To Trach or Not To Trach: Long-Term Tracheostomy Outcomes in Infants with BPD

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In this NeoBrief, I will present an overview of multidisciplinary, family-centered counseling about the option of tracheostomy placement in infants with bronchopulmonary dysplasia (BPD).

The pictures on this slide are of proud graduates of The Nationwide Children’s Hospital BPD Program and used with permission of the children and their families.
Tracheostomy Counseling for Infants with BPD is Challenging

• Tracheostomy placement is infrequent in BPD.

• No consensus indications for tracheostomy placement exist.

• Decision to commit to tracheostomy placement is life-changing for families.

Counseling families of infants with BPD about the option of a tracheostomy is challenging.

For one, tracheostomy placement is fortunately an infrequent event in infants with BPD. Thus, it is difficult to routinely identify infants with BPD who are most likely to benefit from the procedure.

Second, consensus indications for tracheostomy placement in infants with BPD do not exist. So, we lack objective criteria to determine the optimal patient population who will derive the greatest benefit from tracheostomy placement.

Third, the decision to commit to tracheostomy placement is life-changing for families and requires a comprehensive understanding of what caring for an infant with a tracheostomy in the home environment entails. Consequently, tracheostomy placement is ultimately informed by the unique clinical needs of individual patients and value systems of their families.

Focusing tracheostomy counseling on outcomes that are of the greatest
importance to families provides clinicians with the opportunity to present an evidence-based overview of the known risks and benefits associated with the procedure while empathetically addressing future concerns that may vary between families with diverse experiences.
A primary concern for parents considering a tracheostomy is whether their child with BPD will survive following tracheostomy placement.

For infants with BPD, post-tracheostomy survival rates are generally favorable. For example, in published studies, survival to birth hospitalization discharge following tracheostomy placement ranges from 70-100% (animation first table) While post-discharge survival rates range from 80-97% (animation second table)

When an infant with BPD and a tracheostomy does not survive, causes of death include:

- Unplanned decannulation
- Worsening chronic respiratory failure
- Or acute respiratory failure due to a bacterial or viral infection
Respiratory Outcomes – “When will my child no longer require a tracheostomy?”

- Most wean from respiratory support and outgrow need for tracheostomy in early childhood.
- Observed time to wean from respiratory support is highly variable.

Additional concerns shared by most parents of children with BPD who undergo tracheostomy placement relate to long-term respiratory outcomes.

At the forefront of parents’ minds are the anticipated duration of chronic home ventilation and the long-term need for the tracheostomy tube itself.

Recently published data from the BPD Collaborative demonstrate that most infants with BPD who underwent tracheostomy placement wean from respiratory support over the first two years of life with most patients achieving successful decannulation prior to the age of 5.
Neurodevelopmental Outcomes – “Will my child experience developmental delays?”

- Independently associated with neurodevelopmental impairment in childhood.
- Earlier placement may promote earlier transition to developmentally-enriched care.

An additional concern that most parents share is whether their child will experience developmental delays as a consequence of tracheostomy placement.

Results from a large observational study from the NICHD Neonatal Research Network, demonstrated that tracheostomy placement was independently associated with a higher risk of neurodevelopmental impairment in early childhood.

While the specific mechanisms that contribute to this association remain unknown, timing of tracheostomy placement may be a modifiable risk factor for neurodevelopmental impairment.

In the same study, investigators observed higher Bayley scores in infants who underwent tracheostomy placement prior to 120 days of age as compared to infants who underwent tracheostomy placement after 120 days.

It is thought that earlier tracheostomy placement may facilitate the adoption of developmentally enriched care that is not always possible in infants who are
endotracheally intubated. For example, in a single center observational study by Luo et al., investigators observed (animation 2):

   Improved tolerance of developmental therapies as well as a reduction in opiate and benzodiazepine exposures

after tracheostomy placement in a cohort of infants with severe BPD.
The optimal timing for tracheostomy placement in infants with BPD remains unknown. While observational studies have found that tracheostomy placement generally occurs between 48-52 weeks’ post-menstrual age, there is large variation in timing of tracheostomy placement observed both within and between centers. Compelling but competing rationales for placing tracheostomies early versus late contribute to patient and hospital variation in timing.

On the one hand, early tracheostomy placement may
• Reduce exposures to neurosedative medications
• Promote earlier developmental therapy
• And initiate transition home

Alternatively, a rationale for late tracheostomy placement is informed by
• The inability to predict successful discontinuation of mechanical ventilation
• A desire to avoid short- and long-term risks inherent in tracheostomy
• And technical limitations due to inability to place tracheostomies in infants treated with high mean airway pressures and/or high amounts of oxygen
Safe Discharge Planning – “When can my child go home?”

- Elements of safe discharge planning:
  - Equipment and medications
  - Caregiver training
  - Multi-disciplinary medical home team

- Mean age of discharge
  - 5 months post-tracheostomy placement
  - 10 months’ chronologic age

As many parents consider tracheostomy placement to be an important step toward going home, parents are often anxious to know how tracheostomy placement will affect timing of discharge.

Safe hospital discharge of infants with BPD and tracheostomy is a complex, high-stakes process that involves three essential elements

1.) Provision of equipment and medications, listed here (animation 1)
2.) Comprehensive caregiver education and training, listed here (animation 2) and
3.) Establishment of a multi-disciplinary medical home team, listed here (animation 3)

Given the inherent complexities and uncertainties involved in the highly coordinated planning required for infants with BPD who are discharged with a tracheostomy, predicting time to discharge can be difficult. Data from the BPD Collaborative found that the mean age of discharge is 5 months’ post-tracheostomy and 10 months chronologic age, though post-tracheostomy discharge timing is highly variable and influenced by the medical needs of the patient, the psychosocial needs of the family, and the availability of external...
resources including durable medical equipment and home nursing.
Key Takeaways for Clinical Practice:

Balancing Risks, Benefits, and Alternatives

**Benefits**
- Provision of chronic ventilation to facilitate discharge home
- Improved respiratory stability
- Increased comfort, decreased agitation, and decreased need for neurosedatives
- Promotion of age-appropriate developmental and oro-motor therapies

**Risks**
- Short-term procedural risks
- Sudden, acute death due to mucous plugging or accidental decannulation
- Long-term development of airway anomalies
- Bacterial colonization and respiratory infections
- Neurodevelopmental delay in early childhood

**Alternatives**
- Seeking a second opinion
- Ongoing care with mechanical ventilation
- Transition to palliative comfort care

When providing outcomes-centered tracheostomy counseling for families, it is essential that clinicians present a balanced overview of the benefits, risks, and alternatives to the procedure based on best available evidence. The benefits, risks, and alternatives to tracheostomy placement for infants with BPD are summarized here.

After providing families with the spectrum of medical options and alternatives, families then benefit from having the time and space to weigh the relative risks and benefits of tracheostomy placement to make the best-informed decision for their child.
Additional information about long-term tracheostomy outcomes in infants with BPD, along with a list of references included in this NeoBrief, can be found in our NeoReviews manuscript on this topic, which can be found in the November 2023 issue of Neoreviews. Thank you.