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Regional Tracheostomy Management

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Outline

- Purpose and process of the multidisciplinary Aerodigestive clinic
- Transition from Inpatient to Outpatient care for the pediatric tracheostomy patient
- Home and long-term realities, implications for families
- Barriers (SC limitations)
- Statistics and volume of pediatric tracheotomies by year
- Community Outreach (EMS support)

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Background

- We are seeing an increasing volume year after year of preterm infants with chronic lung disease who require tracheostomy and ventilator assistance.
- CLD affects 10,000-15,000 infants annually in US
  - 40% of ELBW infants (BW <1000g) develop BPD
- A majority of SC MUSC pediatric patients travel to multiple specialist appointments hours from the medical center

Sahni and Bhandari, Faculty Reviews 2020

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Inpatient to Outpatient Transition

- Realities for families following discharge
- SC Barriers and rural limitations
  - Ex. Critical lack of home nursing post-discharge
- County level EMS outreach

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Aerodigestive Clinic

- Medically complex pediatric patients who undergo tracheostomy placement are at high risk for morbidity and mortality.
- Patients who pass away were found to be 3 times more likely to have >25% no-shows to outpatient appointments compared to those living.
- AERODIGESTIVE CLINIC: 1st and 3rd Fridays at SMP (Summey Medical Pavilion) in ENT pod
  - ENT, GI, Pulmonary faculty
  - ENT Airway NP
  - Dietician, respiratory therapist, speech pathologist
  - RN coordinator

Tarfa et al., (2021)

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Post-pandemic Telehealth Utilization

- Risk of tracheostomy complications, hospital readmission, incidence of emergency room use, and caregiver anxiety is magnified for families caring for pediatric tracheostomies-especially 30 days post-initial discharge.
- Beyond the Aerodigestive clinic, we've continued a post-pandemic initiative to prevent no-shows for rural families using Telehealth
- Accessible Telehealth in pediatric tracheostomy follow-up has been shown to improve outcomes and decrease rates of readmission and ED utilization.

(Moreno & Peck, 2019)

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Telehealth Structure

- ENT performs a Day 1 post-discharge phone call
- 1st Telehealth visit within 2 weeks of initial discharge
  - 1st AD clinic at 1 month followed by every 1 to 3 months per specialist's needs
- Telehealth encounters every 2-3 months between AD clinic visits dependent on in-person follow-up needs.
- Not every trach patient is followed in AD clinic.
  - AD clinic prioritizes: Distance from medical center, high-risk social situations, and medical complexity.

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Statistics

- End of 2020, MUSC Otolaryngology was actively managing > 80 pediatric tracheostomy patients. This number is now closer to >130, not including patients that are tracheostomy transfers from OSHs that we are now managing.
- 2020-2023 Trach and Vent dependent patients: 65
- **Pediatric tracheostomies performed in the last 3 years**:

2021: 18
2022: 14
2023: 20
(Not including those that passed away prior to initial discharge nor OSH transfers now being managed outpatient)

- **Mortality**:

2023: 4 deaths at home, 1 unrelated to respiratory status
(2) deaths due to poor prognosis inpatient after tracheostomy was placed and prior to initial discharge.
2022: 1 death (hospice), 1 death at home
2021: 4 home deaths, (2) inpatient prior to discharge

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Family experiences

THE JOURNAL OF PEDIATRICS • www.jpeds.com ORIGINAL ARTICLES

(J Pediatr 2021;229:223-31).

Family Experiences Deciding For and Against Pediatric Home Ventilation

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38 families interviewed

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Table IV. Reflecting back on the decision about tracheostomy/HV

Subthemes	Illustrative quotations
Satisfaction with decision	*"Even if I had to do it again today, no matter how hard it was, no matter the heart aching, no matter how bad I missed my child, I can honest to God say I wouldn't change a thing about the choices I made for him…"* (family 1, site 3, no HV)
	"It was the greatest decision I could have made for my son. Because of the vent, my son is still here." (family 9, site 1, yes HV)
Regret about decision	*"Only that I didn't push…to get her trach sooner…she spent more time living in the hospital than at home."* (family 1, site 3, yes HV)
	"I think I'd have not tried to rush it… he was 6 months old and I just wanted him home." (family 1, site 3, No HV)
	"Had I known that [the tracheostomy/HV] would just prolong her life, not actually help her live…" (family 4, site 2, yes HV)
Supports we wish we'd had	Connection with other families
	"No offense to any medical team whatsoever, you all are the experts, but you all don't have the home experience. Just being able to talk to the families about something as simple as bath time and going through a grocery store. 'How do you do it? Give me tips and pointers." Having the family experience is the greatest tool you can have." (family 5, site 2, yes HV)
	"We can hear from doctors and nurses all day long, but if you hear from someone who's actually gone through it and experiencing the same things as you, it means a lot more." (family 6, site 3, yes HV)
	Emotional support during decision
	"Emotional support…when you are in a meeting and it is pretty much just you and the doctor…you need someone there for your emotion." (family 1, site 2, yes HV)
	More information about life with tracheostomy/HV
	"All of the medical stuff, insurance stuff, DME stuff, the everyday stuff you are not aware of. It's that everyday living that wasn't explained." (family 2, site 2, yes HV)
	"The financial part…the loss of income…I wish we had known how long it would take for social security to kick in. It's taken a very long time." (family 4, site 3, yes HV)
	"I wish I would have known that nursing is not reliable…" (family 8, site 1, yes HV)

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Thank you!

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