Original Article

TEXTO & CONTEXTO ENFERMAGEM
TEXT & CONTEXT NURSING TEXTO & CONTEXTO ENFERMERÍA

TRAINING OF CAREGIVERS OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS: SIMULATION CONTRIBUTIONS

Ana Paula Madalena da Silva[1]
Juliana Coelho Pina[1]
Patrícia Kuerten Rocha[1]
Jane Cristina Anders[1]
Ana Izabel Jatobá de Souza[1]
Aline Cristiane Cavicchioli Okido[2]

[1] Universidade Federal de Santa Catarina, Departamento de Enfermagem. Florianópolis, Santa Catarina, Brasil.
[2] Universidade Federal de São Carlos, Departamento de Enfermagem. São Carlos, São Paulo, Brasil.

ABSTRACT

Objective: to know the contributions of simulation regarding the training of caregivers of children with special healthcare needs, in the preparation for hospital discharge.
Method: descriptive-exploratory study, with qualitative approach, carried out with caregivers of children with special healthcare needs. The study was developed in a simulation center of a public university in the South of Brazil, in partnership with a state reference children's hospital. The training program was based on simulations, using low, medium and high fidelity simulators, in which 15 caregivers participated. Data were collected through semi-structured interviews and submitted to content analysis, in its thematic modality.
Results: two categories emerged: simulation as a learning strategy and implications of training for home care. The simulations allowed the improvement of procedural skills and coping with possible complications in the home setting. Feelings of fear and anxiety were initially triggered, especially in the high fidelity simulation. However, after the training, the caregivers felt relieved, self-confident and satisfied with their performance, highlighting the importance of the support provided during the simulations. They reported having greater confidence to perform the procedures on the child and face the challenges of home care.
Conclusion: the simulation was considered a valid strategy for the training of caregivers, stimulating empowerment and self-confidence in the face of complex care required by a child with special healthcare needs. The study innovates by exploring the potentialities of simulation in this context, bringing important contributions to qualify the home care of this clientele.

DESCRIPTORS: Health education. Caregivers. Child Health. Chronic disease. Simulation. Nursing.

HOW CITED: Silva APM, Pina JC, Rocha PK, Anders JC, Souza AIJ, Okido ACC. Training of caregivers of children with special healthcare needs: simulation contributions. Texto Contexto Enferm [Internet]. 2020 [cited YEAR MONTH DAY]; 29: e20180448. Disponível em: https://doi.org/10.1590/1980-265X-TCE-2018-0448

CAPACITAÇÃO DE CUIDADORES DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE: CONTRIBUIÇÕES DA SIMULAÇÃO

RESUMO

Objetivo: conhecer as contribuições da simulação para a capacitação de cuidadores de crianças com necessidades especiais de saúde, no preparo para alta hospitalar.
Método: estudo descritivo-exploratório, com abordagem qualitativa, realizado com cuidadores de crianças com necessidades especiais de saúde. O estudo foi desenvolvido em um centro de simulação de uma universidade pública do Sul do país, em parceria com um hospital infantil de referência estadual. O programa de capacitação foi baseado em simulações, utilizando simuladores de baixa, média e alta fidelidade, do qual participaram 15 cuidadores. Os dados foram coletados mediante entrevista semiestruturada e submetidos à análise de conteúdo, em sua modalidade temática.
Resultados: emergiram duas categorias: experiência da simulação como estratégia de aprendizagem e Implicações da capacitação para o cuidado domiciliar. As simulações permitiram o aprimoramento de habilidades procedimentais e de enfrentamento de possíveis intercorrências no domicílio. Foram desencadeados, inicialmente, sentimentos de medo e ansiedade, especialmente na simulação de alta fidelidade. Porém, após as capacitações, os cuidadores sentiram-se aliviados, autoconfiantes e satisfeitos com seu desempenho, destacando a importância do apoio fornecido durante as simulações. Referiram uma maior segurança para realizar os procedimentos na criança e enfrentar os desafios do cuidado domiciliar.
Conclusão: a simulação foi considerada como uma estratégia válida para a capacitação de cuidadores, estimulando o empoderamento e a autoconfiança frente aos cuidados complexos exigidos por uma criança com necessidade especial de saúde. O estudo inova ao explorar as potencialidades da simulação nesse contexto, trazendo importantes contribuições para qualificar o cuidado domiciliar dessa clientela.

DESCRITORES: Educação em saúde. Cuidadores. Saúde da Criança. Doença Crônica. Simulação. Enfermagem.

FORMACIÓN DE LOS CUIDADORES DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD: CONTRIBUCIONES DE SIMULACIÓN

RESUMEN

Objetivo: conocer las contribuciones de la simulación a la formación de los cuidadores de niños con necesidades especiales de salud en preparación para el alta hospitalaria.
Método: estudio descriptivo-exploratorio, con abordaje cualitativo, realizado con cuidadores de niños con necesidades especiales de atención en salud. El estudio se llevó a cabo en un centro de simulación de una universidad pública del sur de Brasil, en alianza con un hospital infantil de referencia estatal. El programa de formación se basó en simulaciones, utilizando simuladores de baja, media y alta fidelidad, en el que participaron 15 cuidadores. Los datos fueron recolectados a través de entrevistas semiestructuradas y sometidos a análisis de contenido, en su modalidad temática.
Resultados: surgieron dos categorías: la experiencia de la simulación como estrategia de aprendizaje y las implicaciones de la formación para la atención domiciliaria. Las simulaciones permitieron mejorar las habilidades procedimentales y afrontar posibles complicaciones en el hogar. Inicialmente, se desencadenaron sentimientos de miedo y ansiedad, especialmente en la simulación de alta fidelidad. Sin embargo, luego de la capacitación, los cuidadores se sintieron aliviados, seguros de sí mismos y satisfechos con su desempeño, destacando la importancia del apoyo brindado durante las simulaciones. Informaron mayor seguridad para realizar los procedimientos en el niño y enfrentar los desafíos del cuidado domiciliario.
Conclusión: la simulación se consideró una estrategia válida para la formación de los cuidadores, fomentando el empoderamiento y la autoconfianza ante los cuidados complejos que requiere un niño con necesidades especiales de atención en salud. El estudio innova al explorar el potencial de la simulación en este contexto, aportando importantes contribuciones para calificar la atención domiciliaria para esta clientela.

DESCRIPTORES: Educación para la salud. Cuidadores. Salud de los niños. Enfermedad crónica. Simulación. Enfermería.

INTRODUCTION

The technological and care evolution in children's health led to a significant change in the epidemiological profile of the child population in Brazil.[1] Such advances have increased the survival of children with complex conditions, who have differentiated care demands, a group known as Children with Special Healthcare Needs (CSHCN).[2]

Such children have complex clinical needs and require temporary or permanent continuous care, which differ from those offered to children of the same age.[3–4] As a result, they are considered as an emerging group, either because of the complexity of the care required as well as because of their uniqueness and clinical fragility.[5]

In this context, the number of caregivers has been increasing significantly, accompanied by the need to develop effective strategies for their training.[6] Home care for CSHCN represents a challenge for the family, whose knowledge and practices do not belong to their life context, but to the hospital context.[7]

Nurses are the professionals who play the social role of educators of these families regarding home care; however, in the preparation for hospital discharge, the pedagogical approach of knowledge transmission has been used, by means of demonstration, in which the acquisition of skills for the execution of techniques is sought.[2] Therefore, the need for strategies that favor the role of caregivers in the process of caring for the child is observed, as well as their preparation to deal with possible complications in the home setting.

Simulation is considered an educational technology that enables meaningful learning and provides experiences of realistic situations, in a safe and risk-free environment.[8] Through simulated practices, the learner can train technical skills, develop observational, communicative and behavioral skills, learn to work as a team, exercise clinical reasoning and decision-making process.[9] To this end, several levels of complexity can be encompassed, from low-fidelity human simulators - mostly used in specific manual skills, to high-fidelity simulators - especially recommended for learning situations involving the patient's clinical deterioration.[10]

The technology linked to simulation has been used in the training of higher education professionals and in professional qualification programs of health institutions, with evidence of its impact on the level of knowledge, critical thinking, self-confidence and satisfaction of participants.[9,11–13]

Regarding the training of caregivers of chronic patients or patients with complex conditions, the proposal of simulation as an educational technology is relatively new in the health field, with few studies describing and evaluating the use of simulation for this purpose.[14] In the context of pediatrics, publications are even more scarce. In Canada, an experimental study confirmed the positive impact of a simulation-based educational intervention on the self-confidence and competence of parents and guardians of children with acute seizures admitted to the pediatric emergency room of a hospital.[15]

Regarding the care of CSHCN, a Brazilian study reports the use of low fidelity simulators in the preparation of caregivers of children with tracheostomy and gastrostomy.[16] Regarding the high fidelity simulation, only two North American studies report its use in the training of caregivers of children on mechanical ventilation and with tracheostomy.[17–18] No experiences in the use of high fidelity simulation with caregivers of children with other special healthcare needs were identified in the scientific literature. Furthermore, there were no studies found which link the simulation of low, medium and high fidelity, in a pedagogical proposal systematized for the training of caregivers of CSHCN.

In view of the above, it is proposed that the simulation, as a strategy for the training of caregivers of CSHCN, can be used both for the teaching of procedural skills related to home care and to provide caregivers with the acquisition of capacities and self-confidence for the prevention, identification and management of complications in the home care setting. In this sense, the objective of this study is

to identify the contributions of simulation to the training of caregivers of CSHCN in the context of preparation for hospital discharge.

METHOD

Descriptive-exploratory study, with a qualitative approach, developed in a simulation center of a public university in the South of Brazil, in partnership with a state reference children's hospital.

The study included caregivers of CSHCN, defined as family members or professionals hired by the family to care for the child. Caregivers of the CSHCN hospitalized in the hospital, who could or could not have experience in the care of these children were eligible. It was defined that participants who had not completed the training would be excluded from the study.

The recruitment of caregivers occurred through an active search at the participating hospital. The number of participants was not previously defined and followed the criterion of data saturation, which defines the completion of the collection when the themes and categories of the data become repetitive and redundant.[19]

The caregivers participated in a training program based on simulations, which occurred in the hospital and in the university's simulation center. The training was directed to the needs of each child and family, identified through a previous conversation with the caregivers and the hospital nursing team.

Despite being directed to each caregiver, the training program followed a systematic that divided it into two moments, described below:

First moment: low fidelity simulation, focusing on procedural skills training. The training lasted about one hour and was performed in the hospital's own chronic patient inpatient unit, in a reserved room with low-fidelity pediatric simulators.

Second moment: medium and high fidelity simulation, focusing on the identification and management of possible complications in the home setting. The training lasted about 2 hours and was carried out in the university simulation center, with pediatric simulators of medium and high fidelity, in a simulated home environment (simulated house).

It is important to mentioned that there was a time interval (ranging from two days to one week) between the two moments, during which the caregivers had the opportunity to perform the trained procedure in the low fidelity simulator on the child itself, under supervision. Before each high fidelity simulation, the prebriefing was performed - a moment where the simulator and environment were recognized. After the simulation, the *debriefing* was carried out - a moment of discussion and feedback on the simulated practice, during which the facilitator recovered the previous content in order to signify them. The debriefing was structured according to the following steps:[20]

Phase 1 - Meeting: held in order to listen to the participant, using the following initial question: How did you feel attending this child?

Phase 2 - Analysis: in this phase it was sought to facilitate the reflection and analysis of the actions of the participants, based on the following questions: What were the positive actions you performed? What would you do differently if you had another chance? What did you learn?

Phase 3 - Summary: the objective was to identify and analyze the situations.

Data were collected from February to April 2017 by means of semi-structured interviews.[21] The interview was conducted by the principal researcher, in a reserved room of the hospital's inpatient unit, on a scheduled date after the completion of the training. The following guided questions were used: do you think that the training you participated in prepared you to take care of your child at home? The training was done through simulations of reality, in other words, by imitating real situations that can happen in the hospital or in your home? What are the positives and negatives of this way of performing the training? What do you think should be changed? Do you feel more able now to take care of your child at home than before training? Why is that?

In addition to the interview, a structured instrument was used to characterize the participants and a field diary to record the researcher's impressions during the simulations. The interviews were recorded, transcribed and submitted to content analysis in its thematic modality, which encompassed the development of three fundamental stages for its operationalization: pre-analysis from floating reading and constitution of the corpus; exploration of the material by coding the texts in the unit records; and treatment of the results obtained and interpretation, working with meanings that emerged from the data.[21]

The research project followed the recommendations of Resolution 466/12 of the National Health Council and was approved by the research ethics committee and received prior authorization of the participating hospital and used the Informed Consent Form.

RESULTS

The study included 15 caregivers, there were no exclusions by the established criterion. Chart 1 summarizes the characterization of the participants.

The caregivers were between 19 and 53 years old, all of them were relatives of the child, and the mother was the most frequently observed caregiver. The children were between two months and 11 years old, and those with a few months of life were more frequent. All were dependent on technology, using the following technological devices: oxygen therapy, tracheostomy, gastrostomy and nasojejunal catheter. In most cases, the child had more than one device and the caregiver did not have previous experience in the care of CSHCN.

Chart 2 presents the simulations performed with the caregivers, according to each technological device.

In each home interfacing simulation, caregivers were instructed about situations in which there was a need to activate the health service (primary care or hospital outpatient clinic), as well as the Mobile Emergency Care Service (SAMU).

Two categories emerged from the analysis of the interview: the experience of simulation as a learning strategy and complications of training for homecare.

Chart 1 – Characterization of caregivers of children with special healthcare needs. Florianópolis, SC, Brazil, 2017.

Caregiver	Sex	Age	Relation	Schooling	Profession
A	Male	53	Grandfather	4th grade of elementary school	Self-employed builder
B	Female	40	Mother	Complete Secondary Level Schooling	Attendant
C	Female	25	Mother	Complete Secondary Level Schooling	Unemployed
D	Male	28	Father	Complete Secondary Level Schooling	Waiter
E	Female	24	Mother	Complete Secondary Level Schooling	Homemaker
F	Female	31	Mother	7th grade of elementary school	Homemaker
G	Female	32	Mother	Complete Secondary Level Schooling	Self-employed-saleswoman
H	Male	32	Stepfather	Complete Secondary Level Schooling	Driver
I	Female	23	Mother	8th grade of elementary school	Cleaner
J	Female	42	Mother	1st grade of elementary school	Homemaker
K	Male	32	Father	Complete Secondary Level Schooling	Driver
L	Female	22	Mother	Complete Secondary Level Schooling	Homemaker
M	Female	35	Mother	Incomplete Third level education	Salesperson
N	Female	26	Mother	Incomplete Third level education	Salesperson
The	Female	19	Mother	Incomplete Third level education	Unemployed

The experience of simulation as a learning strategy

This category portrays the caregivers experience in participating in the simulations during their training for the care of their children at home, highlighting the feelings experienced by them during this process.

During the simulations, it was possible to perceive the triggering of feelings, both related to the training itself and related to the memories that emerged from the facts experienced during the child's hospitalization process. The initial feelings of panic and nervousness stand out in the statements. *Regarding the feeling of performing the simulation, I had a very bad feeling ,a really bad feeling. I can't even explain it. It reminded me of the last arrest she had. But after the conversation I was able to feel much more at ease, I got used to it, I am* getting used to it, I felt more comfortable (Caregiver B). *I had a moment of panic, it was like seeing my son* (Caregiver D). *I was nervous at first I was afraid to do* [...] (Caregiver G).

Due to nervousness, most caregivers required face-to-face support from the facilitator during high fidelity simulations, even though it is recommended that it is not present in the scenario. This support was necessary both to deal with technology and to provide company and comfort to the caregiver, because many could not continue in the scenario being alone in the simulated environment, behind closed doors. Many times, only the physical presence of the facilitator and non-verbal communication, such as exchange of looks and movements of the head showing approval, were sufficient to stimulate the caregiver's action in the simulated scenario.

Chart 2 – Systematic training of caregivers, according to the device used by the child. Florianópolis, SC, Brazil, 2017.

Device	Low-fidelity simulation	Medium fidelity simulation	High-fidelity simulation
Tracheostomy	• Hygiene, dressing change and cannula fixation; • Aspiration of the cannula and upper airways.	• Identification of respiratory distress/ hypoxia and action; • Identification of obstruction of the cannula by secretion “stopper” and application of clearance maneuvers; • Action before accidental exit from the cannula; • Identification of cardiorespiratory arrest (CRP) and resuscitation.	Household scenario: obstruction of tracheostomy cannula by secretion “stopper” and CPR.
Oxygen therapy	• Oxygen care and flow regulation; • Care of the device and adjustment to the child’s face; • Care of adjacent skin.	• Identification of respiratory distress/ hypoxia and conduct; • Identification of CPF and resuscitation.	Home scenario: respiratory failure and CRP.
Gastrostomy	• Hygiene and care of the stoma and adjacent skin; • Administration of diet and medicines via gastrostomy.	• Identification of signs of infection and action; • Identification of obstruction of the catheter by diet or medications and clearance maneuvers.	Home setting: obstruction of the gastrostomy tube
Nasojejunal catheter	• Hygiene and clamping change of the catheter; • Administration of diet and medications via nasojejunal catheter;	• Identification of signs of bronchoaspiration and aspiration of the airways; • Identification of obstruction of the catheter by diet or medications and clearance maneuvers; • Identification of catheter displacement and conduct.	Household scenario: vomiting and diet bronchoaspiration.

Despite the initial nervousness, feelings of learning are also highlighted in the caregivers’ statements, and were valued as a positive point for the improvement of skills and performance in the face of risk situations. [...] *after I felt relieved, it was well explained* (Caregiver G). *Help, it helps a lot, as I was talking about, I did not know and could let my son die for not being* prepared (Caregiver E). *I had a very good feeling right, I was just a little anxious.* [...] *The feeling I have to day is that I learned a lot, it’s good to learn more. It was good to learn a little* more (Caregiver F).

The caregivers were submitted to low, medium and high fidelity training, in different environments and days; thus, they report experiences related to the different scenarios. *I felt nervous at first, right, afraid to make a mistake. I didn’t think the doll* (high fidelity simulator) was going to do the same as the *child’s stuff. It is very similar* [...]. *My God, it made me nervous there at the time, it’s like I was at* home (Caregiver I). *I felt anxious, right, the first time, we have no experience. I thought it was cool to* do there [high fidelity simulation], *right, because there is space, and the doll is bigger and it is activated too, right?* [...] *After we talked we had more freedom, right, with the explanation, the way we deal there, I liked it, good* (Caregiver A). *I felt more at ease in the first* (low fidelity simulation), *the second was strange, the doll is not the same thing as a child, for example the breathing. My daughter I already know, if she’s not breathing, I’ll know it and the doll I won’t. In the doll it is better to do the procedures than to notice the changes, because you do not notice much difference. I only noticed the purple mouth in the doll. But you can’t tell exactly* (Caregiver B).

From the statements of the previous paragraph, it is perceived that the impression caused by the high fidelity simulation is different according to the caregiver's experience. For caregivers A and I, who had no previous experience in the care of CSHCN, the simulation of high fidelity was so real that it triggered anxiety and nervousness. For caregiver B, experienced in the care of her technology-dependent child, it was difficult to notice alterations in the simulator that would be easily observed in the child. However, this same caregiver reports that the simulated situation itself mimicked reality well.

The simulation [of high fidelity] *was very similar to reality, I recognize what it was as it can happen in the hospital and at* home (Caregiver B). Therefore, another highlight in the caregivers' statements refers to the similarity with reality, standing out as a positive point of the training. *The simulation was similar to the baby's reaction, it was practically the same. The only difference is that one is a real baby and the other is a doll* (Caregiver A). *Everything I have here in the room you've done just like that. Even the sequence process is very similar, to leave the catheter already, to tidy, to put the glove* [...] *doing in the sequence, because otherwise we get lost* (Caregiver C).

Another potential highlighted by caregivers was the possibility of handling the devices and real materials during training, such as: ambu, tracheostomy cannula, gauze, adhesive, catheter and suction, among others. *I thought the training was going to be to explain, explain, and* explain and *not show. I had never used an ambu, the trachea and touched the doll, this is good* (Caregiver E). *I figured the training was just going to talk, I didn't think there was going to be a doll. That's much better. So I've practiced. I've never touched things, now I know* (Caregiver F).

Implications of training for home care

This category addresses the main implications of simulation for the care of CSHCN at home.

Despite the diverse feelings generated by the simulation, all caregivers completed the training and evaluated it as positive, highlighting its importance to avoid errors that would impact the child's health. *Doing the activities on the doll helps a lot, right, because we are practicing, and not just looking. If you make a mistake, you can repeat it, on the child this is not possible, if you make a mistake, you have to discard that mistake, right, and in the doll you can't, repeat* until you learn (Caregiver A). *If I didn't have this training, I would have to do it directly on my son, so I believe this is positive because it avoids mistakes, of having making some mistake on* him (Caregiver D).

Caregivers expressed feeling confident and safe after training; even judging that it was fast, they reported empowerment and feeling better prepared to care for the children after hospital discharge, preventing home complications from harming the child's clinical condition. *I feel more capable, I'm sure it's made a big difference. It was really good, a lot of difference, I learned many* things (Caregiver B). *I felt good, I felt more safe, because we're doing it, then we ask you and you say. Then you remember and do it on your child. Now I feel more safe* (Caregiver C). *My God, it helped a lot, I'll leave here a professional at it* [laughs]*. I've learned a lot, it's helped a lot. In relation to something like this, right, how I was going to do* it (Caregiver I).

The caregivers explained how learning care was in previous hospitalization experiences, and there was no specific training for hospital discharge. *The first time I went home I didn't have any training, and it was harder to learn. I paid attention to the nurses, what they did. They didn't explain, they just did it, and I had to keep paying attention. I thought, how am I going to do that when I go home if no one explains it to me... did not* have (Caregiver E). *The one who taught me was the physical therapist back in the ICU, and they taught me yesterday too, here at the hospital. And through it I learned* [...] *So how isolated he was, and they were sometimes busy, so I took it and did* it (Caregiver G). *It would be nice to do the training in the other hospitals, I wasn´t taught this kind of thing in the hospital. I could prepare more people, to be prepared when the worst happens* (Caregiver E).

In view of the positive experience, some caregivers requested that another family member should trained. *It's good to have one more in the family, if we need to leave, there is another one who can take my place, right, take the place of the caregiver. It's safer. I am the primary caregiver responsible* (Caregiver A). *It's hard, it's tiring. sometimes I can count on the help of some people, such as friends and husband, sister, this helps me* (Caregiver B). *It would be nice, because we need to do things, like showering, washing dishes or drinking water, it would be nice to have someone else to look out for me. I'll take care of him, then there's going to be someone else, but only after I teach, right* (Caregiver F).

DISCUSSION

Caregivers are given innovative care to ensure the survival of CSHCN at home, leading to the transformation of the life habits of these children and their families.[22] The great challenge for the caregiver, who almost always does not have professional support in his daily routine, is to be prepared to perform this care. The continuity of the care of CSHCN at home requires technical, complex and specific procedures, and it is necessary to develop health education strategies for caregivers.[23]

In this process, the emergence of feelings during training becomes inevitable, because it is something inate to the human being, who is present and makes themselves present, often exacerbated in moments of anguish, caused by the unknown. In the experience reported from the high fidelity simulation, feelings of fear and anxiety were the first to be triggered.

No studies have been identified in the literature that report the emergence of feelings in caregivers who participate in simulated clinical experiences. However, research with health students highlights some emotional factors related to high fidelity simulation. The simulation environment itself generates greater stress in students, which can impair clinical reasoning and the ability to solve problems.[24] The self-perception of lack of competence, in view of the increase in responsibility, is also pointed out as one of the main stressors caused by high fidelity simulation.[25] However, the development of self-criticism is pointed out as an initial step towards the acquisition of self-confidence, based on the increase of adaptive strategies for the management of stress and emotions, which contribute to the cognitive and emotional development of the student.[26]

In simulated clinical practices, it is highlighted that the students' previous experiences impact on their perception of stressful factors, influencing the way they would view the simulated experience - whether as a threat, which brings fear, or as a challenge to be overcome.[25] When the student personally identifies with the task to be performed (for example, because he has already experienced something similar in his life, or with a family member), he is more likely to experience the simulated experience with anxiety and to perceive a greater cognitive load, which, in turn, can lead to a worse performance.[27] It is believed that these findings are equally valid for caregivers, but with an even greater impact, due to their relationship with the child and their lack of proximity to the health area.

Therefore, in the present study, in addition to the technology associated with simulation, another factor which triggered feelings was the caregivers' affection with the child. It is important to highlight, in this sense, that the affective proximity with the child represented a particularity with regard to the experience of simulation with caregivers, which potentiates the stressful effects of the simulated situation. This finding indicates the need for differentiated support to the child's family members at the time of the high fidelity simulation, more so than that offered to students and health professionals. Being alone in an environment that simulates the home behind closed doors may have made the experience too real. The impact of experiencing a situation that can happen to the child/grandson/nephew prevented several caregivers from progressing in the scenario.

In these cases, the physical presence of the facilitator in the simulated environment represented a positive strategy for the performance of caregivers who had difficulties. In the literature, the need to develop strategies that reduce the intensity of stressors in high fidelity simulation is highlighted, in order to increase the satisfaction of participants and favor safety.[25,27] Satisfaction with simulated clinical experiences is associated with greater involvement and motivation in the teaching-learning process.[28] In the present study, the initial negative feelings were followed by relief and satisfaction after learning, according to the reports of the caregivers, which demonstrates the effectiveness of the strategy adopted.

As part of the support provided during the simulation, it is important that the facilitator is attentive to the feelings expressed by the participants. It may even be necessary to interrupt the simulation to address intense feelings that have emerged during the experiment. Although there is no need to interrupt the simulated practice, it is necessary that the feelings expressed are addressed after the simulation is finished, during the debriefing. This care will help participants complete the training and feel ready for the challenge of caring for a CSHCN. Thus, it is important to highlight that nurses must be open to the needs of caregivers, and offer qualified and attentive listening in order to enhance the qualities and help to solve their limitations as a caregiver, in addition to creating a relationship of trust between both parties which in turn benefits the teaching and learning process.[29]

The different learning situations proposed in this study triggered feelings that led caregivers to momentary stress because they were experiencing a new situation and because they were, in a way, putting themselves to the test. Despite these feelings, the importance that the scenario brings to the approximation of real situations is evident, preparing them to act in critical conditions, both at home and in the hospital environment.

The scenarios become an education space that breaks with the traditional approach of education, based on the reproductive method, and far from those who teach and those who learn. It consists of the educational approach that aims at reality and the prioritization of the needs of each child, valuing the pre-existing knowledge, experiences and expectations of each caregiver, recognizing them as transforming agents.[30]

Among the highlighted potentialities, it is evident, in the caregivers' speech, that simulation, as a technology for the teaching and learning process, is a strategy capable of achieving the reality experienced, facilitating the relationship with the care provided directly to the child. Direct contact with devices and realistic scenarios allowed a closer approximation of training with reality, allowing a more meaningful approach, which facilitates the learning process. Realism is one of the dimensions involved in the satisfaction of participants in simulated experiences and which positively influences their learning.[28]

In addition to the realism of the devices used, the importance of focusing on the reality experienced by the caregiver stands out from the results of the present study, emphasizing its uniqueness and previous experiences. As observed in some statements, the perception of realism, the manifestation of feelings and training needs differ according to the caregiver's experience, such findings also confirmed in research with health students.[25,27] Therefore, individualized realistic training, differentiated for caregivers with and without previous experience, may lead to greater involvement in the process, contributing to learning.

In view of the reports, there is a problem in the routine and organization of the nursing team, which is not able to offer adequate support to caregivers in their preparation for hospital discharge. The role of nurses during hospitalization and the care process is concomitant with the act of educating in health. Studies show that the hospital discharge plan should be performed by the nurse, with the participation of the other professionals involved in the care of the client.[31]

The conversation wheel has been used by nurses as a health education strategy in the preparation of caregivers of children dependent on technology for hospital discharge. It is a strategy that promotes dialogue, clarification of doubts and the exchange of knowledge and experiences among participants. Its association with low fidelity simulation, performed in order to demonstrate procedural techniques, demonstrated positive results when performed in a procedural manner, during hospitalization.[16] From the results of the present study, it is recommended to associate these strategies with high-fidelity simulation, in a systematic approach, which also prepares the caregiver to face possible home complications. In this sense, the conversation wheel could be used to assess the previous experiences and educational needs of the family - in order to direct and individualize the training program, as well as to evaluate it after its realization. It is important, however, to maintain the focus on dialogue and the exchange of experiences between caregivers and professionals, considering that all participants have experiences to share, which enrich the joint learning.

With regard to CSHCN, the adequate preparation of caregivers for hospital discharge is especially important, because, together with their clinical fragility, the frequent hospitalizations of these children due to inadequately managed home complications can lead to the worsening of their health status.[32] Therefore, the training of caregivers can impact on reducing the deterioration of the children's clinical condition, avoiding new hospitalizations that can sometimes accompany the emergence of new needs. In the United States of America, there was a tendency towards a decrease in hospital readmissions of children on home mechanical ventilation, within seven days after discharge, since the implementation of a family preparation program, which used high-fidelity simulation as one of their strategies.[17] An educational program based on simulations provides the caregiver with knowledge and the ability to apply it under stressful situations, such as handling a complication at home.[15] Caring for a child with special healthcare needs at home implies a change in family routine and requires care different from those provided to a healthy child, increasing the responsibility of those who care. Due to the sudden change in the routine of caregivers, they seek to restructure their lives, so that attention is directed to the member who needs care. In this process, the caregiver is so intensely involved in their new function that they become the principal or sole caregiver.[29] Thus, the training of more than one family member was pointed out by the participants of this study as desirable; it is believed that this strategy can contribute to increasing safety and reducing the burden of the primary caregiver.

Home care of a CSHCN child implies great challenges for caregivers, making it necessary to learn and improve frequently, including the incorporation of complex skills. In this sense, the simulation is evidenced as a great potential in the training of these caregivers, since it allows the improvement of technical skills, as well as the evaluation of clinical manifestations and action in the face of home complications.

The results of the present study are limited to children dependent on technology, who represent only a subgroup of the CSHCN. Moreover, considering this subgroup, only caregivers of children using oxygen therapy, tracheostomy, gastrostomy and nasojejunal catheter participated, limiting the generalization of the results. In this sense, research that contemplates a greater representativeness of the population of CSHCN is suggested. In addition, the development of longitudinal studies, which monitor skilled families, can elucidate the effect of the strategy on home care and evaluate its medium and long-term impact on hospital readmission of these children.

CONCLUSION

The possibility of establishing the main potentialities of simulation was opened up as a strategy for the training of caregivers of CSHCN, bringing to the fore their experience in experiencing this process, as well as the implications for home care. The simulation initially triggered feelings of fear and anxiety. However, after the training, the caregivers felt relieved, self-confident and satisfied with their performance, highlighting the importance of the support provided during the simulations. They reported greater security to perform the procedures in the child and face the challenges of home care.

This study innovates by exploring the potentialities of simulation in the training of caregivers of CSHCN, bringing important contributions to qualify the home care of this clientele. The importance of considering the affective relationship of the caregiver to the child during the conduction of the high fidelity simulation is highlighted, and the facilitator should be prepared to offer support, during and after the simulated experience. In addition, the simulation proposal should be planned according to the experience of each caregiver and specificity of each child, as the results of the study indicate different perceptions related to the simulator and the simulation of low and high fidelity, according to previous experiences.

Considering that health education is one of the dimensions of the nurse's work, the results of this research can equip this professional to play their role in the care network of the CSHCN, especially in the preparation for hospital discharge and in the continuity of care at home.

REFERENCES

1. Brazilian Institute of Geography and Statistics (BR). Infant mortality rate per 1,000 live births, Brazil - 2000 to 2015. Rio de Janeiro, RJ(BR): IBGE; 2016. [cited 2018 Oct 30]. Available from: http://brasilemsintese.ibge.gov.br/populacao/taxas-de-mortalidade-infantil.html
2. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm [Internet]. 2017 [cited 2018 Oct 30];70(1):154-61. Available from: https://doi.org/10.1590/0034-7167-2016-0248
3. Okido ACC, Cunha ST, Neves ET, Dupas G, Lima RAG. Technology-dependent children and the demand for pharmaceutical care. Rev Bras Enferm [Internet]. 2016 [cited 2018 Oct 30];69(4):671-7. Available from: https://doi.org/10.1590/0034-7167.2016690415i
4. Silveira A, Neves ET, Paula CC. Family care of children with special healtcare needs: a process of (super)natural care and (over)protection. Texto Contexto Enferm [Internet]. 2013 [cited 2018 Oct 30];22(4):1106-14. Available from: https://doi.org/10.1590/S0104-07072013000400029
5. Esteves JS, Silva LFS, Conceição DS, Paiva ED. Families' concerns about the care of children with technology-dependent special health care needs. Invest Educ Enferm [Internet]. 2015 [cited 2018 Oct 30];33(3):547-55. Available from: https://doi.org/10.17533/udea.iee.v33n3a19
6. Buriola AA, Vicente JB, Zurita RCM, Marcon SS. Overload of caregivers of children or adolescents suffering from mental disorder in the city of Maringá, Paraná. Esc Anna Nery [Internet]. 2016 [cited 2018 Oct 30];20(2):344-51. Available from: https://doi.org/10.5935/1414-8145.20160047
7. Neves ET, Silveira A. Challenges for family caregivers of children with special health care needs: contributions of nursing. J Nurs UFPE on line [Internet]. 2013 [cited 2018 Oct 30];7(5):1458-62. Available from: https://doi.org/10.5205/1981-8963-v7i5a11633p1458-1462-2013
8. Martins JC, Mazzo A, Baptista RCN, Coutinho VRD, Godoy S, Mendes IAC, et al. The simulated clinical experience in nursing education: a historical review. Acta Paul Enferm [Internet]. 2014 [cited 2018 Oct 30];25(4):619-25. Available from: https://doi.org/10.1590/S0103-21002012000400022

9. Shin S, Park JH, Kim JH. Effectiveness of patient simulation in nursing education: meta-analysis. Nurse Educ Today [Internet]. 2015 [cited 2018 Oct 30];35(1):176-82. Available from: https://doi.org/10.1016/j.nedt.2014.09.009

10. Cooper SJ, Kinsman L, Chung C, Cant R, Boyle J, Bull L, et al. The impact of web-based and face-to-face simulation on patient deterioration and patient safety: protocol for a multi-site multi-method design. BMC Health Services Research [Internet]. 2016 [cited 2018 Oct 30];16(1):475. Available from: https://doi.org/10.1186/s12913-016-1683-0

11. Valizadeh L, Amini A, Fathi-Azar E, Ghiasvandian S, Akbarzadeh B. The effect of simulation teaching on baccalaureate nursing students' self-confidence related to peripheral venous catheterization in children: a randomized trial. J Caring Sci [Internet]. 2013 [cited 2018 Oct 30];2(2):157-64. Available from: https://doi.org/10.5681/jcs.2013.019

12. Bowling AM. The effect of simulation on skill performance: a need for change in pediatric nursing education. J Pediatr Nurs [Internet]. 2015 [cited 2018 Oct 30];30(3):439-46. Available from: https://doi.org/10.1016/j.pedn.2014.12.010

13. Stephenson E, Salih Z, Cullen DL. Advanced practice nursing simulation for neonatal skill competency: a pilot study for successful continuing education. J Contin Educ Nurs [Internet]. 2015 [cited 2018 Oct 30];46(7):322-5. Available from: https://doi.org/10.3928/00220124-20150619-04

14. Coleman EA. Extending simulation learning experiences to patients with chronic health conditions. JAMA [Internet]. 2014 [cited 2018 Oct 30];311(3):243-4. Available from: https://doi.org/10.1001/jama.2013.283057

15. Sigalet E, Cheng A, Donnon T, Koot D, Chatfield J, Robinson T, et al. A simulation-based intervention teaching seizure management to caregivers: a randomized controlled pilot study. Paediatr Child Health [Internet]. 2014 [cited 2018 Oct 30];19(7):373-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/25332677

16. Viana IS, Silva LF, Cursino EG, Conceição DS, Goes FGB, Moraes JRMM. Educational encounter of nursing and the relatives of children with special health care needs. Texto Contexto Enferm [Internet]. 2018 [cited 2018 Oct 30];27(3):e5720016. Available from: https://doi.org/10.1590/0104-070720180005720016

17. Thrasher J, Baker J, Ventre KM, Martin SE, Dawson J, Cox R, et al. Hospital to home: a quality improvement initiative to implement high-fidelity simulation training for caregivers of children requiring long-term mechanical ventilation. J Pediatr Nurs [Internet]. 2018 [cited 2018 Oct 30]; 38:114-21. Available from: https://doi.org/10.1016/j.pedn.2017.08.028

18. Tofil NM, Schier S, Benningfield B, Cooper A, Sloane PA, Zinkan L, et al. Tracheostomy education for parents utilizing simulation: a new paradigm in parental education. Pediatric Nurs [Internet]. 2018 [cited 2018 Oct 30];44(3):111-5. Available from: https://www.pediatricnursing.net/ce/2020/article4403111115.pdf

19. Polit DF, Beck TB. Fundamentals of nursing research: evaluation of evidence for nursing practice. 7th ed. Porto Alegre, RS(BR): Artmed; 2011.

20. Coutinho VRD, Martins JCA, Pereira MFCR. Construction and validation of the Debriefing Assessment Scale associated with Simulation (EADaS). Rev Enf Ref [Internet]. 2014 [cited 2018 Oct 30];4(2):41-50. Available from: https://doi.org/10.12707/RIII1392

21. Minayo MCS. The challenge of knowledge: qualitative research in health. São Paulo, SP(SP): Hucitec; 2013.

22. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm [Internet]. 2017 [cited 2018 Oct 30];70(1):154-61. Available from: https://doi.org/10.1590/0034-7167-2016-0248

23. Monnerat CP, Silva LF, Souza DK, Aguiar RCB, Cursino EG, Pacheco STA. Health education strategy with family members of children in continuous medication. J Nurs UFPE online [Internet]. 2016 [cited 2018 Oct 30];10(11):3814-22. Available from: https://org/10.5205/1981-8963-v10i11a11461p3814-3822-2016

24. Tremblay ML, Lafleur A, Leppink J, Dolmans DH. The simulated clinical environment: cognitive and emotional impact among undergraduates. Med Teach [Internet]. 2017 [cited 2018 Oct 30]; 39(2):181-7. Available from: https://doi.org/10.1080/0142159X.2016.1246710

25. Boostel R, Felix JVC, Bortolato-Major C, Pedrolo E, Vayego SA, Mantovani MF. Stress of nursing students in clinical simulation: a randomized clinical trial. Rev Bras Enferm [Internet]. 2018 [cited 2018 Oct 30];71(3):967-74. Available from: https://doi.org/10.1590/0034-7167-2017-0187

26. Presado MHCV, Colaço S, Rafael H, Baixinho CL, Félix I, Saraiva C, et al. Learning with high fidelity simulation. Ciênc Saúde Colet [Internet]. 2018 [cited 2018 Oct 30];23(1):51-9. Available from: https://doi.org/10.1590/1413-81232018231.23072017

27. Pai HC, Wei CF, Chen SL, Tsai SM, Yen WJ. Modeling the antecedents of clinical examination performance: task characteristics and psychological state in nursing students. Nurse Educ Today [Internet]. 2018 [cited 2018 Oct 30];69:142-8. Available from: https://org/10.1016/j.nedt.2018.07.016

28. Baptista RCN, Martins JCA, Pereira MFC, Mazzo A. Students' satisfaction with simulated clinical experiences: validation of an assessment scale. Rev Latino-Am Enfermagem [Internet]. 2014 [cited 2018 Oct 30];22(5):709-15. Available from: https://doi.org/10.1590/0104-1169.3295.2471

29. Okido ACC, Zago MMF, Lima RAG. Care for technology dependent children and their relationship with the health care systems. Rev Latino-Am Enfermagem [Internet]. 2015 [cited 2018 Oct 30]; 23(2):291-8. Available from: https://doi.org/10.1590/0104-1169.0258.2554

30. Ilha S, Zamberlan C, Piexak DR, Backes MTS, Dias MV, Backes DS. Contributions of a group about the Alzheimer's disease for family members / caregivers, professors and students from the healthcare field. J Nurs UFPE on line [Internet]. 2013 [cited 2018 Oct 30];7(5):1279-85. Available from: https://doi.org/10.5205/1981-8963-v7i5a11610p1279-1285-2013

31. Sousa ETG, Maia DB, Aires NWZ. Preparation for the hospital discharge of neurosurgical patients and their relatives: experience report. J Nurs UFPE on line [Internet]. 2014 [cited 2018 Oct 30]; 8(1):207-12. Available from: https://doi.org/10.5205/1981-8963-v8i1a9626p207-212-2014

32. Okido ACC, Pina JC, Lima RAG. Factors associated with involuntary hospital admissions in technology-dependent children. Rev Esc Enferm USP [Internet]. 2016 [cited 2018 Oct 30];50(1):29-35. Available from: https://doi.org/10.1590/S0080-623420160000100004

NOTES

CONTRIBUTION OF AUTHORITY

Study design: Pina JC, Silva APM.
Data collect: Pina JC, Silva APM.
Data analysis and interpretation: Pina JC, Silva APM, Rocha PK, Anders JC, Souza AIJ, Okido ACC.
Discussion of results: Pina JC, Silva APM, Rocha PK, Anders JC, Souza AIJ, Okido ACC.
Writing and/or critical review of the content: Pina JC, Silva APM, Rocha PK, Anders JC, Souza AIJ, Okido ACC.
Review and final approval of the final version: Pina JC, Silva APM, Rocha PK, Anders JC, Souza AIJ, Okido ACC.

FUNDING INFORMATION

The present work was carried out with the support of the National Council for Scientific and Technological Development (CNPq), through the Institutional Program of Scientific Initiation Scholarships - PIBIC/CNPq, and the Pro-Rectory of Extension of the Federal University of Santa Catarina (PROEX-UFSC), through the Extension Scholarship Program - PROBOLSAS.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the Universidade Federal de Santa Catarina, under opinion number 1,556,428, CAAE 55922616.1.0000.0121.

CONFLICT OF INTEREST

There is no conflict of interest.

HISTORICAL

Received: January 11, 2019.
Approved: April 01, 2019.

CORRESPONDING AUTHOR

Juliana Coelho Pina
pina.juliana@ufsc.br