TRACHEOSTOMY *and* VENTILATOR DEPENDENCE IN ADULTS *and* CHILDREN

Learning Through Case Studies

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Series Introduction

The Medical Speech-Language Pathology book series provides graduate students, clinicians, and clinical researchers with functional, comprehensive material to enhance practice in a medical setting. The books are designed to bolster transdisciplinary knowledge through infusion of information from neurology, pharmacology, radiology, otolaryngology, and other related disciplines. They capture our current understanding of complex clinical populations and offer expert guidance related to evaluation and management strategies. For each book, case studies are used to promote application and integration of the material and are richly supplemented with figures/photographs and clinical resources. Each book in the series is authored by experienced professionals and content experts who are able to transform the research literature into clinically digestible information, allowing immediate application to everyday practice. This book series advances the medical speech-language pathology community by merging fundamental concepts, clinical strategies, and current theories with research evidence, with the goal of fostering outstanding clinical practice and clinical research.

The **first book** of the series set the stage regarding the environment of the medical SLP as an interprofessional team member, the clinical populations encountered by the SLP, and the foundational knowledge needed to understand and interpret neuroimaging, medication influences, and infection control precautions. The **second book** of the series is an invaluable resource on the frontotemporal dementias (FTDs), including primary progressive aphasia and apraxia of speech. It is a cutting-edge tutorial that encompasses differential diagnosis, clinical examinations, speech/language/cognitive assessments, neuroimaging findings, and treatment recommendations, with rich supplementary videos and images on the PluralPlus companion website. In the **third book** of the series, the authors harnessed their extensive clinical and research experience with people with dementia, and created a thought-provoking, practical resource. Centering their approach on dignity and empowerment, the authors reframe the traditional clinical approach and use clinical cases to highlight the fusion of evidence-based practice with culturally responsive care. Clinical guidance is effectively enhanced by materials on the PluralPlus companion website, including photos, forms, and screening tools.

In this exceptional **fourth book** of the Medical SLP Series, Drs. Roxann Diez Gross and Kristin A. King transform their decades of clinical experience into an innovative, indispensable resource on tracheostomy and ventilator dependence. Through the lens of 38 real-world case examples, the authors expertly walk us through the clinical process, deftly weaving in supportive research and background knowledge to guide the reader. The cases represent a diverse series of complex patients, across the lifespan and a vast range of etiologies, including brainstem stroke, COVID-19, Apert syndrome, West Nile virus, spinal cord injury, and Parkinson's disease. Case summaries are thoughtfully enriched with ample photographs and figures, and the authors include invaluable supplementary resources, including patient education materials and clinical decision-making flowcharts. Pediatric and geriatric specialists from around the world join the authors in providing expert

guidance for the safe and effective care of individuals with tracheostomy and/or ventilator dependence. The result is a masterful compilation of resources and recommendations for any professionals involved in the care of this complex clinical population.

Medical Speech-Language Pathology
Series Editors
Kristie A. Spencer, PhD, CCC-SLP
Jacqueline Daniels, MA, CCC-SLP, CBIS

Foreword

The role of speech-language pathologists as part of a team managing the care of patients with pulmonary impairment, across care settings, has evolved and expanded significantly over the past few decades. Indeed, the medical treatment of individuals with respiratory compromise and tracheostomy has improved in parallel with this evolution. The progression from the first efforts at noninvasive support to the sophisticated devices available to support intubated, tracheostomized, and ventilator-dependent individuals is itself a remarkable historical process.

This expansion of care options has benefited pediatric and adult patients in community, long-term, subacute, acute, and critical care settings. Accompanying this increase in medical options is impressive growth in the research supporting new directions in evaluation and treatment for tracheostomized individuals. It is particularly exciting that speech-language pathologists have taken leading roles contributing to the wealth of research and information available to clinicians in multiple disciplines. As practicing clinicians, teachers, and authors ourselves, we recall when there were far fewer resources available on this topic for healthcare professionals, especially speech-language pathologists. We benefited from working alongside medical and allied health professionals, such as respiratory therapists, and from our speech-language pathology colleagues also treating this unique group of patients.

This text, *Tracheostomy and Ventilator Dependence in Adults and Children: Learning Through Case Studies*, is the work of two of these colleagues, speech-language pathologists we have had the privilege of knowing, working with, and learning from over the years. Roxann Diez Gross, PhD, CCC-SLP, F-ASHA and Kristin A. King, PhD, CCC-SLP, are clinicians, teachers, and authors who have dedicated their careers to the care of tracheostomized individuals. As a result, they have refined our body of knowledge in managing communication and swallowing disorders for these challenging and complex individuals in a genuinely impactful manner. They have now taken on the task of editing a book that provides the reader a vast variety of case studies. The text guides speech-language pathologists, and other clinicians, through the care of patients with tracheostomy tubes and ventilator dependence by introducing them to clinical scenarios they may encounter in their own clinical practices and facilities. These range from using a Passy-Muir speaking valve for a child or adult with a tracheostomy and/or ventilator to managing an adult patient with a burn injury or a degenerative neurological condition. By skillfully including specialists from pediatrics to geriatrics and integrating relevant research into the cases, the editors have given us both a unique and valuable clinical resource and a further contribution to the field they support.

As authors in our own right, we can appreciate this text for the vast amount of work it represents and applaud this addition to the tools available to speech-language pathologists everywhere. Dr. Diez Gross and Dr. King continue to be leaders in our field and speech-language pathologists we are proud to call

colleagues. We are honored to contribute to their text and to write this foreword for you, their reader, introducing you to this very special resource.

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Preface

Several books about tracheostomies and ventilators are available; however, there are no comprehensive learning-from-case-studies books that address considerations for evidence-based care and troubleshooting through detailed case studies. To address this disparity, we created a book about the care of patients of all ages with tracheostomy and ventilator dependency that facilitates learning through the lens of stimulating real-world cases.

The chapters are organized by clinically relevant topics that are composed of case studies that illustrate each chapter's theme. Both pediatric and adult cases are presented when applicable. Each case was given a title that is based on the primary diagnosis so that readers may easily choose cases relevant to their clinical practice or educational objectives. National and international authors from different disciplines were invited to contribute so that readers may learn from a broad, multidisciplinary perspective. Basic guidelines were provided; however, contributors were free to present their case(s) as best fit their experience. Because this book is published in the United States, standard American English spelling and punctuation are used.

This book is meant to be an inspirational and educational resource that provides a multidisciplinary perspective on the care of patients with tracheostomies and enhances the knowledge of health care professionals. The cases may supplement academic coursework by providing examples of patient care that can be used for problem-based learning. By offering a wide range of case studies from a variety of disciplines with a multitude of diagnoses and medical settings, this book helps fill a void in the clinical and educational literature currently found on the topic of working with patients with tracheostomies and/or ventilator dependence.

CHAPTER 2

Finding the Best-Fitting Tracheostomy Tube

When a patient exhibits ongoing respiratory issues, they are often transitioned from an endotracheal tube to a tracheostomy tube for more long-term intervention. Tracheostomy tubes are manufactured by several companies, which leads to a wide variety of tracheostomy tube styles. When selecting the best-fitting tracheostomy tube for a patient, one must consider the appropriate size, status of cuffed or cuffless, single or double lumen, and manufacturing material. Selecting the correct fit is part science and part art form.

In addition, not all tracheostomy tubes are available in all hospitals or countries. When working with tracheostomies, having the best fit can impact the patient's progress, recovery, and access to the upper airway. This, in turn, impacts access to communication and other benefits. If a patient cannot use a standard tube that is readily available, then a custom tracheostomy is considered. Creation of custom tubes may be necessary to address a person's unique anatomy. Anatomical variations may be secondary to surgery, part of a disease process, congenital, or due to other factors and may impact the ability to use a standard tracheostomy tube. The pediatric and adult cases presented in this chapter address how physicians have determined the best-fitting tracheostomy tube under a variety of circumstances.

Pediatric Tracheostomy Tube Selection

Nicolas S. Poupore, Lydia B. Redden, William W. Carroll, and Phayvanh P. Pecha

CASE STUDY 2–1. CHILD WITH SCOLIOSIS AND VENTILATOR DEPENDENCE

BACKGROUND

More children with complex anatomy are receiving tracheostomies for long-term airway management (Law et al., 1993; Watters, 2017). Complex anatomy presents a challenge in finding an appropriate tracheostomy tube because standard-sized tubes may not function properly in these children (Trousdale et al., 2018; Tweedie et al., 2018). Poor-fitting tracheostomy tubes may cause irritation or ischemia of the tracheal mucosa (Naina et al., 2020; Trousdale et al., 2018). A tracheostomy tube with excessive length could lead to chronic cough and bronchospasm, whereas shorter tracheostomy tubes may cause ulceration of the posterior tracheal wall (Fuller et al., 2021; Weiss et al., 2006). In children requiring long-term ventilation, poor fit can lead to further issues such as tracheal stenosis, scarring, bleeding, granulation tissue, and chronic hypoventilation (Naina et al., 2020; Trousdale et al., 2018).

Recent retrospective reviews have highlighted elevated complication rates ranging from 40% to 80% in children with long-term ventilation (Gergin et al., 2017; Roberts et al., 2020; Wilcox et al., 2016). A particularly challenging population to consider includes children with neuromuscular scoliosis who require long-term ventilatory support. Scoliosis can lead to decreased size of the tracheobronchial lumen from torsion of the airway or compression from the innominate artery or sternum (Appachi et al., 2021; Donnelly & Bisset, 1998; Farrell & Garrido, 2018; Tatekawa et al., 2007). Moreover, these children with scoliosis are at a higher risk of restrictive lung disease that further complicates their ventilation status (Muirhead & Conner, 1985). A recent retrospective review highlighted the increased complication rate and challenging tube requirements for these patients with scoliosis requiring long-term ventilator dependence (Appachi et al., 2021). In their cohort, 18.6% of patients required at least one tracheostomy tube size adjustment secondary to granulation tissue, poor positioning, or hypoventilation (Appachi et al., 2021). Because scoliosis can influence the anatomy of the airway, extra attention toward finding the right fitting tube is required for these children (Appachi et al., 2021; Donnelly & Bisset, 1998; Farrell & Garrido, 2018; Tatekawa et al., 2007).

To avoid complications and increase effective ventilation in children with complex anatomy, custom tracheostomy tubes can be made. Before such custom tubes were commercially produced, historic case reports of handmade tracheostomy tube extensions were described in order to supply extra length (Galvis et al., 1977; Martin & Shapiro, 1981). Even more recently, a handmade custom tracheostomy tube was made in an emergency situation using the technique described in the older reports (Reilly & Volk, 2012). Case reports of children with rare medical conditions have described ordering custom tracheostomy tubes of variable lengths to adequately improve ventilation and decrease complications in their patients undergoing long-term

ventilation (Shinhar et al., 2004; Stater et al., 2015).

Properly fitting custom tracheostomy tubes are essential for patients with complex needs in addition to chronic ventilator support (Watters, 2017). However, the utility and challenges that come with a custom tracheostomy are underappreciated. Therefore, we present a case of a child who underwent multiple trials of different custom tracheostomy tubes to further educate providers on the nuances and difficulties of finding a proper fit with a custom tube in a child with complex anatomy.

CASE HISTORY

We describe a case of a 12-year-old male with a history of scoliosis and ventilator dependence. He had been tracheostomy dependent for seven years and required variations of a custom tracheostomy for the past several years. He was able to vocalize around his tracheostomy and communicate over his ventilator. This patient initially began needing the ventilator only at night but has since progressed to day and night ventilator dependence. His additional past medical history was significant for neuromuscular scoliosis, *LMNA*-related congenital muscular dystrophy, developmental delay, gastrostomy-jejunostomy tube dependence, and feeding intolerance. In addition, he had a significant cardiovascular history that included supraventricular tachycardia treated with an ablation procedure and progressive heart failure with an ejection fraction below 20%.

Despite variations in his custom tracheotomies, this patient developed persistent leak issues over the past year that were unresolved by inflation of his tracheostomy cuff. His issues began when his stoma became enlarged and L-shaped most likely due to contracture and positioning (Figure 2–1). His most recent

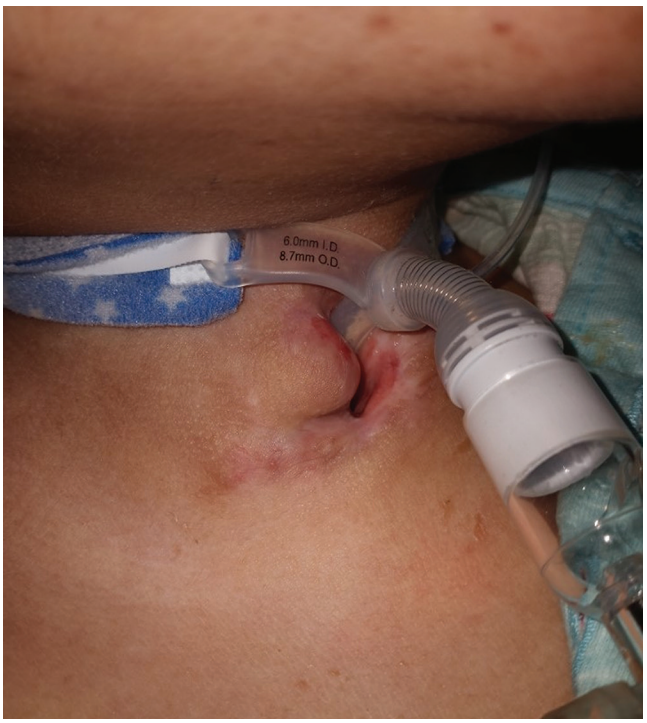

Figure 2–1. L-shaped stoma.

airway surveillance with microlaryngoscopy and bronchoscopy (MLB) last year revealed stable mild distal tracheomalacia and bronchomalacia and a wide tracheostoma with right-sided hypertrophic scar. The tip of his tracheostomy tube was found to be 3 cm above the carina with a high riding cuff that was also not sitting appropriately in the middle of his trachea. These findings contributed to his difficult tracheostomy tube changes at home. In addition to persistent leak, the family reported defective tracheostomy cuffs rupturing with inflation. While it is unknown how many defective cuffs this patient may have had, the patient's mother had been inflating the cuff with a reported 5 ml of water in an attempt to resolve these leak issues. Overinflation with that much water was initially a red flag for tracheomegaly, which can sometimes be lethal and impossible to treat (Hubbard et al., 2003; McHugh et al., 2010). Fortunately, further investigation did not confirm tracheomegaly. The vendor was notified of multiple defective trach cuffs, and the family was educated that the patient may benefit from tracheostomy upsize. It was recommended to increase his tracheostomy diameter from his current 6.0 to a 6.5 inner diameter (ID) as well as consider an increase in his tracheostomy tube length.

As previously mentioned, this patient had underlying cardiac comorbidities that further complicated his ability to receive anesthesia for formal airway evaluation in the operating room. Surveillance MLBs had been useful in documenting airway changes along with the removal of granulation tissue. His most recent anticipated surveillance MLB had to be postponed after cardiology advised a delay in anesthesia due to his progressive heart failure and associated risks. Therefore, this patient was evaluated in the office by flexible tracheoscopy with subsequent custom tracheostomy adjustments being made at that time.

Additional challenges for this patient included significant barriers to medical care. The distance from his home to the clinic was more than 2 hours, making routine follow-up difficult for the family. Also, his cardiac history, disease progression, and ventilator dependence resulted in multiple admissions to the pediatric intensive care unit that has further fragmented his care. The SARS-CoV-2 pandemic also made scheduling his appointments challenging and added another layer of difficulty. Last, there had been issues with the tracheostomy tube supply chain. While a custom order typically takes 9 to 12 days to arrive at the patient's house, back orders and other problems have likely contributed to the delays in shipment that have left him without a comfortable and proper-fitting tube for weeks.

This patient's tracheostomy course required multiple changes and adjustments. This patient initially began with a 5.5 standard FlexTend Bivona around 7 years ago. His first change was to a 6.0 custom tracheostomy tube for longer length secondary to his growth. He was later changed to a custom length 6.0 FlexTend TTS Bivona 52 mm, again due to his growth. He had been using this tracheostomy tube successfully for the past several years. However, his persistent leak issues started after the migration and changing of his stoma to a large, L-shape (see Figure 2–1). This can happen with contracture where the contracted scar tissue can eventually adhere to the trachea (Castel et al., 2016). This leads to "tracheal tug," which is where the skin and the trachea move concurrently leading to an irregularly shaped stoma (Skigen et al., 1999). Therefore, he underwent stomaplasty that temporarily improved his leak issues. Afterward, MLB showed the tip of the tracheostomy tube 3 cm above the carina and a high riding cuff with poor positioning in the airway. As a tracheostomy tube is recommended to be 1 to 2 cm above the carina, ordering a tube with increased length seemed like the first logical step (Naina et al., 2020; Weiss et al., 2006). Due to the patient's positioning and anatomy, a Hyperflex tracheostomy tube was initially considered. As this type of tracheostomy tube

can provide more structure, this was initially felt to be the best fit for this patient. However, there were concerns that the Hyperflex tracheostomy tube could worsen back-walling for this patient. The authors have experienced this complication seemingly more frequently with the Hyperflex since the tube is straight at rest and does not have a built-in natural curve. Moreover, after discovering that the patient's mother was inflating the cuff with 5 ml of water in an attempt to overcome his large leak, it was recommended that his inner diameter be increased in addition to the added length as it was causing his tube to sit at a poor angle for proper ventilation. Increasing length properly with the Hyperflex to align with his anatomy and increasing his diameter were the two interventional strategies used to fix this patient's persistent leak issues and improve his long-term ventilation status.

First, it was decided to increase his tracheostomy tube length. A 6.0 straight flange cuffed Hyperflex Bivona with 67-mm length was ordered. This new custom tracheostomy tube added an additional 15 mm of length to his tracheostomy tube along with a straight flange. The tracheostomy tube change went smoothly, but he complained of pain below his stoma. This pain did not improve with acetaminophen or positioning. His mother changed his tracheostomy tube back to his previous custom tube because she did not feel the longer Hyperflex tube was well tolerated. His pain was relieved as soon as the Hyperflex tracheostomy tube was removed and the older, shorter custom tube was placed back. He did have bleeding at the superior portion of his stoma with tracheostomy tube removal, potentially suggesting that the tube was pressing upward on his stoma. However, his leak issues had improved from a ventilator standpoint with the longer tracheostomy tube in place. Unfortunately, the Hyperflex was not tolerated, so the patient returned to his previous tracheostomy tube and notified the clinic.

For this patient, one large improvement in resolving persistent leak issues was his stomaplasty. However, this improvement was only temporary, and his leak issues returned after about a year, presumably due to continued growth and accompanying airway changes. After the failed conversion to the longer Hyperflex tracheostomy tube, there was another episode of a ruptured cuff of the patient's remaining shorter tracheostomy tube. The patient was changed to a curved 6.0 straight flange cuffed Bivona 67 mm in length. This was the same style as the tube used in his failed conversion but without the Hyperflex. He again initially complained of pain around his stoma and was given dexamethasone drops as a temporary measure until his new tracheostomy tube arrived. However, after approximately 1 week, the patient stated that his pain was gone, and the new tube was much more tolerable. Adding this extra 15 mm in length to the tracheostomy tube improved his ventilation status; however, some leak issues persisted. He ultimately was transitioned to a 6.5 ID FlexTend curved Bivona custom tracheostomy with the same additional 15-mm length. He tolerated this tracheostomy change well in the office, and upon tracheoscopy, it was confirmed to be well positioned above the carina and in the middle of the trachea.

After the last tracheostomy change, the patient was doing well, and his ventilation status was stable. There had been no further leak issues, and he was requiring less water in the tracheostomy tube cuff. Despite his weakness, he was still able to push air past the inflated cuff in order to vocalize with full sentences. He denied any pain or discomfort.

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