Parental Preferences in Decisional Autonomy and Values Guided Approaches in Tracheotomy Decisions

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• The authors have no conflicts of interest
What we know about high stakes tracheotomy decisions.

Decisions are HARD

ICU physicians often say, “Your child is going to need a tracheotomy…”

ICU physicians more often ask, “What do you want us to do?”

Palliative care practice advises, “Ascertain parents’ values. Decisions should be shared.”

ICU physicians, nurses, trainees get little or no training.
Research questions

• Do parents want to share the decision?
• Do they want their values elicited?
• What about the framing of a trache decision influences the decision...
• ...and the regret?
The Chris Feudtner Model

The SPACE Model of Decision Support

- Worries, Fears, Sadness
- Ceiling
- Hopes (Goals)
- Wall Ahead
- Floor
- Sense of Parental Duties
- Sense of Problem-Solving Decision-Making and Coping
- Wall Behind
- Medical Information

* Supportive Practices for Affirmation, Acceptance, Commitments, Coping, Empathy and Evaluation

Goal: Increase the space
The Chris Feudtner Model

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- Fears
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Medical Information

The SPACE for Problem-Solving Decision-Making and Coping

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Sense of Parental Duties

Goal: Increase the space
Survey Study 1:  Case: “Aiden”

- 3 week old term infant
- Complicated delivery, prolonged resuscitation including intubation
- At 12 hours of age developed seizures
  - Confirmed on EEG
  - Treated with escalating doses of anti-convulsants
- Aiden has remained on mechanical ventilation and NG tube feeds
- EEG: abnormal pattern with frequent seizures despite medications
- Brain MRI: hypoxemic brain injury with some areas of hemorrhage
Case: “Aiden”

- Two attempts at extubation unsuccessful
- Permanent blindness is possible, abnormal hearing screen
- Prognosis anticipated to be very poor
  - Unlikely he will be able to ever eat independently, walk, talk or communicate
  - Impossible to be absolutely sure
- Otherwise a normally formed, “cute” baby
Design: Survey One

93 parents in the US using Mturk

Created 6 versions, or "framings", of a hypothetical scenario of a child’s parents faced with deciding between tracheostomy or comfort care

These framings varied by approach, burden, and recommendation
Design: Survey One

193 parents in the US using Mturk

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These framings varied by approach, burden, and recommendation

Hypotheses

• Parents would be more decisive and accept a recommendation for comfort IF the recommendation were framed with values.

• Some parents would always chose tracheostomy no matter how it was framed and presented.

• Indecision would be highest when the parents felt that the burden was on them and not on the physician.
Physicians

Parents

Shared

Choose or Accept Tracheotomy

Choose or Accept Comfort Care

Cannot Decide without more PME or information

Decision
Physicians

Parents

Shared

Choose or Accept Tracheotomy
Choose or Accept Comfort Care
Cannot Decide without more time or information
Your baby has suffered a significant injury to the brain and is unable to breathe without continued ventilator support. To survive for longer, it would mean dependence on a tracheostomy and likely a ventilator.
You have told me what is most important for you and your family. You have said that you are most worried about your child’s suffering and what life would be like on a machine. You are doing the best you can to be a good parent.
Physician Directed Decision

You will be meeting lots of people who will explain the risks, and explain to you what you will have to learn about taking care of a baby with a tracheostomy.

OR

We advise against this as we think this will unnecessarily prolong your baby's suffering. We would ensure your baby is comfortable once we remove the tube and you could hold your baby.
Parents bear the decision burden.

Many loving parents have decided that a short life off a machine is better than a longer life on a machine. If this is your choice of what is best for your baby, we will make sure your baby is comfortable. Other parents feel that their children need to be given every chance, even if it means a long time in the hospital, lots of sedating medications, and a life dependent on a machine.

We will support whatever decision you make.
Physician and parents share the burden.

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Based on what you have told me, I believe we should...
Results on Decisions

- **Cannot decide now**
- **Decide or accept Comfort Care**
- **Decide or accept Tracheotomy**

Parents

- Decide
- Trache recommended
- Comfort recommended
1. Indecision was always high. Highest when tracheotomy recommended without values

Parents
Decide

Trache
recommended

Comfort
recommended
Results on Decisions

1. Indecision was always high. Highest when tracheotomy recommended without values

2. Comfort was most likely to be accepted when recommended
Results on Decisions

1. Indecision was always high. Highest when tracheotomy recommended without values.

2. Comfort was most likely to be accepted when recommended.

3. At least 10% of parents chose tracheotomy no matter how it was presented.
Results on Decisions

1. Indecision was always high. Highest when tracheotomy recommended without values.

2. Comfort was most likely to be accepted when recommended.

3. At least 10% of parents chose tracheotomy no matter how it was presented.

4. Values approach led to more parents choosing comfort when it was their choice.
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When parents were asked to make the choice, comfort was more often chosen when the choice was framed with the language of values.
Limitations

• This was a **hypothetical** scenario, not a real one

• The framings with the values-guided approach **assumed** (randomly assigned) values to the participants, who may not necessarily share those values in actuality
Next steps / studies

• Interviewing real ICU parents who have just made or accepted a tracheotomy decision

• Next M-turk surveys:
  • Ask values and preferences first, then frame the question with and without congruence.
  • Add a framing that includes social norms: “Most parents in this situation choose ________.”
  • Survey experienced parents. (SMA 1, Single ventricle heart disease, Trisomy 13 and 18, etc.).
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• Ultimate goal: Informed curriculum for teaching the skills of decision support.
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