

A Tough Decision: Parents' Perspective on Shared Decision-Making About Tracheostomies

Authors

Kenneth Pituch, MD; University of Michigan, Department of Pediatrics

Stephanie Kukora, MD; Children's Mercy Kansas City, Department of Pediatrics, Division of Neonatology and Bioethics Center; University of Missouri Kansas City School of Medicine, Department of Pediatrics

Cynthia Arslanian-Engoren, PhD, RN; University of Michigan Department of Health Behavior and Biological Sciences, School of Nursing

Haoyang Yan; Department of Psychology, University of Michigan

Subject keywords or phrases

Pediatric Tracheostomy, Shared Decision-Making, Decision-Support Tool, Tracheostomy Education, Decision Education

Abstract

Often when patients and families face the decision to pursue a tracheostomy or not, there is not a clear "right answer" as to whether this is in the child's best interest. These decisions should be instead based on anticipated outcomes and patient/family values around those possible outcomes, and the burden of making these decisions shared between clinicians and patients/parents. Limited decision tools exist, however to support parents and clinicians facing pediatric tracheostomy decisions. This is likely because most patient- or parent-facing decision tools focus on communicating specific information about the options, risks, and outcomes, which differ widely across pediatric conditions. For many of these conditions, no population data exist to guide decision-making. Most the education around shared decision-making has targeted clinicians; relying on the assumption that clinicians will become adept at this and utilize it effectively in practice. Unfortunately, not all clinicians receive or use this training, and evidence shows that patients and families are not well engaged in shared decision-making in practice.

To address this gap, we sought to develop a clinical, bedside intervention with peer parent narratives to help parents understand the shared decision making (SDM) process, their role in the decision, and other parents' considerations in this context. We identified nine parents of eight parents who had faced a tracheostomy decision for their child and were willing to talk about their experiences on a video recording. Half of the parents had chosen tracheostomy; some children of parents making either choice had died. We included parents of diverse racial backgrounds whose children had different diagnoses. Parent interviews, along with an explanation of SDM for parents based on the literature and professional society recommendations, were edited into a 17-minute video guided by iterative feedback from parents and clinicians. This video is intended to

complement individualized counseling about the tracheostomy decision and discussions of patients/families goals, values, and preferences.

Funding sponsors

University of Michigan M-Cubed 3.0 Grant