A Patient- and Family-Centered Model of Feeding and Swallowing Management for Children With Tracheostomies

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Purpose: With increasing frequency, speech-language pathologists are asked to provide feeding and swallowing evaluations and treatment to children with tracheostomies. The following article provides a topic-based review of the existing evidence and a model of collaborative decision making to guide clinicians who evaluate and treat these children.

Conclusion: Although the barriers to feeding and swallowing in children with tracheostomies may seem daunting, this model provides a patient- and family-centered approach that is rooted in scientific evidence.

Life-saving medical technology continues to advance, and tracheostomies are more commonly used both inside and outside the intensive care unit to relieve airway obstruction, improve secretion clearance, provide an avenue for long-term ventilation, and offer improved opportunities for normalization of development and/or rehabilitation (Cheung & Napolitano, 2014). An infant or child with a tracheostomy may have multiple comorbidities that influence oropharyngeal function. These include premature birth, limited or negative oral experiences, prolonged or traumatic intubation, immature or impaired upper and lower airway function, gastroesophageal reflux or other gastrointestinal abnormalities, developmental delays, physical impairments, and neurological deficits (Giambra & Meinzen-Derr, 2010; Joseph, Evitts, Bayley, & Tulenko, 2017; Sterni et al., 2016). Circumstances surrounding the decision to place a tracheostomy include the likelihood of survival, psychosocial burden, prolonged hospitalization, and variability in the child's medical status (Liu et al., 2014; Montagnino & Mauricio, 2004; Sterni et al., 2016; Watters, 2017). The pediatric feeding and swallowing specialist has a growing responsibility to integrate knowledge of the properly functioning and disordered upper aerodigestive tract with the demands of developing aerodigestive and neurological systems.

The three components of evidence-based practice are using the best available scientific evidence, applying informed clinical expertise, and incorporating the patient/caregiver perspective (American Speech-Language-Hearing Association, n.d.). These are of critical consideration for this patient population. There are known limitations to conducting robust research on children

with tracheostomies and ventilators. Specifically, this group of children is both highly complex and heterogeneous. Given this paucity of evidence, dysphagia and aerodigestive research in adults and children with other conditions can serve to guide clinical reasoning. As experts in understanding the synergistic relationship between aerodigestive tract anatomy, speech and swallowing as overlaid functions, and critical periods of development, the speech-language pathologist is uniquely trained to connect these dots for patients, families, and medical professionals. We must, however, go beyond our technical knowledge into the fields of counseling and health care ethics in order to best treat an individual patient and his or her family within the context of their own values, morals, and culture. Because it is not within the scope of this article to explore these complexities, the reader is encouraged to further consider resources including the Seedhouse grid (Seedhouse, 1998), Goal Attainment Scale (Kiresuk & Sherman, 1968), and motivational interviewing techniques (Miller & Rose, 2009; Rollnick & Miller, 1995). Tracheostomy management and pediatric dysphagia are advanced areas of practice, and clinicians interested in treating this population should obtain additional continuing education and mentorship.

In the following sections and diagrams, we will share our experience with implementing a feeding and swallowing guideline for use with children with tracheostomies in a pediatric facility. We propose that an inclusive and comprehensive approach to evaluating and treating these children accounts for each child's medical status, development, and family dynamics. Such an approach to feeding and swallowing disorders is highly collaborative, working together with physicians, other clinicians, respiratory care, nursing, and, most important, the patient and his or her family.

Foundations

Within our own practice at a pediatric hospital, across the continuum from the intensive care unit to outpatient multidisciplinary clinics, we identified gaps in provider education as a key barrier to patient progress. In order to establish a framework for the management of feeding and swallowing in children with tracheostomy, we summarized the following evidence to inform and guide clinical practice. The clinician should anticipate how the tracheostomy, tracheostomy cuff (whether inflated or deflated), and one-way valve alter the child's swallow. These devices may also affect the child's respiratory drive, core stabilization, ability to manage secretions, and ability to completely and properly close the airway at the appropriate time during swallowing.

Tracheostomy

The presence of a tracheostomy tube has the potential to affect both swallowing and communication development in children. The degree of impact can be influenced by factors such as age at tracheostomy placement and prior experiences with communication and swallowing, duration of tracheostomy dependence, ventilator dependence, frequency of suctioning, repetitive trauma to the airway such as difficult tracheostomy changes, and exposure to oral stimulation. To date, no reliable data suggest that the presence of a tracheostomy tube alone is directly associated with dysphagia or aspiration (Donzelli, Brady, Wesling, & Theisen, 2005; Giambra & Meinzen-Derr, 2010; Joseph et al., 2017; Leder, Baker, & Goodman, 2010; Leder, Joe, Ross, Coelho, & Mendes, 2005; Suiter, 2014; Terk, Leder, & Burrell, 2007). However, some specific effects of tracheostomy tubes have been reported. These include disordered abductor and adductor laryngeal reflexes, desensitization of the oropharynx and larynx as a result of airflow diversion through the tracheostomy tube, delayed swallow initiation resulting in laryngeal penetration, reduced effectiveness of the cough reflex to clear accumulated supraglottic secretions, reduced subglottic air pressure, and diffuse atrophy of the laryngeal muscles (Abraham & Wolf, 2000; Suiter, 2014). The type, size, and cuff status of the tracheostomy tube, as well as the presence or absence of air leak, has further potential to change the child's laryngeal and pharyngeal sensation and the integrity of airway protection reflexes.

Multidisciplinary Management of Feeding and Swallowing

Evaluating readiness for oral intake goes beyond the child's mouth and pharynx. It requires the clinician to collaborate with the medical team to evaluate and consider the whole child. In the intensive care unit, where children are severely ill, this collaboration is critical to a child's safety. The evaluation includes assessing the dynamic interconnected workings of the body, as well as the goals of the patient, his or her family, and medical team. When conducting treatment sessions, bedside evaluations, or instrumental evaluations of swallowing, the clinician should take into account the child's positioning, sensorimotor system, muscle tone, cognition, and medical stability. This must be done in an ongoing fashion, as the medically complex child's status may change frequently. A team approach may lead to improved outcomes when all team members have an individual responsibility for knowing relevant research and demonstrating clinical competence at the top of their scope of practice (Hofmann, Bolton, & Ferry, 2008; Speed & Harding, 2013). As teams vary across practice settings, it is important to identify which professionals have the appropriate clinical expertise to evaluate and treat each complex child (Udall, 2007).

Medical Status

Both the patient's medical history and current status are important to consider. Traumatic brain injury or critical illness may cause dysphagia, apart from the presence of a tracheostomy, by damaging peripheral and bulbar nerves, altering cognition, or causing the dysregulation of the reflexes involved in swallowing (Goldsmith, 2000). Aspiration has a potential to further complicate medical status by adding injury to already impaired lungs, prolonging time to weaning off respiratory support, and increasing length of stay. In infants and children with limited oral feeding experiences, it is important to consider gut maturation, lung development, positional stability, gross motor development, and suck–swallow–breathe coordination. Upper airway abnormalities may serve as the underlying rationale for trach placement, as in the case of bilateral vocal fold paralysis or structural obstruction. These anomalies often require surgical intervention for eventual decannulation from the tracheostomy, and it is important to consider the potential impact of airway manipulation on all phases of swallowing. In circumstances that warrant consideration of quality of life and end-of-life care, feeding and swallowing specialists should collaborate with the patient, his or her family, and medical team to establish a feeding plan, with the patient's overall well-being as the top priority (Keeler, 2010; Moynihan, Kelly, & Fisch, 2005; Roe & George, 2016).

Instrumental Evaluation

The clinical or bedside feeding and swallowing evaluation holds significant utility for gaining case history information and assessing readiness to introduce or resume oral feeding. The clinician should evaluate feeding skills including the oral preparatory and oral phases of swallowing. These assessments will aid in determining strategies and modifications to attempt during instrumental evaluation. In addition, they will help in establishing a feeding plan and time frame for moving to a formal instrumental evaluation if indicated. A clinical swallow evaluation is not useful for evaluating the pharyngeal and laryngeal anatomy or the pharyngeal phase of swallowing. Bedside evaluations are unreliable for predicting bolus flow characteristics, laryngeal penetration, and silent aspiration (Calvo, Conway, Henriques, & Walshe, 2016; Leder, 2015). A formal evaluation utilizing videofluoroscopy (videofluoroscopic swallowing study [VFSS]) or endoscopy (fiberoptic endoscopic evaluation of swallowing [FEES]) is the gold standard for evaluation of airway compromise during swallowing (Arvedson & Lefton-Greif, 2017; Leder & Karas, 2000). VFSS or FEES may be beneficial for early and efficient swallow management in this population (Leder et al., 2010). Not all children with tracheostomies must receive an instrumental evaluation. However, indicators for such an evaluation include restricted laryngeal movement (slowed laryngeal vestibule closure, reduced laryngeal excursion), increased secretion accumulation in the larynx or trachea, inherent airway protection difficulties, and other medical comorbidities associated with dysphagia (Abraham, 2005). Children who need frequent reassessments with changes to their medical status or who have mobility limitations, in particular, may be excellent candidates for FEES (Burkhead, 2011).

Modified Evans Blue Dye Tests

The "blue dye test" is a clinical tool that is used at the bedside to screen for the presence of aspiration. According to a review by Swigert (2003), results of the modified Evans blue dye test are inconsistent when compared to VFSS and FEES and may be falsely negative in up to 50% of cases. Furthermore, small volume aspiration is less likely to be detected because the aspirated material may not pass to the level of the tracheostomy cannula at the moment of suctioning. In the literature, there is a great deal of variability in the process of administering the modified Evans blue dye test, and sensitivity estimates vary widely, ranging between 38% and 95% (Bechet, Hill, Gilheaney, & Walshe, 2016). At best, a blue dye test or any variation thereof (such as offering brightly colored foods or liquids) functions only as a screen and should not be used as a substitute for formal evaluation via VFSS or FEES (Donzelli, Brady, Wesling, & Craney, 2001).

Cuff Inflation Versus Deflation

It is well established in the adult literature that tracheostomy cuff inflation does not prevent aspiration (Davis, Bears, Barone, Corvo, & Tucker, 2002; Ding & Logeman, 2005; Hernandez et al., 2013; Suiter, McCullough, & Powell, 2003). When aspiration is present, an inflated cuff may result in pooling of aspirated contents in the midtrachea. This may result in a larger volume aspiration event, which could be clinically detrimental. According to Terk et al. (2007), there is no causal link between cuff inflation and reduced hyolaryngeal excursion. By extension, the presence of an inflated cuff does not cause aspiration resulting from decreased hyolaryngeal elevation. Whether cuff deflation improves swallow function is unclear. Whereas the literature specific to the swallow function is equivocal, there is a potential benefit to cuff deflation for restoring olfactory and oral sensory input to support a child's multisensory interaction with food and liquids (Lichtman et al., 1995; Rolls, 2015). Cuff deflation is the preferred status for oral feeding, but a child's inability to tolerate cuff deflation should not prevent working on oral feeding readiness skills and introducing oral tastes with medical team approval (Suiter, 2014). The evaluating clinician should consider the patient as a whole, including the underlying reason for cuff inflation and medical stability.

One-Way Valves

A one-way valve, commonly known as a *speaking valve*, is connected to the outer hub of the tracheostomy tube. It allows airflow in through the tracheostomy tube during inhalation but closes to prevent airflow out through the tracheostomy tube during exhalation. Airflow is then directed up past the tracheostomy tube, through the vocal cords, and out through the upper airway, thus providing multiple benefits to an upper airway that has been altered. A definitive and direct causal link between improvements in swallow function and use of a one-way valve has not yet been established in the literature (Zabih et al., 2017). However, the one-way valve may be used as a compensatory strategy to address a specific physiological impairment (i.e., decreased supraglottic airflow leading to reduced oropharyngeal sensation, decreased subglottic air pressure to promote glottic closure) that may contribute to dysphagia (Eibling & Gross, 1996; Gross, Mahlmann, & Grayhack, 2003). One-way valve placement may improve swallow safety for select patients and/or food consistencies (Abraham, 2005; Suiter, 2014). Therefore, it is best to trial a patient both with and without a one-way valve during an instrumental evaluation of swallowing by a trained speech-language pathologist and respiratory therapist.

At our facility, from June 2013 to January 2018, 85 children and infants received one-way valve evaluations. Sixty-eight of those children (40 inline with ventilator circuit) used the one-way valve to support speech and swallowing with a tracheostomy (Harendt et al., 2018). Further research is needed to evaluate the long-term impact of one-way valve use on oral feeding and swallowing outcomes.

Implementation

Foundational knowledge in hand, we soon faced practical barriers to change within a large facility. In the following paragraphs, we will discuss these in more detail. We will also offer models for decision making about specific aspects of feeding and swallowing management and a case example to demonstrate implementation with a patient.

Feeding and Swallowing as a Continuum

A second barrier to progress for our pediatric tracheostomy patients was inconsistency of practice. At first glance, the best option was to make a rule (e.g., "the patient must be able to tolerate cuff deflation before beginning oral intake"). We soon discovered that a strict guideline created more barriers and was not universally applicable, for example, in the case of a child with a high cervical spinal cord injury.

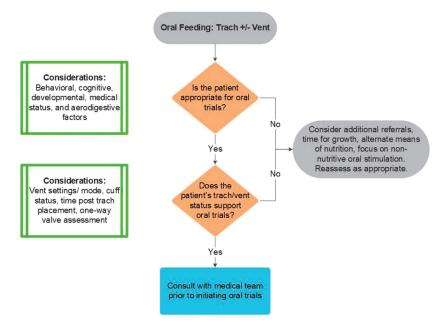
We instead shifted to a more developmentally supportive approach. Children at risk for oropharyngeal dysphagia include those with a history of preterm birth (before 37 weeks gestation), cardiac defects, gastrointestinal disorders, and neurological disorders (Dodrill & Gosa, 2015). Many children with tracheostomies have one or more of these comorbidities. The clinician must work collaboratively with a multidisciplinary team and think critically about the interplay between dysphagia, chronic or recurrent aspiration, and ventilator dependence (Sterni et al., 2016). Thus, when addressing feeding and swallowing in children with tracheostomies, the clinician should determine whether the child's care is focused on habilitation (i.e., learning new skills), rehabilitation (i.e., relearning lost skills), or quality of life management. This will help direct treatment planning and goals.

In infancy, feeding/swallowing management centers on remediation of nonnutritive sucking; promotion of positive oral feeding and oral feeding readiness; and coordination of sucking, swallowing, and breathing with pharyngeal and esophageal motility (Gosa & Dodrill, 2017; Jadcherla, 2016; Lau, 2016). Caregiver education is critical to long-term oral feeding success. Specifically, at the beginning of the caregiver–child feeding relationship, the feeder must learn to respond appropriately to the child's cues. Teaching-coregulated feeding techniques have been shown to support parent–infant attachment, reduce stress, and improve oral intake (Shaker, 2013). In later childhood, feeding and swallowing management may shift toward interventions adapted from the adult literature, especially in cases of acquired dysphagia following traumatic brain injury, stroke, or degenerative conditions such as muscular dystrophy or other neuromuscular disease. It is likely that many children with tracheostomies will benefit from a combination of compensatory and rehabilitative interventions (Gosa & Dodrill, 2017; Morgan, 2017).

Oral Feeding Readiness

A third barrier we identified was that our fellow speech-language pathologists and occupational therapists needed guidance for when and how to begin oral feeding after tracheostomy. Figure 1 details our suggested pathway for decision making.

Figure 1. Oral feeding readiness decision tree.



To determine whether a child is appropriate to introduce oral trials, a number of medical, behavioral, cognitive, and developmental factors should be considered. The need for a critically ill child to be medically ready to begin trials cannot be overstated. When medically fragile, a single aspiration event can cause a life-threatening respiratory decompensation. Once the medical team has agreed to introduce trials, other important factors must also be addressed. Specifically, eating and drinking are closely intertwined with cultural beliefs and preferences. Patient- and family-centered care for children with tracheostomies must incorporate these perspectives. The clinician should encourage primary caregivers to identify their own goals for their child's oral intake, family mealtime routines, and dietary preferences (Arvedson, 2008). This fosters an essential partnership with the family from the very beginning. This trusting relationship allows for healthy long-term communication and collaboration.

Observation of medical stability during feeding is critical with children with tracheostomies. Based on expert consensus at our facility and available literature (Engleman & Turnage-Carrier, 1997; Thoyre, Shaker, & Pridham, 2005), we suggest the following as a broad guideline for clinicians to consider. However, additional criteria may pertain to specific patients.

Medical stability may be defined as follows:

- oxygen saturation (SpO₂) of 88% or greater, except where otherwise indicated by the medical team;
- heart and respiratory rate change of no greater than 10% from baseline with repositioning and transfers;
- relaxed breathing, without significant retractions, tachypnea, or nasal flaring;
- minimal physiological response changes (i.e., muscle tone, skin color, work of breathing, facial expressions) during basic cares;
- after the first tracheostomy, change has occurred (to ensure healing of the stoma/tract); and
- stable ventilator settings and respiratory status for at least 24 hr (ideally up to 3 days).

Specifically for children with tracheostomies, the ability to manage oral secretions, to spontaneously swallow saliva, and to require tracheal suctioning infrequently may be indicators of oral feeding readiness. In addition, it is recommended that the child

- be able to clear tracheal secretions with a cough or tracheal suctioning,
- be breathing comfortably for more than 30 min between tracheal suctioning,
- be able to produce a cough or otherwise demonstrate vocal cord mobility formally via scope or informally via vocalization,
- be tolerating at least small volumes of enteral tube feeds (may be continuous or bolus), and
- have completed a one-way valve readiness assessment.

Introduction of Oral Tastes

A fourth, and often overlooked, barrier with medically complex children is actively involving the patient and caregivers in decisions related to oral feeding. Introduction of oral tastes can be a major milestone for the child and his or her family. The clinician is strongly encouraged to engage the parent or primary caregiver in offering the first tastes while balancing the need to perform the professional responsibility of evaluation and intervention.

The introduction of oral feeds requires close observation and critical thinking about the signs and symptoms of dysphagia. These signs and symptoms may vary in their presentation in children with tracheostomies. Therefore, quick decision making about modifications is essential to ensuring a safe and pleasurable oral feeding experience. Oral and tracheal secretions may change with the introduction of a food or liquid bolus, so a suction machine, appropriately sized suction catheters, and spare tracheostomy tubes should be readily available. Feeding should be attempted during a child's typical mode of ventilation, humidification, and tracheostomy occlusion. Although nonessential, it is recommended that pulse oximetry be monitored and documented, particularly if the patient has a history of oxygen desaturations or tachypnea during feeding. Pulse oximetry may provide information within the context of the feeding in its entirety about how the child's overall system is responding to the demands of feeding. If appropriate, the clinician should observe feeding with and without a one-way valve and document clinical changes between the two conditions.

Preliminary data collection at our facility from April 2016 to April 2018 showed that, by following our proposed guidelines, 26 of our 36 neonatal intensive care unit graduates with tracheostomies were discharged from the hospital consuming at least some portion of their nutrition by mouth. Six of those patients were consuming greater than 80% of feeds by mouth (Larson & Fleming, 2018).

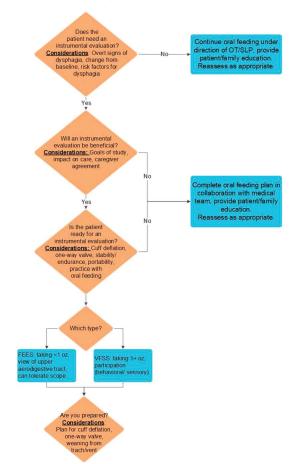
Dynamic Assessment

A final barrier to progress at our facility was our understanding of the limitations of the clinical or bedside evaluation, as well as the known benefits and challenges of completing an instrumental evaluation of swallowing on a child with a tracheostomy. Many of the same basic principles regarding overt clinical signs of dysphagia apply to children with or without tracheostomy tubes. Coughing, choking, worsening pulmonary function, inability to wean oxygen, unexplained refusal behaviors, decline in oral intake, and difficulty in gaining weight may be causes for concern for dysphagia. In the presence of a tracheostomy, other indicators of airway compromise may be seen: food or liquid seeping from sides of stoma, suctioning food or liquid from the tracheostomy tube, or a sudden change in the quality or amount of airway secretions suctioned from the airway. As previously mentioned, the absence of a cough, increased secretions, or food or liquid suctioned from the tracheostomy does not exclude the possibility of aspiration. Similarly, other components of oral, pharyngeal, or esophageal dysphagia are not assessed in this manner. To accurately diagnose and characterize suspected pharyngeal or esophageal dysphagia, a VFSS or FEES may be warranted.

Although airway compromise may occur acutely as described above, chronic or silent aspiration may lead to subacute respiratory symptoms such as chronic cough, hypoxemia, and respiratory distress caused by airways inflammation (Elpern, Scott, Petro, & Ries, 1994). Untreated aspiration may result in bronchiectasis (a condition where airways become enlarged due to chronic inflammation, infection, and fibrosis), impaired mucus clearance, and decreased lung function (Piccione, McPhail, Fenchel, Brody, & Boesch, 2012). Children with chronic aspiration have baseline inflammation, which places them at greater risk for severe decompensation in the context of viral or bacterial respiratory illness.

The question remains: How does one know when to conduct an instrumental evaluation of swallowing? The goal for the patient is a safe and functional feeding plan. Therefore, the instrumental evaluation is a tool, not a goal. Please see Figure 2 as a model for decision making related to the instrumental swallow evaluation.

Figure 2. Instrumental evaluation of swallowing decision tree. OT = occupational therapist; SLP = speech-language pathologist; FEES = fiberoptic endoscopic evaluation of swallowing; VFSS = videofluroscopic swallowing study.



Pursuing VFSS or FEES, the clinician should consider and discuss with the patient/family and medical team how the study results may influence ongoing care, the availability of therapeutic interventions, and informed decision making about oral intake. This helps to set clear expectations and maximize the child's willing participation in the study. With the results of the instrumental evaluation, recommendations for compensatory strategies, treatment approaches, treatment location and frequency, and home programming can be made or modified. Please see Figure 3 for a brief case review exemplifying this model.

Figure 3. Case review. PT = physical therapist; OT = occupational therapist; RT = respiratory therapist; SLP = speech-language pathologist.



In this process, it is important to balance the child with tracheostomy's constant need for care with the psychosocial aspects of parenting. This includes addressing the child's developmental needs and normalizing the family's involvement. The clinician's role then shifts to providing appropriate intervention and reassessing with changes to ventilator settings, airway patency, and/or medical status. When new clinically relevant information emerges, the clinician must change the interventions and recommendations accordingly.

Conclusion

When managing feeding and swallowing in children with tracheostomies, a dynamic assessment within the context of developmental and physiological changes is necessary. As a member of an interdisciplinary team, the speech-language pathologist has a unique and important role in understanding, sharing, and acting upon the best available research. We must actively work to gain clinical skills specific to feeding, swallowing, and tracheostomies. Above all, we must maintain a thoughtful and comprehensive approach in patient- and family-centered care and collaboration to promote the best and safest oral feeding outcomes for children with tracheostomies.

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