



**AAC Intervention in the Pediatric ICU:
*The Children's Hospital Boston Model***

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**The Temporary Nonspeaking Condition
in the ICU = High Emotional Distress
Coupled with a Sense of Loss**



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**Some non-speaking conditions
may be anticipated before surgery**

- Maxillofacial/Orofacial surgery
- Organ transplantation (lung, heart)
- Disorders of the airway requiring tracheolaryngeal or tracheoesophageal reconstruction
- Oncology related interventions
- Scheduled ventilation supports


 Tracheostomy

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ICU stay in an inopportune time for new learning:

- Pain
- Potential changes in motor status
- Potential changes in sensory status
- Potential changes in alertness secondary to medications
- Effect of depression


RESULT: Ineffective processing of new information



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Ineffective information processing results in:

- Confusion
- Lack of Comprehension
- Misinterpretation
- Increased fear and tension



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Researchers have reported:


- Anxiety, fear, insecurity, anger all result from ineffective information processing and the inability to speak and contribute to interference with sleep



Mentzel, 1984

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It is recognized that sleep patterns of persons in the ICU are highly irregular and disturbed – sometimes leading to ICU Psychosis.



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IT IS SUGGESTED THAT ALL OF THIS MAY HAVE AN INFLUENCE ON:

- **MEDICAL RECOVERY**
- **PAIN MANAGEMENT**
- **LENGTH OF HOSPITAL STAY**




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Christiano and Tarbell (1998)


Children with the lowest pain scores were given relevant information in significantly more preoperative intervals than children with higher pain scores.

This suggests that preoperative training may assist Patients to cope with pain management issues better than Those without preoperative training.



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Stress of the nonspeaking condition reaches beyond the child



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Family/Primary Care Providers

- Parents have expressed fear of their child's inability to communicate basic needs
- Fear that child may feel abandon and not be able to call for parents
- Parents feel helpless to assist child who is going through distress



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Medical Staff

- The need to identify appropriate means to communicate with intubated/vent dependent patients identified as a high research priority
- Because of duties, medical staff must limit the time available to interpret
- Nurses have reported patients being angry and then abandoning attempt because of nurse inability to interpret



Studies reveal that nurse communication with patient is positively correlated with the patient's ability to give feedback.


Ashworth (1984)



Ashworth (1978) reported a study from five established ICUs


Tracked interaction between nurses and patients with endotracheal tubes

- 32% of verbal communication was short term info (I'm going to suction you)
- 18% was commands or requests (lift your arm)
- 21% were questions (most related to physical care)
- 7% longer information such as teaching or orienting




Historically, primary communication interventions include:

- Alphabet board
- Picture boards
- Small typing systems
- Paper and pen
- Magic slate
- Electrolarynx
- Eye gaze systems
- Computer



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- We know that not being able to speak in the ICU is extremely stressful to the patient, family and medical staff
- We know that positive correlation has been suggested between the inability to communicate and poorer recovery time in the ICU setting
- We know positive correlation has been suggested between a patient's ability to communicate and the quantity and quality of communication interactions with the nursing staff.
- We know that some patients in the ICU have planned operative procedures and a nonspeaking condition was anticipated before hospital admission.



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Since 1993
The Children's Hospital Boston
Model of AAC Intervention in the
Pediatric ICU


- Preoperative Intervention
- Postoperative Intervention
- Discharge Intervention



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Preoperative Intervention


- Patient expectations/education
- Initial introduction to communication tool
- Vocabulary selection
- Brief review of sensory/motor and literacy skills.
- Introduction to symbols
- Review of mounting and positioning options
- Voice and message banking



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Postoperative Intervention


- Bedside screening of awareness, sensory and motor skills
- Mounting of AAC device
- Assessment of functional use of communication tools
- Family and staff inservicing



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Discharge Intervention


- Interview with patients
- Interview with family
- Interview with medical staff
- Planned dissemination of a formal questionnaire



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Referral source

- Craniofacial team
- Plastic surgery
- Tracheostomy team
- Organ transplant team
- Physicians
- Nurses
- Respiratory therapy
- Radiology
- Social work
- Child Life
- Psychiatry
- Pastoral care




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Preoperative training is scheduled 24 hours to months before surgery time



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Review Patient Expectations



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Initial introduction to communication tools



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Vocabulary Selection part I


- Patient directed focus
- Patients are asked to imagine nonspeaking condition or reflect on previous experience
- Patient and family members 'free flow' selection



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Vocabulary Selection part II


- Clinician guidance
- Encourage to select approximately 30 messages
- Encourage vocabulary that that focuses on representing individual personality, personal interests, personal humor or phrases particular to the individual



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Gries and Fermisler (1988)

Confirmed need for person-specific vocabulary as patients who had previously been nonspeaking in the ICU expressed significant stress related to the inability to express their personality.




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Brief review of sensory, motor and literacy skills

Sensory:


- Baseline status established
- Document need for staff
- Make arrangement for accommodations for glasses or hearing



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Brief review of sensory, motor and literacy skills


- Motor
- Symbol display with graduated size for baseline of motor, target size, range
- Ability to apply sufficient pressure to VOCA



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Brief review of sensory, motor and literacy skills


- Screening of alphabet use or first letter pointing for patients over the age of 5 years.
- Introduction to QWERTY and ABC format
- Review use of 'space', 'end word', 'backspace' and 'start over'
- For patients with functional literacy, general topic cue is reviewed along with first letter cue
- Message get letter board/spell board is added
Custom topic boards may be created



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Introduction to symbols


- Mayer-Johnson symbols
- Digital photos
- Custom symbols (Children's Hospital Boston Medical Symbol set)
- ** Even people with established literacy skills have chosen symbols in anticipation of challenge with
Visual focus



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Alternative Access Strategies


Changes in motor or sensory status related to swelling, harvest of tissue, arterial lines/intravenous lines appropriate alternative access is reviewed.



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Alternative Access Strategies

- Unaided yes/no
- Adapted nurse call
- Tactile direct selection
- Eye gaze selection
- Visual assisted scanning
- Single switch scanning
- Auditory scanning




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Mounting of VOCA



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Voice and Message Banking



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Voice and Message Banking: Benefits

Patient:


- Preserve part of personality
- Emotional connection with significant others
- Requires patient to take an active role in care, assisting with postoperative recollection

Family:

- Comfort in hearing child's voice

Staff:


- Allows for more personal connection with patient



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Voice and Message Banking: Instructions

- **Speak clearly**
- **Say it like you mean it (entertaining for some and appears to aid recall)**
- **Elect a proxy voice as needed**




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Postoperative Bedside Intervention


- **Level of alertness assessed by medical staff**
 - Neurological signs*
 - ability to attend*
 - Follow simple directions*
 - Ease of comforting*
- SLP re-assess awareness, motor, sensory status

Introduction of tools



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Discharge Interview



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Outcomes: Patients

- 32% craniofacial
- 19% intubation or tracheostomy for airway
- 16% experience tumor of face or airway
- 15% lung transplant
- 11% compromised airway secondary to venous malformation
- 7% Tracheolaryngeal, tracheoesophageal reconstruction




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It made me really think about what it is going to be like [to be nonspeaking] so I won't be surprised after surgery
- AL, age 17 years



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Required patients to think about issues such as suctioning



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Initial introduction to communication tool


- Message Mate 40/600 used most often
- Dynamic display system was eliminated as every patient declined it
 - Fear of confusion
 - Accidental activation
 - Repair time



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Vocabulary Selection


- Medical
- Personal comfort
- Psychosocial



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Medical


- I need to be suctioned
- I need to throw up
- I need to cough
- I am in pain
- I want medicine
- Something doesn't feel right
- I feel sick
- It hurts
- My breathing feels weird



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Personal Comfort


- Personal needs
- Positioning
- Statements/Directives



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Personal needs:


- I need to go to the bathroom
- I want to eat
- I want a drink
- I want ice chips on my lips
- Please put a wet cloth on my mouth
- Please brush my teeth
- I am really thirsty!
- Please cover me up
- Put on my glasses
- Wipe my nose
- I need my hearing aid
- I am hot
- I am cold



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Positioning:


- Please move the bed up/down
- I am uncomfortable
- I want to turn over
- I want to sit in the chair
- I want to go to bed
- Place a pillow under my legs
- Roll up towels and put them under my right shoulder
- Bring my left knee over to my right hip



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Statements/Directives:


- Nurse I need you
- I want to see the doctor
- Tell me what is going on
- Don't touch my IV
- Don't move me
- I want to go to the floor
- Turn the lights on
- Turn the lights off
- Open the curtain
- Close the curtain
- Be careful you don't unplug that!



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Psychosocial:


- Social
- Emotional
- Comfort
- Control
- Sarcasm and humor
- Leisure and entertainment
- Questions



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Social


- Thank you
- I am sorry
- I appreciate it
- You are nice
- What is your name
- I love you
- I am glad you came to see me
- How is _____
- Please talk to me
- God Bless you



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Emotional

- I am afraid
- I am mad
- I'm okay
- I am not stupid
- This sucks
- I hate you
- I love you
- I am tired
- I am afraid I will be like this forever



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Comfort


• Please don't leave me	• I am going to be fine
• Hold my hand	• I am okay
• Rub my head	• Tell me a puppy story
• Stay with me	• Talk about anything.
• Get in bed with me	• Visualize with me
• Read me a story	• Pray with me
• Keep talking to me	



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Humor and sarcasm


- What are you looking at Doogie?
- Go jump in the lake!
- You are a turkey!
- I think I just heard them page you doctor.
- Give me a break!
- Duh!
- Yeah, right!
- I love this place!



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Leisure and entertainment


- I want to watch TV
- I want to listen to music
- I want my walkman
- I want to watch a video
- Can I go to the playroom
- I want to draw
- Please turn the volume up/down
- Can I look at my photos
- Please read to me



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Questions

- How am I doing?
- When can I go home?
- When can the tube come out?
- When can I eat?
- When can I drink?
- Who are you?
- What are you doing?
- Will it hurt?
- Where is my mother?
- Am I going to die?
- I have a question.
- Who is feeding the dogs?



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Review of sensory, motor and literacy skills



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Sensory


- **Advanced modification to glasses**
- **Available auditory trainer/ amplification**
- **Advanced learning of tactile strategy**



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I know where all the messages are without even looking which is good since I won't be able to see after surgery.

BL, age 23



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When I was so upset and uncomfortable, I don't think I could have learned to use that switch to scan; so it is really good that I learned to use it before the surgery.
AT, age 26



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Motor outcomes


- Nearly all could direct select
- Seven in sample used single switch scanning
- More may have used single switch scanning, but instead chose to use partner assisted scanning.



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Introduction to Symbols


- Patients with literacy skills and previous ICU experience chose symbols



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Voice and Message Banking


- *I'm gonna yell the next message so everyone knows I'm mad.* KD, age 13
- *Oh, that one sounds good, it sounds like I'm really scared* AB, age 6.5
- *The nurses spend so much time taking care of me. I want them to know me as a person – this way [with the Message Mate] they will hear my voice and know my sense of humor,* KF, age 24



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Voice and Message Banking

Parents reported that hearing the voice of their critically ill child was emotionally beneficial to them.




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I knew she was still there; even though she looked so sick, because it was her voice. It was not only her needs that were met, but it was my need to hear my daughter talk to me. It was a really nice thing.
mother of AB.




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I knew that he would need the device to talk, but I think I am getting more benefit out of it[than he is] because I can hear his voice talk to me!
Mother of 2.8 year old A.K.




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I know that she is going to be able to talk again, but I can't describe how important it is to me to hear my daughter's voice talking to me. She looks so sick, but I know that even though they removed her mandible, they left her personality.
Father of AB



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Nursing staff have commented that voice banking has allowed them to better know a patient's personality, providing a greater appreciation of the person behind the patient



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-I would hear his voice, and it would make me smile...it's like I knew him better.

-When you hear the voice of the patient, it gives you so much more of a connection with the person.




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Hearing his little voice say 'thank you' every time I did something melted my heart. It wouldn't have been the same if it was somebody else's voice or just a picture board.




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**Outcomes:
Postoperative
Intervention**



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**Outcomes:
Discharge Interview**



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Unlike reports of feeling depersonalized and being 'worked on' versus 'worked with' (Belitz, 1983), patients reported that they felt like they had a role in their own care:

It was one thing I could do that I knew would be there after surgery to help me get through this. DC, age 20




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I knew exactly what to tell you [that I felt like my lungs were full] since we went over everything before the surgery and I knew the doctor would listen to me



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To some extent, it provided a degree of fun and made what could have been a miserable experience a bit better.




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It was something that we could do as a family to prepare. Father of SW

It gave me something concrete to do to prepare her for surgery. We could have taken her to the Aquarium or had a special dinner. But this was meaningful and was a part of getting her through the whole experience. Mother of AB


It was great because his sister really helped him select vocabulary and she was the designated recorder if something needed to be added after surgery. It gave her a role in her brother's recovery. Mother of JA



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Upon reflecting on maintaining a role of care giver during he daughter's hospitalization, KB's mother stated:

As a parent you feel so helpless, and all you want is to do something to make your child feel better. It is so frustrating not being able to do anything but look at her. When she used the device to tell me she was cold, I could make her feel better and that made me feel so much better.




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Parent's also commented on their perception of a higher standard of care.
This [model of intervention] is an example of the caliber of the institution. It makes us know that we did the best job we could as parents. It was a tough decision to have this surgery and if we had chosen another medical center, we don't know if this would have been available.
Father of AB



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Parents reported comfort that their child could communicate in their absence.
I know that I can go for a cup of coffee or go to the bathroom, and she can communicate an emergency need. Without this [VOCA] I would be afraid to leave her side because someone else might not be able to figure out [what she is trying to communicate] the way I could.
Mother of NJ



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Staff reported:

- Window into personality of patient
- Ability to more efficiently care for urgent needs



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I could talk with her about non-medical stuff because I saw on the board that she had a way of chatting with me. So we talked about our cats.



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Nurses commented on a patient's ability to efficiently communicate urgent needs.

- He can tell me something he is worried about immediately, and I can respond. Otherwise, he would just be lying there stewing in his anxiety without being able to tell me.
- She came back from the OR, and she immediately told me she needed to be suctioned. We got up all this gunk from her lungs, and otherwise we wouldn't have known she needed it until she was in distress.
- She could say, 'I am in pain', and then we could ask the right questions to figure out how to comfort her.



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Redefinition of Success



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**Patient reports differ sharply
from literature**

- **Exhaustion** (Hafsteindottir 1996)
- **Isolation** Belitz 1983, (Villarie 1995)
- **Lack of control** (Stovsky 1988)
- **Fear and Anxiety** (Borsig & Stenacher 1982)
- **Poor recollection** (Hafsteindottir 1996)



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