

AMERICAN THORACIC SOCIETY DOCUMENTS

Care of Infants and Children with Tracheostomies An Official American Thoracic Society Clinical Practice Guideline

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Abstract

Background: The increase in tracheostomies among infants and children, driven by medical advances and evolving family preferences, underscores the need for standardized, evidence-based guidelines. This guideline outlines management recommendations for these medically complex and resource-intensive children with tracheostomies, incorporating best evidence on diagnostic tools and streamlined care protocols.

Methods: This Clinical Practice Guideline adheres to American Thoracic Society policies and procedures, using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach to form clinical questions, summarize evidence, and develop recommendations with a health equity perspective. A multidisciplinary panel with expertise in pediatric tracheostomy care contributed to recommendations for ethical considerations, discharge processes, in-home caregiver requirements, and diagnostic tools (tracheal aspirate cultures, bronchoscopy, and polysomnography).

Results: The panel recommends applying ethical principles to guide shared decision-making about tracheostomy placement

(strong recommendation). We also recommend a standardized discharge process involving comprehensive family caregiver training for safe transitions from hospital to home (conditional recommendation). A continuously awake, trained caregiver to manage emergencies is also recommended for high-risk patients (strong recommendation). The panel recommends tracheal aspirate cultures during acute respiratory episodes to guide antibiotic therapy, but not for routine surveillance (conditional recommendation); bronchoscopy for thorough airway examination before tracheostomy decannulation (strong recommendation); and polysomnography before decannulation to ensure respiratory stability (conditional recommendation).

Conclusions: These guidelines aim to standardize and improve the management of pediatric patients with tracheostomies by providing evidence-based recommendations for ethical considerations, discharge planning, and diagnostic assessments. Implementing these guidelines aims to enhance patient safety and quality of life through a structured and patient-centered approach.

Keywords: tracheostomy; pediatric; home mechanical ventilation; bronchoscopy; shared decision-making

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Summary of Recommendations

Recommendation 1. We recommend applying ethical principles (beneficence, nonmaleficence, autonomy, and justice) to guide shared decision-making about tracheostomy placement (*strong recommendation, very low certainty of evidence*).

Recommendation 2. We suggest implementing a standardized discharge process to facilitate the safe transition of tracheostomy-dependent children

from hospital to home (*conditional recommendation, low certainty of evidence*).

Recommendation 3. We recommend that an awake and alert trained caregiver always be present with children at risk of immediate decompensation due to tracheostomy-related complications (*strong recommendation, very low certainty of evidence*).

Recommendation 4A. In well children with tracheostomy tubes, we suggest against routine surveillance of tracheal aspirates for bacterial growth (*conditional recommendation, low certainty of evidence*).

Recommendation 4B. In children with tracheostomy tubes and concerns for lower respiratory tract infection, we suggest culturing tracheal aspirate when needed to guide management (*conditional recommendation, low certainty of evidence*).

Recommendation 4C. In children with tracheostomy tubes who were recently treated with antibiotics and are clinically improving, we suggest against test-of-cure tracheal aspirates (*conditional recommendation, low certainty of evidence*).

Recommendation 5A. For children with tracheostomies, we suggest performing an endoscopic airway evaluation in those

A data supplement for this article is available via the Supplements tab at the top of the online article.

Artificial Intelligence Disclaimer: No artificial intelligence tools were used in writing this manuscript.

with a change in symptoms or with persistent symptoms unresponsive to medical management (*conditional recommendation, low certainty of evidence*).

Recommendation 5B. For children with tracheostomies, we recommend performing a complete airway evaluation before a decannulation attempt. Airway evaluation should include an assessment of 1) nose and nasopharynx; 2) oropharynx and oral cavity; 3) supraglottis and larynx; and 4) subglottis, trachea, and bronchi (*strong recommendation, low certainty of evidence*).

Recommendation 6A. We suggest that, in addition to a formal airway evaluation, either a polysomnogram or pulse oximetry study (with or without capnography) under direct observation with a capped tracheostomy (or occluded stoma) be performed as part of the evaluation for decannulation readiness (*conditional recommendation, low certainty of evidence*).

Recommendation 6B. We suggest polysomnography with a capped tracheostomy (or occluded stoma) in the following situations: 1) assessing transition readiness from invasive to noninvasive ventilation; 2) unclear cause of failed capping trials; 3) for patients with medical and/or airway complexity (*conditional recommendation, low certainty of evidence*).

Introduction

The population of infants and children requiring tracheostomies has grown rapidly over the past two decades because of medical advances and evolving patient and family preferences. These medically complex children have significant utilization across all healthcare sectors. Total healthcare spending in the 2 years after tracheostomy placement was \$53.3 million for a cohort of 502 children (1). Children with tracheostomies are at high risk of significant morbidity and mortality. The rates of in-hospital mortality and tracheostomy-related complications in the 2 years after tracheostomy placement are 9% and 38.8%, respectively (1). The delay in recognizing and responding to emergencies can have deleterious or fatal consequences. Thus, evidence-based guidelines to standardize pediatric tracheostomy care are urgently needed (2). Caregivers therefore play a central role in ensuring the health, safety, and well-being of individuals with a tracheostomy. In this guideline, a caregiver is defined as any family member, trained

professional, or community member who provides essential support—such as airway management, monitoring, and daily care—for an infant or child with a tracheostomy outside of the hospital setting (3). In accordance with the American Thoracic Society (ATS) mission to improve global health through research, clinical care, and public health in respiratory disease, critical illness, and sleep disorders, this guideline aims to standardize best practice, improve clinical outcomes, and identify disparities that contribute to inequitable health care for this high-risk population.

In 2000, the ATS published a statement on the care of the child with a chronic tracheostomy tube, a comprehensive, consensus-based review of essential equipment, caregiver competencies, and potential complications (4). This document, structured as an official statement rather than a clinical practice guideline, is a key resource for pediatric pulmonologists, critical care clinicians, rehabilitation specialists, and other providers who care for children with tracheostomies. In 2013, the American Academy of Otolaryngology–Head and Neck Surgery (AAO-HNS) published a clinical consensus statement on pediatric and adult tracheostomy care (5). Among the 77 clinical care statements, 8 applied to children. The ATS published a clinical practice guideline in 2016 for pediatric chronic home invasive ventilation, which did not necessarily apply to all infants and children with tracheostomies (6). Thus, despite these consensus statements and guidelines, critical gaps in care remain, including guidance on the ethics and health disparities affecting children with tracheostomies, discharge processes, in-home caregiver monitoring of a child with a tracheostomy, tracheitis management, bronchoscopic airway evaluation, and the utility of polysomnography in this population. In addition, the significant growth in the field's literature over the past 20 years highlights the need for up-to-date, rigorously developed, data-driven, comprehensive guidance for clinicians that considers differences in access to health care and resources.

This clinical practice guideline focuses on clinical topics that have not been addressed by prior consensus statements. Patient/intervention/comparator/outcome (PICO) questions were chosen using a combination of clinical priority topics and available literature. Important areas for future research are also identified.

Methods

This clinical practice guideline was developed in accordance with ATS policies and procedures. We used the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach to formulate clinical questions, identify and summarize relevant evidence, and develop recommendations for clinical practice (7, 8). The co-chairs (C.D.B. and R.A.) submitted a proposal that was reviewed and approved by the ATS Assembly of Pediatrics, Program Review Subcommittee, and Board of Directors. A multidisciplinary panel of international specialists with expertise in pediatric tracheostomy and guideline development methodology was formed. Represented disciplines included pediatric pulmonology, pediatric otolaryngology–head and neck surgery, respiratory therapy, and nursing, together with families of patients with tracheostomy. Conflicts of interest were disclosed and managed appropriately. The committee identified six specific questions: three addressing the role of diagnostic tools (tracheal cultures, bronchoscopy, and polysomnography) and the other three focusing on ethical framework, standardizing discharge process, and caregiver requirements at home. The PICO format was used to formulate each question, and formal searches in Medline, Embase, CINAHL (for the first three PICO questions: ethics, standardized discharge process, and awake caregiver), and the Cochrane Central Register of Controlled Trials were performed. We included studies of infants, children, and adolescents who had undergone tracheostomy. Recommendations were described as “strong” or “conditional” based on the evidence (Table 1) (7–9). Recommendations were decided by consensus, requiring at least 80% agreement from panelists to be accepted. Detailed methods are included in the online supplement.

Question 1: Should Ethical Principles be Applied to Conversations with Families about Tracheostomy Tube Placement for Their Infants and Children?

Background

Tracheostomy prevalence and severe chronic conditions requiring this procedure have

Table 1. Implications of Strength of Recommendations to Stakeholders

Stakeholder	Strong Recommendation	Conditional Recommendation
Patients	Most individuals in this situation would want the recommended course of action, and only a small proportion would not.	The majority of individuals in this situation would want the suggested course of action, but many would not.
Clinicians	Most individuals should receive the recommended course of action.	Recognize that different choices will be appropriate for different patients and that you must help each patient arrive at a management decision consistent with her or his values and preferences.
Policy makers	The recommendation can be adopted as policy in most situations, including for the use as performance indicators.	Policy making will require substantial debates and involvement of many stakeholders. Policies are also more likely to vary across locations.

increased because of clinical innovations and shifts toward family-centered care (10–13). Patients and families increasingly share decision-making with providers. In the United States, home-based care for children with tracheostomies became possible 40 years ago through the Tax Equity and Fiscal Responsibility Act Medicaid Eligibility Option, which expanded Medicaid coverage to children with disabilities regardless of family income (14). Although these changes improved care for children with critical airway obstruction or chronic respiratory failure, decisions around this potentially life-sustaining intervention remain challenging.

Tracheostomies are not curative and involve risks that affect both the child and family. Decision-making must account for child-, family-, and community-level factors. Tracheostomy may serve as a bridge to recovery or a lifelong necessity. Clinical norms and care options for those with severe disabilities or reduced life expectancy continue to evolve (15, 16). Thus, providers should respect family preferences and avoid imposing personal values on families who may choose tracheostomy for their child (17, 18).

Ethical principles. Four guiding ethical principles should be used to guide shared decision-making before tracheostomy placement (19).

Beneficence is the ethical duty of providers to act in the patient's best interest. When physicians believe a tracheostomy will prolong life, reduce sedation needs, enable discharge to home, and facilitate growth and development, they may recommend tracheostomy as a preferred treatment option.

In contrast, **nonmaleficence** is the obligation to first do no harm. If a tracheostomy would merely prolong suffering—because of severe disability, intractable pain, lack of autonomy, severely

restricted childhood development and life expectancy, or other grave circumstances—providers may elect not to recommend tracheostomy.

Autonomy recognizes that all individuals have value and are worthy of self-determination to make healthcare decisions. This principle encourages honest communication about tracheostomy risks and benefits, including the reality of community support or the lack thereof (20, 21). In pediatrics, supporting autonomy is challenging, because children often cannot express their wishes. Although both family members and providers aim to act in the child's best interest, their views may not always align. A child lives within a family context; thus, the family is poised to assess their child's best interests. Therefore, we recommend applying the principle of constrained parental autonomy, which honors the sometimes conflicting principles of autonomy and nonmaleficence (22). If a provider deems a tracheostomy acceptable, the family has the authority to make an informed decision regarding its placement, even if their decision differs from the physician's recommendation.

Justice entails fair, equitable, and appropriate treatment of persons. Providers act within the context of their profession and society. Although devoted to the child's care, they must also consider societal factors that impact tracheostomy care in the community, such as resource scarcity and societal inequities.

Evidence Base

We identified 10 studies describing how ethical principles can be applied to conversations with families about tracheostomy tube placement for their infants and children (21, 23–31). Additional

literature review by the panel members led to the inclusion of five more studies (32–36).

One randomized trial, unrelated to tracheostomy or pediatrics, met inclusion criteria (29). Other studies explored the impact of ethics consultation through participant interviews, often comparing provider and family perspectives or exploring cases of conflict (23, 31). One study evaluated the impact of pediatric ethics consultation programs (24). A qualitative study explored the moral experiences of families with ventilator-assisted children at home (21). Another used interviews to create and test a decision-support booklet for tracheostomy placement (25). Interviews with family caregivers and providers informed a tracheostomy decision-making process framework and process described as collaborative decision-making (28).

Studies on ethics and palliative care consultation suggest that families express satisfaction and experience benefits from exploring ethical considerations and hearing different perspectives from families of children with tracheostomies. Families acknowledge the stress of tracheostomy decision-making but report benefit from comprehensive information, including the option to decline tracheostomy (32) and reasons that some families may decline it (33). Notably, ethics consultations can reduce ICU length of stay (LOS), identify and resolve ethical issues, and align management choices with patient and family values (29).

We recommend using ethical principles (beneficence, nonmaleficence, autonomy, and justice) in shared decision-making to guide family and provider conversations regarding tracheostomy. Our expert panel recognized that each case requires an individualized approach. However, these principles can be applied to tracheostomy decision-making in any context, and

healthcare providers should ensure families are well-informed and presented with all reasonable options based on the child's specific circumstances.

In our expert discussions, panel members shared experiences of moral distress related to uncertainty about prognosis and the long-term consequences of their actions, similar to the moral distress of providers during decision-making described in the literature (34, 35). Ethical principles can frame decision-making when the healthcare team has determined that tracheostomy is an acceptable option, acknowledging that decisional conflict among providers can be inevitable, given the lack of universal consensus on the appropriate circumstances to offer tracheostomy (36).

Certainty of Evidence

Our recommendation is strong, despite a very low certainty of evidence. In GRADE methodology, such a recommendation is justified when there is benefit in a life-threatening situation (9). This choice will dramatically impact both child and family, as life is either prolonged by tracheostomy or the transition is made toward comfort care. This aligns with other guidelines regarding tracheostomy and long-term ventilation decision-making (37, 38).

Benefits

When the benefits above outweigh nonmaleficence, tracheostomy may be offered. However, when providers collectively do not believe a tracheostomy is a justifiable option (such as in the example of a baby born with anencephaly or if imminent death is anticipated within days to weeks), our expert panel suggests that tracheostomy not be provided as an option.

Harms

Providers supporting families to make decisions about tracheostomy for their child must also recognize that some families may be unequally poised to support a child with a tracheostomy. The associated financial, employment, marital, and sibling impacts are substantial and may overtly or subconsciously influence decisions and recommendations about tracheostomy (39–42). Ubiquitous shortages in home nursing have severe implications for parents' caregiving responsibilities and their family life (43).

Parental Preference

Using ethical principles to guide decision-making is of high value to patients and their families. A parent on our panel shared, "The decision for tracheostomy for my child wasn't taken lightly by the team, but I knew her quality of life was just miserable because [her child frequently] had to be intubated."

Costs

The decision to pursue tracheostomy has a significant financial impact on families, hospitals, and insurance companies. Although costs should not be the deciding factor regarding tracheostomy as an option, our panel believes that financial concerns should be considered and addressed.

Conclusions

Considering ethical principles during tracheostomy decision-making is overall beneficial.

ATS Recommendations

RECOMMENDATION 1: We recommend applying ethical principles (beneficence, nonmaleficence, autonomy, and justice) to guide shared decision-making about tracheostomy placement (*strong recommendation, very low certainty of evidence*).

Implementation

Institutions have adopted varying clinical practices to aid in decision-making before tracheostomy insertion, but there is no standard approach to this sensitive topic at present. To the extent possible, available options should be explained to families in an accessible (e.g., in the family's primary language with attention to healthcare literacy levels and learning styles), comprehensive (including short- and long-term considerations), and balanced (the provider avoiding bias and presumption of family values while acknowledging prognostic uncertainty) manner.

Health Equity

Tracheostomy care must be adapted to fit the varied economic, cultural, and structural contexts of different health systems, including considerations that may arise in resource-restricted areas. This approach includes understanding the resource constraints that may affect the availability and quality of tracheostomy supplies, the cultural acceptability of homecare versus long-term facility care, and the economic

burden on families, which can vary greatly by region (44–48). Ensuring equitable access to care requires advocating for policies that recognize and address these diverse needs (49). Ultimately, working within an ethical framework to support families must directly address these factors and advocate at a societal level to reduce disparities in homecare, paid family medical leave, and support systems that threaten to worsen upstream inequities and constrain decision-making.

Justification

These ethical principles should be used in a shared decision-making approach, in which healthcare providers, children with capacity, and families establish partnerships to reach decisions after considering all reasonable options available in the child's specific circumstances. This includes the patient's and family's values and preferences, provider knowledge and experience, and local resources at the time of this decision and throughout the child's medical journey.

Question 2: Should a Standardized Process for the Initial Discharge be Used for Infants and Children with Tracheostomy Tubes?

Background

Children with tracheostomy tubes have a high risk of adverse events, as well as mortality, and require intensive education for family caregivers. Hospital practice patterns differ regarding whether children with tracheostomy tubes are managed exclusively in ICUs or transferred to step-down or inpatient wards after achieving medical stability (50). Discharge and caregiver education processes vary greatly across institutions.

Evidence Base

We identified seven studies describing quality improvement projects evaluating the discharge process for tracheostomy-dependent infants and children at different institutions (51–57).

A standardized discharge process can reduce LOS. Such standardization for children requiring invasive home mechanical ventilation (iHMV) resulted in a 42% LOS reduction (249 to 142 d; $P = 0.002$) without increased unplanned readmissions,

emergency department visits, or mortality 12 months after discharge (51). Similarly, another study reported a 28% reduction in LOS from 133 to 96 days ($P = 0.003$) after development of a multidisciplinary tracheostomy team (52). A formal process for neonates with tracheostomies resulted in a 25% LOS reduction (157.3 to 117.2 d; statistical significance not reported) (54). However, hiring a dedicated discharge coordinator alone did not significantly change the LOS (53).

Standardizing the discharge process can also reduce costs. One study reported a 43% reduction in direct costs per patient ($P = 0.01$) (51). Another study showed no difference in costs overall but observed lower costs in the subset of patients with LOS <90 days (52).

Other benefits of a standardized process include a reduced time to the first follow-up appointment (from 6.4 to 0.86 wk; $P = 0.01$) and a reduced medical complications composite score (from 15.2 to 1.3; $P = 0.02$) (55). In addition, the use of a discharge checklist resulted in a sense of preparedness at discharge in 80% of surveyed family caregivers (56). The use of a discharge coordinator increased satisfaction for both family caregivers and the hospital team ($P < 0.001$ for both comparisons) (53). Finally, a standardized process markedly reduced the 7-day and 30-day unplanned readmission rate (from 18.2% to 0% and from 6.7% to 0%, respectively; statistical significance not reported) (57).

Certainty of Evidence

The panel's confidence in the effectiveness of a standardized discharge process for tracheostomy-dependent children was low. Although most studies had positive results, the studies mainly describe institutional quality improvement initiatives with variable interventions, small patient cohorts, and uncontrolled study designs that were not powered to demonstrate significant outcome differences.

Benefit

A standardized discharge process can decrease LOS and costs, improve family caregiver and provider satisfaction, and reduce readmission rates.

Harms

Because of finite healthcare resources and staff, investment in a standardized process for tracheostomy care may reduce healthcare

cost and avoid potential harms but result in decreased investments in other populations requiring acute care.

Parental Preference

Standardization improves family caregiver satisfaction by providing anticipatory guidance, establishing clear expectations, and ensuring that all discharge steps are completed. However, some families, such as single-parent families or those lacking a second caregiver, may face challenges providing the care demanded by their high-risk child, meeting the education schedule, and completing all discharge criteria. Therefore, both medical and social determinants of health may impact discharge timelines (58).

Costs

Developing a standardized discharge process incurs up-front institutional infrastructure and human healthcare resource costs not recoverable through insurance billing. Nevertheless, implementing the standardized process can reduce future direct costs.

Conclusions

A standardized discharge process reduces LOS and unplanned rehospitalizations while increasing patient, family, and healthcare provider satisfaction and patient care.

ATS Recommendation

RECOMMENDATION 2: We suggest implementing a standardized discharge process to facilitate the safe transition of tracheostomy-dependent children from hospital to home (conditional recommendation, low certainty of evidence).

Implementation

Although a standardized process is recommended, each center must determine which steps should be included to best address their patients' needs using the unique resources available in their area. A multidisciplinary team (*see* Table 2) led by a clinician with expertise in tracheostomy care, protected time for this task, and familiarity with process improvement is invaluable for implementing a standardized discharge process for children with tracheostomy tubes. A comprehensive and staged educational approach should begin before tracheostomy placement and continue until the child is discharged.

Health Equity

Disparate access to resources and healthcare inequities impact children with tracheostomies even when a standardized process is used. Both race and socioeconomic disadvantage have been shown to impact the care received, emphasizing the importance of standardization (59, 60).

Justification

This recommendation prioritizes standardization of the discharge process, the potential for improving patient and family satisfaction and health-related QOL, and other clinical outcomes, including decreasing the number of emergency room visits and hospitalizations. The limitations, including the acute care sector infrastructure and human healthcare resource costs, were also considered.

Question 3: Should Infants and Children with Tracheostomies Always Have an Awake and Attentive Trained Caregiver Present?

Background

Caring for children with tracheostomy tubes at home is associated with significant, even life-threatening, risk, with mortality ranging from 10% to 26% (1, 61–65). In a prospective pediatric study of children with tracheostomy tubes, there was a 17% overall mortality, with 9% of deaths ($n = 4$) being directly related to the tracheostomy (66).

Evidence Base

We identified 26 studies describing the morbidity and mortality associated with a tracheostomy tube in children.

Unanticipated rehospitalization after tracheostomy occurs in 44%, 66%, and 76% of children within 3, 6, and 12 months, respectively, after initial hospital discharge (67–69). In addition, 47% of children require four or more emergency department visits or hospitalizations within 24 months of tracheostomy insertion (70). Preventable death occurs in up to 27.5% of children receiving iHMT (71).

Among 228 children with iHMT with a mortality rate of 21%, 19% ($n = 9$) of those deaths were deemed to be tracheostomy related (72). In another cohort of 204 children receiving iHMT, 8 of 43 (18.6%) deaths were attributed to tracheostomy-

Table 2. Recommendations for Developing a Standardized Process for the Initial Discharge from the Hospital for Infants and Children with Tracheostomies

Category	Recommendations
Interdisciplinary team	• Clinician with expertise in tracheostomy care and process improvement • Care coordinator • Respiratory care provider • Speech language pathologist • Nurse • Registered dietitian • Social worker • Case manager
Caregiver education	• Understanding the role and use of devices and equipment • Comfort with routine tracheostomy and respiratory care • Day-to-day respiratory management and troubleshooting • Emergency care • Medication administration, intended effect and side effects • Individualized instruction • Audiovisual and written materials • Supervised practice using home equipment • Use of dolls or mannequins for skill demonstration • Simulation of airway emergencies
Community education	• Identifying a primary care physician • Durable medical equipment company • Home nursing agency (or independent home health nurses) • Informing local emergency medical service that a child with a tracheostomy resides in their area • Determining how and/or where to receive urgent care at all hours • Medical daycare (if available) • Early intervention programs for habilitative services • School-based services (via individualized education plans) • Assistance with transportation needs to medical appointments • Disability parking

related complications (73). Accidental tracheostomy dislodgement caused 4 of the 11 deaths among children with congenital heart disease receiving iHMV (74). Notably, safety measures reduced tracheostomy-related deaths from 9 to 1 in a study of 286 children (57% requiring iHMV) (3).

Root causes of preventable death in children with iHMV include inadequate family caregiver training, improper emergency response (e.g., undetected tracheostomy decannulation or obstruction by a mucous plug or hemorrhage), and equipment failure (71). Tracheostomy-related mortality risk factors include prematurity, low birth weight, younger age at tracheostomy placement, and underlying neurological, cardiopulmonary, and oncologic diseases (63, 75). Small tube diameter and high secretion burden further increase the risk of obstruction, particularly in young children.

Pulse oximetry, capnography, and ventilator alarms can detect potential airway obstruction in children with iHMV. However, alarms may not always detect tracheostomy obstruction or displacement (76, 77), particularly with smaller

tracheostomy tubes. As no mechanized monitoring system is infallible, current guidelines call for an awake, trained caregiver to always monitor children with iHMV outside of an acute care hospital (6, 78). Parents, trained lay caregivers, and/or skilled home nurses can provide this monitoring (71, 79–82).

Certainty of Evidence

Our recommendation is strong, despite a very low certainty of evidence because of the potential life-threatening sequelae of deciding not to have an awake and alert trained caregiver always be present with children who are at risk of immediate decompensation due to tracheostomy-related complications. Evidence is stronger for children with iHMV than for those with tracheostomy alone (6).

Benefits

An attentive and trained family caregiver, trained lay caregiver, or healthcare provider with specialized training may detect subtle signs of respiratory distress or complications that precede alarms or that machines might miss, such as alterations in skin color,

behavior, or breathing. The caregiver can intervene to prevent potentially critical situations, such as tracheostomy tube obstruction or displacement.

Harms

Skilled nursing care represents a large healthcare expenditure (83). Availability varies across centers, but there is a generally recognized shortage (84). This problem is exacerbated by greater need, inadequate training, noncompetitive pay, and limited benefits (84–86). Our family panel noted that inadequate home nursing resources delayed hospital discharge and contributed to family caregiver fatigue and poor health-related QOL:

- “Unfortunately, relatives of ours are afraid to take on his care, so it heavily relies on me and my husband ... we have gone without [nursing] quite a bit, especially during the day.”
- “I have a major shortage of day nursing.”
- “We never had nursing, but do now that I have gone back to work ... otherwise we have zero nursing.”

Providing constant skilled observation for a child with a tracheostomy can strain family caregiver well-being (87). Parental caregivers are more likely to have poor sleep quality, chronic fatigue, diminished daytime functioning, and family strain, all of which negatively impact their overall health-related QOL (88–91). Some families resort to alternating overnight shifts to ensure their child's safety, while also maintaining a modicum of effective daytime functionality. Parents of children with tracheostomies have identified gaps in mental health care, respite care, and other support services (84, 92).

Many parents of children with tracheostomies reduce or leave employment to provide specialized care for their children and, as a result, face financial hardship (39, 93–95). Increased financial and care burdens can lead to decreased medical treatment adherence (55, 96, 97). One parent said, “I feel like the financial impact of all this is very difficult. I’m constantly having to fundraise just to supplement, because we only have one income coming in, and there’s no actual funding.” Another shared, “If I would have been presented with the option of having my income supplemented rather than going back to work, and having been my son’s caregiver, that would have been an option that we definitely would have considered.”

Parental Preference

There are circumstances when trained homecare providers cannot always be available, and families wish to avoid the alternative of emergent and unexpected hospitalization. Although technologies such as remote telemonitoring can aid early detection, they cannot replace skilled care in the event of emergency. In addition, the adoption of technology requires careful consideration of the benefits and challenges, including data privacy security considerations.

Costs

A continuous alert and trained caregiver at home is cost effective compared with hospital admission to the ICU. Advocating for payer reform to align home nursing reimbursement with hospital-based nursing salaries could help address the widespread home nursing shortage. In addition, paid family caregiving can address gaps in traditional healthcare employment and lost parental wages from deferred employment for the care of a child with a tracheostomy. Paid family caregivers performing certified

nursing assistant–level care can result in reduced job turnover and reduced costs compared with nonfamily caregivers or paid healthcare community care providers (98).

Although primary caregivers must learn all nursing and respiratory skills and become independent, less intensive training of “watchers” can also expand the caregiver pool (58). Watchers receive basic training to recognize signs of respiratory distress or need for tracheostomy care, so they can provide respite to fully trained family caregivers who are immediately available in the home to intervene if needed.

Conclusions

An awake and alert trained caregiver should be present when there is high risk that a child with a tracheostomy will immediately decompensate because of tracheostomy-related complications. Examples of children at high risk of immediate decompensation include those with ventilator dependence, severe airway obstruction, young age, or those with an inability to call for help. When trained community healthcare provider shortages exist, HMV clinicians should discuss potential risks and mitigation strategies to overcome these shortages, such as remote monitoring and telehealth.

ATS Recommendation

RECOMMENDATION 3: We recommend that an awake and alert trained caregiver always be present with children at risk of immediate decompensation due to tracheostomy-related complications (*strong recommendation, very low certainty of evidence*).

Implementation

The panel’s recommendation that an awake and alert trained caregiver always be present may not be possible in all situations. Some families may choose to be discharged home without an awake caregiver in lower-risk situations in which immediate decompensation is unlikely. Shared decision-making is critical to finding the balance between avoiding prolonged hospital stays and supporting parental caregivers’ well-being while prioritizing the child’s safety.

Family caregivers should receive comprehensive and effective education and training to manage all aspects of tracheostomy-related care, including troubleshooting and emergency management. These caregivers require not only initial training to achieve competency

but also ongoing training to maintain skills (99). Remote telemonitoring and improved home ventilator alarms may help but will not supplant the need for an awake and alert trained caregiver. This recommendation underscores the high value placed by the panel on patient safety.

Health Equity

Few studies have addressed equity issues around homecare support for children with tracheostomies. A U.S. study evaluating healthcare-related costs in the first year after tracheostomy insertion found that the median cost per child is more than \$25,000; however, these may exceed \$100,000 per child, with more than \$1,000 in ventilation-related out-of-pocket expenses per month among families of children using iHMV (1, 39). In addition to direct, out-of-pocket expenses, lost wages by caregivers who chose to or were forced to leave their jobs, change jobs, or work fewer hours to tend to their child’s medical needs are considerable (39). A Canadian study examining the out-of-pocket costs incurred by caregivers of children who use HMV found that the estimated median monthly cost of lost wages (calculated using the human capital approach based on age- and sex-based earnings estimates) was \$9,929 per child (100). These recommendations may be more accessible to financially and socially resourced families and communities with greater home nurse availability. Advocacy for paid trained family caregivers and improved support services will help address disparities.

Justification

The panel is confident that the benefits of this recommendation outweigh the potential downsides. Our recommendation is strong, despite very low certainty of evidence, because the absence of a trained caregiver places a child with a tracheostomy at significant risk for morbidity and mortality.

Question 4: Should Tracheal Aspire Cultures be Obtained for Infants and Children with Tracheostomies during Routine Clinic Visits and Acute Respiratory Illnesses?

Background

Lower respiratory tract infections, including pneumonia and tracheitis, are common

complications of pediatric tracheostomies and can result in prolonged hospital stays and an annual mortality rate of 5% (101). More than 60% of pediatric patients may be readmitted within 6 months of initial tracheostomy placement, often for management of infections (102, 103). Although a tracheostomy tube is an indwelling foreign body within the airway and a potential nidus for infection, distinguishing between true bacterial infections requiring antibiotic therapy and viral infections with concomitant colonization with a bacterial biofilm can be challenging, and quantitative cultures may have limited utility (101, 104, 105).

Viral infections in patients with tracheostomies are common. They can clinically mirror bacterial tracheitis or pneumonia, with fever, change in tracheal secretions, and need for escalation of respiratory support or hospital admission. In addition, biofilms can be isolated from most tracheostomy tubes as early as 1 week after placement (106, 107). Furthermore, healthcare costs for respiratory-related hospital admissions for pediatric patients with tracheostomies are high; in the United States alone, these expenditures likely exceed \$900 million annually in adjusted 2024 U.S. dollars (USD) (108).

Although methods for sample collection and processing of tracheal aspirate cultures vary widely, common methodology has been described (109, 110).

Evidence Base

We identified nine studies describing tracheal aspirate cultures obtained during acute respiratory illness and routine clinic visits (111–119). Additional literature review by the authors led to the inclusion of three more studies (120–122).

There is conflicting evidence on the utility of obtaining routine tracheal aspirate cultures during clinic visits when patients are at their clinical baselines (hereafter referred to as surveillance cultures). The acquisition of *Pseudomonas aeruginosa* between tracheostomy placement and discharge from index hospitalization was associated with a threefold increased risk of readmission for tracheostomy-associated bacterial respiratory tract infection within 12 months of initial discharge in a retrospective cohort of 240 children (119). However, in another cohort, there was no association between *P. aeruginosa* or methicillin-resistant

Staphylococcus aureus isolation and the likelihood of future antibiotic therapy (122).

A critical question is whether surveillance cultures can predict microbiology during acute illness and thus guide antibiotic choice, recognizing that there is no consensus for acute respiratory infection management in children with tracheostomies. Bacterial pathogens likely responsible for acute respiratory infection have been previously isolated on surveillance cultures in approximately 75% of cases, increasing to 95% with *P. aeruginosa* (113). There may be bacterial “blooms” of colonized *Haemophilus* and *Moraxella* that occur at the onset of acute respiratory illness (120). *Acinetobacter*, *Corynebacterium*, and *Pseudomonas* were less commonly observed in cultures obtained during acute respiratory illness compared with surveillance cultures (121). The site of the infection may also affect this link; the correlation between surveillance culture organisms and acute respiratory illness cultures was 64% in tracheobronchitis versus 52% in pneumonia (111).

Because surveillance cultures may have different flora from cultures during acute illness, a key issue is whether empiric antimicrobial therapy based on surveillance cultures matches therapy based on cultures obtained during acute infection. Compared with surveillance cultures, 86% of acute respiratory cultures had a change in bacterial species in 36 cases; 53% required the addition of one or more antibiotics to the original empiric therapy (112). Some tracheal infections (*Pseudomonas* and *Acinetobacter*) could be treated with antibiotics empirically based on institutional resistance patterns (115).

Independent of the predictive value of tracheostomy cultures, surveillance or otherwise, cultures appear to have limited diagnostic value. In screening for bacteria during acute respiratory infections, among 3,578 cultures from 533 children with tracheostomies, the sensitivity was 24.3%, specificity was 85.2%, positive predictive value was 36.5%, and negative predictive value was 76.3% (117). Despite these test characteristics, strategies such as standardized sampling criteria and technique and limiting repeat cultures to >72-hour intervals have been shown to decrease resource utilization and antibiotic use (116). There are likely many clinical markers associated with acute respiratory illnesses in addition to positive culture findings,

including radiographic findings consistent with pneumonia, elevated white blood cell counts, changes in respiratory support, and the presence of polymorphonuclear white blood cells on tracheal aspirate Gram stain (118).

Certainty of Evidence

The certainty of evidence was low, given that most studies were indirect or retrospective in nature.

Benefits

Potential benefits of routine surveillance tracheostomy cultures in patients at their clinical baseline could include predicting future outcomes and microbiology during acute illnesses, which can guide antimicrobial therapy. Benefits of tracheostomy cultures during acute illnesses may include more tailored antibiotic courses, which in turn can shorten the duration of therapy and reduce future antibiotic resistance.

Harms

Serial cultures potentially result in increased or inappropriate antibiotic use and the development of antibiotic resistance. Obtaining cultures may suggest to families that all or most respiratory infections are bacterial and thus can lead to pressure on providers to prescribe antibiotics. Last, families may experience anxiety associated with positive tracheal aspirate cultures if antibiotics are not initiated.

Parental Preference

Parents and healthcare providers place variable value on tracheostomy cultures. Some trust cultures as a “gold standard” test and prefer to drop off specimens at laboratories, forgo in-person evaluations in a clinic setting or emergency department, and request test-of-cure cultures. Family panel members identified tracheostomy cultures as easily obtainable but possibly an inappropriate use of resources for routine use. They preferred cultures to be obtained when their child was sick or symptomatic if it would change management and expressed a dislike for obtaining cultures during mild illness owing to barriers to traveling to health care facilities.

Primary care providers and subspecialists often have differing prescribing practices, with pediatricians being more likely to start antibiotics. *Pseudomonas*-positive cultures solicit different prescribing practices, with some providers using

antipseudomonal antibiotics and others choosing agents more commonly prescribed for community-acquired pneumonia. Of note, obtaining respiratory viral panels at the time of bacterial cultures does not necessarily lead to reduced antibiotic use in a pediatric ICU setting (123).

Costs

Unnecessary testing strains healthcare resources, including, but not limited to, human healthcare resource time for obtaining cultures, transport resources for specimens, costs of culture, as well as copays and deductibles. Therefore, the panel recommends tracheostomy cultures only when there is concern for an acute respiratory tract infection and not for surveillance or test of cure.

Conclusions

The panel suggests obtaining tracheostomy cultures only when there is concern for an acute lower respiratory tract infection, and not for surveillance or test of cure. These recommendations promote antibiotic stewardship and avoid unnecessary diagnostic testing that does not change management.

ATS Recommendations

RECOMMENDATION 4A: In well children with tracheostomy tubes, we suggest against routine surveillance of tracheal aspirates for bacterial growth (*conditional recommendation, low certainty of evidence*).

RECOMMENDATION 4B: In children with tracheostomy tubes and concerns for lower respiratory tract infection, we suggest culturing tracheal aspirate when needed to guide management (*conditional recommendation, low certainty of evidence*).

RECOMMENDATION 4C: In children with tracheostomy tubes who were recently treated with antibiotics and are clinically improving, we suggest against test-of-cure tracheal aspirates (*conditional recommendation, low certainty of evidence*).

Implementation

Cultures should be considered for patients requiring hospital admission or markedly increased respiratory support. The threshold for pursuing tracheostomy cultures during an acute respiratory illness may be lower for patients with impaired airway clearance or more severe lung disease, such as patients with ventilator dependence, immunocompromised state, neuromuscular

disease, or neurological impairment. Obtaining concurrent respiratory viral panels may be considered. Parental education around the indications for antimicrobial therapy considering the culture results is suggested. Tracheal aspirate cultures may aid in determining readiness for airway surgery, but the panel did not study this.

Health Equity

Obtaining cultures when a child is sick can lead to disparities in healthcare access because of limited access to pharmacies, costs for an initial antibiotic, and additional costs if antibiotics are changed. Typical costs for a generic course of treatment may be \$8–\$40 in the United States, 2.78 times higher than in other Organization for Economic Co-operation and Development countries (124, 125). Patients with less access to respiratory viral testing may have greater rates of unnecessary antibiotic use and repeat cultures.

Justification

These recommendations aim to minimize unnecessary testing and antibiotic use. For Recommendation 4A, evidence as delineated above suggests that surveillance culture results do not necessarily predict the pathogens causing acute illnesses. For Recommendation 4B, cultures obtained when acutely ill may help guide antibiotic therapy, which may decrease duration of therapy and minimize risks of antibiotic resistance. For Recommendation 4C, almost all patients with tracheostomies are colonized with bacteria. Treatment is initiated based on the assessment of symptoms, respiratory support needs, culture positivity, and other laboratory studies. Therefore, the goal of treatment should be the improvement of symptoms, rather than culture data.

Question 5: When Should Infants and Children Who Have Tracheostomy Tubes Undergo Evaluation with Bronchoscopy (Rigid and/or Flexible) to Evaluate the Airway?

Background

Children with tracheostomies often have airway lesions, such as granulation tissue, suprastomal collapse, or tracheal wall

ulceration (126). If distal to the tracheostomy stoma, these lesions can be evaluated in awake children by passing a flexible scope down the tracheostomy tube or through the stoma (127). However, if proximal to the stoma, evaluation usually requires rigid and/or flexible bronchoscopy under general anesthesia (127). Airway lesions can obstruct the tracheostomy tube, render reinsertion more difficult when it is intentionally or accidentally removed, decrease vocalization or breathing around the tube, cause bleeding, or preclude oral intubation in an emergency (3, 126, 128–131). Airway lesions may thwart planned decannulation if children fail tracheostomy capping attempts or experience airway obstruction after decannulation necessitating tracheostomy tube reinsertion (132, 133). These scenarios increase healthcare resource utilization and costs.

Evidence Base

We identified 15 studies describing rigid or flexible bronchoscopy for airway evaluation of children with tracheostomy tubes (3, 126, 128–131, 134–142).

Airway evaluation as surveillance for infants and children with a tracheostomy was addressed by 14 studies. Approximately 55–87% of children were diagnosed with an airway lesion, the most common being suprastomal granulation (31–59%), subglottic stenosis (17–57%), glottic edema (37%), suprastomal collapse (2–15%), peristomal granulation (10–13%), distal tracheal granulation (5%), or tracheal wall ulceration (1–3%) (3, 126, 128–131). Approximately 23–48% of patients were symptomatic before bronchoscopy because of increased secretions (23–78%), difficulty with tracheostomy tube changes (23%), ventilation problems (7–31%), blood-tinged secretions (10%), stoma obstruction (5%), hemoptysis (3–8%), voice complaints (1%), dysphagia (1%), aspiration (1%), air leak around the tracheostomy (1%), tracheitis (1%), or erythema around the tracheostomy stoma (1%) (126, 134). In three studies, airway lesions were more likely to be found bronchoscopically in symptomatic patients (70% vs. 42%, 92% vs. 73%, or with an odds ratio of 6.75) (126, 128, 139). Airway lesions were also more common in patients with iHMV or who underwent tracheostomy for cardiopulmonary disease or traumatic injury in some, but not all, studies (126, 128, 134).

Data were mixed regarding the timing of endoscopy after tracheostomy insertion

and likelihood of finding airway lesions; one study found a significantly lower incidence of lesions <6 months (36%) versus >6 months (61%), whereas another found no difference using these same cutoffs (126, 128).

Intervention for an airway lesion was required in 26–58% of children (3, 134, 135). Most interventions were performed for removal of suprastomal granulation (41–89%), tracheostomy tube exchange (27%), steroid injection (22%), or subglottic dilation (10–19%) (3, 134, 135).

Institutionalized children with long-term tracheostomies who were ventilator dependent had a higher rate of complications (84%), consisting of peristomal granulation (48%), suprastomal granulation (44%), distal granulation tissue (37%), accidental decannulation (33%), tracheitis (30%), bleeding (26%), and stomal migration (26%) (136). In one cohort, 63% of children with iHMV required an emergent airway evaluation, with 48 unplanned admissions and 45 urgent procedures performed in 20 children (136). Similarly, others found a higher proportion of children using iHMV in their unanticipated mortality group (3).

Children <2 years of age with a tracheostomy had a 10% risk of cardiopulmonary arrest in the first 30 days after tracheostomy insertion and an accidental decannulation rate of 33% after longer-term follow-up (3). In addition, another study reported that all unanticipated mortalities in their study occurred in children <2 years of age (3).

Bronchoscopic findings, together with indication for tracheostomy insertion, and duration of tracheostomy all were associated with decannulation success (130). Using a protocol of downsizing the tracheostomy for 48 hours followed by capping for an additional 48 hours, these authors found that 91% of children were eventually decannulated; all children with suprastomal granulation were successfully decannulated, and those with subglottic stenosis, laryngomalacia, or tracheomalacia failed decannulation (130). A more rapid protocol of flexible or rigid bronchoscopy followed by a capped sleep study produced a decannulation failure rate of 22%, with 86% of those failing decannulation immediately and 14% failing within 6 months (137). In that study, bronchoscopy without airway lesions increased the chance of successful decannulation (137). Overall, 72% of children had corrective surgery for laryngomalacia, subglottic stenosis,

granulation tissue, tonsillectomy, or adenoidectomy; however, these procedures were not associated with improved rates of decannulation in this series (137).

Children with tracheostomies and a supplemental oxygen requirement had a 92% chance of successful decannulation after removal of suprastomal granulation, laryngotracheal reconstruction for subglottic stenosis, or tracheal reconstruction, when required (131). In addition, 58% of patients noticed a decrease in oxygen requirement after decannulation, attributed to conversion to a more physiological airway (131).

Certainty of Evidence

The certainty of evidence was low, limited mostly to cohorts that were not representative of the general population of children with tracheostomies and with lack of standardized follow-up protocols. Several studies were small (<20 patients), included only young children (<2 yr of age), or excluded children with congenital malformations. In many studies, it was unclear if bronchoscopy was universally performed, what criteria were used for airway examination, or whether bronchoscopy findings influenced decisions for decannulation.

The low certainty of evidence resulted in a conditional recommendation for bronchoscopy to evaluate symptoms. However, a strong recommendation was made for bronchoscopy before tracheostomy decannulation based on the panel's unanimous opinion that decannulation without bronchoscopy could be life threatening if an airway lesion was not identified and addressed (9).

Benefits

There are benefits of performing airway evaluations in children with tracheostomies and a change in symptoms, or with persistent symptoms unresponsive to medical management. Anomalies can be identified, prompting interventions that could alleviate symptoms, such as improved ventilation or vocalization after granuloma removal. Families may have decreased anxiety knowing their child is safer at home, therefore improving QOL. Addressing airway findings can obviate the need for urgent visits to the emergency department that would have otherwise arisen from untreated or unidentified airway complications.

There are also benefits of performing a complete airway evaluation (nose,

nasopharynx, oropharynx, oral cavity, supraglottis, larynx, subglottis, trachea, bronchi) before a decannulation attempt in children with tracheostomies. Identification of treatable anomalies can allow for successful decannulation and prevent unanticipated complications afterward. Furthermore, identification of untreatable anomalies can clarify the need to delay decannulation until further growth and development supports reevaluation.

Harms

Airway evaluation in children with tracheostomies requires additional hospital visits and possible admissions. This also increases healthcare resource utilization and costs, including otolaryngology and/or pulmonology consultant time and possibly anesthesiology, operative time, and hospitalization. General anesthesia or sedation can lead to adverse events. Incidental findings that prompt intervention can delay decannulation without improving decannulation success.

Parental Preference

For patients with minimal symptoms, parents may be more willing to proceed with bronchoscopy when combined with other procedures requiring sedation or anesthesia. For patients with more severe symptoms, parents are generally supportive of undergoing bronchoscopy when required. Before decannulation, combination with other procedures is preferable when decannulation would not be delayed too long. Some parents may hesitate to proceed with decannulation because of concerns about losing homecare nursing support or reluctance to transition away from their child's tracheostomy.

Costs

Adherence to this protocol could increase utilization of operative time, anesthesia, otolaryngology and pulmonology services, or inpatient admission. However, there may be cost savings in reducing the emergency use of these resources for tracheostomy-related complications. Although this approach increases the burden on patients and their families for elective hospital admissions and procedures, it may reduce costs associated with emergency or inpatient care.

Conclusions

The panel recommends an airway evaluation for patients experiencing change in

symptoms or with persistent symptoms unresponsive to medical management. In addition, a complete airway evaluation is paramount before attempting decannulation for all patients. The panel believes that the benefits of this approach, including preventing decannulation failure and emergent tracheostomy-related complications, outweigh the cost and use of elective healthcare services.

ATS Recommendations

RECOMMENDATION 5A. For children with tracheostomies, we suggest performing an endoscopic airway evaluation in those with a change in symptoms or with persistent symptoms unresponsive to medical management (*conditional recommendation, low certainty of evidence*).

RECOMMENDATION 5B. For children with tracheostomies, we recommend performing a complete airway evaluation before a decannulation attempt. Airway evaluation should include an assessment of 1) nose and nasopharynx; 2) oropharynx and oral cavity; 3) supraglottis and larynx; and 4) subglottis, trachea, and bronchi (*strong recommendation, low certainty of evidence*).

Implementation

We suggest bronchoscopy for patients with worsening or persistent symptoms unresponsive to medical management and strongly recommend comprehensive airway evaluation before decannulation. In centers with limited access to equipment or operative time, these guidelines may optimize local resources. Where necessary equipment, operative time, or specialized expertise are not available, we suggest referral to a center that specializes in these procedures.

The panel noted that variations in airway lesion type, frequency, and location likely differ by patient age, underlying the rationale for recommendation 5B. Differences are also probable between infants and children with tracheostomy alone and those with iHMV. Moreover, distinctions likely exist between patients with long-term tracheostomies for neurological conditions and those with tracheostomies for double-stage airway reconstructions.

Health Equity

Access to care could influence the implementation of these recommendations. However, access may improve with a

recommendation to conduct airway evaluations. Implementing surveillance measures, like evaluation of the airway before discharge, could promote equitable care.

Justification

These recommendations aim to ensure a safe and patent airway for children undergoing decannulation. Evidence was of low certainty because of limited evidence. However, there was a consensus supporting a strong recommendation for Recommendation 5B, given the potential morbidity and mortality associated with premature decannulation.

Question 6: Should All Infants and Children with Tracheostomies Undergo a Capped Polysomnogram before Decannulation?

Background

Decannulation requires careful planning to ensure patient safety and success. The 2013 AAO-HNS tracheostomy consensus statement outlined prerequisites for considering decannulation in children: 1) no ventilation support for 3 months before decannulation; 2) no recent aspiration events; 3) flexible laryngoscopy exam; and 4) a child ≥ 2 years of age should have the tracheostomy tube capped all day and the cap removed at night for several weeks without respiratory distress or desaturations (5). However, this guidance was based on expert opinion rather than clinical evidence and did not consider the role of polysomnograms (PSGs), which many centers include in their decannulation protocols (143). The routine use of PSG in decannulation protocols warrants further review (144).

Evidence Base

We identified 21 studies that examined the role of PSG in pediatric decannulation (132, 133, 137, 142, 143, 145–160).

Study outcomes were categorized into four common themes regarding the role of PSG in decannulation: 1) diagnostic yield (ability of an abnormal capped PSG to predict successful decannulation); 2) detection of the need for surgical intervention before decannulation; 3) ability to modify ventilator settings and/or discontinue nocturnal ventilation; and 4) transition from invasive to noninvasive

ventilation (NIV) in patients with congenital central hypoventilation syndrome (CCHS).

Abnormal capped PSGs can be defined as clinically significant sleep-disordered breathing and/or respiratory distress with the tracheostomy tube capped during sleep. Abnormal capped PSGs were identified in 15 of the 21 studies included, occurring in 6–50% of the PSGs performed. Several studies reported either unfavorable or favorable predictors of successful decannulation. Among 148 children undergoing evaluation for decannulation, unfavorable PSGs were linked to higher obstructive apnea–hypopnea indices, a greater percentage of total sleep time with end-tidal CO_2 (etCO_2) > 50 mm Hg, higher percentage of total sleep time with oxygen saturations (SpO_2) $< 90\%$, and a lower SpO_2 nadir (143). In contrast, a lower obstructive apnea–hypopnea index, respiratory disturbance index, and peak etCO_2 were associated with successful decannulation (154). The most consistent predictor of decannulation outcomes appeared to be total apnea–hypopnea index (143, 150, 152). A review of decannulation studies from 1995 to 2022 found higher failure rates in studies omitting capped PSG before decannulation (median failure rate about 14% without capped PSG vs. 2–3% with capped PSG) (161). However, successful capped PSG did not guarantee successful decannulation, as some studies reported decannulation failures after PSG because of suprastomal granulomas or multilevel airway collapse (132, 133).

In an additional study, PSGs were conducted immediately after decannulation with an occluded stoma using a protocol that recommended recannulation for apnea–hypopnea index > 10 events/h, $\text{etCO}_2 > 45$ mm Hg for 20% of total sleep time, respiratory distress, or prolonged desaturations (137, 147). A total of 210 attempts were performed in 189 patients, with a 79.5% success rate (147). Most failures were immediate, with 26 of 40 attempts (65%) displaying respiratory distress (137).

Two studies used capped tracheostomy with overnight in-hospital pulse oximetry with or without capnography rather than PSG (146, 148). One decannulation protocol involved replacing the existing tracheostomy tube with a fenestrated tube that was then capped. Patients were then monitored with continuous pulse oximetry. If they maintained adequate oxygenation ($\text{SpO}_2 > 90\%$) without signs of obstruction,

decannulation then proceeded (146). Twenty-three patients underwent a total of 27 decannulations; of the 26 protocol decannulations, 22 (85%) were successful (146). In comparison, a 5-day protocol included downsizing the tracheostomy tube before capping and then observing overnight with transcutaneous oxygen and carbon dioxide monitoring (148). Forty-five children underwent 57 decannulation attempts, and 33 (58%) were successful; 10 children had more than 1 decannulation attempt, with failure occurring at every stage of the protocol (148).

Several studies have reported on the need for surgical interventions after PSGs, which resulted in a wide range of patients (3–63%) undergoing procedures because of PSG findings. In one cohort, decannulation was not pursued in 18 of 67 children because of abnormalities identified on capped PSG; 5 patients were subsequently successfully decannulated after additional surgery, and 3 more were scheduled for surgery before reevaluation (132). The most common surgical intervention cited was adenotonsillectomy (132, 145, 148, 149). However, other reported procedures included supraglottoplasty, epiglottopexy, and tongue base reduction for supraglottic stenosis, and laryngotracheal reconstruction for subglottic stenosis (133, 145, 152).

Setting changes to the ventilator and/or discontinuation of ventilation were evaluated in two studies (142, 143). In both studies, PSGs were completed at multiple time points, including before tracheostomy insertion, adjustment of home ventilator settings, at the time of discontinuation of ventilation and with the tracheostomy tube capped (142, 143). Not all patients had PSGs at every step. Of 49 children using iHMV, 37 children (75%) had 43 PSGs to assess readiness to discontinue nocturnal ventilation (143). Thirty-four (92%) had a successful first PSG. Of the remaining three children, two children failed the PSG once and one child failed twice (143). Among 15 children undergoing PSGs for ventilator settings adjustment, 19% of children had an increase in ventilator settings and 29% had a decrease in settings (142). Of the 42 children undergoing PSGs for ventilation discontinuation, 38 (90%) were liberated from the ventilator (142). In addition, discontinuation of nocturnal ventilation was intentionally delayed in 6 of 79 patients (7%) based on abnormal PSG results (142). In one of the two studies, three patients (4%)

required tracheostomy tube upsizing after PSGs because of nocturnal hypoventilation secondary to a large stomal leak (143).

Transition from iHMV to NIV was evaluated in two studies; 100% of the patients included had CCHS (149, 151). In total, 7 (100%) patients with CCHS underwent capped PSG, and all were successfully decannulated to NIV. Both studies had strict eligibility criteria for decannulation that included medical stability, intact cough reflex, ability to manage secretions, ventilation dependency during sleep only, and the ability to tolerate daytime capping (149, 151).

Certainty of Evidence

The certainty of evidence is low, because the literature was heterogeneous, with a diversity of populations evaluated and varying time frame definitions for decannulation failure, ranging from 6 months to 2 years. Several studies included a retrospective review of a program's outcomes, and not all patients completed PSGs. In addition, some studies did not describe outcomes for children who did not undergo PSGs. Although most studies used capped PSGs, a few performed PSGs after decannulation or used oximetry with or without capnography as an alternative evaluative tool. The exact impact of PSGs on decannulation decision-making was not explicitly described in a subset of studies, and many included multiple investigations as part of their decannulation protocol. Formal airway assessments were indicated to be crucial, with most studies reviewed (18 of 21) documenting completion of a formal airway assessment.

Benefits

The benefits of completing capped PSGs include the ability to obtain both a functional and dynamic assessment of the airway during sleep, when pharyngeal muscle tone is maximally decreased and airway obstruction risk is at its greatest. It may also provide objective information on control of breathing and identify those who require surgical intervention. There may be a reduction in failed decannulations when capped PSGs are performed (161). Finally, the literature suggests that a capped PSG can support titration of ventilator settings and/or safe transition from iHMV to NIV in patients with CCHS (142, 143, 149, 151).

Harms

PSGs are resource and cost intensive and may delay decannulation. Furthermore, even with a reassuring PSG, successful decannulation is not certain, and the PSG may provide false reassurance. An abnormal PSG may lead to potentially unnecessary interventions and decannulation delays. These delays can prolong morbidity related to the ongoing use of tracheostomy tubes, including risk of tracheal irritation and/or bleeding, infection, granulomas, mucous plugs, and fistula formation or stenosis, as well as increased mortality from a fatal tracheostomy tube blockage or dislodgement (5).

Parental Preference

PSGs can be challenging for patients and families because of the extensive montage, need for specialized equipment for some patients (e.g., Hoyer lift), sleeping away from home, and parental caregiver missed days from work. In addition, limited access to PSGs and long waitlists can delay decannulation, potentially prolonging complex care for children with tracheostomies.

Costs

The cost of outpatient PSGs versus hospital admission with overnight oximetry, with or without capnography, varies by location. In the United States, the average cost for a PSG is \$3,075 USD, compared with \$2,880/night USD for an inpatient bed (162). In Ontario, Canada, a PSG costs approximately \$400 in Canadian dollars, whereas an inpatient bed will cost the provincial healthcare system approximately \$2,500/night in Canadian dollars (163). Thus, healthcare professionals need to be cognizant of healthcare system-related costs when considering best practice for decannulation readiness in their patients.

Conclusions

An overnight evaluation of gas exchange and SDB is useful for assessing decannulation readiness. Pulse oximetry, which assesses desaturations from SDB, generally suffices when combined with medical observation (146, 148). By offering these two surveillance options and with flexibility for clinical judgement, providers can balance access, resource, and cost considerations.

The evidence supports added value in pursuing PSGs in certain populations, such as those transitioning from invasive to noninvasive ventilation (particularly patients

with CCHS), those with behavioral challenges during daytime capping, and those with complex airways prone to multilevel airway obstruction.

ATS Recommendations

RECOMMENDATION 6A: We suggest that, in addition to a formal airway evaluation, either a polysomnogram or pulse oximetry study (with or without capnography) under direct observation with a capped tracheostomy (or occluded stoma) be performed as part of the evaluation for decannulation readiness (*conditional recommendation, low certainty of evidence*).

RECOMMENDATION 6B: We suggest polysomnography with a capped tracheostomy (or occluded stoma) in the following situations: 1) assessing transition readiness from invasive to noninvasive ventilation; 2) unclear cause of failed capping trials; 3) for patients with medical and/or airway complexity (*conditional recommendation, low certainty of evidence*).

Implementation

The panel suggests a stepwise approach when evaluating a patient for tracheostomy tube decannulation readiness (Figure 1).

A speaking valve is a one-way device placed on the external opening of a tracheostomy tube to redirect air flow upward through the vocal folds during expiration (164). Not only can speaking valves aid in oral communication but also they can improve secretion management, augment olfaction (which can impact eating), and may improve swallowing (164–166).

They should be considered for all pediatric patients with tracheostomies (164). In addition, speaking valves can ease the transition to decannulation, providing a gradual acclimatization to laryngeal airflow and changes in hypopharyngeal pressure (167). A well-tolerated one-way valve may suggest readiness for tracheostomy capping. Valve intolerance should be investigated as a potential indicator of airway obstruction. Proceeding toward decannulation in cases of intolerance requires extreme caution.

Some authors recommend downsizing of the tracheostomy tube as standard practice when pursuing decannulation (133, 152, 155, 156). Others caution against it because of concern that a smaller-diameter tracheostomy tube may increase the likelihood of mucous plugging (143). One study found no clinical disadvantage to keeping the current size tracheostomy tube *in situ* during favorable capped PSGs; however, not downsizing the tube was associated with an increased chance of an unfavorable capped study (143). PSGs after tracheostomy tube downsizing typically show less severe SDB than those without downsizing (143). One study reviewed the use of fenestrated tracheostomy tubes rather than tracheostomy tube downsizing before capping (146). Although fenestrated tubes also enhance the flow of air to the upper airway and may promote speech, the use of such tubes in children, particularly for extended periods, is not standard practice because of concerns for granulation tissue development around the fenestration (4).

Health Equity

Pediatric PSGs are a limited resource with long wait times in many institutions, geographic regions, and countries. Inequitable access to PSGs may be heightened in underserved communities or populations, remote and/or rural geography, or low- and middle-income countries. Health providers may be faced with the challenging decision of balancing patient-specific needs and best practice with equity considerations when using a potentially limited resource that may not be accessible to all patients.

Justification

Recognizing the limited evidence surrounding the use of capped PSGs for decannulation, we support providers in choosing the most appropriate surveillance option (i.e., PSG vs. oximetry), based on clinical characteristics and accessibility to PSG. Studies indicate that patients who fail overnight tracheostomy tube capping or decannulation are identified relatively quickly, suggesting other measurements of gas exchange in conjunction with direct observation may suffice (157). This recommendation prioritizes timely decannulation opportunities without compromising patient safety.

Limitations and Future Research

These clinical practice guidelines have important limitations. The certainty of the evidence was low or very low, with a paucity

Proposed Decannulation Steps

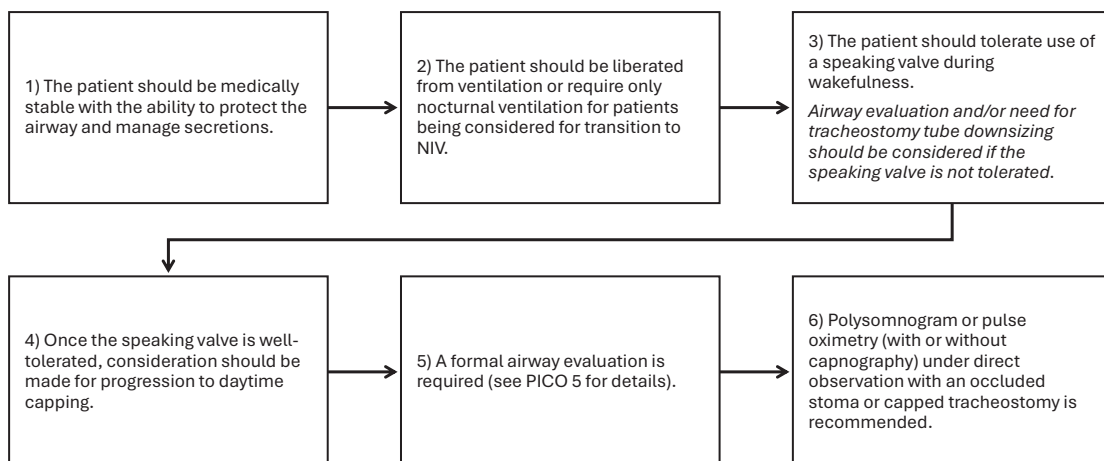


Figure 1. Clinical and diagnostic evaluations recommended before tracheostomy decannulation.

Table 3. Areas for Future Research

Category	Research Needs
Patients	• Clinical biomarkers to differentiate between acute respiratory infection and airway colonization • Indications for antimicrobial therapy • Optimal approaches to bronchoscopy/airway endoscopy • Role of polysomnography throughout the clinical course of a child with a tracheostomy
Families	• Approaches that result in successful tracheostomy decannulation • Effective education, skills verification, ongoing competency • How to best integrate technology (remote monitoring, telehealth, alarms) • Expanding home health teams to better support families (home nurses, extended family, lay caregivers, community members)
Healthcare providers	• The role of “watchers” who receive basic training to know when to alert the fully trained caregiver • Development of patient- and family-informed interdisciplinary care teams for children with tracheostomies • Evaluation of shared decision-making training (to align with patient and family goals of care) • Implementation of resiliency training for care team members • Examining the impact of tracheostomy-specific implicit bias training to ensure equity in outcomes

of randomized controlled trials in infants and children who have or are being considered for tracheostomy. In addition, many studies had no comparator group. Therefore, most of the panel’s recommendations are conditional.

Research is needed for infants and children with tracheostomies focusing on patients, families, and healthcare providers (Table 3).

To move the science forward for patient-level clinical care, we must better understand which clinical biomarkers can distinguish airway microbial colonization and acute respiratory infection and identify clinical scenarios that warrant antimicrobial therapy to prevent development of antimicrobial resistance. In addition, further research is needed to determine optimal bronchoscopy type, level of anesthesia, and which airway findings warrant surgical intervention. Standardizing practices will allow for more accurate correlation of bronchoscopic protocols, findings, and treatments with symptomatic improvement and decannulation success. Furthermore, existing literature on the utility of PSGs for evaluating readiness for decannulation is limited secondary to retrospective, uncontrolled studies that have included heterogeneous populations, varying decannulation protocols, and different time frame definitions for decannulation failure (or success). Prospective, multicenter studies,

including randomized controlled trials evaluating PSG versus overnight oximetry, are needed, especially considering the limited access to PSG globally.

For family caregivers, we need a better understanding of how to balance alarm sensitivity to alert them promptly while minimizing alarm fatigue. We should examine how education can provide standardized, accessible, comprehensive, and balanced information to families (to establish a truly shared decision-making process); how to expand tracheostomy training for non-family members and lay caregivers to enhance support networks and provide respite care for parents; and how to ensure ongoing competency of in-home caregivers.

Finally, the role healthcare providers play in the care of children with tracheostomies is understudied. Research on healthcare provider moral distress and resiliency should be studied to support those who guide families through these difficult decisions. The impact of implicit bias and disability-based discrimination on our counseling and care must continue to be identified and mitigated (168). We must learn from prior mistakes and false assumptions about brief survival, poor health-related QOL, and family burden, which discriminated against children with disabilities and medical complexity.

Conclusions

This clinical practice guideline addresses six priority PICO questions deemed to be of highest clinical relevance by the international panel of specialists and not previously addressed by clinical guidelines. The goal is to standardize and improve the clinical care of infants and children with tracheostomy tubes. Future research should focus on well-designed studies that use a data-informed, precision-based medicine approach to these medically complex patients. In addition, special consideration is warranted regarding implementation of these guidelines in low- and middle-income countries. These recommendations were reviewed by the ATS Quality Improvement and Implementation Committee and are not intended for performance measure development.

Note from the ATS Documents Editor

This clinical practice guideline was reviewed by the ATS Quality Improvement and Implementation Committee for potential performance measures as is done routinely for every ATS clinical practice guideline. None of the recommendations are considered suitable for performance measure development. ■

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