

Development of an educational booklet on caring for children with tracheostomies at home

Desenvolvimento de cartilha educativa sobre cuidados à criança com traqueostomia em domicílio

Desarrollo de un folleto educativo sobre el cuidado de niños con traqueotomía en el hogar.

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Abstract

Objective: To develop an educational booklet on caring for children with tracheostomies at home.

Methods: This is a methodological study carried out in 2024 and 2025 in four stages: conceptualization; development; implementation; and assessment. Assessment was carried out by specialists, stomal therapy nurses and nurses from the pediatric, home care and outpatient units of the Universidade de São Paulo University Hospital. After adjustments suggested by specialists, it was assessed by users, family members of children with tracheostomies. Family members under the age of 18, illiterate and visually impaired were excluded. Statistical analysis was descriptive and the Content Validity Ratio (CVR) was considered adequate if $CVR \geq 0.8$. The research was approved by an ethics committee.

Results: The booklet development was based on nursing theories, according to the Nursing Process stages, using standardized languages and with the aid of a decision support system. In order to provide up-to-date guidance in line with best practice, a literature review was carried out. According to the nursing diagnoses identified, expected outcomes and proposed interventions, the booklet contains child identification data, guidance on the Basic Health Unit of reference and the materials provided, followed by information on what a tracheostomy is, hand washing, positioning children, care for cleaning the stoma, handling the cannula, aspirating secretions, what to do in emergencies, feeding, hydration, sleep, clothing, hygiene, communication with children and social life. It ends with advice on family members' health. The layout was done by professionals in the field. The booklet was made available in printed and digital versions. It was assessed and approved by 15 nurses, with an average CVR of 0.97, and 10 family members, with an average CVR of 0.95.

Conclusion: The educational booklet developed provides guidelines for comprehensive child and family care at home and can be used as educational material in preparation for de-hospitalization.

Resumo

Objetivo: Desenvolver uma cartilha educativa sobre cuidados com crianças com traqueostomia em domicílio.

Métodos: Estudo metodológico realizado em 2024 e 2025, em quatro etapas: conceituação, desenvolvimento, implementação e avaliação. A avaliação foi feita por especialistas, enfermeiros estomaterapeutas e de unidades pediátricas, atendimento domiciliar e ambulatorial do hospital universitário da Universidade de São Paulo. Após adequações sugeridas pelos especialistas, foi avaliada por usuários, familiares de crianças com traqueostomia. Foram excluídos familiares menores de 18 anos, analfabetos e deficientes visuais. A análise estatística foi descritiva e pela Razão de Validade de Conteúdo (CVR), considerado adequado $CVR \geq 0,8$. A pesquisa foi aprovada pelo comitê de ética.

Resultados: O desenvolvimento da cartilha foi fundamentado em teorias de enfermagem, de acordo com as etapas do Processo de Enfermagem, utilizando linguagens padronizadas e com auxílio de um sistema de apoio à decisão. Para fornecer orientações atualizadas e de acordo com as melhores práticas, foi realizada revisão da literatura. De acordo com os diagnósticos de enfermagem identificados, os resultados esperados e as intervenções propostas, a cartilha contém dados de identificação da criança, orientações sobre unidade básica de saúde de referência e materiais fornecidos, seguida de informações sobre o que é traqueostomia, lavagem das mãos, posicionamento da criança, cuidados com a limpeza do estoma, manuseio da cânula, aspiração de secreções, o que fazer em emergências, alimentação, hidratação, sono, vestuário, higiene, comunicação com a criança e vida social. Finaliza com orientações sobre saúde dos familiares. A diagramação foi realizada por profissionais da área. A cartilha foi disponibilizada nas versões impressa e digital. Foi avaliada e aprovada por 15 enfermeiros, CVR médio de 0,97 e 10 familiares, CVR médio de 0,95.

How to cite:

Soares LA, Rogenski KE, Santos NC, Diogo RC, Toriyama AT, Nogueira PC. Development of an educational booklet on caring for children with tracheostomies at home. Rev Soc Bras Enferm Ped. 2024;24:eSOBEP2024991.

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Conflicts of interest: nothing to declare.

Submitted: May 19, 2024 | **Accepted:** December 20, 2024

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DOI: 10.31508/1676-37932024991

Keywords

Pediatric nursing; Educational technologies; Child; Family; Tracheostomy

Descritores

Enfermagem pediátrica; Tecnologias educacionais; Criança; Família; Traqueostomia

Conclusão: A cartilha educativa desenvolvida fornece orientações para o cuidado integral da criança e família no domicílio e pode ser utilizada como material educativo no preparo da desospitalização.

Resumen

Objetivo: Desarrollar un folleto educativo sobre el cuidado de niños con traqueotomía en el hogar.

Métodos: Estudio metodológico realizado en 2024 y 2025, en cuatro etapas: conceptualización, desarrollo, implementación y evaluación. La evaluación fue realizada por especialistas, enfermeros estomaterapeutas y de unidades pediátricas, atención domiciliar y ambulatoria del hospital universitario de la Universidad de São Paulo. Tras las adaptaciones sugeridas por los especialistas, fue evaluado por los usuarios, familiares de niños con traqueotomía. Se excluyó a los familiares menores de 18 años, analfabetos y con discapacidad visual. El análisis estadístico fue descriptivo y se realizó mediante la razón de validez del contenido (CVR), considerándose adecuado un $CVR \geq 0,8$. La investigación fue aprobada por el comité de ética.

Resultados: El desarrollo del folleto se basó en teorías de enfermería, de acuerdo con las etapas del Proceso de Enfermería, utilizando lenguajes estandarizados y con la ayuda de un sistema de apoyo a la toma de decisiones. Para proporcionar orientaciones actualizadas y de acuerdo con las mejores prácticas, se realizó una revisión de la literatura. De acuerdo con los diagnósticos de enfermería identificados, los resultados esperados y las intervenciones propuestas, el folleto contiene datos de identificación del niño, orientaciones sobre la unidad básica de salud de referencia y los materiales proporcionados, seguido de información sobre qué es una traqueotomía, lavado de manos, posicionamiento del niño, cuidados con la limpieza del estoma, manejo de la cánula, aspiración de secreciones, qué hacer en emergencias, alimentación, hidratación, sueño, vestimenta, higiene, comunicación con el niño y vida social. Finaliza con orientaciones sobre la salud de los familiares. El diseño fue realizado por profesionales del área. El folleto está disponible en versión impresa y digital. Fue evaluado y aprobado por 15 enfermeros, con una CVR media de 0,97, y 10 familiares, con una CVR media de 0,95.

Conclusión: El folleto educativo desarrollado proporciona orientaciones para el cuidado integral del niño y la familia en el hogar y puede utilizarse como material educativo en la preparación para el alta hospitalaria.

Descritores

Enfermería pediátrica; Tecnologías educativas; Niño; Familia; Traqueostomía

Introduction

Nursing care for children with chronic illnesses is essential during hospitalization and allows nurses and their teams to prepare children and their families for de-hospitalization or discharge.⁽¹⁾ The use of life-support technologies allows children with chronic illnesses to use devices in home environments, providing quality of life. One of the devices commonly used by children with chronic illnesses is a tracheostomy.⁽²⁾ A tracheostomy is a surgical procedure that consists of opening the anterior wall of the trachea, creating communication with the external environment to ensure airway patency. Its indication may be related to different factors, such as airway obstruction, prolonged intubation, tracheal secretion accumulation or respiratory muscle weakness. Moreover, tracheostomy can be classified according to its therapeutic purpose (preventive, curative or palliative), the appropriate time for it to be performed (urgent or elective) and the length of time the cannula remains in place (temporary or permanent).^(3,4)

Transition of care for children with tracheostomies from the hospital environment to the home is a challenge for families and nurses. Studies have found that family members report anxiety, fear and insecurity about the new routine, mainly due to doubts about how to carry out daily care. Among the main concerns are the management of tracheal secretions, maintenance

of the cannula, hygiene of the stoma, feeding, bathing, prevention of complications (such as accidental decannulation) and children's social interaction.^(1,5)

However, training family members should take place gradually during hospitalization, allowing them to acquire the necessary skills for care at home. This process, led by nurses and involving multidisciplinary health teams, contributes to empowering families, promoting autonomy and safety.^(1,5)

In addition to practical training, nurses can use educational technologies as a strategy to reinforce guidance and standardize information provided to family members. Visual educational technologies, such as educational booklets, stand out for their low cost, accessibility, and simplified language, allowing family members to consult the information whenever necessary. Educational technologies not only facilitate learning but also promote families' active participation in the care process, contributing to the dissemination of scientific information in society.⁽⁶⁻⁹⁾

Despite its relevance, there is a lack of visual educational technologies in the literature that address care related to the biological, psychological and social aspects not only of children with a tracheostomy at home, but also of their family members.^(10,11) We believe that comprehensive care for children/families with tracheostomies is extremely important for the process of health education for family members, with nurses being the professionals capable of helping to

promote family caregivers' skills and competencies, resulting in health promotion and maintenance, prevention of complications such as readmissions and an increase in children's and families' quality of life.

This research aims to develop an educational booklet on caring for children with tracheostomies at home.

Methods

This is a methodological study carried out at the *Universidade de São Paulo* University Hospital (USP-UH), in the Pediatric Intensive Care Unit (PICU), Children's Emergency Room (CER), Pediatric Clinic (PC), Outpatient Clinic and Home Care Program (HCP), from January 2024 to February 2025.

The educational booklet was developed in stages:⁽¹²⁾

Conceptualization

Definition of the objective, target audience, nursing care model and theoretical content covered in the booklet.

In their care practice, nurses use scientific methodology, based on nursing theories and in accordance with the Nursing Process (NP) stages. The NP is defined as a method that guides nurses' critical thinking and clinical judgment, directing the nursing team towards individualized and comprehensive care for the person, family, community and special groups.⁽¹³⁾ Nursing care was based on the Family-Centered Care (FCC) philosophy,⁽¹⁴⁾ which emphasizes the essential role of families in care, promoting caregivers' involvement, participation and empowerment. Based on the pillars of dignity and respect, information sharing, active participation and collaboration, FCC encourages an integrated approach with the multidisciplinary team.

It was also based on nursing theories. Dorothea Orem's Self-Care Theory⁽¹⁵⁾ highlights the importance of self-care, in which individuals must be able to meet their own health needs. In the pediatric context, children have a deficit in self-care and are dependent on their parents and caregivers to carry out actions that ensure their well-being. Faced with this need, nursing intervenes through three systems: educational-sup-

portive system, which guides and trains caregivers to provide adequate care; partially compensatory system, in which there is a division of responsibilities between caregivers and healthcare professionals; and fully compensatory system, in which the nursing team fully takes over care when children/caregivers do not have any capacity to carry it out on their own. In this way, the application of Orem's theory reinforces the importance of nursing's role in promoting children's health and supporting caregivers.⁽¹⁵⁾

In addition to Orem's theory, the booklet was based on Wanda Horta's Theory of Basic Human Needs,⁽¹⁵⁾ which classifies human needs into psychobiological, psychosocial and psychospiritual. In the pediatric context, because children are developing and dependent on their families, they need a nursing approach that includes comprehensive care. Horta's theory reinforces nursing as a science and highlights the importance of holistic care, ensuring that all patient dimensions are considered in order to promote their adaptation and balance. Thus, by recognizing children's individual needs and family members' essential role, nursing plays a mediating and assisting role, promoting children's well-being and health.

Standardized nursing languages were used for the NP stages (diagnosis, interventions and outcomes), with the NANDA International Classification of Diagnoses (NANDA-I),⁽¹⁶⁾ and the Nursing Interventions Classification (NIC) for interventions,⁽¹⁷⁾ and the Nursing Outcomes Classification (NOC) for outcomes⁽¹⁸⁾, with the help of the *Processo de Enfermagem da Universidade de São Paulo* (PROcEnf-USP®) electronic documentation system, which is a nursing decision support system that has been used in pediatric units since 2016.^(19,20)

To provide up-to-date guidelines in line with best practices, a literature review was carried out with the following research question: What are the best practices for caring for children and families using tracheostomies? The search was carried out in national and international nursing databases in July 2024 with the support of a librarian. Articles published in the last 10 years in English, Portuguese and Spanish were included. Chart 1 shows the search strategy.

A total of 196 articles were found. After analyzing the titles and abstracts, 28 articles were selected to be read in full. Of these, 20 were removed because they

Chart 1. Database and search strategy

Database	Search strategy
Cumulative Index to Nursing and Allied Health Literature	Airway Management OR/AND, Tracheostomy AND Nursing Care AND Home Nursing Care
Virtual Health Library	Airway Management OR/AND Tracheostomy AND Nursing care AND Home care

did not address tracheostomy-related care. Eight articles were included in the booklet (Chart 2).

Selection of the free online platform for the booklet, definition of the layout, font, colors, figures and content organization.

Based on conceptualization, the script was developed with all the necessary content. The booklet was designed by the researchers, and information and content were organized using the free online platform Canvas® and shared with everyone for them to assess

and make suggestions. Images of children on the cover were drawn by one of the researchers. The photos illustrating the materials and equipment, child positioning and stoma care were taken with mannequins in the skills laboratory at the *Universidade de São Paulo* School of Nursing (USP-SN).

Implementation

The educational booklet was sent to USP-UH's marketing department for layout, in line with the standard educational materials made available by the institution.

A digital and printed version of the booklet was made available. The digital version was emailed to specialists/nurses for assessment. After adjustments, users/family members assessed the printed booklet.

Chart 2. Characterization of articles included in the educational booklet

Authors	Year	Journal	Title	Relevant Information
Pinto et al., (2015) ⁽²¹⁾	2015	<i>Revista da Escola de Enfermagem da USP</i>	<i>Segurança do paciente e a prevenção de lesões cutâneas mucosas associadas aos dispositivos invasivos nas vias aéreas</i>	Stoma care; fixing a tracheostomy; aspirating secretions; identifying the need for aspiration.
Urrestarazua et al., (2016) ⁽²²⁾	2016	<i>Archivos Argentinos de Pediatría</i>	Clinical consensus statement on the care of the child with a tracheostomy	Tracheostomy tube care; aspiration; humidification; device care; decannulation; social inclusion.
Avelino et al., (2017) ⁽²³⁾	2017	Brazilian Journal of Otorhinolaryngology	First Clinical Consensus and National Recommendations on Tracheostomized Children of the Brazilian Academy of Pediatric Otorhinolaryngology (ABOPe) and Brazilian Society of Pediatrics (SBP)	Aspiration of secretions; choice of probe caliber; depth of aspiration to avoid trauma to the distal trachea and the tip of the cannula; aspiration time to avoid hypoxia, pneumothorax, vagal reflexes; child's data; warning about airway patency above the tracheostomy tube; materials needed to care for children with a tracheostomy; accidental decannulation; insertion of a tracheostomy tube by a caregiver in an emergency; communication.
Silva et al., (2018) ⁽²⁴⁾	2018	<i>Revista Sociedade Brasileira de Pediatría</i>	<i>Consenso de Aspiração de Crianças com Tubo Endotraqueal da Sociedade Brasileira de Enfermeiros Pediatras (SOBEP)</i>	Biosafety standards; aspiration time; number of repetitions; instillation of saline solution; depth of aspiration.
Wang et al., (2017) ⁽²⁵⁾	2017	Australian Critical Care	Instillation of normal saline before suctioning: a meta-analysis of specific clinical trials.	Guidance on the importance of not instilling saline solution in a tracheostomy tube.
Lawrence et al., (2021) ⁽²⁶⁾	2021	Rehabilitation Nursing	Evidence-Based Care for Children with Tracheostomy: From Hospitalization to Home Care	Fixing the tracheostomy; aspirating secretions; frequency of aspirations; identifying the need for aspiration; inserting the aspiration tube according to the size of the tracheostomy tube to avoid tracheitis and ulceration; stoma care; humidification; hydration.
Pitzer et al., (2023) ⁽²⁷⁾	2023	<i>Revista Rene</i>	<i>Orientação ao paciente em pós-operatório de traqueostomia no processo de alta para o domicílio: revisão integrativa</i>	Care with endocannula cleaning; stoma; tracheostomy fixation; stoma protection; emergency situations; humidification; secretion aspiration; hydration; oral hygiene; nutrition; communication.
Center for quality and patient safety, Pediatric Otorhinolaryngology Service and Pediatrics Service HC UNICAMP, (2024) ⁽²⁸⁾	2023	<i>Universidade Estadual de Campinas</i>	<i>Manual de Cuidados da Criança com Traqueostomia</i>	Information on tracheostomy; fixing the tracheostomy tube; aspiration; warning signs; decannulation; food, hygiene; clothing; leisure.

Assessment

Conducted with experts (nurses) and users (family members). Experts assessed the booklet in terms of its objectives, content, usability and efficiency. After making the changes suggested by experts, the booklet was assessed by family members in terms of usability and efficiency.

The sample was non-probabilistic and by convenience. The sample included stomal therapy nurses and nurses working in the PC, CER, PICU, HCP and outpatient sectors at USP-UH and family members of children who use tracheostomies at home. Family members who were under 18, illiterate or visually impaired were excluded.

Data was collected using two instruments containing variables for specialist sociodemographic characterization (gender, age, sector of work, specialty in enterostomal therapy and highest academic degree) and booklet assessment in terms of objectives (purposes and goals), content (organization, structure and presentation), usability (ease of use) and efficiency (expected performance of the material). It also had variables for user sociodemographic characterization (gender, age, education, relationship with children, income, profession, main caregiver and number of caregivers) and booklet assessment in terms of usability (ease of use) and efficiency (expected performance of the material). The evaluators rated each item of the assessment variables as “disagree” (0) or “agree” (1), with space for justifications and suggestions.

Nurses were invited personally and those who agreed to take part provided their e-mail address. They received the invitation, the booklet and the data collection instrument by e-mail. Family members were invited during hospitalization, home care or while waiting for an appointment at the outpatient clinic. They received the printed booklet and had 30 minutes to read it. Assessment was carried out by means of an interview, where after signing the Informed Consent Form (ICF), they answered the characterization data and questions about usability (words used in the booklet are easy to understand; the content is easy to learn; it can be put into practice clearly; and the booklet is interesting) and efficiency (the booklet caught the attention; the drawings and pictures help to understand; letter size is adequate; and it arouses interest).

The data collected was entered into Microsoft Excel® and processed in the R⁽²⁹⁾ statistical package, with the support of a professional statistician. Sociodemographic and academic/professional variables were analyzed using descriptive statistics. Measures of central tendency and dispersion were presented for quantitative variables. Absolute and relative frequencies were calculated for categorical variables.

To check the level of agreement between nurses and family members, the Content Validity Ratio (CVR) was used.⁽³⁰⁾ The weighted average of the booklet assessment variables was calculated based on participants' responses, and “agree = 1” and “disagree = 0” values were assigned. Items with an average CVR \geq 0.80 were considered relevant and appropriate.

The project was submitted and approved by the USP-SN Research Ethics Committee, under Opinion 6.928.76, and by the USP-UH Research Ethics Committee, under Opinion 6.995.202. All participants signed the ICF.

Results

The planning of nursing care for children/families with tracheostomies, based on FCC, Orem's theory and Horta's theory, using standardized languages and with the support of PROCEnf-USP®, made it possible to identify risk diagnoses and focused on physiological, psychological and social aspects, contributing to the individualized and comprehensive child and family care. Chart 3 shows the diagnoses, outcomes and interventions that guided the content of the booklet's guidelines.

The “*Como cuidar da criança com traqueostomia?*” booklet was developed, containing 23 pages, with guidelines and care according to nursing care planning, on the following topics: child and family identification; recording/controlling cannula replacement; guidance on the reference Basic Health Unit; list and photos of materials provided by the Brazilian Health System (In Portuguese, *Sistema Único de Saúde - SUS*); information on what a tracheostomy is; the importance of handwashing before and after care; positioning children for handling the tracheostomy cannula; care with cleaning the stoma; handling and fixing the cannula; handling the manual secretion aspirator; type of suc-

Chart 3. Planning nursing care for children/families with tracheostomies

Diagnoses (NANDA-I)	Expected Outcomes (NOC)	Interventions (NIC)
Ineffective breathing pattern (00032)	Respiratory status: ventilation (0411)	Respiratory monitoring (3350)
Risk for infection (00004)	Risk management (1902)	Risk identification (6610)
Ineffective airway clearance (00031)	Respiratory status: airway permeability (0410)	Airway suction (3160)
Risk for impaired skin integrity (00047)	Tissue integrity: skin and mucous membranes (1101)	Skin surveillance (3590) Ostomy care (0480)
Risk for aspiration (00039)	Aspiration prevention (1918)	Aspiration precautions (3200) Positioning (0840)
Impaired verbal communication (00051)	Communication: expression (0903)	Improved communication: speech deficit (4976)
Inadequate health knowledge (00435)	Knowledge: disease management (1803)	Education: disease process (5602)
Body image disturbance (00118)	Self-esteem (1205)	Strengthening self-esteem (5400)
Risk for excessive caregiving burden (00401)	Family support during treatment (2609) Caregiver well-being (2508)	Family involvement promotion (7110) Caregiver support (7040) Family support (7140)

tion tube; secretion suction; what to do in emergencies such as accidental decannulation (cannula removal); communication with children; feeding; breastfeeding; clothing; hygiene and bathing; sleep and rest; social life; and guidance on family members' health and leisure. In addition, credits (authorship), bibliographical references and Quick Response Code (QR code) were presented, for easy access to the digital booklet.

Physical copies were printed, and a digital version was generated in Portable Document Format. Figure 1 shows some images of the booklet.

Thirty-three nurses were invited to take part in expert assessment. Of the 24 who agreed to take part, only 15 responded. Of the respondents, eight (53.3%) worked in the PICU, four (26.7%) in the CER, two (13.3%) in the PC and one (6.7%) was a stomal therapist. The HCP and outpatient nurses did not answer the

questionnaire. The majority of participants were female (14; 93.3%), with a mean age of 45.67 (SD=9.0) years. Ten (66.7%) had a *lato sensu* specialization; two (13.3%) had a master's degree; two (13.3%) had a doctoral degree; and only one (6.7%) had an undergraduate degree. In nurses' assessment of the booklet, the item related to usability, "The educational booklet is developed in an interesting way and is not tiring", was rated "disagree" by two participants, with a CVR of 0.73. To adapt this item, the order of information was changed so that it follows the care routine that should be adopted at home. The other items were considered relevant and adequate with a CVR >0.80. Other suggestions and corrections made were: adding a space for the identification and stamp of the professional in charge in the cannula change record; highlighting the importance of keeping the stoma dressing dry; mentioning children



Figure 1. Illustration of the "Como cuidar da criança com traqueostomia?" booklet cover and content

who use gastrostomy tubes and enteral/gastric tubes in feeding instructions; emphasizing that aspiration can be carried out with procedure gloves.⁽²³⁾ The total average CVR was 0.97, as shown in Chart 4.

Nurses gave positive comments to the booklet as a whole:

I found it very practical, objective and visually beautiful. Congratulations! (Evaluator 1)

The booklet design and construction were excellent, objective and clear. (Evaluator 4)

And comments on the content:

Congratulations on your beautiful work. I'm sure it will be very useful. I found the approach to the limit of introduction of the suction tube to avoid carinal injury to be excellent. (Evaluator 2)

After the corrections/suggestions made by nurses/specialists, the booklet was assessed by users. Ten

family members took part, nine mothers and one caregiver, all female, with an average age of 36.3 (SD= 8.54) years. Five (50%) had completed high school; six (60%) were housewives; and six (60%) reported a family income of two minimum wages. Three (30%) reported that the child was cared for by both the mother and the father.

Concerning booklet assessment by family users, all items in the sections assessed had a CVR \geq 0.80. Users made suggestions which were incorporated into the booklet, including: adding information about the "stopper" in the tracheostomy tube; adding hand hygiene with alcohol gel and inhalation; highlighting important information; adapting certain terms in the booklet for better understanding. The total average CVR was 0.95, as shown in Chart 5.

One family member made the following positive comment about the booklet:

Very nice booklet, I wish I had received it at the beginning of my son's tracheostomy use. (Evaluator 5)

Chart 4. Distribution of educational booklet assessment results by nurses (n=15)

Criteria	CVR
Objectives	
The content is in line with the proposed objectives	1.00
The objectives are consistent with the health education needs of family members of children with tracheostomies	1.00
Educational booklets are important for the care of children with tracheostomies	1.00
The educational booklet can be used to teach family members about caring for a child with a tracheostomy at home	1.00
Contents	
The content facilitates the process of learning how to care for a child with a tracheostomy at home	1.00
The content follows a logical sequence	1.00
The content contains the necessary care for children with tracheostomies at home	1.00
The booklet contains the materials needed to care for children with tracheostomies	1.00
The booklet covers the use of the Nursing Process in health education for family members regarding the care of children with tracheostomies	1.00
The booklet provides care for children with tracheostomies at home in accordance with biosafety criteria	1.00
Usability	
The text is clear and objective	1.00
The material is appropriate to the profile of family users of the university hospital	1.00
The booklet language is easy to understand for the target audience	1.00
The booklet is suitable for family members of children with tracheostomies	1.00
The educational booklet is developed in an interesting way and is not tiresome	0.73
The booklet clarifies doubts	1.00
Efficiency	
The information on the cover is coherent	1.00
The information is structured in agreement and spelling	0.87
The drawings and pictures in the booklet are appropriate	1.00
The letter size and type are adequate	1.00
The information is scientifically correct	1.00
Printed material is appropriate	1.00
The number of pages is adequate	0.87

Note: CVR - Content Validity Ratio.

Chart 5. Distribution of educational booklet assessment results by family members (n=10)

Criteria	CVR
Usability	
The words used in the educational booklet are easy to understand	1.00
The educational booklet content is easy to learn	1.00
It is easy to put the educational booklet content into practice	1.00
The educational booklet allows to learn about tracheostomy care for children at home in a clear and practical way	1.00
The educational booklet is developed in an interesting way and is not tiresome	1.00
Efficiency	
The educational booklet cover caught the attention	0.80
The drawings and pictures in the educational booklet help understand the texts	1.00
The letter size and type are adequate	1.00
The educational booklet makes to want to read to the end	1.00

Note: CVR - Content Validity Ratio.

The booklet can be accessed at the following address: https://www.canva.com/design/DAGRSx-HEHyc/-QOlCRJr_txuHmie5JXow/view?utm_content=DAGRSxHEHyc&utm_campaign=design-share&utm_medium=link&utm_source=editor#2

Discussion

The “*Como cuidar da criança com traqueostomia?*” educational booklet was developed, assessed and approved by specialists and users. The development of educational material in stages that range from conceptualization to assessment with specialists in the field and users (target audience) guarantees the content quality, clarity and relevance, making it possible to identify possible gaps in the approach, inappropriate language and complex or irrelevant information, ensuring that the booklet meets users’ real needs.^(6,31)

Considering the sociodemographic characterization of the booklet’s target audience, such as level of education, age group and social context, it is crucial for building effective and comprehensible educational material capable of promoting children’s health and well-being in an equitable manner. The language used, the format and illustrations should be adapted to facilitate understanding and access to information, empowering family members to care for children with tracheostomies.^(6,31)

Two studies were found that developed and validated educational booklets aimed at caring for children with tracheostomies. A study used the Delphi technique for validity, while the other applied the Content Validity Index. Both studies adapted the language to make the information more accessible, ensur-

ing that the target audience understood the necessary care.^(10,11)

In this research, the educational booklet developed was based on the FCC philosophy and Orem’s and Horta’s theories, according to the NP stages, using the NANDA-I, NIC, NOC classifications and with the support of PROCEnf-USP®, i.e., the content was not limited to tracheostomy care alone, as nursing care involves comprehensive care for children and their families. According to the nursing diagnoses identified, the outcomes to be achieved and the interventions needed to achieve them, the booklet contains guidance on communicating with children, preventing infections such as hand washing, positioning during feeding, care to avoid foreign bodies entering the tracheostomy tube during hygiene, wearing clothes and during sleep, stoma care, the importance of social life, contact with other children and attending school, among others.

A study carried out by Bossa *et al.* (2019) found that parents feel fearful about life after tracheostomy, reporting the adaptations they use to facilitate children’s and families’ daily living and carry out basic activities from hygiene to social life, which is often exchanged for isolation, since they do not know how to act on certain occasions, such as tracheostomy tube aspiration in an environment other than their own home, the concern about comments from outside people and even the fear of letting children play.⁽³²⁾ This demonstrates that the guidance provided by the nursing team during the hospitalization process should not be limited to tracheostomy care alone; it should consider the changes to the entire family routine and consider individuals as a whole. This allows for guidance in developing strategies that will make these patients’ lives easier.

Studies have also shown that parents find it difficult to find out what materials and devices they need to care for their children, as well as difficulties in acquiring them within the health network, as they are not directed to the correct places for collection.^(5,32) Bossa *et al.* (2019) also pointed out that the need to purchase materials causes financial losses for the family.⁽³²⁾ The booklet lists the materials needed to care for children according to what is provided by the SUS, indicating that they should be picked up at Primary Care and that the family will be duly directed by the hospital staff.

Moreover, the pediatric tracheostomy consensus recommends that, on discharge from hospital, a child with a tracheostomy should be accompanied by an identification card containing essential information such as children's details, healthcare services of reference for the family, and the number and size of the cannula.⁽²³⁾ It was considered valid to add this data to the booklet, as documenting and recording this information is fundamental to guaranteeing the continuity and safety of the care provided to the child, both at home and in hospital. Detailed records allow parents and caregivers to quickly access essential information, facilitating decision-making and the correct implementation of guidelines.⁽²³⁾ In emergencies, these records' availability can be decisive for the adoption of quick and effective measures. Thus, keeping this information recorded contributes directly to the quality and safety of childcare, encouraging active family participation in care.⁽²³⁾

Another important aspect addressed in the booklet was the management of emergency situations, since this is a recurring concern of parents and caregivers addressed in studies.^(5,32) According to previous research, such guidance should be provided during the hospitalization process.⁽²³⁾ Thus, the booklet contains guidelines that should be adopted in the case of accidental decannulation, prevention of tracheostomy stoppers, signs and symptoms of hypoxia and infections, as well as guidance on when to call the emergency service or seek the family's reference healthcare service.

About suctioning children's tracheostomy tube, a study suggests that family members should be given guidance on the depth of tube insertion to avoid trauma to the distal trachea, tracheitis and ul-

ceration. In addition, aspiration should take place at least on waking and before bedtime.^(23, 26) Furthermore, the Brazilian Society of Pediatrics does not recommend instilling saline solution in tracheostomies, since the solution is not completely aspirated by the aspiration tube, remaining in the respiratory system and not fluidizing secretions.⁽²⁴⁾ In this way, the booklet sought to list care related to aspirating secretions from a tracheostomy tube, such as identifying the need for aspiration, the frequency of aspirations, the materials needed, the limit for inserting the tube and handling the home aspirator, as well as guidelines for preventing stoppers and fluidizing secretions with the aid of humidification and oral hydration.^(23,26)

In line with other studies on validity of educational booklets for parents and caregivers, this study also identified the mother as the main caregiver.^(6,8) A study that analyzed the associations between the clinical course of children with tracheostomies and the psychological state of their caregivers revealed that all participants were mothers and main caregivers, with the majority being home workers.⁽³³⁾ Moreover, the results showed that these mothers' psychological status tends to deteriorate, especially when the children are colonized by microorganisms and undergo frequent hospitalizations. Given this scenario, it is essential that the health system allocates more resources to meeting these children's and their families' psychosocial needs, with special attention to home health support,⁽³³⁾ with nurses being the professionals who can facilitate transition of care from hospital to home.⁽³⁴⁾

In this research, risk factors for recreation and insufficient rest for family members/caregivers were identified, and the "Risk for caregiver role strain (00062)" nursing diagnosis was identified, currently in the 13th edition of NANDA-I, "Risk for excessive caregiving burden (00401)"⁽¹⁶⁾. Two expected outcomes were established⁽¹⁸⁾: "Family support during treatment (2609)" and "Caregiver well-being (2508)". The interventions⁽¹⁷⁾ were "Family involvement promotion (7110)", "Caregiver support (7040)", and "Family support (7140)". The booklet contains guidelines for caregivers to adopt healthy habits, engage in physical activity, have leisure and rest periods, and for families to be involved in care. During the booklet assessment, family members expressed surprise and were grate-

ful for the guidance provided to them, as they are not used to thinking about themselves or receiving guidance on the importance of recreation and rest from family caregivers.

Finally, it is important to highlight the ways in which the educational booklet can be accessed, both in print and digitally. The use of educational materials in digital format, with access facilitated by QR Code, represents a sustainable and innovative alternative, connecting the physical and digital worlds and allowing quick and practical access to essential information anywhere. This approach enhances new learning methodologies, making teaching more dynamic and interactive⁽³⁵⁾, as well as contributing to environmental preservation.

This research has limitations that need to be highlighted. It was not possible at this time to develop an inclusive booklet with audio-only guidance, which does not require reading and allows access for illiterate and visually impaired family members.

Conclusion

The educational booklet was developed and approved by specialists and users and can be used as educational material to prepare for de-hospitalization, as it provides guidelines for comprehensive care for children and their families at home. The booklet is available in USP-UH's inpatient and PICUs, CER, home care and outpatient clinics in digital and printed format. Future research could assess nursing care outcomes by measuring outcome indicators with users of the booklet. Future research is also needed into the development of inclusive educational material that can be accessed by illiterate and visually impaired parents and caregivers.

Contributions

Soares LA, Rogenski KE, Santos NC, Diogo RCS, Toriyama ATM, Nogueira PC, declared that they contributed to study conception, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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