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Discussing Benefits and Risks of Tracheostomy: What Physicians Actually Say

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Abstract

Objectives—When contemplating tracheostomy placement in a pediatric patient, a family-physician conference is often the setting for the disclosure of risks and benefits of the procedure. Our objective was to compare benefits and risks of tracheostomy presented during family-physician conferences to an expert panel's recommendations for what should be presented.

Design—We conducted a retrospective review of 19 transcripts of audio-recorded family-physician conferences regarding tracheostomy placement in children. A multi-center, multi-disciplinary expert panel of clinicians was surveyed to generate a list of recommended benefits and risks for comparison. Primary analysis of statements by clinicians was qualitative.

Setting—Single-center Pediatric Intensive Care Unit (PICU) of a tertiary medical center.

Subjects—Family members who participated in family-physician conferences regarding tracheostomy placement for a critically ill child from April 2012 to August 2014.

Measurements and Main Results—We identified 300 physician statements describing benefits and risks of tracheostomy. Physicians were more likely to discuss benefits than risks (72% vs 28%). Three broad categories of benefits were identified: 1) tracheostomy would limit the impact of being in the PICU (46%), 2) perceived obstacles of tracheostomy can be overcome (34%), and 3) tracheostomy optimizes respiratory health (20%). Risks fell into two categories: tracheostomy involves a big commitment (71%) and it has complications (29%). The expert panel's recommendations were similar to risks and benefits discussed during family conferences; however, they suggested physicians present an equal balance of discussion of risks and benefits.

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Conflicts of Interest

The remaining authors have disclosed that they do not have any potential conflicts of interest.

Conclusion—When discussing tracheostomy placement, physicians emphasized benefits that are shared by physicians and families while minimizing the risks. The expert panel recommended a balanced approach by equally weighing risks and benefits. To facilitate educated decision making, physicians should present a more extensive range of risks and benefits to families making this critical decision.

Keywords

Decision Making; Informed Consent; Tracheostomy; Otolaryngology; Palliative Care; Pulmonary Medicine

Introduction

The decision to place a tracheostomy tube has been reported as one of the most stressful decisions for a family of a seriously ill child to consider (1). Although it has become a relatively common procedure in adult intensive care units, rates of tracheostomy placement are reported as 2% in pediatric intensive care units (PICUs) (2,3). PICU placed tracheostomies frequently result in decannulation, but tracheostomy placement is not without risk. Mortality is variable based on the indications for tracheostomy, with tracheostomy placement commonly offered to our most critically ill, complex diseased children (4,5). Families want to understand the benefits and risks of this critical decision to guide them in their ultimate choice, and presentation of this information should occur prior to consent. Although the literature informs us of what families want during these discussions (6–8), we do not know which benefits and risks physicians disclose to families. We also do not know which risks and benefits the general medical field believes should be discussed.

In this study, we aimed to evaluate the benefits and risks physicians most frequently discussed with families of children offered a tracheostomy. We also surveyed a multi-disciplinary expert panel of clinicians about the benefits and risks they deemed important to include during these meetings and compared the benefits and risks actually discussed during family-physician conferences to the panel's recommendations.

Materials and Methods

We conducted a two-tiered approach to better understand the benefits and risks of tracheostomy placement discussed with families of seriously ill children. Our primary design was a retrospective review of de-identified transcripts from audio-recorded family-physician conferences in a single center PICU of a tertiary medical center. The audio-recordings were part of a larger study aimed at gaining a baseline understanding of family-physician communication during decision-making conferences (9). Eligible family-physician conferences included formal meetings during weekdays convened to discuss tracheostomy placement. We chose to include weekdays only because our full complement of team members, including social workers and consultants, are not available on weekends and at night. Participants included English-speaking families of children in the PICU from April 2012 to August 2014 and all clinicians who attended the conference (Table 1). This study was approved by our institutional review board. All participants in the family conferences signed written consent to participate.

We also convened a multi-centered, multi-disciplinary expert panel tasked with generating a list of benefits and risks that, in their opinion, should be included in decision-making family-physician conferences regarding tracheostomy placement. A convenience sample of clinicians who were not involved in the transcribed family meetings or have access to the transcripts, but who routinely participate in tracheostomy family conferences, was approached via email and invited to provide their expert opinion. The expert panel included 27 clinicians from the following subspecialties: Pediatric Critical Care (57%), Otolaryngology (26%), Palliative Care (13%) and Pediatric Pulmonology (4%) in tertiary medical centers geographically representative of the United States. Experts were not provided with the transcripts for review.

Our primary outcome measure was generation of a conceptual model describing how physicians balance the discussion of benefits and risks of tracheostomy placement with families. We used qualitative analysis, the structured extraction and description of the intended meaning of narrative content (10), to deconstruct and categorize individual quotes made by physicians during family-physician conferences. Individual quotes made by physicians were identified and sorted into two categories: benefits and risks. Themes were then generated from the quotes. An iterative process was employed to compare each individual quote to other quotes for both overlapping and unique meaning, leading to reductions and merging of similar themes. Three coders (LH, AW, TO) created a code book by examining three transcripts. The remaining transcripts were independently coded. A random sample of 20% of the transcripts was selected to determine inter-rater reliability between coders. The Cohen's kappa was 0.94 ($p<0.001$). Finally, themes were organized into larger concepts using content analysis.

Survey responses from the expert panel were classified using the code book developed by content analysis. New codes were developed when the content did not fit the definitions in the code book. Our primary analytical approach for survey responses used descriptive statistics, including frequency and percentiles. A chi-square test of independence was performed to compare benefits and risks between those actually discussed during family-physician conferences and those recommended for discussion by the expert panel.

Results

Of the 21 eligible families who engaged in family-physician conferences regarding tracheostomy, nineteen (92%) consented to participation. Demographics of the patients and a list of the healthcare team participants are provided in Table 1. The primary indication for tracheostomy was respiratory disease, such as acute respiratory infection or an exacerbation of chronic lung disease, in 48% of patients and neurologic disease in 42% of patients. The median length of time from admission to the PICU to the family conference to discuss tracheostomy was 14 days. The family conference that was recorded was the first formal family-ICU discussion regarding tracheostomy for 15/19 (79%) of subjects.

All 19 conferences included discussion of at least one benefit and one risk of tracheostomy placement. There were 300 individual quotes regarding a benefit or risk. Benefits were more frequently discussed ($n=217$, 72%) than risks ($n=83$, 28%). Eight benefit themes were

generated from 217 individual quotes (Table 2). Most commonly, physicians described benefits of placing a tracheostomy as: (1) will lead to a faster discharge (18%), (2) does not have to be permanent (17%), (3) is a more stable airway (16%), and (4) allows reduced sedation needs (12%). Each theme was further categorized into three broad concepts reflecting the benefit the physician was attempting to convey. The first concept, “decreased need for ICU level care” included themes advocating that a tracheostomy can move a child’s care forward by leading to a faster discharge and decreasing sedation needs, allowing the child to be awake and interact with the environment. The second concept, “overcome obstacles,” included themes suggesting life with a tracheostomy might not be as difficult as families fear, in that the child may have the ability to regain speech, engage in normal activities of daily living, and have the tracheostomy reversed once the child’s health improves. The third concept, “optimize respiratory health,” suggests the tracheostomy can be a tool to improve airway mechanics, with the possibility of less infection, better airway clearance and reduced need for ventilator support. When evaluating the benefit themes by concept, we found physicians were most likely to present the “decreased level of ICU care” concept (46%) compared with “overcome obstacles” or “optimize respiratory health.”

Six risk themes were generated from 83 individual quotes (Table 3). Most commonly described risks were that tracheostomy (1) requires extensive medical support (25%), (2) may involve long-term ventilator dependence (20%), and (3) presents an airway risk (19%). Each theme was further categorized into two broad concepts reflecting risks the physician attempted to convey. Tracheostomy is a “big commitment” included themes highlighting the impact of tracheostomy on multiple aspects of caregiving, such as the extensive medical support it will require, lifestyle adjustments and implications of long-term ventilator dependence. The concept “complications exist” included risks describing difficulty with the airway, such as infection and obstruction and peri-operative problems. Physicians were more likely to present “big commitment” (71%) compared to “complications exist” (29%) themes to families when discussing the risks of tracheostomy.

Twenty-three expert clinician panel members listed 272 individual benefits (n=117, 43%) and risks (n=155, 57%) of tracheostomy placement. Compared to benefit themes generated from statements in family conferences, only two additional themes emerged: tracheostomy may result in fewer hospitalizations, and it can prolong life. The most commonly cited benefits from the expert panel were similar to benefits presented during family-physician conferences.

Of the 155 individual risks listed by the expert panel, eight themes were developed. Compared to the quotes made during the family conference, three new risk themes emerged: developmental delay, quality of life considerations, and tracheal or airway injury such as granuloma formation, stenosis or fistulas. Risk themes from the expert panel most commonly fell into the concept of “complications exist” (68%) compared with “big commitment” (33%).

In general, the expert panel recommended risks and benefits were similar to those presented during actual family conferences, with only a few additions. “Limit ICU impact” was the most commonly mentioned benefit concept in both family conferences (46%) and among

responses from the expert panel (55%). However, comparing risk concepts revealed an inverse relationship: “big commitment” was emphasized during family-physician conferences compared to the expert panel recommendations (71% vs 33%), while “complications exists” was emphasized more in the panel recommendations compared to the physician quotes (68% vs 29%, $p<0.001$). Lastly, the expert panel recommended giving equal weight to describing risks and benefits when discussing tracheostomy placement with families.

Discussion

The decision to place a tracheostomy is one of the most difficult decisions the family of a seriously ill child could face, and little is known about how physicians guide families through the decision-making process. The shared decision-making paradigm suggests physicians should make decisions with the patient and family considering the best medical evidence and patient values and equally weighing the risks and benefits. Our results show physicians are almost three times more likely to state benefits than risks, stressing the benefit of shortening the PICU stay over other potential benefits.

The emphasis of benefits compared to risks discussed in family-physician conferences suggests several interpretations. First, focusing on benefits may reflect an element of selection bias early in the process, where the decision to discuss a tracheostomy happens when physicians already believe a tracheostomy is the best or only course of treatment, leading to a discussion in which physicians aim to convince families to opt for the tracheostomy. Physician bias toward a tracheostomy has been shown in several studies which suggest physician recommendations often reflect personal values and cultural differences (11–16). Second, the assertion that having a tracheostomy is better than not having one is difficult to refute, especially if the alternatives presented are continued ventilator requirement, longer hospitalization, or even death. In fact, families have previously reported they feel the decision to have a tracheostomy was not a “choice” (17).

Of all the benefits discussed, those within the “limit ICU impact” concept were most frequently mentioned to families. We suspect physicians gave more weight to this concept because it represents a common goal shared by physicians and families, thereby resulting in the least conflict. Themes in this category do not have corresponding risks. For instance, the statement that having a tracheostomy tube will result in less sedation and more alertness is difficult for families to challenge because most families want to see their child awake and interacting with their environment.

Contrastingly, the benefit concept “overcome obstacles” carries less certainty and mutual agreement. In explaining that a child might be able to speak again, a physician is admitting that the child might not maintain normal speech. Similarly, statements of how the tracheostomy tube will not restrict activities tacitly acknowledge that it will interfere with daily life. Therefore, while the benefits of limiting the impact of the ICU are shared by physicians and families, the other benefits and all the risks presented are absorbed by the families alone.

The risks of tracheostomy that fall into the “big commitment” concept can be described using the term “burden,” which has been established in the literature to express undesirable effects of tracheostomy (18,19). Physicians noted the immense amount of care a child with a tracheostomy will need throughout his or her lifetime, which is supported by a large body of literature on the need for chronic complex care coordination in this population (20–22). In addition, families of children with tracheostomies experience significant degrees of social isolation, disruption of the rhythms of daily life, and less satisfaction with interpersonal relationships (23–28). While not all of these outcomes are inevitable, they are important factors to be considered by families as they make their decision.

The panel’s emphasis on tracheostomy complications, rather than caregiving burdens, is supported by data indicating that serious complications of tracheostomy, such as airway loss, wound issues, or the need for further surgical intervention, are occurring more frequently as more tracheostomies are performed in children with complex chronic conditions and ventilator dependence (29–34). Simultaneously, there is some evidence decannulation rates are dropping, with recent reports suggesting rates as low as 25–38% (4,35–37), leading to an increased prevalence of children with tracheostomies.

Overall, tracheostomy burdens were minimized by physicians compared with the discussion of benefits, which may be doing a disservice to families faced with this critical decision. Families want information that is clear, balanced and unbiased (38). Because indications for and outcomes of tracheostomy vary, providing such subjective information can be challenging; however, the complexity of the decision does not preclude the obligation to provide disclosure of common and major risks and benefits of the procedure.

The strengths of our study include giving insight into what is said during actual family conferences and offering theories as to why physicians might place emphasis on benefits over risks. These findings do need to be interpreted with several limitations in mind. Our physicians’ discussions of tracheostomy may be reflective of a single institution’s culture. Secondly, tracheostomy discussions between families and physicians are not limited to formal family conferences. We have not fully captured the information sharing that occurs during family-centered rounds or at the bedside or with consultants. We could not control for the information families may have already received regarding tracheostomy prior to the recorded family conference, which may influence the risks/benefits the medical team discusses. While this an extremely important point, it should also be noted that there is no system in place to systematically track discussions to ensure appropriate risks and benefits discussions have occurred in these various settings, either. Thirdly, we enrolled only English-speaking families. Communication experiences of non-English speaking families may be quite different. Finally, the underlying biases and decision-making processes of the medical team with respect to tracheostomy placement in specific patient populations was not ascertained, information that might clarify specific how physicians tailor their discussions of risks and benefits. For example, while it appears physicians often cite benefits over risks, does that pattern reverse when faced with the moral distress of offering a tracheostomy to a patient who they believe will have a poor outcome or quality of life? While the sample of family conferences and survey participants was adequate for the current analyses, it will be

important in future research to examine how recommendations and physician statements vary according to the indication for tracheostomy placement.

Conclusion

Physicians focus on benefits when discussing tracheostomy placement in family conferences and particularly stress the benefit of limiting the impact of the ICU. We suspect physicians focus on benefits they share with families to avoid more challenging discussions. An expert panel recommends a more balanced approach that gives equal weight to benefits and burdens to families as they contemplate this critical decision.

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References

1. Montagnino BA, Mauricio RV. The child with a tracheostomy and gastrostomy: Parental stress and coping in the home--a pilot study. *Pediatr Nurs*. 2004; 30:373–380. 401. [PubMed: 15587530]
2. Edwards JD, Houtrow AJ, Lucas AR, et al. Children and young adults who receive tracheostomies or were initiated on long-term ventilation in PICUs. *Pediatr Crit Care Med*. 2016; 17(8):324–334.
3. Wood D, McShane P, Davis P. Tracheostomy in children admitted to paediatric intensive care. *Arch Dis Child*. 2012; 97(10):866–869. [PubMed: 22814521]
4. McPherson ML, Shekerdemian L, Goldsworthy M, et al. A decade of pediatric tracheostomies: Indications, outcomes, and long-term prognosis. *Pediatr Pulmonol*. 2017; 52(7):946–953. [PubMed: 28263440]
5. Lee JH, Smith PB, Quek MBH, Laughon MM, Clark RH, Hornik CP. Risk factors and in-hospital outcomes following tracheostomy in infants. *J Pediatr*. 2016; 173:39–44. [PubMed: 26944265]
6. Anderson WG, Cimino JW, Ernecoff NC, et al. A multicenter study of key stakeholders' perspectives on communicating with surrogates about prognosis in intensive care units. *Ann Am Thorac Soc*. 2015; 12:142–152. [PubMed: 25521191]
7. de Vos MA, Bos AP, Plötz FB, et al. Talking with parents about end-of-life decisions for their children. *Pediatrics*. 2015; 135:465–476.
8. Van Cleave AC, Roosen-Runge MU, Miller AB, Milner LC, Karkazis KA, Magnus DC. Quality of communication in interpreted versus noninterpreted PICU family meetings. *Crit Care Med*. 2014; 42:1507–1517. [PubMed: 24394631]
9. October TW, Hinds PS, Wang J, Dizon ZB, Cheng YI, Roter DL. Parent satisfaction with communication is associated with physician's patient-centered communication patterns during family conferences. *Pediatr Crit Care Med*. 2016; 17:490–497. [PubMed: 27058750]
10. Krippendorff, K. Content analysis: An introduction to its methodology. Third. Thousand Oaks: Sage; 2013.
11. Benson RC, Hardy KA, Gildengorin G, Hsia D. International survey of physician recommendation for tracheostomy for spinal muscular atrophy Type I. *Pediatr Pulmonol*. 2012; 47:606–611. [PubMed: 22170631]
12. de Weerd W, van Tol D, Albers M, Sauer P, Verkerk M. Suffering in children: Opinions from parents and health-care professionals. *Eur J Pediatr*. 2015; 174:589–595. [PubMed: 25326280]

13. Neville TH, Wiley JF, Yamamoto MC, et al. Concordance of nurses and physicians on whether critical care patients are receiving futile treatment. *Am J Crit Care*. 2015; 24:403–410. [PubMed: 26330433]
14. Piers R, Azoulay E, Ricou B, et al. Inappropriate care in European ICUs: Confronting views from nurses and junior and senior physicians. *Chest*. 2014; 146:267–275. [PubMed: 24832567]
15. Roper H, Quinlivan R. Implementation of the "Consensus statement for the standard of care in spinal muscular atrophy" when applied to infants with severe type 1 SMA in the UK. *Arch Dis Child*. 2010; 95:845–849. [PubMed: 19819869]
16. Wang CH, Finkel RS, Bertini ES, et al. Consensus statement for standard of care in spinal muscular atrophy. *J Child Neurol*. 2007; 22:1027–1049. [PubMed: 17761659]
17. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*. 2006; 117:48–60.
18. Hartnick CJ, Bissell C, Parsons SK. The impact of pediatric tracheotomy on parental caregiver burden and health status. *Arch Otolaryngol Head Neck Surg*. 2003; 129:1065–1069. [PubMed: 14568788]
19. Hopkins C, Whetstone S, Foster T, Blaney S, Morrison G. The impact of paediatric tracheostomy on both patient and parent. *Int J Pediatr Otorhinolaryngol*. 2009; 73:15–20. [PubMed: 19019462]
20. Abode KA, Drake AF, Zdanski CJ, Retsch-Bogart GZ, Gee AB, Noah TL. A multidisciplinary children's airway center: Impact on the care of patients with tracheostomy. *Pediatrics*. 2016; 137:1–9.
21. Berry JG, Goldmann DA, Mandl KD, et al. Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Serv Res*. 2011; 11:117. [PubMed: 21605385]
22. Zhu H, Das P, Roberson DW, et al. Hospitalizations in children with preexisting tracheostomy: A national perspective. *Laryngoscope*. 2015; 125:462–468. [PubMed: 24986601]
23. Pandian V, Garg V, Antar R, Best S. Discharge education and caregiver coping of pediatric patients with a tracheostomy: Systematic review. *ORL Head Neck Nurs*. 2016; 34:17–18. 20–27. [PubMed: 27164767]
24. Patel MR, Zdanski CJ, Abode KA, et al. Experience of the school-aged child with tracheostomy. *Int J Pediatr Otorhinolaryngol*. 2009; 73:975–980. [PubMed: 19403179]
25. Overman AE, Liu M, Kurachek SC, et al. Tracheostomy for infants requiring prolonged mechanical ventilation: 10 years' experience. *Pediatrics*. 2013; 131:1491–1496.
26. DeMauro SB, D'Agostino JA, Bann C, et al. Developmental outcomes of very preterm infants with tracheostomies. *J Pediatr*. 2014; 164:1303–1310. [PubMed: 24472229]
27. Mah JK, Thannhauser JE, McNeil DA, Dewey D. Being the lifeline: The parent experience of caring for a child with neuromuscular disease on home mechanical ventilation. *Neuromuscul Disord*. 2008; 18:983–998. [PubMed: 18974004]
28. Joseph RA, Goodfellow LM, Simko LM. Parental quality of life: Caring for an infant or toddler with a tracheostomy at home. *Neonatal Netw*. 2014; 33:86–94. [PubMed: 24589900]
29. Meert KL, Eggly S, Pollack M, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2008; 9:2–7. [PubMed: 18477906]
30. de Trey L, Niedermann E, Ghelfi D, Gerber A, Gysin C. Pediatric tracheotomy: A 30-year experience. *J Pediatr Surg*. 2013; 48:1470–1475. [PubMed: 23895956]
31. Douglas SL, Daly BJ, Lipson AR. Neglect of quality-of-life considerations in intensive care unit family meetings for long-stay intensive care unit patients. *Crit Care Med*. 2012; 40:461–467. [PubMed: 21963580]
32. Lawrason A, Kavanagh K. Pediatric tracheotomy: Are the indications changing? *Int J Pediatr Otorhinolaryngol*. 2013; 77:922–925. [PubMed: 23537927]
33. Mahida JB, Asti L, Boss EF, et al. Tracheostomy placement in children younger than 2 years: 30-day outcomes using the National Surgical Quality Improvement Program Pediatric. *JAMA Otolaryngol Head Neck Surg*. 2016; 142:241–246. [PubMed: 26822902]

34. Ogilvie LN, Kozak JK, Chiu S, Adderley RJ, Kozak FK. Changes in pediatric tracheostomy 1982–2011: A Canadian tertiary children’s hospital review. *J Pediatr Surg.* 2014; 49:1549–1553. [PubMed: 25475792]
35. Zenk J, Fyrmpas G, Zimmermann T, Koch M, Constantinidis J, Iro H. Tracheostomy in young patients: Indications and long-term outcome. *Eur Arch Otorhinolaryngol.* 2009; 266:705–711. [PubMed: 18766359]
36. Ozmen S, Ozmen OA, Unal OF. Pediatric tracheotomies: A 37-year experience in 282 children. *Int J Pediatr Otorhinolaryngol.* 2009; 73:959–961. [PubMed: 19395057]
37. Funamura JL, Durbin-Johnson B, Tollefson TT, Harrison J, Senders CW. Pediatric tracheotomy: Indications and decannulation outcomes. *Laryngoscope.* 2014; 124:1952–1958. [PubMed: 24430892]
38. Edwards EA. Sending children home on tracheostomy dependent ventilation: Pitfalls and outcomes. *Arch Dis Child.* 2004; 89:251–255. [PubMed: 14977704]

Table 1**Patient Demographics/Clinical Characteristics and Family Conference Attendees**

Patient	n=19 (%)
Sex, male	11 (58)
Age, months (Median, Interquartile range)	15 (2 – 16)
Race	
African American	10 (53)
Caucasian	6 (32)
Asian	1 (5)
Other ^a	2 (10)
Diagnostic Category	
Respiratory	8 (43)
Neurology	5 (26)
Hematology/Oncology	4 (21)
Shock/Trauma	1 (5)
Cardiac Arrest	1 (5)
Indication for tracheostomy	
Pulmonary	9 (48)
Neurologic	8 (42)
Other ^b	2 (10)
Disposition	
Home	10 (53)
Chronic Care Facility	5 (26)
Deceased	4 (21)
Hospital Length of Stay, days (Average, SD)	58 (42)
PICU Length of Stay, days (Average, SD)	50 (31)
Time from PICU admission to family conference Days, (Median, Interquartile range)	14 (9–34)
Family Conference Attendees	n=19 (%)
Family	
Mother	19 (100)
Father	16 (84)
Healthcare Team	
ICU Attending Physician	19 (100)
Consultant Physician	16 (84)
Neurology	10 (53)
Hematology/Oncology	5 (26)
Pulmonology	5 (26)
Genetics	4 (21)
Complex Care	4 (21)
Palliative Care	2 (11)

Patient	n=19 (%)
Surgery	1 (5)
Ear Nose Throat	1 (5)
Infectious Disease	1 (5)
Nurse Practitioner	4 (21)
Social Work	15 (79)
Case Manager	10 (53)
Bedside Nurse	7 (37)
Other ^c	8 (42)

^a Other race: listed as "other" in medical record

^b Other indication: frequent operating room visits and airway burn

^c Other attendee: medical student; intern; genetic counselor; chaplain

Table 2

Benefits: Theoretical Concepts and Themes Generated from Clinician Statements During Family Meetings about Tracheostomy Placement

Concept	Theme	Definition of Theme	Frequency n=217 (%)	Sample Quotes
Limit ICU Impact	Faster Discharge	Earlier transition out of ICU	39 (18)	"This decision about something like the tracheostomy is merely to follow him on the path and to keep moving forward on the path."
	Stable Airway	Secure and safer tube option	35 (16)	"It is a secure airway that if it falls out, it can be replaced very simply."
	Reduced Sedation Needs	Allows for increased arousal and wakefulness	25 (12)	"It will get her in a place where she can have little or no sedation, interact with you."
Overcome Obstacles	Non-Permanence	Tracheostomy can be reversed	36 (17)	"We see a lot of our kids get trachs, and have the trachs come out."
	Normalize Life	Can engage in activities of daily living, including eating and reintegrating into society	23 (10)	"They really can do what anybody else can do, they just breathe from a different place."
	Speech	Regain ability to talk	15 (7)	"She can get the Passy-Muir, and then she can work on talking."
Optimize Respiratory Health	Improved Airway Clearance	Reduces infection and improves ability to manage secretions	24 (11)	"Trach would make that easier to get out secretions, before it builds up and causes problems."
	Reduced Ventilator Needs	Ability to wean or stabilize ventilator support	20 (9)	"If he's getting better, we can actually take him off the ventilator all together"

Table 3

Risks: Theoretical Concepts and Themes Generated from Clinician Statements During Family Meetings about Tracheostomy Placement

Concept	Theme	Definition of Theme	Frequency n = 83 (%)	Sample Quotes
Big Commitment	Extensive Medical Support	Caring for a tracheostomy requires a team and increased vigilance	21 (25)	"If he's on some kind of machine ... there needs to be an adult with him 24 hours a day."
	Functional Limitations	Requires lifestyle and activity adjustments	13 (16)	"It's going to be a completely different life style change for you."
	Speech	Loss of sound	8 (10)	"if you're hooked to a ventilator, you can't get the [speaking] valve."
	Long Term Ventilator Dependence	Having a tracheostomy might not reduce the need for mechanical ventilation	17 (20)	"likely what would happen, is that he would require ventilatory support even after he has the tracheostomy."
Complications Exist	Airway Risk	Increased chance of lung infection and tube obstruction or dislodgment	16 (19)	"It might be a bacterial infection from having a tracheostomy because that puts you at risk for pneumonias."
	Invasive Procedure	Peri-operative problems can occur	8 (10)	"There's always, there's a risk, with any kind of procedure."