



Facilitating Shared Decision Support for Pediatric Tracheostomy

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Life Sciences

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OVERVIEW

In pediatric and neonatal critical care units, a growing number of children with serious underlying illness can only continue to survive with artificial respiratory support. Placement of a tracheostomy and possibly long term mechanical ventilation is a high stakes decision that in many situations could be ethically either an acceptable or a non-acceptable choice. Shared decision-making leads to more acceptable outcomes for these children and their parents and relieves the overwhelming burden that parents can face when asked, 'what do you want us to do?' The materials in PART ONE of this package describe include the approaches developed by parents and clinicians at our children's hospital for supporting the shared decision-making process when a decision regarding placement of a tracheostomy needs to be made.

The first resource on the site is a video of parent stories and advice regarding their decision journey. Next, is a training module directed at the clinicians outlining the process of shared decision making along with suggested language to be used in these situations, followed by a 'Road Map' for identifying patients who are appropriate for a shared decision and the processes and materials designed to support the shared decision-making process. Other resources include more parent-narrated videos, written and on-line resources available to parents, and guidelines for the content of team and family meetings.

For our colleagues who wish to initiate or participate in the research that might evaluate and advance these approaches, PART TWO of this package of resources includes the background surveys and interviews with critical care unit staff and with parents that indicate the need for the educational tools and supports found In part one, along with PDF's of the posters and presentations with results. These approaches and guidelines can be used and adapted for

implementation in any children's hospital's intensive care unit where high stakes decisions need to be made.

INNOVATION

Part one: The Decision Support Intervention Resources.

- Parent Video - A Tough Decision: Parents' Perspective on Pediatric Tracheostomy
- Learning Module - Facilitating Shared Decision-Making in Pediatric Tracheostomy
- Guidebook to the comprehensive intervention (The Road Map)
- Videos of Patient Outcomes (8 short videos)
- Booklet - Understanding the Tracheostomy Option - Other Parents' Experiences

Part two: The Research Components. (to be added later)

- Learning Module Survey form
- Pre-and Post Intervention Parent Survey Forms
- Pre-and Post Intervention Parent Interview Form
- Pre-and Post Intervention Staff Survey Form
- Pre-Intervention Chart Review protocol

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