REVISTA DE ENFERMAGEM REFERÊNCIA
homepage: https://rr.esenfc.pt/rr/
ISSNe: 2182.2883

RESEARCH ARTICLE (ORIGINAL)

Family caregivers' access to pediatric gastrostomy home care education: A qualitative study

Acesso de familiares aos conhecimentos para cuidar em casa de criança com gastrostomia: Estudo qualitativo

Acceso de los cuidadores familiares a los conocimientos sobre cómo cuidar en casa a un niño con gastrostomía: Estudio cualitativo

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Abstract

Background: Family caregivers' information on caring for a child's gastrostomy at home.
Objective: To analyze family caregivers' access to pediatric gastrostomy home care education.
Methodology: This study used an arts-based creative research method (*Dinâmica Corpo-Saber do Método Criativo Sensível*) with ten family members of hospitalized infants and preschool-aged children. The study was conducted between June and December 2019 in a public hospital in Rio de Janeiro, Brazil. Lexical analysis was performed using the IRAMUTEQ® software.
Results: Family caregivers had access to two sources of information to prepare for their children's hospital discharge. The first was the education received through nurses' guidance and demonstration of procedures. The second was the caregivers' observation of health professionals' care delivery to their children. Some family caregivers received no guidance, showing limitations in discharge preparation.
Conclusion: Families of children fed via gastrotomy tube must be mobilized to deliver safe care based on nursing knowledge. Nurses must consider family members' needs regarding the continuity of care at home.

Keywords: caregivers; child; gastrostomy; health education; nurses

Resumo

Enquadramento: Conhecimento de familiares cuidadores sobre a gestão do cuidado de crianças com gastrostomia no processo de cuidar.
Objetivo: Analisar o acesso de familiares cuidadores a conhecimentos sobre como cuidar de crianças com gastrostomia em casa.
Metodologia: Aplicado a dinâmica corpo-saber do método criativo sensível, com10 familiares de lactentes e pré-escolares, em internamento. Estudo realizado entre junho e dezembro de 2019, em um hospital público do Rio de Janeiro, Brasil. Utilizou-se a análise lexical, do software Iramuteq®.
Resultados: Cuidadores acederam a duas fontes de conhecimentos na preparação para a alta do internamento. A primeira, treino com orientações e demonstração de procedimentos do campo da ciência de enfermagem. A segunda, observação livre dos cuidados prestados pelos profissionais de saúde. Houve cuidadores que não receberam instruções, demonstrando limitação na preparação para a alta.
Conclusão: Viver com gastrostomia mobiliza a família para cuidados seguros, dependentes de conhecimentos de enfermagem. Os enfermeiros precisam atentar para às necessidades dos familiares, na continuidade do cuidar em casa.

Palavras-chave: familiares cuidadores; criança; gastrostomia; educação em saúde; enfermeiras

Resumen

Marco contextual: Conocimiento de los cuidadores familiares sobre la gestión de los cuidados de los niños con gastrostomía en el proceso de asistencia.
Objetivo: Analizar el acceso de los cuidadores familiares a los conocimientos sobre cómo cuidar a los niños con gastrostomía en casa.
Metodología: Aplicada la dinámica cuerpo-conocimiento del método creativo sensible, con 10 familiares de lactantes y preescolares hospitalizados. Estudio realizado entre junio y diciembre de 2019 en un hospital público de Río de Janeiro, Brasil. Se utilizó el análisis léxico, del software Iramuteq®.
Resultados: Los cuidadores accedieron a dos fuentes de conocimiento en la preparación del alta hospitalaria. La primera, la formación con directrices y demostración de procedimientos en el campo de la ciencia enfermera. La segunda, la observación libre de los cuidados prestados por los profesionales sanitarios. Hubo cuidadores que no recibieron instrucciones y mostraron limitaciones en la preparación para el alta.
Conclusión: Vivir con una gastrostomía moviliza a la familia para conseguir unos cuidados seguros, basados en los conocimientos de enfermería. Los enfermeros deben prestar atención a las necesidades de los familiares dentro de la continuidad de los cuidados en el domicilio.

Palabras clave: cuidadores familiares; niño; gastrostomia; educación para la salud; enfermeras

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Received: 07.10.22
Accepted: 08.05.23

How to cite this article: Moraes, J. R., Ribeiro, A. P., & Cabral, I. E. (2023). Family caregivers' access to pediatric gastrostomy home care education: A qualitative study. *Revista de Enfermagem Referência*, *6*(2), e22097. https://doi.org/10.12707/RVI22097

Introduction

Infants and preschool-aged children fed via gastrostomy tube have complex care needs regarding feeding, hydration, skin integrity, and medication administration. These needs must be accounted for when transitioning from hospital to home care and are the responsibility of the children's family caregivers. Thus, family caregivers should receive education about pediatric nursing fundamentals to maintain and ensure their children's body functions and life processes (Collliére, 1999), as well as safeguard the delivery of safe home care. This way, they can promote their children's daily comfort and well-being based on nursing fundamentals and procedures learned from the nursing team during hospitalization.

Infants and preschool-aged children fed via gastrotomy tube have unique health needs resulting from the surgically implanted feeding tube. Gastrotomy is a procedure indicated for a broad set of pediatric patients who cannot meet their long-term nutritional needs without supplementation. This set includes children with delayed neuromotor development, long-term gastroesophageal reflux, or failure to thrive (Ribeiro et al., 2022).

Compared with other children, children fed via gastrotomy tube require differentiated, specific, and complex care and monitoring provided by a specialized multidisciplinary team combining nursing, medical, nutritional, and physical therapy professionals.

In Brazil, infants and preschool-aged children fed via gastrotomy tube are considered Children with Special Health Care Needs (CSHCNs) (Cabral et al., 2004) and are primarily assisted by the Brazilian National Health System (Precce et al., 2020). Due to the complex care they require, CSHCNs may undergo long hospitalization periods. Therefore, healthcare institutions must develop institutional care policies that enable these children's access to health services and adequate discharge planning. Moreover, healthcare institutions should properly prepare family members for their children's discharge to reduce their dependence on hospital care (Góes & Cabral, 2017).

Regarding access to information, Ribeiro et al. (2022) argue that better-informed – thus, calmer and more confident - family caregivers are better prepared to meet their children's needs. In this sense, expanding family caregivers' access to pediatric gastrostomy home care education is essential. Nurses are responsible for educating family members about home care and preparing and providing them with access to information on gastrotomy so that they can deliver care safely and autonomously (Dipasquale et al., 2022). Family caregivers with little information experience fear, distress, and depression, which ultimately and directly affects the quality of care provided to the children (Broering & Crepaldi, 2018). Hence, this study aimed to analyze the family caregivers' access to pediatric gastrostomy home care education.

Background

Health education is an intrinsic part of the care process in daily nursing practice. It transforms and rebuilds family caregivers' knowledge by giving them access to education for care delivery (Bazzan et al., 2021).

In this sense, access to education is essential as it allows family members to become active, critical, and insightful subjects in the learning continuum and empowers them to deliver care. For Freire (2011), every person is a relational being with spatiotemporal roots whose main task is to be a subject of transformation and not an object of transformation. Change is not exclusive to some people but to those who choose change.

As a professional whose work directly impacts society, the nurse cannot remain neutral in the world, indifferent to the (de)humanization processes. In this sense, this health professional's role is to consider people's realities and expand their education through reflection.

The need to learn mobilizes people to seek education that, in turn, produces real meaning in their lives (Freire, 2011). The nurse's role is to act as a means and/or a facilitator of access to information within an active process that involves need and reflection and (re)creates conditions for learning integrated into real-life contexts.

Some studies highlight family caregivers' access to pediatric gastrostomy home care education. However, they focus on functionality and the dependence on another caregiver to feed the child through a feeding tube (Dipasquale et al., 2022). Furthermore, other biopsychosocial needs are disregarded, as feeding tube care procedures occupy family caregivers for substantial periods, limiting their and their children's interactions in other social activities (Berman et al., 2022). Hence, nurses must empower, train, and ensure family caregivers' broad access to education to promote the children's and family caregivers' better quality of life based on a humanizing pedagogical approach (Freire, 2011).

Research question

How do family caregivers access pediatric gastrostomy home care education?

Methodology

This study develops a qualitative approach using an arts-based creative research method - *Dinâmica Corpo-Saber do Método Criativo Sensível*. This group research method collects data by resorting to art creation, collective discussion, and participant observation conducted during meetings with participants in a space conducive to promoting their dynamics of creativity and sensitivity (DCS). The investigator operates as a cultural facilitator, actively motivating the participants to produce arts-based data by appealing to their DCS (Cabral & Neves, 2016).

Participants answer a discussion-generating question by writing keywords in an empty body's silhouette drawn on an A_3 sheet of paper. This metaphorical conception of a body is a tool for demonstrating knowledge of care delivery. The empty body's silhouette is gradually filled to create an artistic production (Ribeiro et al., 2022).

According to the arts-based creative research method - *Dinâmica Corpo-Saber do Método Criativo Sensível,* used in this study, the investigator and the participants have five meetings (moments). In the first meeting, each participant is presented to the investigator and introduced to the material used in the activity (an A_3 sheet of paper with a silhouette drawing of a child's body and colored markers). The investigator explains the study's purpose to each participant and introduces the discussion-generating question - "How do you care for your child's gastrotomy at home?". In the second meeting, participants are asked to write or draw in the empty body's silhouette to create a unique artistic production. During the third and fourth meetings, participants are asked to show the completed body's silhouettes, justifying their choices, and reflect on the themes emerging from their artistic productions. In the fifth and last meeting, the participants make a thematic synthesis of the data collected.

This study's five meetings (moments) were conducted between July and December 2019. They were recorded digitally and lasted, on average, one hour, totaling approximately five hours. Each meeting was attended by Brazilian family caregivers representing different family groups. Five collective artistic productions were created and subjected to group discussion.

This study's inclusion criteria were as follows: to be over 18 years of age; to be the primary family caregiver, experienced and active, of an infant or preschool-aged CSHCNs fed via gastrotomy tube; and to be able to communicate orally. Family members whose CSHCNs fed via gastrotomy tube were hospitalized and had no experience caring for them at home were excluded. Before each meeting, an instrument to collect sociodemographic information was applied to characterize the family caregiver and the child. Twenty family caregivers of infants and preschool-aged CSHCNs that met the inclusion criteria were invited to participate in this study. From these, ten family caregivers (n = 10) participated in the study.

The study was conducted at the pediatric outpatient clinic of a medium- and high-complexity care network hospital of the Brazilian National Health Service in Rio de Janeiro. This is a general hospital specializing in elective pediatric surgical procedures.

The data were submitted to lexical analysis in three stages: pre-analysis, analysis, and inference/ interpretation. The pre-analysis stage was carried out in two phases. In the first, the text corpus was prepared. In the second, the data were processed with the help of the French lexical analysis software IRAMUTEQ® (*Interface de R pour lês Analyses Multidimensionnelles de Textes et de Questionnaires*). It is worth noting that to be considered efficient, minimum retention of 75% of the text segments is required (Brigido et al., n.d.)

For the software to recognize the text corpus, the underline (_) tools were used to collect the words that made sense in the family caregivers' statements. The command lines were separated according to the variables presented by specific codes (type of caregiver, age, education, time of gastrostomy). Each command line started with four asterisks (****), followed by space, plus an asterisk (*), next the participant family member (mother_CSHCNs_no.), space, plus an asterisk (*), the age (age_no.), space, plus an asterisk (*), the education (educ_no.) and space, plus an asterisk (*), and the gastrostomy time (time_no.), as in following example: **** *mother_CSHCNs_1 *age_4 *educ_6 *time_3

The study conducted a factor correspondence analysis that adopted a Descending Hierarchical Classification (DHC) (Kami et al., 2016). In the DHC, the analytical software calculated the most repeated vocabulary and identified the most represented text segments in each text segment cluster (colorful corpus). Each cluster comprised textual segments grouped according to these text segments' classification and vocabulary distribution (forms). The software organized the text segments in clusters primarily according to their characteristic vocabulary (*lexicon*) and variables (words with asterisk).

The data's internal validity was assured by the data analysis of the research group *Crianças com Necessidades Especiais de Saúde* (Children with special health needs) of the Brazilian National Research Council (CNPq), with which this study's investigators are associated. The CNPq is composed of researchers experienced in qualitative research approaches. After being transcribed, the interviews were double-checked during the text corpus's preparation to ensure the data's anonymity, reliability, and viability before being entered into the software for analysis.

Considering it is a qualitative study, this study followed the COREQ - Consolidated Reporting Criteria for Qualitative Research checklist.

This study complied with the ethical guidelines of Resolution No. 466 of December 12, 2012, and Resolution No. 580 of March 22, 2018, from the Brazilian National Health Council. This study's project was approved by the Ethics Committees of its proponent institution, the Anna Nery School of Nursing, from the Federal University of Rio de Janeiro, Brazil, according to opinion 3.236.884/2019, as well as of its coparticipant institution, according to opinion 3.399.703/2019. All participants signed Informed Consent Forms before the meetings were held.

Results

Of the ten family caregivers who participated in this study, nine were biological mothers, and one was an adoptive mother. The participants' ages ranged from 23 to 61 years, with a mean of 34 years. Considering the participants' education, one had complete elementary education, another had incomplete higher education, and eight had complete secondary education. It is worth noting that most family caregivers at home are women - mothers, sisters, grandmothers, aunts, and significant others (godmothers). Fathers and brothers stand out among the male caregivers.

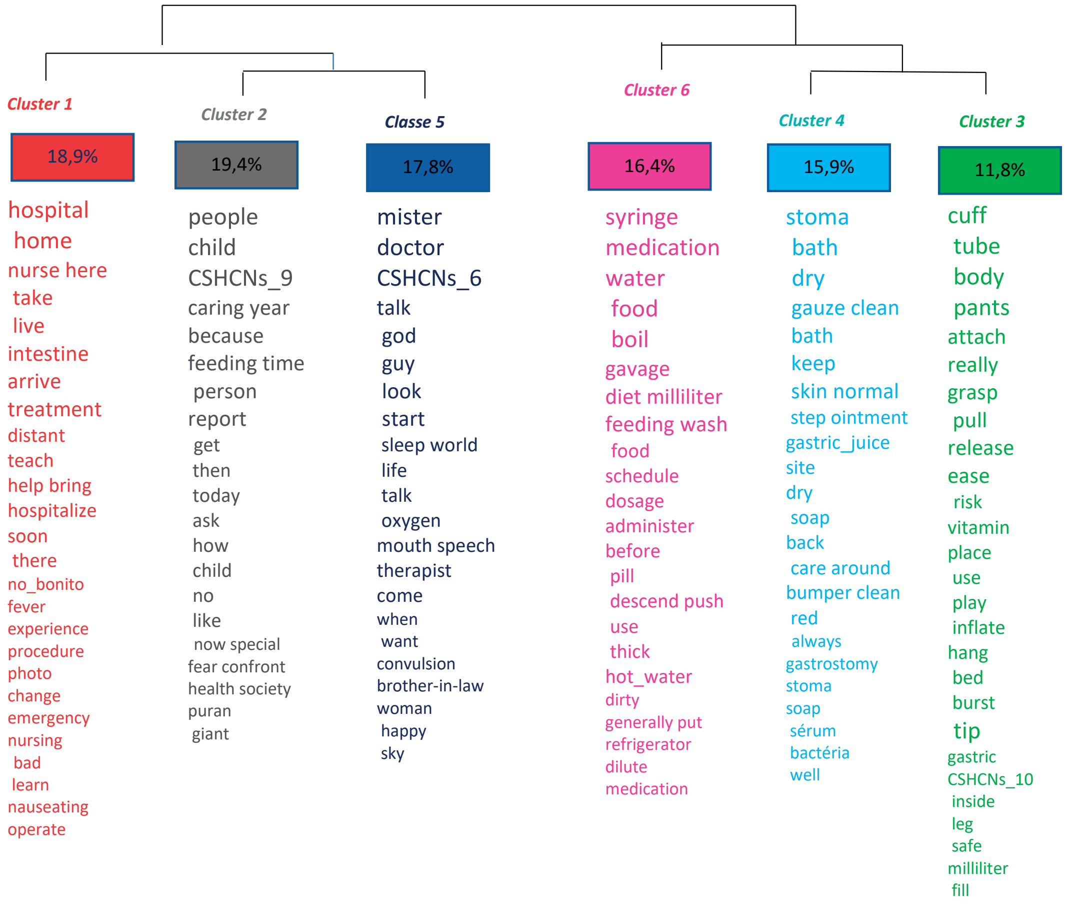
The ten CSHCNs were aged between one year and three months (infants) and five years (preschool-aged children) and diagnosed with a variety of medical conditions (microcephaly due to Zika virus [2]; DiGeorge syndrome

[1], hypotonia due to fetal distress [1], hydrocephalus [1], cerebral palsy [1], Down syndrome [1], meningitis [1], H1N1 infection sequelae [1], and chronic renal failure [1]). Most CSHCNs were technology-dependent due to the gastrostomy alone or its association with a tracheostomy with Bipap® non-invasive ventilator, ventriculoperitoneal (VP) shunt, nephrostomy, totally implantable venous access devices (TIVADs), or foot orthoses.

IRAMUTEQ® analyzed 677 text segments out of 805 (84.10%), generating two themes and three clusters in each theme. This study focused its analysis on cluster one, whose most represented text segments (18.9%) were "hospital" and "home," the places where there was most significant access to pediatric gastrostomy home care education. Next, the text segment "nurse" emerged as the most representative among the health professionals facilitating access to education (Figure 1).

Figure 1

Dendrogram classification tree, produced by IRAMUTEQ® software, with the percentage of words of each cluster



Cluster one's text segments are part of the theme "Nurses as facilitators of family caregivers' access to pediatric gastrostomy home care education."

"Nurses as facilitators of family caregivers' access to pediatric gastrostomy home care education."

During their children's hospitalization and before discharge, family caregivers had access to pediatric gastrostomy home care education. This access was provided by nurses, who were facilitators of the formal and informal teaching-learning process.

"They taught me in the hospital" (mother_CSHCNs_5). "I started doing (giving food through a gastrostomy tube) in the hospital" (mother_CSHCNs_6). "Before I went home, the nurse spent about three days teaching me, training me" (mother_CSHCNs_7). "At the hospital, the nurse taught me, [and] explained everything to me" (mother_CSHCNs_8).

In the beginning, when faced with the novelty of dealing with the technology associated with pediatric gastrostomy home care, family caregivers experienced fear. They also showed signs of nervousness and insecurity. Nurses and physicians played a crucial role by encouraging family caregivers' participation in care delivery and integrating them into the learning process.

Before the CSHCN was discharged, the nurses taught me. I was very nervous then and said I couldn't do it at home, but the nurses taught me; they told me that I had to learn. They taught me step by step. At home, the beginning was a little bit difficult. But now I can do it. (mother_CSHCNs_4)

"In the beginning, the nurses would watch how I did it. Then, I already did it by myself; I have always learned things very fast" (mother_CSHCNs_6). "I was afraid, I was afraid to put the tube in. Everything was new" (mother_CSHCNs_7).

Gradually, family caregivers overcame their difficulties and learned to acquire autonomy and independence in their care delivery. Caregivers learned to recognize when tubes needed to be changed and felt more confident.

"I don't need to come here to the hospital to change the tube; I remove and change it myself, just like [the] nurses. I learned here at the hospital" (mother_CSHCNs_3). "When the tube gets loosened, I change it at home. I only went to the hospital twice. I learned by watching the nurses change, I learned, that's it, I never went back" (mother_CSHCNs_5). "At home, it was easier. The doctors told me I could do it and, in the beginning, the nurses would watch how I did it. Then, I already did it by myself; I have always learned things very fast." (mother_CSHCNs_6)

One of the family caregivers participated in a health education activity implemented by nursing professionals as preparation for hospital discharge, thus having access to two sources of pediatric gastrostomy home care education - observation of procedures and formal training.

"I would see [observation] the nurses change the tube, [but] when I was going to change the tube, it would burst. The nurses [formal training], here at the hospital, showed me how I could do it" (mother_CSHCNs_3).

However, some family caregivers had no access to pediatric gastrostomy home care education, which caused them difficulties during the hospital-home transition. Family caregivers underscored the frequent returns to the hospital emergency room to change the tube and having to learn based on trial and error and the fortuitous observation of the feeding procedure via gastrostomy tube in other care situations.

"I actually learned by doing it at home, because the nurse didn't sit down and say: 'it's like this . . . you see here . . . No. If you're too thickheaded, you don't learn" (mother_CSHCNs_5).

The nurse didn't teach me; I learned gradually. The nurse asked me if I could see the syringe . . . 'you can't push it when you offer the soup.' Because I didn't know how to change it, I watched when I brought the CSHCNs_8 to the emergency room on the day of the change. The nurses taught other people, and I just watched them change. When CSHCNs_8 had the gastrostomy done, they didn't teach me. I came here desperate. On the first day, they just showed me and said: from now on, you will do it daily. (mother_CSHCNs_8)

"I was not trained, I was not trained to change the gastrostomy tube, so much so that I came here to the hospital countless times" (mother_CSHCNs_ 9).

Some caregivers had no access to pediatric gastrostomy home care education due to the absence of guidance from the nurse or because the information was poorly transmitted.

"The nurse who went there. The first time [was] one day before he was discharged. He was eating through a tube, and the nurses said: 'You take it and put this syringe in the gastrostomy'" (mother_CSHCNs_1). "Because no one taught me, I had to learn alone... the mother of CSHCNS 1 gave me guidance... by telephone, and also by looking at the other mothers" (mother_CSHCNs_2).

It is worth noting that when people's realities are not considered, knowledge is not transmitted, and reflection is not encouraged. Knowledge becomes empty of real meaning in the person's world, and the search for it is postponed. Moreover, health professionals stop facilitating the teaching-learning process because this process does not occur. Furthermore, learning based on trial-and-error attempts can create a vicious cycle of unsafe care when caregivers find themselves alone at home.

Discussion

The access to knowledge of how to care for infants and preschool-aged children occurred within a health education space through formal and informal teaching-learning processes. Each step of the feeding procedure via a gastrotomy tube was privileged during formal training and the observation of procedures. Nursing care served as a model for family caregivers to reflect on the needs of their infants and preschool-aged children during the hospital-home transition.

Nursing professionals understood it was necessary to conduct the learning process centered on family caregivers' needs to learn how to deal with the gastrotomy tube, providing them with the knowledge to improve the lives of the children under their care (Góes & Cabral, 2017). In addition to formal training based on procedure demonstration and feedback, observing the technical procedures performed by nursing professionals was another source of knowledge for family caregivers. In this sense, nurses facilitated the teaching-learning process by developing mechanisms that strengthened their relationships with family caregivers, thus ensuring safe and conscious care delivery.

This study's results contrast with that conducted by Precce et al. (2020) with CSHCNs. In Precce et al.'s study, when reporting about the preparation for discharge, the family caregivers did not highlight nursing professionals' interventions. When questioned about the guidance provided during hospitalization and for discharge, the family caregivers revealed the fragility of the bond between them and the nursing team.

Instead, this study observed that the teaching-learning process was based on establishing a relationship of dialogue and empathy, allowing all stakeholders in the care process to benefit from feedback and collaborative care. These are essential aspects for learning and overcoming the daily difficulties of home care. Family caregivers' first contact with the information required to care for their children was marked by fear, nervousness, and insecurity regarding the unknown, demonstrating the intensity of their emotional state. After overcoming these initial barriers, family caregivers were able to develop their caregiving skills and feel more secure and competent in their care delivery. Caregivers' emotional state can compromise learning. Occasionally, the guidance provided during hospitalization loses its real meaning, and family caregivers cannot learn at that moment. Therefore, nurses must encourage family caregivers during hospitalization, respecting their time and moments of availability. Only then will caregivers be able to learn how to care for their children autonomously when they transition from hospital to home care. (Precce et al., 2020).

Family caregivers may feel insecure to continue caring for their CSHCNs at home because they no longer have the constant presence of the health team supporting them with the necessary information (Góes & Cabral, 2017). Nursing professionals are facilitators and sources of information whose work has social repercussions. Nurses humanize the teaching-learning relationship, respecting each family caregiver's limitations and learning time.

The knowledge acquired during the hospitalization period transforms the family caregivers that embrace change as part of their need to be autonomous in their care delivery. Adherence to change acquires real meaning when family caregivers feel safe to deliver care autonomously, manipulating and changing the gastrotomy tube. Thus, data from this study reinforces what is currently in the literature regarding the importance of parents deciding to accept feeding via gastrostomy tube to increase their children's quality of life and allow for home care (Dipasquale et al., 2022).

Empowerment contributes to overcoming challenges inherent to learning to operate with a gastrostomy tube, exchange the tube, and care for peristomal skin, among others. Therefore, the relationship between health teams and family caregivers facilitates the provision of care and health education. This relationship strengthens the bonds of trust and favors the development of joint actions that promote the family caregiver's autonomy to care for the child. These findings align with the provision of safe care focused on a health education approach that empowers caregivers to deliver quality care to their children (Bazzan et al., 2021).

Thus, nurses can assist caregivers in dealing with the gastrostomy tube and provide the guidance and health education families need to become independent in their care delivery (Rosseto et al., 2019; Góes & Cabral, 2017). Caregivers' gradual integration into the care process, still during hospitalization, allows for incorporating new experiences. Encouraging their feedback, nurses implement interventions to train family caregivers to assume the leading role in home care, providing guidance on medication administration, feeding, body hygiene, playing, and social interaction at home (Góes & Cabral, 2017).

Health education is a teaching-learning process aimed at health promotion. In this context, nurses greatly facilitate the achievement of educational objectives that positively change care delivery to infants and preschool-aged children fed via gastrotomy tube (Freire, 2011).

Educational activities are part of nurses' professional practice in different settings and allow for acquiring knowledge and establishing interpersonal relationships and dialogue (Rosseto et al., 2019).

Freire (2011) believes a professional committed to change shares knowledge in a humanized and respectful way, aiming to meet the learner's need to learn. Also, the nurse's role as an educator is more appreciated and recognized when dealing with complex procedures essential to maintaining the life of CSHCNs (Góes & Cabral, 2017).

This study is limited by its implementation in an outpatient rather than a home setting. Moreover, the representation of family caregivers was restricted to a single caregiver per family, which did not allow access to knowledge about caregiving by other family members. In this sense, the sharing of care delivery among other family members may be limited by the concentration of information in a single caregiver.

Conclusion

Access to education was provided via a teaching-learning process based on training procedures related to tube exchange, peristomal skin care, medication administration, and feeding, and implementing caregiving activities that fostered family caregivers' demonstration of feedback. Family caregivers also observed nurses while they delivered care and received general guidance on care delivery beyond managing the gastrostomy tube.

Nurses implemented health educational actions aligned with the care needs of technology-dependent CSHCNs during hospitalization, actively participating with family caregivers in the process of social transformation that made them autonomous, aware, and confident to deliver safe home care to their children. This success was achieved because family caregivers were considered vital allies in care delivery during the hospital-home transition.

This study seeks to improve family caregivers' care for children fed via gastrotomy tube, promoting safe care and fostering confidence to perform complex everyday procedures. The preparation for discharge must start from the beginning of hospitalization, seeking family caregivers' autonomy in delivering safe care to their children fed via gastrotomy tube.

New life-sustaining treatments, such as safe feeding through a gastrostomy tube, must be integrated into families' living habits, beliefs, and customs. Discharge planning during the hospital-home transition must also put the family at the center of the care process without this being considered a cultural invader.

This study has implications for nursing research and practice as it considers expanding care delivery to children fed via gastrotomy tube beyond the biomedical dimension by integrating the biopsychosocial dimension into the promotion of safe complex everyday care, thus fostering the children's and their caregivers' well-being.

Author contributions

Conceptualization: Moraes, J. R., Ribeiro, A. P., Cabral, I. E.

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Writing – Review & editing: Moraes, J. R., Ribeiro, A. P., Cabral, I. E.

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