AAC and Pediatric Tracheostomy in Acute Care:

When Speech isn’t an Option, Communication is Possible

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Focus for today...

Augmentative and alternative communication strategies for children with tracheostomies who are non-speaking OR have a reduced ability to use spoken language secondary to a tracheostomy.

*Speaking valve/leak speech for spoken language is IDEAL when POSSIBLE
Background: Bedside AAC at BCH

- ICU and Acute Care floors
- 1.0 FTE inpatient AAC bedside service delivery
- Preoperative and Postoperative interventions
- Separate SLP communication and feeding teams

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Background: Bedside AAC at BCH

- 581 patients in Tracheostomy Database
  - 384 active
  - 110 decanulated
  - 87 deceased

- ~50 tracheostomies/year
- ~10-15 inpatients w/ tracheostomies/day

- Multi-disciplinary Tracheostomy Clinic
Quick Review: Tracheostomy

When is a Speaking Valve NOT Appropriate?

Typically:
• Patient not awake
• Presence of upper airway obstruction or anatomical interference
• High end-expiratory pressure (EEP) (ideal: <10cmH2O)
• Copious secretions
• Severe aspiration risk
• Chronic, severe pulmonary disease
• Severe medical instability
• Inability to tolerate cuff deflation
• Inadequate air leak
  – Tube size vs. patient size

Uttechkij, J. et al, 2005)
Pediatric Patients at BCH w/ AAC Needs:

- Often difficult decision to undergo pediatric tracheostomy
- Careful medical and respiratory management
  - Long-term ventilation
- Complex medical needs
  - Preliminary GTC data

- Often:
  - Severe medical instability
  - Chronic respiratory insufficiency
    - Bridge to lung transplant
    - Inability to extubate
  - Inability to tolerate cuff deflation

Who?

- Children requiring
  - Short term strategies
  - Long term strategies
Who?

– Children with short term AAC needs
  • All patients ~1 week post-op
  • Short term ventilation needs with anticipated speaking valve tolerance

Who?

– Children with long term AAC needs
  • Long term ventilation needs
  • No air leak; long term
  • 8 vs. 24 hr communicators
    – i.e. Night time ventilation
Anticipated Trajectory at BCH

- Pre-trach decision & education
- Tracheostomy by ORL
- ~5 days until 1st trach change
- 1st tracheostomy change
- Assess for speaking valve/leak speech readiness

Preoperative Message Banking
- Older patients + patients with mobility = potentially awake/alert postop
- Ongoing ventilation & inflated cuff
- Low tolerance for deflated cuff, speaking valve

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Anticipated Trajectory at BCH

Preopera+ve Message Banking

Older patients + patients with mobility = potentially awake/alert postop

Ongoing ventilation & inflated cuff

Low tolerance for deflated cuff, speaking valve

Pre-trach decision & education

Tracheostomy by ORL

~5 days until 1st trach change

1st tracheostomy change

Assess for speaking valve/ leak speech readiness

When is referral for AAC appropriate?

**INPATIENT:**

<table>
<thead>
<tr>
<th>Patient Status:</th>
<th>Intervention:</th>
</tr>
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</table>
| WILL undergo tracheostomy:  
1. Patient speaks at baseline  
2. Patient does not speak at baseline  
**Trach at baseline**  
3. Tolerates deflated cuff/speaking valve but requires mechanical ventilation  
4. Does not tolerate deflated cuff/speaking valve at baseline | WILL undergo tracheostomy:  
1. Preoperative message banking; set up communication system  
2. Identify supports/strategies to enhance patient-provider communication.  
**Trach at baseline**  
3. Identify supports/strategies to enhance patient-provider communication until able to tolerate deflated cuff/speaking valve.  
4. -Support use of existing augmentative and alternative communication (AAC) supports/strategies.  
-Identify new AAC supports/strategies |
Feature Matching Process

Systematic process by which a person’s strengths, abilities, and needs are matched to available tools and strategies

- Shane and Costello, 1994

Think about **baseline and anticipated** strengths, abilities, and needs

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Domains of Assessment

1. Cognition
   - Alertness/awareness expectations
   - Baseline status
2. Speech and Language Skills
   - Use of speech, symbols, text, and communication displays
3. Sensory
   - Vision
   - Hearing
   - Anticipated swelling/incision sites
4. Respiratory Status
5. Gestures
6. Sign Language
7. Literacy
8. Vocabulary selection
9. Medical Status
10. Motor Skills
11. Team members & Communication Partners
AAC Tools and Strategies

• Unaided:
  – Natural forms of communication (including gestures and facial expressions) as well as manual signs and American Sign Language (ASL).

• Aided:
  – Communication that requires some form of external support (including line drawings, pictures, printed words, speech-generating device, etc.)

www.asha.org

Unaided Strategies

May include:
  – Sign language
  – Gestures
  – Body language
  – Facial expressions
  – Vocalizations
Aided Strategies

May incorporate:
– Objects
– Pictures
– Writing
– Typing

May be high-tech, mid-tech, or low-tech

Phases of AAC need in the **Acute Care Setting**

1. Preoperative
2. Emerging sedation
   – Example: bridge to lung transplant and early rehab needs
3. Increased wakefulness
4. Broader communication needs
5. Long term communication needs → Rehab & Outpatient
Phases of AAC Need: Pre-Tracheostomy

Benefits of early preparation (IF POSSIBLE)

• The hospital admission is stressful enough
• Postoperative status → misunderstanding, confusion, waxing and waning mental status
• Patients can participate in selection of tools and messages during less acute and stressful time
• Patient can record own voice if able
• Time to familiarize → easier and more functional use
• Sense of control in own care and preservation of personality

Phases of AAC Need: Pre-Tracheostomy

• Understand expected outcomes → Influences assessment
  – Length of admission
  – Length of ICU stay
  – Anticipation of respiratory support needs
    • Trajectory of ventilation requirements?
  – Motor weakness?
  – Sedatives/other drugs?
  – Positioning needs?
  – Surgical incisions and other relevant sensory information
Phases of AAC Need: Pre-Tracheostomy

- Hospital Narratives and Social Stories™
- Design varies based on language skill and use of visuals
  - Photographs
  - Picture-communication symbols
  - Symbol supported text
  - No visuals
- Outline expected details and outcomes of the procedure
If sedated or otherwise unable to participate in preoperative message banking, preparation is STILL beneficial!

Consult family members, nurses, multi-disciplinary team members

Phases of AAC Need: Emerging from Sedation

- High likelihood of reduced phonation for ~5 days
- Sedatives → generalized weakness; temporary vision deficits, confusion or delirium

Possible Interventions:
- Yes/no/I don’t know communication board
- Adapted nurse call system
- Simple voice-output communication aid (VOCA) to gain attention
- Also – developmentally young/emergent communicators and ‘control’
Phases of AAC Need: 
Increased Wakefulness

- Possible Interventions:
  - ALL PRIOR SUPPORTS
  - Additional vocabulary
  - Simple picture board
  - Alphabet board:
    - QWERTY
    - ABC
  - Body/positioning board
  - General comfort board
  - Customized communication board
  - Multi-message voice output devices
  - Digitally recorded messages

Phases of AAC Need: 
Broader Communication

- Possible Interventions:
  - ALL PRIOR SUPPORTS
  - Broader range of vocabulary
  - More sophisticated page sets
  - Generative communication with alphabet
  - Word/grammar prediction
  - Internet access
Message Considerations: Acute Care & Beyond

- Gaining attention
  - Call for help
- Medical Needs
  - Discuss and understand
- Social interaction
- Making choices & indicating preferences
- Feeling in control
- Asking questions
- Communicate to regulate the task
  - Opt in/out
  - Take a break
- Commenting
- Personality
- BEYOND...

When does AAC become a long term need?

Not yet able to tolerate:
- Deflated cuff
- Inadequate air leak (tube size?)

- Alternative source of vibration:
  • Electrolarynx

- Speaking valve
Presence of:
- Baseline or new onset speech/language production difficulties
  - Dysarthria
  - Apraxia
  - Aphasia
- Vocal cord paresis or paralysis
- Anatomical or structural deficits
- Baseline cognitive skills
- Baseline language skills
- 8 hr vs. 24 hr AAC users
  - i.e. night time ventilation requirements

Communication Boards

- Picture-symbols and/or photographs
- Paired written labels
- Access:
  - Direct selection?
  - Partner assisted scanning?
Communication Boards

- Eye gaze communication board
- Eye gaze letter frame
- E-tran system

Speech-Generating Devices
Low-tech; Mid-tech

- Digitized voice
  - Direct selection?
  - Multiple levels?
  - Auditory/visual scanning?
- Examples:
  - Step-by-Step
  - Big Mack/Little Mack
  - Italk 2
  - MessageMate 40
  - GoTalk
  - QuickTalker
  - Smart Scanner
  - Tech/Talk
Digital Recording Tool
i.e. MessageMate

- Speech generating device
- Digitized voice
- Up to 40 messages
- Access: direct selection or switch scanning
- Can be mounted for optimal access

Speech-Generating Devices
High-tech

- Digitized or Synthesized voice
- Access:
  - Direct selection
  - Eye gaze
  - Single or multi-switch scanning
- Mounting:
  - Rolling mount
  - Bedside mount
  - Wheelchair mount
  - Tabletop mounts
Mounting personal equipment at bedside

Speech-Generating Devices
Mobile-tech

- Customizable AAC apps
- Picture-symbol
- Text-to-speech
- Full-communication apps
- Medical Communication apps – with prestored messages
Communication Applications

- Picture Symbols
  - GoTalk NOW
  - Proloquo2Go
  - TouchChat
  - SoundingBoard

Text-to-Speech

- Dedicated systems:
  - i.e.:
    - Lightwriter
    - Dynawrite
- Apps:
  - AssistiveExpress
  - Predictable
  - Proloquo4Text
  - Verbally
  - And more!
- Laptop:
  - Software
  - GoogleTranslate
    - Non-English speakers or text-to-speech
- Within communication systems
CASE STUDY

CASE STUDY:
Hadley

• Baseline:
  – 15 y.o.
  – Glasses
  – Hearing aid; left ear
  – Hx of progressive cervico-medullary region pilocytic astrocytoma s/p resection and prolonged chemotherapy
  – Medical complications s/p brain tumor including:
    • Vocal cord paralysis
    • Swallow dysfunction
    • Laryngomalacia
    • Right hemiparesis
CASE STUDY:
Hadley

• Date of admission:
  – Increased work of breath (WOB) at Jimmy Fund Clinic
  – Limp and unresponsive
  – Acute respiratory decompensation
  – Intubated; transferred to ICU

CASE STUDY:
Hadley

Emerging from Sedation

Patient Presentation:
• Intubated; awake throughout day
• Drowsy; moderate sedation
• Nodding to simple questions
• Per report – tried typing on own iPad
  – Bilateral IV boards
  – Significant discoordination
• Baseline anxiety + related to intubated state
• Unable to extubate
HADLEY: Emerging from Sedation

<table>
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<tr>
<th>Domains of Assessment</th>
<th>Observations</th>
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<tbody>
<tr>
<td>Cognition</td>
<td>Awake and alert</td>
</tr>
<tr>
<td></td>
<td>Moderate sedation</td>
</tr>
<tr>
<td>Sensory</td>
<td>Glasses donned upon request</td>
</tr>
<tr>
<td></td>
<td>Hearing aid not at bedside; functional hearing regardless</td>
</tr>
<tr>
<td>Language Comprehension</td>
<td>Answering Q’s appropriately w/ head nods</td>
</tr>
<tr>
<td>Motor Access</td>
<td>Bilateral IV boards on hands/wrists; position restriction d/t intubation</td>
</tr>
<tr>
<td>Speech Production</td>
<td>Non-speaking d/t oral intubation</td>
</tr>
<tr>
<td>Vocabulary Selection</td>
<td>Able to participate by answering simple questions and pres. of template vocabulary; basic wants/needs, comfort/medical, attention</td>
</tr>
<tr>
<td>Environmental Considerations</td>
<td>Noise: minor</td>
</tr>
<tr>
<td></td>
<td>Lights: on</td>
</tr>
<tr>
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<td>Frequent bedside RN cares</td>
</tr>
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<td>Communication Partners</td>
<td>Parents, RN, providers</td>
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CASE STUDY: Hadley

• Interventions:
  – Encouraged glasses + hearing aid (at home)
  – Reduced size of bilateral IV boards to accommodate direct selection
  – Lights on, as able
  – Noise reduced, as able
  – Gain attention: Step-by-Step communicator; mom recorded voice
  – Express wants/needs: Template ICU communication boards
CASE STUDY:
Hadley

**Increased Wakefulness → Need for Broader Communication Access (same day)**

**Patient Presentation:**
- Awake throughout day
- Mild sedation; very alert
- Increased strength
- Accessing all materials appropriately
- Baseline anxiety + related to intubated state
- **NEW PLAN:** tracheostomy d/t inability to extubate safely
**HADLEY:**

**Increased Wakefulness → Broader Comm. Needs**

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<td>Accessing prev. provided materials well</td>
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<td>Motor Access</td>
<td>Downsized IV board on left (dominant) hand</td>
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<td>- Need for generative communication + beyond comfort/medical</td>
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**CASE STUDY:**

**Hadley**

- **Interventions:**
  - Encouraged glasses + hearing aid (at home)
  - Reduced size of bilateral IV boards to accommodate direct selection
  - Lights on, as able
  - Noise reduced, as able
  - Gain attention: Step-by-Step communicator; mom recorded voice
  - Express wants/needs: Ongoing access to communication boards + customized board and modifications
  - Generative Communication:
    - iPad w/ application: Assistive Express
    - Secured iPad mount to left bedrail
    - During RN cares = low-tech strategies
CASE STUDY:
Haley
Pre-trach: Introduced iPad w/ Assistive Express
• Participated in preoperative discussion about tracheostomy
• Accessed during conversations and pre-op prep with psychologist, MDs
  – “Can it be pink?”
  – Thoughtful questions about trajectory of need and expectations
• Saved messages into Favorites List
  – Helpful for post-op
• Utilized word prediction

CASE STUDY:
Hadley
Post-trach: Customized and modified communication boards:
CASE STUDY:
Hadley
Broad Communication Needs

Patient Presentation:
• Anxious, sad about having trach; feeling “stuck”
• Communicating “well” per RN – access to communication boards + ABC supports [Assistive Express and QWERTY board]
• Further participation in customizing communication boards
• Using humor to engage:
  – “Welcome to Entertaining You in the ICU”
  – “My brother’s gonna think I’m an alien!”
  – “I like to move-it move-it”

HADLEY:
Broad Communication Needs

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<td>Hearing aid not at bedside; functional hearing regardless</td>
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<td>Language Comprehension</td>
<td>Engaged in conversations</td>
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<tr>
<td>Motor Access</td>
<td>During RN cares, will access low-tech materials. Otherwise text-to-speech</td>
</tr>
<tr>
<td>Speech Production</td>
<td>Non-speaking d/t tracheostomy until first trach change</td>
</tr>
<tr>
<td>Vocabulary Selection</td>
<td>- Participating in further customization of messages</td>
</tr>
<tr>
<td></td>
<td>- Saved prestored messages to Assistive Express *Favorites List:</td>
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<td>- Humor!</td>
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<td></td>
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<td>iPad mount – bedrails, chair rails, tabletop</td>
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CASE STUDY: Hadley

```
mama?
piano please?
whisper words of wisdom, let it be.
hi!
did I do that?
I'm tired
do what you'd like to!
did I dream that?
I need to go to the bathroom.
```

CASE STUDY: Hadley

```
the book on the t
i take it cause i always do it relaxes med
can i swish my mouth
i need my position changed
i need to be cathed
I need to be changed
thank you
can i have something for pain
```
CASE STUDY:
Hadley
Broad Comm. Needs $\rightarrow$ Long Term Needs

Patient Presentation and Interventions:
• Transition to neurology unit
• Back to baseline
• Introduction of Speaking Valve
• Tolerating for ~30 min – 1 hour initially
• Continued access to AAC as needed

• Recs for ongoing speaking valve use
• Reviewed text-to-speech apps upon discharge as ‘back-up’

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References