

## ORIGINAL ARTICLE

# HOME CARE FOR CHILDREN USING A TRACHEOSTOMY: CAREGIVERS' PERSPECTIVE IN THE AMAZON CONTEXT\*

### HIGHLIGHTS

1. Some caregivers don't feel safe to perform tracheal aspiration.
2. Health education is fundamental in the hospital discharge process.
3. Health professionals must respect the cultural and social values of caregivers.

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### ABSTRACT

**Objective:** To describe caregivers' perception of tracheostomized children about the challenges in discharge to their homes in the Amazonian context. **Method:** A descriptive, qualitative study was conducted with 16 caregivers of tracheostomized children who experienced dehospitalization in a children's hospital in Rio Branco – Acre – Brazil. Saturation-defined sampling, data collected with a semi-structured script from August to December 2021, submitted to Bardin Content Analysis. **Results:** the analysis resulted in four categories: (1) feelings experienced with the use of the tracheal device; (2) routine tracheostomy care that caregivers consider important; (3) questions and reports about tracheal aspiration; and (4) conduct in the face of complications in children using tracheostomy. **Final remarks:** the fear of learning the tracheal aspiration technique and of being discharged from the hospital reinforces the need for early and continuous education for caregivers, focusing on routine and emergency care for tracheostomized children.

**KEYWORDS:** Pediatric Nursing; Tracheostomy; Child Health; Home Nursing; Caregivers.

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## INTRODUCTION

A tracheostomy is an invasive procedure that guarantees ventilation in cases where the airway is compromised or due to the need for prolonged mechanical ventilation<sup>1</sup>. International literature reports that 0.5 to 2% of children submitted to intubation and mechanical ventilation in intensive care units require tracheostomy<sup>2</sup>. A study that addresses the epidemiology of pediatric tracheostomy indicated that 24.8% of the causes were cardiorespiratory, 28.7% neurological, and 46.5% due to anatomical airway obstruction<sup>3</sup>.

Institutional data from the Hospital Infection Control Commission department of a hospital in Rio Branco, Acre, showed that the pediatric tracheostomy rate was 1.83% per month in 2020. They were associated with longer survival of preterm infants and of children requiring prolonged ventilation.

The care of children using a tracheostomy is addressed in discussions and consensus among professionals who serve this population. In 2017 the Clinical Consensus of National Recommendations in Tracheostomized Children from the Brazilian Academy of Pediatric Otorhinolaryngology (ABOpe) and the Brazilian Society of Pediatrics (SBP) was published<sup>2</sup>. However, the invisibility of the nurses' participation in preparing this document, a key actor during hospitalization and preparation for hospital discharge, was noted.

Faced with the health circumstances of tracheostomized children, caregivers express anxiety about the future, fear, internal conflicts, impotence, and difficulty in adapting to the new reality of life<sup>4</sup>. Since they are closer to the patient and their caregiver, the health team, especially the nursing team needs to accept and understand their challenges, which require preparation and training to carry out care in the home environment after discharge from the hospital. In addition, they need to be prepared to act in emergencies, generating physical and emotional exhaustion<sup>5</sup>.

Cultural differences and locoregional characteristics are some aspects that must be considered for health education for caregivers of tracheostomized children. In addition to providing quality care, health professionals must consider and value these aspects, as they will influence the understanding of what is being said and the daily care provided. In 2006, the Pact for Health already addressed this issue, strengthening the dynamic and flexible nature necessary for regionalization, as opposed to closed methods, which are rigid in their application<sup>6</sup>.

Currently, the pediatric hospital, the setting of the study, which treats tracheostomized children in the Amazonian context, does not have post-discharge care. Thus, for caregivers to develop home care without risks to children's health, health education actions must be carried out, seeking the understanding of the target audience and valuing their stories, customs, knowledge, and experiences.

Developing strategies to support these caregivers in preparing for hospital discharge, based on understanding their feelings, routines with a tracheostomy, and their difficulties in managing care, is an inclusive process adapted to the needs of the assisted population<sup>7</sup>. Thus, the objective of this study was to describe caregivers' perception of tracheostomized children about the challenges in the process of discharge to their homes in the Amazon context.

## METHODS

A descriptive study with a qualitative approach, conducted with caregivers of tracheostomized children, extracted from a professional master's thesis. In preparing this manuscript, the criteria for qualitative study reports, present in the COREQ checklist —

Consolidated criteria for reporting qualitative research<sup>8</sup>, were considered.

The study was conducted at the only referral unit in the Acre state to care for children from 0 to 14 years old, providing clinical and surgical hospital care. This hospital has 50 beds and receives regulated patients from Acre, almost every state in the Western Amazon, and the countries bordering Acre. Some of the public served comes from places where access is difficult, such as rural areas, riverbanks, isolated areas, and indigenous villages.

It was decided to recruit all caregivers for post-operative tracheostomy patients in the wards from August to December 2021. The inclusion criteria were the companions of tracheostomized children over 18 years of age and at least 15 days after surgery, and those scheduled to remove the tracheostomy tube before hospital discharge were excluded.

A prior conversation was held with the caregiver to discuss the research objectives and a subsequent invitation to participate in the study. Those who accepted agreed on the most appropriate day and time for the interview.

Each interviewee participated in the research voluntarily, being informed about the risks and benefits, voice recording, and the estimated time to conduct the interview (average of twenty minutes)<sup>9</sup>. The interviews were terminated when data saturation was noticed.

Two interviews were conducted as a pilot test to verify the adequacy of the questions and were subsequently excluded from the final sample. There was a need to readjust some questions to improve communication, including the signature in the TCLE, Interview Script, and Voice Recording Term for the illiterate, using a pad and ink for stamping.

It should be noted that in some situations, due to the linguistic limitation, it was necessary to mimic so that caregivers could understand the questions and, also, help was obtained from people from the Casa do Índio, indigenous professionals who were accompanying the children and their caregivers and made the necessary translations.

Data collection took place through an interview divided into two parts: the first was to characterize the participants, with questions about sociodemographic data: gender, age, place of residence, level of education, type, and housing conditions. In the second, six questions were asked related to activities of daily living and tracheostomy care: (1) How do you take care of a tracheostomized child daily? (2) Do you think knowing how to care for a child with a tracheostomy is important? (3) What complications do you think might happen to a tracheostomized child? (4) Do you have questions about tracheal aspiration? (5) What if the cannula comes out accidentally do you know what to do? (6) What is your greatest fear during tracheostomy care?

Participants' characterization data were stored in the Microsoft Excel program and analyzed using simple descriptive statistics. The data from the interview recordings were fully transcribed, stored in the Microsoft Word program, and analyzed according to Content Analysis, developed by Bardin<sup>10</sup>. A fluctuating reading of the material and searching for elements to compose the analysis was performed, the categories were defined and, then, the results were interpreted. The content analysis of the interview took place in three phases: pre-analysis, exploration of the material, and the categorization of the data.

The research was approved by the Research Ethics Committee (REC) of the Universidade Federal Fluminense, opinion No. 4,897,760. To guarantee the anonymity of the participants, each one was identified with the name "Caregiver", followed by the number "1", and so on.

## RESULTS

The sample comprised 16 caregivers. Among the interviewees, 81% are female (12 biological mothers and an aunt), and 19% are male (two biological parents and a caregiver), with 31% of the participants being indigenous from three different ethnicities with their language. All participants are between 18 and 46 years old.

Regarding the residence of these participants, 25% are from other states. Among those living in Acre, 69% are from Rio Branco, and 31% are in regions far from the capital, between 228 km and 635 km, in hard-to-reach areas. Regarding the level of education, 20% are illiterate, 12% have incomplete elementary education, 12% have incomplete secondary education, 44% have completed high school education, and 12% have completed higher education. However, most interviewees showed a low level of understanding during the interviews. Regarding housing, 50% live in wooden houses, 37% in brickwork houses, and 13% in mixed houses.

Based on the analysis of interview data, four categories were defined, as described below:

### Category 1 — Feelings experienced with the use of the tracheal device

This category of analysis presents the diverse feelings that caregivers experience when dealing with a child with a tracheostomy.

*It is very delicate care [...] it is a child that requires much greater care, we are afraid of something, [...] it is care with increased attention, [...] greater attention, as I said. It's about being alert at all times. (C3)*

After inserting a tracheostomy, caregivers express anxiety about the future, fear, internal conflicts, and powerlessness in the face of the new reality.

*It's hard to say, [...] because before I had one experience and now I have another, [...] much more careful. Very high hygiene, great care. (C4)*

*Caring is hard, isn't it? [...] But we have to take care because we are mothers and we have to do what we know because at first I didn't know, [...] I cried even so I could vacuum, but now I care for her. I take care of her alone at home. (C5)*

### Category 2 — Routine tracheostomy care that caregivers deem important

Caregivers report that, in addition to the difficulties of dealing with the new one, there is a need for a second caregiver to perform some actions, and the risk of decannulation is evident when replacing the tracheostomy fixation. In addition, there is a need to develop skills in the face of emergencies that may be present from now on.

*I can't do this thing about changing her fixation on my own. I have to switch with my boy so that he can hold on, help me, because only I can't do it, I'm afraid to let go and I get scared and I call him to help me [...] just like that, sometimes, he breaks up and I can't get rid of it at all, so I have to call the SAMU to be able to remove it [...] because I can't do it and, from time to time, it goes away very quickly, get there and take it off and she's calm down. (C5)*

*When I'm going to change the fixation, you have to be very careful, because in an oversight, sometimes, he even hits my hand, he hits my hand here. And you want to take my hand away. (C11)*

*That's very important, having people always be there with their mothers, right? To teach properly, not teaching just once and already thinking that the mother already knows how to vacuum, because she has to be slow and patient [...] vacuuming, exchange, cleaning, right? Inside the tracheostomy, both outside and inside. (C9)*

### **Category 3 - Questions and reports about tracheal aspiration**

During the interview, there were two specific questions about tracheal aspiration, as it is the main procedure performed constantly. It should be noted that not all caregivers consider themselves capable of performing such a procedure, and when they do, they fear causing other problems or harm, jeopardizing the smooth progress of the care offered to the child at home.

*Sometimes I'm afraid, because when I'm going to vacuum it, [...] despite vacuuming it a long time ago, I don't know exactly the right point to arrive at, [...] afraid of hurting, of not knowing, because there are times when I vacuum it, I finish vacuuming it, [...] it's already secreted right out here again. Then I get scared of putting too much inside and hurting him and I don't know, I'm afraid of that. (C4)*

*I'm afraid of vacuuming and hurting her inside. [...] Because her father, once vacuumed and hurt her, because he didn't know how much about the probe, and then, when he saw that it hurt, he sat down and started crying [...] because he didn't know what it was, because it had bled, blood came out, and then he became nervous. (C5)*

*[...] I wanted to know how you care for and vacuum. [...] If you had material, I could see. How is it. (C8)*

*(...) And the child's limits, in order to vacuum, I have to know the limit, because here, in the hospital, I've seen even a professional many times, I see them exceeding my son's limit (...) (C10)*

It should be noted that C8 states that she would like to know how to care for and vacuum, and she cites the desire to have educational support material to serve as a guide.

*Because I still don't know how to vacuum inside the trachea, [...] I don't know how deep the probe goes; I don't know how far it goes. For me, it's important, isn't it, to know why I'm afraid of hurting, hurting, blood coming out, something. (C7)*

### **Category 4 - Conduct in the face of complications by children using a tracheostomy**

Interruptions with patients who have a tracheostomy are common, due to the device requiring specific care, and caregivers address the main fears:

*Fear of coming out of the windpipe or vacuuming it and not being able to remove 'the thing' [cork]. (C1)*

*Decanular is one thing, obstruction by corks, another, [...] I have a normal pulse oximeter. So, I'm afraid that at home at night I'll go to bed and he'll be very secretive, and I won't wake up. (C10)*

We know that accidental decannulation is a possibility that requires emergency procedures so that the airway does not collapse, in addition to being associated with morbidity and mortality.

*The problem, I think, is that if I don't keep an eye on it, it will come out, and he will die; my fear is if the trachea comes out. [...] He's going to die; I'm not going to be able to do*

anything. (C8)

*Fear of bacteria and infection; take the greatest care with the trachea. (C2)*

*The greatest fear is broncho-aspiration, [...] I believe that something will fall into the windpipe and we will not be able to remove or possibly release cork-like secretion, for example, that it could cover this tracheal hole [...] because it's such a small hole, and then there comes a thicker secretion or even water falls, or when it grows up, it will be able to insert a foreign body and you are afraid. (C3)*

*[...] a fly comes in and I can't remove the cork so it can breathe and tear off the windpipe. (C4)*

*Feeling sick. Because the baby has low saturation from time to time. Then we have to take the Ambu and use it, I think so. Because it's very difficult. We know more or less how it is monitored, when we go home, it is without a device, we will not know how to monitor it and then we will always be watching. To find out if he's well or if he's feeling sick. (C7)*

*Because it saturates and turns purple. My concern is that, with her. (C12)*

## DISCUSSION

The insertion of any new device, even to make life easier, has brought with it numerous questions<sup>1</sup>. The presence of a health team that encourages caregivers to assist and participate can effectively contribute to the improvement of psychological aspects<sup>11</sup>.

Caregivers have a significant emotional impact in dealing with children with chronic respiratory impairment at home<sup>12</sup>. The need to reorganize family life in the face of the child's dependence on the device and the demands of care comes to the fore.

Feelings of uncertainty and insecurity, reported by the participants in this study, add to the need to consider the location where each family resides. In the Amazonian context, while some families live near large centers, others require large movements, either by water or by land, to reach the nearest health facility. A study that described the contributions of community health agents in the Amazonian context points to family care and the difficulties faced by these professionals in meeting the needs of each family.

Even if complex planning is used, visits can take place every two months due to access conditions. Another highlight is poor sanitation situations, which are a considerable problem when it comes to the management of tracheostomias<sup>13</sup>.

Care to ensure maintenance and continuity of life are not simple behaviors. Nurses should promote safe and high-quality care in order to reduce hospital admissions, assess the learning needs of family caregivers, and provide health education about tracheostomy care<sup>6-14</sup>.

A highlight is that complications with tracheostomy occur with a high frequency, with late complications occurring in greater numbers than early<sup>12</sup>. A meta-analysis highlighted those complications, whether early or late, can vary between 5% and 46.9% of cases, and may occur: accidental decannulation, stoma infection, bleeding, subcutaneous emphysema, granulation, tracheocutaneous fistula, fistula for the unnamed artery, rupture of the posterior tracheal wall, subglottic stenosis, pneumothorax, fatal or near-fatal tube obstruction, and pneumonia<sup>15</sup>.

Studies indicate that inadequate humidification, irregular aspiration using the wrong technique, and dehydration can lead to the formation of mucosal plug<sup>16</sup>, one of the main emergencies in the use of tracheostomy, which could be prevented with some

care and guidance. Another highlight is the continuous presence of moisture in the skin, which enables the development of erythema, which is why frequent fixation changes are recommended to keep the skin dry and prevent tissue maceration and skin breakage<sup>17</sup>.

Caring for a child with a tracheostomy requires training and guidance from health professionals, considering that at home this responsibility will be the responsibility of the caregiver, who will provide care that until then was performed by a specialized team at the hospital<sup>16</sup>. This transfer of roles is an essential component in the care process<sup>12</sup>, it must take place in a clear and careful manner, for the learning process to be healthy.

Hygiene allows the permeability of the child's airways, avoiding obstructions<sup>17</sup>, this care practice is one of the most important and will depend on the amount of secretions the child has. The tracheal mucosa is delicate and sensitive to catheter trauma and pressure, so aspiration should be performed gently, whenever necessary<sup>16</sup>. Every tracheostomized patient who requires aspiration should use aspiration tubes appropriate to the diameter of the tracheostomy cannula<sup>18</sup>.

Respiratory infections in children with a tracheostomy may be common because the device is a door, facilitates colonization, and promotes the growth of bacteria<sup>17</sup>. It is one of the causes leading to recurrent hospital admissions. It is necessary that during the discharge process, the professionals responsible for the health education of these family members discuss safety measures, and parents must be instructed to avoid dust, smoke, animal hair, small toys, water sports, and bathing with only 1-2 inches<sup>18</sup>.

Training with these families on how to deal with emergencies, such as accidental decannulation, which requires immediate replacement of the cannula<sup>16</sup>, is extremely important and is a major concern on the part of the caregivers interviewed. One way to minimize these caregivers' distress is to prepare and ensure that families have access to and know how to use emergency equipment. The use of "GO-bags", a type of bag with emergency supplies, can reduce the number of adverse events<sup>19</sup>.

Resources used in the health education process, such as conversation circles using puppets carrying technological devices<sup>20</sup>; and printed educational technologies, assist family members in the transition process, empowering them to carry out new knowledge, and, through educational strategies with family members and caregivers of children, it is possible to provide an improvement in the quality of care in the family context<sup>21-22</sup>.

In this context of education and health, educational actions aimed at specific care related to the use of technological devices are indispensable, by improving the quality of care provided, they allow and provide opportunities for dialogue, listening, and exchange of information, making it possible for this family to clarify the yearnings experienced<sup>1</sup>. It should be noted initiatives that focus on the construction of materials focused on local contexts, such as a study that prepared an educational booklet for caregivers of the elderly in the Amazon region, encouraging, through its own language, the dialogue between patients, caregivers, and health professionals<sup>23</sup>.

Giving caregivers a voice to express their doubts about this care is essential. Although studies point to the importance of preparing families for home care, most do not indicate possible health education strategies with the families of these children<sup>1,22</sup>.

Nursing must prioritize the educational aspects of care, with the co-responsibility of the care provided by the family, so that satisfactory communication occurs between caregivers and the health team<sup>24</sup>.

The limitation of the study lies in the fact that it was conducted with caregivers of tracheostomized children admitted to a single pediatric institution, which, even as a reference in the state, the results cannot be generalized, representing only the outcome of a group of participants that have peculiarities in the Amazonian context. In addition, the interviews took place close to the bed, which may have interfered with the interviewee's attention to the answers, as the unit does not have an outpatient clinic.

## FINAL CONSIDERATIONS

Based on this study, it was possible to identify the challenges presented by the caregivers of tracheostomized children in the process of discharge from the hospital. The first of these was the shock of the reality of entering the hospital with a child and returning home with a patient. The second is related to the lack of familiarity with the tracheal aspiration technique and the management of possible complications that these patients may experience, as they are caregivers who have no health education and, suddenly, need to perform an invasive procedure for the survival of the child being cared for.

The fear of learning the technique of tracheal aspiration and hospital discharge represented in the caregivers' speech reinforces the need for early and continuous education for caregivers focusing on routine and emergency care for tracheostomized children.

Although not reported in the statements, the importance of these caregivers' cultural and regional aspects is highlighted. This study identified some peculiarities, such as indigenous people of different ethnicities with their own languages and residents of different regions of the Amazonian context, some with difficult access to health services. Both situations must be respected and valued by health professionals, with the main focus on ensuring the appropriate level of understanding so that caregivers are safe to provide care at home.

This study may contribute to the visibility of tracheostomized children and the challenges faced by their caregivers. Furthermore, it is expected that health professionals, especially nursing professionals, can provide quality education so caregivers can develop safer home care.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Pereira IC, Flores PVP**. Drafting the work or revising it critically for important intellectual content - **Pereira IC, Flores PVP, Silva LF da**. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Pereira IC, Flores PVP**. All authors approved the final version of the text.

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