knowledge through dialogue and discussion about the handling of technology is emphasized. The pedagogical model of Paulo Freire's purpose is to break with the methods that are based on the power over the other and to emphasize the discussion of ideas, opinions and concepts in the search of problem solving.<sup>9</sup>

The conversation circle aims to encourage and stimulate the dialogue, as seen in the speech of family members; it seeks the complementarity of knowledge and expertise of its participants. It

corroborates a study that says that the great objective of this strategy is the exchange of dialogue that is based on the fact that an individual apprehends information that was previously unknown to them, at the same time that they share knowledge that is of their domain. Therefore, the fundamental part of this relationship is that there is an exchange of knowledge and experiences, the two parts being enriched by the knowledge of the other, making the relationship and the caring process more effective, affective, unique and expanded.<sup>8</sup>

It is noticed that the conversation circle gave to the relatives the awakening of the knowledge through the dialogue, exchange of experiences and reflections on their actions. The dialogue is the encounter between men, mediated by the world to designate it, the dialogue is imposed as the way by which men find their meaning as men, and the dialogue is an existential necessity. In this sense, the educational practice needs to move away from the banking education, which says that education is an act of deposit, in which the depositary is the educator and the depositor, the educator.<sup>9</sup>

Thus, as devices of this dialogic construction, the circles produce collective and contextualized knowledge, privileging the critical speech and sensitive listening in a playful way. They favored the rapport and trust between the participants, overcoming the dichotomy: subject-object.<sup>21</sup> It is added that the conversation, trust and empathy developed are factors that facilitate the care relationships of the nursing team with the family.<sup>22</sup>

By establishing the dialogue with a form of care, it allows the building of an authenticity between individuals in which each has a different experience to share. At the same time, it is clear that from the dialogue between two authentic human beings, knowledge and experiences emerge, these being different, but with equally important perspectives, which are valued in the context of the encounter of individuals.<sup>23</sup>

Relatives spend much of their time inside the hospital accompanying their child. For this reason, many end up getting to know each other and exchanging experiences among themselves, precisely because their children have the same demands for care. The family caregivers, in the Freirian perspective, are relational beings, who have the capacity to become aware of their reality, thus developing care for CSHCN in the home context.

In this context, the practice of health education is a means of integrating caregivers into the hospital environment. The conversation circles as an



educational and integrative method allow dialogic encounters, creating possibilities of production and re-signification of meaning - knowledge - about the experiences of the participants. The choice of this methodology is based on the horizontalization of the power relations. The subjects that compose them are involved, dialectically, as historical and social actors critical and reflective of reality.<sup>21</sup>

Analyzing the statements of the accompanying relatives, it was noticed that they are satisfied with the educational practice and with the approach of the professional offering them security. Studies<sup>22,24</sup> showed that the interaction between professionals and family strengthens a relationship of trust, thus providing quality care, since it is a condition that enables the nurse to identify the needs of the child and their family, favoring the care planning. When the relative reported that through the conversation circle she was able to improve her safety in the care, one can say that her autonomy for the management of the technology was strengthened. Thus, the proposal of the circles is coherent with the promotion of health, in defending the production of autonomous, critical, reflexive and free subjects, that constitute the encounter with the other, in democratic and participative groups.<sup>21</sup>

Freire's theory defends the active participation of the learner in the educational process as co-participant, understanding education as a practice of freedom, as an act of knowledge and as a critical approach to reality. This theory aims at the pupil to develop critical awareness, reflecting on their reality, and to move from awareness to action. Thus, awareness is the critical development of awareness, implying that the person surpasses the naive view of reality to get to a critical view in which reality occurs as an object that can be known and in which the individual assumes an epistemological position.<sup>9</sup>

Considering the results obtained in this study, it was identified the need to sensitize health professionals to establish authentic dialogical relationships with caregivers who value the safety and responsibility of these subjects in the care of the child.<sup>23</sup>

As a limitation of this study for generalized considerations about the investigated phenomenon, it is important to mention that the generation of data occurred in a teaching hospital unit, reference of the Unified Health System. Therefore, it is necessary to develop other research that uses and evaluates the conversation circle as a health education strategy in different settings.

## CONCLUSION

It was possible to know the doubts that the relatives of children with special health care needs dependent on technology presented in home care. The doubts were sketched from the beginning of the contact with the technology, passing through the waiting and preparation of hospital discharge, going through the difficulties in the home care and getting to the doubts related to emergency situations.

The conversation circle favored the exchange of knowledge and experience among the participants. The strategy was well accepted by the relatives, who highlighted positively the resources used in the conduct of the conversation circle, the dialogue established between the participants and the promotion of safety in the care promoted by it.

Thus, the conversation circle is a strategy of health education, which can be used by Nursing in the preparation of the hospital discharge of children with special health care needs, dependent on technology. And this preparation should be performed not only at the time of hospital discharge, but throughout the hospitalization, in a procedural way with the relatives of these children.

The research aims to contribute to the scientific production of nursing by proposing and understanding the conversation circle as an innovative health educational practice capable of raising doubts and facilitating the development of contextualized and dialogic guidelines in the preparation of the hospital discharge of children with special health care needs. Therefore, it is expected that in the transition from hospital to home, family members can be empowered to take care of their children's technological needs through reflection and critical awareness in order to develop safe and quality home care.

## REFERENCES

1. Esteves JS, Silva LF, Conceição DS, Paiva ED. Families' concerns about the care of children with technology dependent special health care needs. *Invest Educ Enferm* [Internet]. 2015 [cited 2016 Oct 26]; 33(3):547-55. Available from: [http://www.scielo.org.co/scielo.php?script=sci\\_arttext&pid=S0120-53072015000300019](http://www.scielo.org.co/scielo.php?script=sci_arttext&pid=S0120-53072015000300019)
2. Bethell CD, Newacheck PW, Fine A, Strickland BB, Antonelli RC, Wilhelm CL, et al. Optimizing health and health care systems for children with special health care needs using the life course perspective. *Matern Child Health J* [Internet]. 2014 [cited 2016

- Oct 26]; 18(2):467-77. Available from: <https://link.springer.com/article/10.1007%2Fs10995-013-1371-1>
3. Neves ET, Cabral IE, Silveira A. Family network of children with special health needs: implications for Nursing. *Rev Latino-Am Enfermagem* [Internet]. 2013 [cited 2016 Oct 26]; 21(2):562-70. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692013000200562](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692013000200562)
  4. Silveira A, Neves ET, Paula CC. Family care of children with special healthcare needs: a process of (super)natural care and (over)protection. *Texto Contexto Enferm* [Internet]. 2013 [cited 2016 Oct 26]; 22(4):1106-14. Available from: [http://www.scielo.br/pdf/tce/v22n4/en\\_29.pdf](http://www.scielo.br/pdf/tce/v22n4/en_29.pdf)
  5. Okido ACC, Pina JC, Lima RAG. Factors associated with involuntary hospital admissions in technology-dependent children. *Rev Esc Enferm USP* [Internet]. 2016 [cited 2016 Oct 26]; 50(1):29-35. Available from: <http://www.scielo.br/pdf/reeusp/v50n1/0080-6234-reeusp-50-01-0029.pdf>
  6. Landeiro MJL, Martins TV, Peres HHC. Nurses' perception on the difficulties and information needs of family members caring for a dependent person. *Texto Contexto Enferm* [Internet]. 2016 [cited 2017 Aug 01]; 25(1). Available from: [http://www.scielo.br/pdf/tce/v25n1/pt\\_0104-0707-tce-25-01-0430015.pdf](http://www.scielo.br/pdf/tce/v25n1/pt_0104-0707-tce-25-01-0430015.pdf)
  7. Silveira A, Neves ET. Crianças com necessidades especiais de saúde e o cuidado familiar de reservação. *Cienc Cuid Saúde* [Internet]. 2012 [cited 2016 set 29]; 11(1):74-80. Available from: <http://dx.doi.org/10.4025/cienccuidsaude.v11i1.18861>
  8. Rodrigues PF, Amador DD, Silva KL, Reichert APS, Collet N. Interaction between the nursing staff and family from the family's perspective. *Esc Anna Nery* [Internet]. 2013 [cited 2016 Oct 26]; 17(4):781-7. Available from: <http://www.scielo.br/pdf/ean/v17n4/1414-8145-ean-17-04-0781.pdf>
  9. Freire P. *Pedagogia da Autonomia: saberes necessários à prática educativa*. 43ª ed. São Paulo: Paz e Terra; 2011.
  10. Santos RP, Neves ET, Severo VRG, Carnevale F. Educação em saúde com familiares de crianças com necessidades especiais de saúde: aproximações Canadá-Brasil. *Biblioteca Lascasas*. 2014 [cited 2016 Oct 26]; 10(1). Available from: <http://www.index-f.com/lascasas/documentos/lc0757.php>
  11. Minayo MCS. *O desafio do conhecimento: pesquisa qualitativa em saúde*. 12 ed. São Paulo: Hucitec; 2010.
  12. Brazil. Lei n. 8069, de 13 de julho de 1990: dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. *Diário Oficial da República Federativa do Brasil*, 13 Jul 1990.
  13. Pereira ARPE, Matsue RY, Vieira LJES, Pereira RVS. Análise do cuidado a partir das experiências das mães de crianças com paralisia cerebral. *Saude Soc* [Internet]. 2014 [cited 2016 Oct 26]; 23(2):616-25. Available from: <http://www.scielo.br/pdf/sausoc/v23n2/0104-1290-sausoc-23-2-0616.pdf>
  14. Oliveira FS, Vasconcelos VM, Martins MC, Lúcio IML. Cuidado à criança com distrofia muscular dependente de tecnologia no domicílio: concepção de mães. *Rev Rene* [Internet]. 2013 [cited 2016 Oct 26]; 14(1):82-91. Available from: [http://www.repositorio.ufc.br/bitstream/riufc/4656/1/2013\\_art\\_imllucio.pdf](http://www.repositorio.ufc.br/bitstream/riufc/4656/1/2013_art_imllucio.pdf)
  15. Góes FGB. *Do hospital para casa: o processo de alta de crianças com necessidades especiais de saúde na perspectiva da integralidade do cuidado e implicações para a enfermagem* [tese]. Rio de Janeiro (RJ): Universidade Federal do rio de Janeiro, Programa de Pós-Graduação em Enfermagem; 2013.
  16. Silva RVGO, Ramos FRS. Processo de alta hospitalar da criança: percepções de enfermeiros acerca dos limites e das potencialidades de sua prática para a atenção integral. *Texto Contexto Enferm* [Internet]. 2011 [cited 2016 Sep 26]; 20(2):247-54. Available from: <http://www.scielo.br/pdf/tce/v20n2/a05v20n2.pdf>.
  17. Khalaila R. Simulation in nursing education: An evaluation of students' outcomes at their first clinical practice combined with simulations. *Nurse Education Today* [Internet]. 2014 [cited 2016 Sep 30]; 34(2):252-8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24060462>
  18. Okido ACC, Pizzignacco TMP, Furtado MCC, Lima RAG. Criança dependente de tecnologia: a experiência do cuidado materno. *Rev Esc Enferm USP* [Internet]. 2012 [cited 2016 Sep 26]; 46(5):1066-73. Available from: <http://www.scielo.br/pdf/reeusp/v46n5/05.pdf>.
  19. Brittan MS, Sills MR, Fox D, Campagna EJ, Shmueli D, Feinstein JA, et al. Outpatient follow-up visits and readmission in medically complex children enrolled in Medicaid. *J Pediatr* [Internet]. 2015 [cited 2016 sep 26]; 166(4):998-1005. Available from: [http://www.jpeds.com/article/S0022-3476\(14\)01191-3/pdf](http://www.jpeds.com/article/S0022-3476(14)01191-3/pdf)
  20. Martins JCA, Mazzo A, Baptista RCN, Coutinho VRD, Godoy S, Mendes IAC, Trevizan MA. A experiência clínica simulada no ensino de enfermagem: retrospectiva histórica *Acta Paul Enferm* [Internet]. 2012 [cited 2016 Sep 26]; 25(4):619-25. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0103-21002012000400022](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002012000400022)
  21. Sampaio J, Santos GC, Agostini M, Salvador AS. Limites e potencialidades das rodas de conversa no cuidado em saúde: uma experiência com jovens no sertão pernambucano. *Interface (Botucatu)* [Internet]. 2014 [cited 2016 Oct 26]; 18(Suppl 2):1299-311. Available from: <http://www.scielo.br/pdf/icse/v18s2/1807-5762-icse-18-s2-1299.pdf>
  22. Silva TP, Silva IR, Leite JL. Interactions in the management of nursing care to hospitalized children with chronic conditions: showing intervening conditions. *Texto Contexto Enferm* [Internet]. 2016 [cited 2017 Aug 01]; 25(2). Available from: <http://>

- [www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-07072016000200307&lng=en&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072016000200307&lng=en&tlng=en)
23. Milbrath VM, Siqueira HCH, Motta MGC, Amestoy SC. The family of children with cerebral palsy: perception about health team orientations. *Texto Contexto Enferm* [Internet]. 2012 [cited 2016 Sep 29]; 21(4):921-8. Available from [http://www.scielo.br/pdf/tce/v21n4/en\\_24.pdf](http://www.scielo.br/pdf/tce/v21n4/en_24.pdf)
24. Poletto D, Gonçalves MI, Barros MTT, Anders JC, Martins ML. A criança com estoma intestinal e sua família: implicações para o cuidado de enfermagem. *Texto Contexto Enferm* [Internet]. 2011 [cited 2016 Oct 26]; 20(2):319-27. Available from: <http://www.scielo.br/pdf/tce/v20n2/a14v20n2.pdf>

Correspondence: Liliâne Faria da Silva  
Rua Dr. Celestino, 74, 5º andar  
24020-091 - Centro, Niterói, RJ, Brazil  
E-mail: [lili.05@hotmail.com](mailto:lili.05@hotmail.com)

Received: March 20, 2017  
Approved: November 09, 2017  
This is an Open Access article distributed under the terms of  
the Creative Commons (CC BY).