

## Development and validation of educational material for parents of tracheostomized children

Elaboração e validação de material educativo para pais de crianças traqueostomizadas

Desarrollo y validación de material educativo para padres de niños con traqueostomía

 Natalia Maria Finato,  Alexandre Lins Werneck,  Simone Cavenaghi  
 Ana Elisa Rosselli Folchine

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**Objective:** to develop and validate a multidisciplinary educational booklet aimed at parents of tracheostomized children. **Methods:** methodological validation study by consensus of experts carried out using the Delphi technique and carried out in 2020, as well as evaluation of the booklet by parents, in a city in the interior of the state of São Paulo, Brazil. **Results:** 15 professionals were consulted in the first round and nine in the second; and five parents evaluated the 24-page booklet entitled: “*Caring for your child's tracheostomy: A guide for parents*”, by answering a questionnaire. There was 80% consensus for both groups. **Conclusion:** validation had consensus on all items by both groups.

**Descriptors:** Tracheostomy; Child; Health education; Patient care.

**Objetivo:** elaborar e validar uma cartilha educativa multidisciplinar voltada aos pais de crianças traqueostomizadas. **Método:** estudo metodológico de validação pelo consenso de especialistas feito por meio da técnica Delphi e realizado em 2020, bem como, avaliação da cartilha pelos pais, em uma cidade do interior paulista. **Resultados:** foram consultados 15 profissionais na primeira rodada e nove na segunda; e cinco pais em uma avaliação da cartilha intitulada: “*Cuidados com a traqueostomia de sua criança: Um guia para os pais*”, com 24 páginas, no formato de perguntas e respostas. Houve consenso de 80% para ambos os grupos. **Conclusão:** a validação teve consenso em todos os itens pelos dois grupos.

**Descritores:** Traqueostomia; Criança; Educação em saúde; Assistência ao paciente.

**Objetivo:** elaborar y validar un folleto educativo multidisciplinar para padres de niños con traqueostomía. **Método:** estudio metodológico de validación por consenso de expertos hecho mediante la técnica Delphi y realizado en 2020, así como evaluación del folleto por los padres, en una ciudad del interior de São Paulo. **Resultados:** 15 profesionales fueron consultados en la primera ronda y nueve en la segunda; y cinco padres evaluaron el folleto titulado: “*Cuidados con la traqueostomía de su hijo: Un guía para padres*”, con 24 páginas en formato de preguntas y respuestas. Hubo un consenso del 80% en ambos grupos. **Conclusión:** la validación tuvo consenso en todos los ítems por parte de ambos grupos.

**Descriptores:** Traqueostomía; Niño; Educación en salud; Atención al paciente.

Corresponding Author: Natalia Maria Finato – nataliafinato@yahoo.com.br

1. Physical therapist. Master. Faculdade de Medicina de São José do Rio Preto. São Paulo Brazil.

2. PhD. Professor of the Postgraduate Nursing Program at the Faculdade de Medicina de São José do Rio Preto. São Paulo Brazil

3. Physical therapist. PhD. Faculdade de Medicina de São José do Rio Preto. São Paulo Brazil.

4. Physical therapist. Master. Faculdade de Medicina de São José do Rio Preto. São Paulo Brazil.

## INTRODUCTION

**A** tracheostomy is a surgical opening made through the neck into the trachea. It is indicated when there is obstruction of the upper airways to promote prolonged mechanical ventilation or facilitate bronchial hygiene<sup>1</sup>.

In the United States, approximately 4,500 children undergo tracheostomy every year<sup>2</sup>. There was an estimated reduction in the incidence of the procedure between 2000 and 2012 from an average of six and eight tenths (6.08) cases for every 100,000 children per year, to an average of six (6.0). This decline is possibly related to the expansion of vaccination and better endotracheal intubation strategies<sup>3</sup>. Epidemiological data related to the percentage of tracheostomized children nationwide is scarce in Brazil. In 2016, including the adult and pediatric population, there were 17,532 procedures in public hospitals<sup>4</sup>.

Tracheostomized children are subject to complications, and rates vary from 12.6% to 30%. The most common complications are cannula obstruction, formation of mucous plugs and accidental decannulation<sup>5</sup>. Most complications related to tracheostomy originate from failures in preventive or assistance actions and can be avoided through continuing education practices focused on care<sup>6</sup>. During discharge, the caregiver must quickly adopt professional behaviors and, if they are not sufficiently prepared, they may experience increased stress, creating greater risks for the child<sup>7</sup>.

The work of multidisciplinary teams in assisting tracheostomized patients has demonstrated a reduction in episodes of adverse effects<sup>8</sup>. The educational materials offered to patients and family members are read later and reinforce the guidance that was received, being able to resolve doubts and support the conduct adopted in daily care<sup>9</sup>. Therefore, the objective of this study was to develop and validate a multidisciplinary educational booklet aimed at parents of tracheostomized children.

## METHODS

This is a methodological study whose data were collected in a pediatric university hospital, in the Northeastern region of the state of São Paulo, Brazil, between May and November 2020. Initially, the researchers developed the theoretical content and, later, validation was carried out in two stages: analysis of this information by invited experts and the final booklet by parents of tracheostomized children admitted to the pediatric ward.

In the first phase, employees of the institution with at least three years of experience in caring for tracheostomized children and who, after receiving information, agreed to sign the Free and Informed Consent Form (FICF) were considered for the study.

A questionnaire was used about the multidisciplinary care provided to tracheostomy children in the institution, aimed at parents or caregivers by a consensus of experts, using the Delphi method.

The Delphi technique is the name of a set of procedures that are carried out with the aim of elucidating and refining the opinions of a group of people. It can be used by a group of experts or individuals with specific knowledge<sup>10</sup>. Depending on the method, evaluations divided into rounds or rounds were used. A minimum consensus percentage of 80% was stipulated for each of the responses evaluated in the questionnaire, a value commonly used in similar research<sup>9</sup>.

The development of the questionnaire was the product of information contained in the institution's current protocols on guidelines and care for tracheostomy and tracheostomy aspiration in pediatrics, and also in manuals of international assistance programs for children with tracheostomy<sup>11-14</sup>.

In addition, scientific articles were used, the result of a search carried out in the electronic databases PubMed and Regional Portal of the Virtual Health Library (VHL) in the period between 2016 and 2020. The following keywords were used in the search, in Portuguese and English : “*tracheostomia/tracheostomy*”, “*criança/child*”, “*guia/guidelines*”, “*mortalidade/mortality*”, “*valvula de fala/speaking valve*”. Titles and abstracts were read in order to obtain potentially relevant articles.

The original questionnaire was composed of eighteen questions with their respective answers. The professional marked the alternative “I agree” or “I disagree” or “This question is not part of my daily life” and could also add opinions and corrections to each sentence. The form with the questions was created and sent by email to the participants, using a research management application Google Forms™, a free application that allows the user to create their own forms or use already existing ones, with a spreadsheet<sup>15</sup> . All questions demanded mandatory answers, and feedback was anonymous, so that it was not possible to identify the participant's email, according to the Delphi method. After the first round, the content was adapted according to the professionals' suggestions.

A second round of the questionnaire was sent, pointing out the statistical data from the first questionnaire and requesting a new answer for those sentences, in which the minimum consensus was below 80%. After analyzing the responses, the information was used to formulate the booklet, which was illustrated by a graphic designer, that is, four drawings were added, developed by an illustrator. The photographic images were taken by the researchers and the layout by a design agency.

The second stage involved the evaluation of the booklet by parents of tracheostomized children, admitted to the pediatric ward who agreed to sign the Free and Informed Consent Form, and respond to an adapted questionnaire with 13 simple questions with three possible answer: positive, neutral and negative after reading the booklet<sup>16</sup>. The minimum percentage of 80% of positive responses was considered for validation.

This research followed the guidelines and standards of Resolution No. 466, of December 12, 2012, of the National Health Council and was submitted to the institution's Research Ethics Committee. This is a by-product of the matrix research "Health education and management: Interrelated approaches to assistance, teaching and research".

## RESULTS

The participants of the first phase were 20 healthcare professionals working in different hospital sectors with training in the areas of: medicine, nursing, physiotherapy and speech therapy. In the second phase, the participants were five parents of tracheostomized children. Also in the review process, five articles were considered.

The booklet was titled: "*Caring for your child's tracheostomy: a guide for parents*", with 24 pages. In total, 12 references were used. The researchers were concerned about adapting the language of the material to facilitate understanding. Of the 20 professionals, 15 responded to the initial questionnaire sent by email in the first stage. The participants were six physical therapists (40%), five nurses (33.3%), two doctors (13.3%) and two speech therapists (13.3%).

After analyzing the statistical data provided by Google Forms™, it was observed in the first round that one of the 18 responses did not obtain the minimum percentage of 80% consensus, as seen in Table 1.

**Table 1.** Number of professionals and percentage who marked the options “agree”, “disagree” and “this question is not part of my daily life”. São José do Rio Preto, SP, Brazil. 2020.

Questions	No (%) “I agree”	No (%) “I disagree”	No (%) “*npdl”
What is a tracheostomy?	15 (100.0%)	0	0
How is a tracheostomy performed?	9 (60.0%)	6 (40.0%)	0
Why does a child need a tracheostomy?	14 (93.3%)	1 (6.7%)	0
How long will my child need a tracheostomy?	15 (100.0%)	0	0
How does the doctor choose the size of the cannula to use?	14 (93.3%)	1 (6.7%)	0
Why do some cannulas have a balloon?	15 (100.0%)	0	0
Will my child be able to talk with the tracheostomy?	15 (100.0%)	0	0
Will my child be able to eat and drink with a tracheostomy?	14 (93.3%)	1 (6.7%)	0
Will my child be able to smell and taste food after a tracheostomy?	13 (86.7%)	2 (13.3%)	0
How should I bathe my child after a tracheostomy?	15 (100.0%)	0	0
How should the tracheostomy be cleaned and bandaged?	14 (93.3%)	1 (6.7%)	0
How and how many times a day should I change the cannula attachment?	14 (93.3%)	0	1 (6.7%)
How is a tracheostomy suctioning performed?	14 (93.3%)	1 (6.7%)	0
How many times should I suction the tracheostomy?	14 (93.3%)	1 (6.7%)	0
How to prevent the secretion from becoming too thick?	15 (100.0%)	0	0
Is my child more likely to catch the new coronavirus because of the tracheostomy?	13 (86.7%)	2 (13.3%)	
What can I do to protect my child?	15 (100.0%)	0	0
What are the main issues that can occur with a tracheostomy?	15 (100.0%)	0	0

\*npdl. Not part of my daily life.

Despite the consensus above 80% in the other responses, the experts left 17 comments, with suggestions for changes to the text that were added to the work. In the second round, of the 15 initial participants, nine responded to the questionnaire, namely: five physical therapists (55%), two nurses (22.2%), two speech therapists (22.2%) and no doctor. The answer to the question that received 60% consensus was reformulated and, in the second round, it received 100% approval.

The content was divided into nine sessions: questions about the tracheostomy, talking and eating, bathing, cleaning and dressing, changing the attachment, aspiration and management of secretions, about the coronavirus, problems with the tracheostomy and references. The material consisted of front cover, title page, summary, content, references and back cover.

The educational booklet was printed with 21x15cm, 24 pages, in the “landscape” configuration format in the form of questions and answers, containing one figure, 22 photographs and four drawings. Furthermore, the file can be easily sent via messaging applications in Portable Document Format™ (PDF).

The last stage of validation, with the target audience, obtained a percentage above 80% of positive responses in the questionnaire, with the items: evaluation of the organization, writing style, appearance and motivation. There was no negative response, according to Table 2.

**Table 2.** Assessment of the organization, writing style, appearance and motivation of the booklet by the target audience (parents of tracheostomized children). São José do Rio Preto, SP, Brazil. 2020.

Questions	Positive Answers	Neutral Answers	Positive Answers %
<b>Organization</b>			
Did the cover catch your attention? (Yes/Partially/No)	5	0	100%
Is the content sequence adequate?	5	0	100%
Is the structure of the educational booklet organized?	5	0	100%
<b>Writing style</b>			
As for the understanding of the sentences, they are: (Easy to understand/Do not know/Difficult to understand)	5	0	100%
The written content is: (Clear/Do not know/Confusing)	5	0	100%
The text is: (Interesting/Do not know/Uninteresting)	5	0	100%
<b>Appearance</b>			
The illustrations are: (Simple/Do not know/Complicated)	5	0	100%
Do the illustrations complement the text?	4	1	80%
Do the pages and sections look organized	5	0	100%
<b>Motivation</b>			
In your opinion, will anyone who cares for children with tracheostomies who read this booklet understand what it is about?	5	0	100%
Did you feel motivated to read the booklet until the end?	5	0	100%
Does the educational material cover the topics necessary for parents to provide adequate care?	5	0	100%
Did the educational booklet suggest you take action or think about caring for your child's tracheostomy?	5	0	100%

## DISCUSSION

In the two validation stages of this study, agreement of at least 80% was observed in the first stage. Consensus occurred in the second round in the first phase, and in a single round in the second phase.

Of the 20 invited participants, 15 responded to the first questionnaire and nine to the second. The number of experts in the Delphi technique can range from six to thousands of participants, representation and experience are more significant than the sample size<sup>17</sup>.

The Delphi method has been used to validate instruments and programs in the health sector. In a recent study, the technique was used to develop and validate an instrument that estimates the costs of best practices for preventing and controlling hospital infections<sup>18</sup>. Still focusing on health education, researchers, also using the method, created and validated a training program for families and caregivers of people with dementia<sup>19</sup>.

Reinforcing the importance of attention focused on assisting people with tracheostomies, The Global Tracheostomy Collaborative was created in 2014. This group includes professionals, patients and family members who worked to outline and disseminate best practices regarding tracheostomy care<sup>20</sup>.

In 2017, the first clinical consensus and national recommendations for tracheostomized children were published, which highlighted the deficit in the standardization of care for this population, which can be attributed to the lack of guidelines for the Unified Health System (*Sistema Único de Saúde - SUS*) and the Brazilian National Agency of Health (*Agência Nacional de Saúde - ANS*)<sup>21</sup>. There are more recent initiatives, such as Ordinance No. 68, of November 23, 2018, which decides to add home invasive mechanical ventilation for respiratory failure, within the SUS domain, an action that includes and benefits tracheostomized children dependent on mechanical ventilation<sup>22</sup>.

In the United States, the impact on the readmission rate seven days after discharge and the perceptions of 87 caregivers of tracheostomized children on mechanical ventilation were evaluated regarding each element of a program that included videos, printed materials, cardiopulmonary resuscitation training and high fidelity simulation. The simulation was well received, and the questions that took place after the simulation were chosen as the component that most contributed to its training. There was a reduction in the readmission rate within seven days after implementing this program<sup>23</sup>.

In recent research in a children's hospital, a standardized care and education program for caregivers was developed and implemented, in order to generate data that evaluated its efficiency, through the review of conduct, educational booklets, materials and creation of a website. After the program, there was a drop in the rate of unplanned readmission within 7 days from 18.18% to 6.67% in 2014 and to 0% in 2015. In 2015, the 30-day readmission rate fell from 6.67% to 0% in 2016<sup>24</sup>.

Given the need for a multidisciplinary approach, there were 20 participants in the first round of the questionnaire, and nine in the second. The physical therapists had better adherence in both stages, with no medical professional participating in the second round. During the period in which the study took place, the new coronavirus pandemic began, which required new routines and restructuring of hospital sectors.

In this context, sending questionnaires by email via Google Forms™ made things easier. Furthermore, due to the importance of this subject, one of the questions in the booklet deals with the risks of these children contracting the new coronavirus and ways to prevent the disease in tracheostomized children.

A recent study analyzed 12 systematic reviews from different health science sectors that used the Delphi method to discuss the processes used and the quality of the findings, showing the lack of an epistemological and methodological basis<sup>25</sup>. Therefore, further investigations into the instrument now validated will be necessary.

In turn, the organization of the writing style, appearance and motivation for reading the booklet by the target audience was favorable and unanimous. This is low-cost educational material, and can also be sent to families in digital PDF format, via mobile phone, through messaging applications. Within the hospital context, it can complement multidisciplinary practices aimed at preparing the family for the important care role for this population and can also stimulate researchers in the construction of new instruments within this topic.

## CONCLUSION

The content of the booklet was validated through a consensus of experts and, in the final version, by parents of tracheostomized children. One can point out as limiting factors of this research the use of the Delphi method, which despite being widely used, has restrictions. Furthermore, the dichotomous approach used (agree or disagree) made it impossible to apply a consistency test and verify that the concordant responses were not the result of chance. Also, the number of parents evaluated was small.

Although the dichotomous approach used makes it impossible to apply a consistency test and verify that the concordant answers were not the result of chance, the instrument can contribute to the prevention of complications, with its inclusion in training programs for parents or caregivers, to guide them regarding the necessary care in assisting tracheostomized children, during the hospital discharge process or in subsequent hospitalizations. It can also be used by other researchers or institutions.

It is suggested to evaluate the further use of the instrument now validated with a greater number of parents and other studies that deepen the use of booklets in guiding parents of children with tracheostomy.

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