AAC and the Intensive Care Unit: What, When and Why

Addressing the Needs of Patients who are Communication Vulnerable

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Boston Children’s Hospital

- Program History
- Model of Intervention

Inpatient Augmentative Communication Closet
What is communication vulnerability?

- Vision so poor that the patient is unable to read/see, even with corrective lenses
- Inability to understand loud speech, even with hearing aids
- Inability to produce speech that is intelligible to the team
- Altered mental status
- Inability to speak or understand the language of the medical team

Poor Communication Impacts Patient Safety

- Patients with communication vulnerability are at risk for:
  - Serious medical events (Cohen et al., 2005)
  - Sentinel events (The Joint Commission, 2007)
  - Poor medication compliance/adherence (Andrulis et al., 2002, Flores et al., 2003)
Risk for Serious Medical Events

- Communication-vulnerable patients are:
  - Higher rates of hospitalization
  - Higher rates of drug complications
  - Highest use of resources to provide care
  - Lowest levels of satisfaction with care
  - Increased risk of delayed care
  - Increased risk of malpractice
  - Increased length of hospital stay
  - Less likely to return for follow-up appointments after Emergency Room visits

Bartlett, G. et al.
CMAJ 2008;178:1555-1562

- "The presence of physical communication problems was significantly associated with an increased risk of experiencing a preventable adverse event"
- "We found that patients with communication problems were three times more likely to experience preventable adverse events than patients without such problems"
Why is this topic timely in the United States?

- Changes to THE JOINT COMMISSION hospital standards for accreditation that address "communication vulnerability" in 2011 (measured as of 2012 July).
- Increased focus nationally and internationally on the impact of communication vulnerability on patient care.
- Increased focus on the Joint Commission International Standards of Care.
Fracture of third and fourth cervical vertebrae, leaving him paralyzed.
Guidelines for admission to Pediatric ICU
American Academy of Pediatrics and the Society of Critical Care Medicine, Pediatrics, V 103, No. 4 April 1999

- Severe or potentially life threatening (Endotracheal intubation and potential mechanical ventilation)
- Pulmonary or airway disease
- Severe, life threatening or unstable cardiovascular conditions
- Neurological conditions or seizures
- Hematology/oncology disease: (tumors or masses compressing airway)
- Endocrine/metabolic disease

In general, these conditions include

- issues of:
  - airway patency/management of air gasses
  - Muscle function, strength and coordination
  - Neuro-cognitive/neuro-linguistic impairment

My son’s ability to communicate, allowed me to advocate for him

Post heart-transplant, a mother’s perspective
Importance of communication and potential impact on patient outcomes is recognized by:

- American Association of Critical Care Nurses
- Society for Critical Care Medicine
- National Institute of Health
- The Joint Commission

Roadmap `Guide` to help facilities implement standards

p. 10 Recommended issues and related practice examples to address during Admission:

Identify whether the patient has a sensory or communication need 
— “it may be necessary for the hospital to provide auxiliary aids and services or augmentative and alternative communication (AAC) resources to facilitate communication.”

Identify if the patient uses any assistive devices — “make sure that any needed assistive device are available to the patient throughout the continuum of care.”

p. 18 Monitor changes in the patient’s communication status 
— “Determine if the patient has developed new or more severe communication impairments during the course of care and contact the Speech Language Pathology Department, if available. Provide AAC resources, as needed, to help during treatment.”
Patients may have hearing or visual needs... or be unable to speak due to their medical condition or treatment. Additionally, some communication needs may change during the course of care. Once the patient’s communication needs are identified, the hospital can determine the best way to promote two-way communication between the patient and his or her providers in a manner that meets the patient’s needs.

Examples of communication needs include the need for personal devices such as hearing aids or glasses, language interpreters, communication boards and devices...

**Communication Vulnerable Patients**

- Pre-existing hearing, speech, cognitive disabilities who may (may not) have access to communication tools/supports
- Recent communication difficulties occurring as a result of their disease/illness/accident/event
- Communication difficulties that occur as a result of medical treatment (e.g., intubation, sedation)
- Linguistic differences
- Limited health literacy
- Limited ability to read/write
- Cultural differences
Communication vulnerable populations in the U.S.

- People with low health literacy:
  - 47 million
- People with about 76 million
- People with reduced English:
  - 10 million
- People with physical, sensory, or cognitive impairment:
  - Unknown

**Communication Vulnerability: Who does it impact?**

- Patient
- Family
- Staff

[http://www.patientprovidercommunication.org/](http://www.patientprovidercommunication.org/)
Communication Vulnerability: Who does it impact?

- Patient
  - Loss of control of environment, sense of self, ability to participate in own care (Garrett et al., 2007)
  - Inability to speak is closely linked to: insecurity, panic, worry, fear, anger, stress, and sleep disturbances (Happ et al., 2004)
  - Feelings of low mood can lead to withdrawal from family and care givers. This impacts participation in care and recovery (Magnus and Turkington, 2005)

- Family
  - Afraid child will not be able to communicate wants and needs
  - Concern that child will not be able to call out for them and may feel abandoned
  - Distress over temporary loss of child’s personality (Costello, 2000)

- Staff
  - Delivery of nursing care
  - Nurses typically do not have time to “figure out” what patient is trying to communicate.
  - Education regarding patient care and delivery of medical information
  - Supporting a child from an emotional, psychological, and developmental perspective
  - May lead to limiting communication attempts beyond what is essential (Costello, 2000 and Garrett et al., 2007)
Communication Vulnerability: Who does it impact?

- **Patient Population**
  - Communication vulnerable at baseline
  - Acute onset of communication vulnerability
  - At risk for communication vulnerability

Communication Vulnerability: Who does it impact?

- **Communication Vulnerable at Baseline**
  - Baseline speech, language, and/or communication deficits
  - Congenital
  - Acquired prior to inpatient admission Intellectual disability
  - Trach or other form of mechanical ventilation
  - Language difference
  - Baseline motor skills that impact use and access to nurse call system

Communication Vulnerability: Who does it impact?

- **Acute onset of Communication Vulnerability**
  - New trach
  - Intubation or other form of mechanical ventilation
  - Medical procedure, treatment, or device that impedes a patient’s ability to effectively speak
  - Brain injury, aphasia
  - Aphonia or new onset vocal chord paresis
  - Dysarthria
  - Altered mental status
  - Psychiatric disorder
  - Decreased motor skills needed to effective use and access the nurse call system
Communication Vulnerability: Who does it impact?

- At risk for communication Vulnerability
  - Risk for intubation or other form of mechanical ventilation
  - Anticipated tracheostomy
  - Medical procedures or treatments
  - Degenerative condition

Role of the SLP

- Baseline communication vulnerability
  - Assist with adding medical related vocabulary to patient’s current communication system
  - Design and construct new communication supports
  - Explore optimal access options
  - Set up adapted call button
  - Identify patients who are appropriate for referral to our outpatient department
  - Disseminate information about how the patient communicates

- Acute onset communication vulnerability
  - Evaluate current communication skills
  - Design and construct new communication supports
  - Periodic reevaluation and modification or enhancement of communication supports as needed
  - Explore optimal access options
  - Set up adapted call button
  - Identify patients who are appropriate for referral to our outpatient department
  - Disseminate information regarding how the patient communicates
  - Provide education regarding communication supports and strategies to the family and medical team
Role of the SLP
- At risk for communication vulnerability
  - Voice/message banking
    - Allows patient participation in selection of tools and messages during less acute and stressful situation
    - Allows for time to familiarize with communication supports, leading to more functional use
  - Sense of control in own care
  - Preservation of personality
  - Pre- and Post-op Process

Feature Matching in the Acute Care Setting: Quick Considerations
- Cognitive status
  - Alertness
  - Awareness
  - Orientation
- Impact of medications/sleep/delirium/time of day
- Vision
- Hearing

Feature Matching in the Acute Care Setting: Quick Considerations
- Other sensory considerations:
  - Swelling
  - Incision site
  - Respiratory Status
    - Respiratory support
    - Trach
    - Ventilator
    - Mask
  - Phonation
  - Language Skills
Feature Matching in the Acute Care Setting: Quick Considerations

- Motor skills: Pre and post morbid
  - Control
  - Strength
  - Access
  - Ability to write/type/point
- Physical Positioning
- Use of symbols vs. photographs vs. text
- Motivation and participation of the patient
- Age of the patient

Working with Care Providers: Family and Staff

- Recognize the need for communication supports
- Demonstrations
- Establishing the need to have equipment ready, available, and accessible
  - Bedside signs
  - Documentation
- Periodic reevaluation and modification

Communication Needs: What to consider?

- Communicate medical information (i.e. pain, positioning, comfort, etc.)
- Understand medical information
- Emotional needs and social interaction
- Control
- Personality
- Ask questions
- Call for help or assistance
- Other
Phases of Communication - Vulnerable Patient

- Phase 1: Emerging from sedation
  - Yes/no/I don’t know board
  - Adapted nurse call system
  - Simple voice-output communication aid (VOCA) to gain attention
  - Also - developmentally young/emergent communicators and ‘control’

- Phase 2: Increased wakefulness
  - Phase 1 supports
  - Additional vocabulary
  - Simple picture board
  - Alphabet board:
    - QWERTY
    - ABC
  - Body/positioning board
  - General comfort board
  - Customized communication board
  - Voice amplification
  - Multi-message voice output devices
  - Digitally recorded messages

(Costello, Patak, and Pritchard, 2010)
Phases of Communication
Vulnerable Patient

- Phase 3: Need for broad and diverse communication access
  - Phase 1 and 2 supports
  - Broader range of vocabulary
  - More sophisticated page sets
  - Generative communication with alphabet
  - Word/grammar prediction
  - Internet access

Phases of Communication
Vulnerable Patient

- Not so black-and-white
- Timing of recovery and ability to participate in communication varies greatly

Key Components to Successful Intervention:

- Getting the Referral
  - Recognizing when a patient is communication vulnerable or at risk for communication vulnerability
- Providing effective resources
  - Making sure provided resources and materials are available and accessible to the patient.
- Follow through
  - Implementation of communication supports and modification as needed throughout admission
Areas to focus:
- Universal awareness of patient-provider communication
- Consistency in provider awareness for identifying and addressing patient communication needs.
- Addressing communication vulnerability at all points of care
  - Inability to speak
  - Inability to see/hear
  - Understand the language
  - Inability to physically access the nurse call

AAC: What can it look like?

Sample Bedside Signs
- “I can understand what you are saying. Please speak directly to me.”
- “I blink once for YES and twice for NO”
- Please write when speaking with me. Use the dry erase board or typewriter”
Communication Boards

- General comfort
- Body board
- Body positioning
- ABC
- QWERTY
- Customized

- Fix pillow
- Swab mouth
- Dry
- Hold hand
- Stay with me
- Light on
- Light off
- I love you
- Cold
- Hot
- Open
- Close
- Curtain
- Washcloth
- Clean glasses
- Leave me alone
- Television
- Listen to music
- Read book
- Body comfort
Customized Communication Boards

PAIN CHART

http://www.vidatak.com/

http://www.vidatak.com/

Costello and Santiago  ATIA January 2013
Partner Assisted Scanning

- Establish patient’s “yes/no” response
- Scan by row/column to identify target

Dry Erase Board

- Used to write messages
- Receptive and expressive language
- No training required

Boogie Board

- Used to write messages
- Can use fingernail
- Lightweight
- Often motivating
Step-by-Step

- Allows for recording and playback of a series of messages
- Used for:
  - Gaining attention
  - Social scripts
  - Participation in motivating activities
  - Cause-effect
  - And (lots) more

Jellybean Switch

- Used for access to communication tools, computer, and switch toys
- Can be mounted securely for optimal access
- Used with adapted nurse call system

Powerlink Timer

- Timer for switch operated toys and appliances
- Environmental control unit
- Variety of control options
- Good for toys with plugs, switch toys, music players, etc.
MessageMate 40

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

GoTalk

- Speech generating device
- Digitized voice
- Multiple levels and storage for overlays
- Core vocabulary
- Lightweight and portable

Patient video or Patient Photos
Patient video or Patient Photos

Patient video or Patient Photos

Speaking Valve (in conjunction with ORL, Respiratory Therapy, and Nursing)
More Speech-Generating Devices

- Nova Chat 7
- Dynavox Maestro
- Quick Talker

Lightwriter

- "Speaks" aloud typed messages
- Synthesized voice (multiple options)
- Dual screen
- Ability to store frequently used messages
- New Lightwriters = word prediction

Patient video or Patient Photos
Voice Amplifier

- Amplifies a weak voice
- Helpful for patients with vocal fold dysfunction and prolonged intubation
- Able to add headphones to amplify others speech for patient in need of auditory amplification

C Eye

- Requires calibration
- Over-the-bed mount

iPad

- Example Apps:
  - Assistive Chat
  - Predictable
  - Talk Assist
  - Touch Chat
  - Sounding Board
  - Proloquo2Go
  - SonoFlex
  - GoTalk Now
Communication applications

- Full featured symbol based apps:
  - Picture symbols and text-to-speech

Physical Access

- Bedside mount
- Angled switch
- Eye gaze frame
- Rolling mount – Eye Gaze SGD over the bed

Patient video or Patient Photos
The Importance of Patient-Provider Communication: "That's not what I'm saying!"

Case Study: Robert

- **Age:** 11 years
- **Diagnosis:** Cerebral Adrenoleukodystrophy
  - X-linked
  - Mismatched Bone Marrow Transplant on June 2, 2011

"Adrenoleukodystrophy, or ALD, is a genetically determined neurological disorder that affects 1 in every 17,000 boys worldwide. The presentation of symptoms occurs between the ages of 4 and 10, and affects the brain with demyelination.

"Boys develop normally until the onset of symptoms occurs. Symptoms typically rival those of attention deficit disorder before serious neurological involvement becomes apparent. The symptoms progress rapidly and lead to vegetative state within two years, and death anytime thereafter."

Adrenoleukodystrophy

- **Common symptoms**
  - behavioral changes
  - abnormal withdrawal
  - Aggression
  - poor memory
  - poor school performance

- **Other symptoms**
  - visual loss
  - Seizures
  - difficulty swallowing, deafness
  - disturbances of gait and coordination
  - Fatigue
  - intermittent vomiting
  - increased skin pigmentation
  - progressive dementia

"www.adlfoundation.org"
Case Study: Robert

- Treatment
  - Bone marrow transplants can provide long-term benefit to boys who have early evidence of X-ALD, but the procedure carries risk of mortality and morbidity
  - Rare

Case Study: Robert

- Robert’s Baseline Skills:
  - Typical development
  - Quiet disposition
  - Bolivian
  - Primarily Spanish speaking
  - Understands English

- Initial Consult
  - Recommended by Child Life Specialist
  - Transfer to ICU

Initial Consult – ICU 5/2

- Altered motor function, dysphagia, and dysarthria
- Speaking few words
  - Typically one word utterances
  - Reduced intelligibility
  - Benefits from prompting by family members
  - More easily understood given clear context
- Motor skills – somewhat reduced strength and coordination, however functional
- Significant pain and itchiness
Initial Consult – ICU  5/2

- MessageMate 40
  - Mounted
  - Approximately 20 messages
  - Appropriate access w/ direct selection (i.e. "UNO").
- General Inpatient Picture-Communication Boards
- Father recorded messages in Spanish and English

Case Study: Rob  5/7

- Clinical Status:
  - Transfer to BMT unit
  - Speech slowly improved followed by decline
  - Frequently fatigued
  - Decreased coordination of tongue, jaw, and lips
  - Frustrated by inability to speak
  - Hand tremors
  - GoTalk 20 – keyguard, larger targets, easier access
  - Customized communication boards
Case Study: Rob  5/7

- GoTalk 20
- Customized communication boards

Case Study: Robert  5/14

- Clinical Status:
  - Brief awake periods
  - Infrequently engaged
  - Increased motor deficits: strength and coordination, hypotonic
  - Partner assisted auditory-visual scanning
    - GoTalk overlay
    - Communication Boards
  - Visual Cue Cards
    - Orientation, receptive language

Case Study: Robert  5/23-5/30

- Clinical Status:
  - Mental Status: waxes and wanes
  - Medical Plan: Weaning Medication
  - Motor Skills: significantly reduced
  - Some approximated verbalizations? (i.e. “I love you”)
  - BORED
  - Velcro choice board – 2-4 pictures at a time
  - Yes/No/I don’t know
  - Powerlink Timer, cassette player, switch interface
  - Partner assisted auditory-visual scanning
Case Study: Rob 5/23-5/30

- Velcro choice board

Clinical Status:
- Increased alertness x2 days
- Increased vocalizations and laughter
- Mother noticed increased movements of his tongue in an apparent attempt to formulate words.
- Complaining more (parents pleased)
- Velcro choice board – increased # of choices
- Yes/No/I don’t know board + speech-sound production
- Powerlink Timer, cassette player, switch interface
- Partner assisted auditory-visual scanning

Case Study: Rob 6/14

- Clinical Status:
  - Gestures: raise left arm for “yes”
  - Increased pain
  - Modified body/pain board – some reaching/pointing
  - Velcro choice board
  - Yes/No/I don’t know
  - Powerlink Timer, cassette player, switch interface
  - Partner assisted auditory-visual scanning
Case Study: Rob  6/14
- Modified body/pain board

Clinical Status:  6/25
- Improving mental status
- Increased alertness
- Longer sustained attention
- Minimal vocalizations
- Continued use of previously provided materials
- Partner assisted auditory-visual scanning
  - Alphabet board – “Abue” (grandmother), “pray”
  - Customized communication boards
- MessageMate 40
  - 10 identified messages
  - Single switch scanning – Big Red Twist, left hand
**Case Study: Rob 7/2**

- **Clinical Status:**
  - Improving mental status
  - Increased alertness
  - Increased pain
  - Little to no vocalizations

- Continued use of previously provided materials
- Partner assisted auditory-visual scanning
  - Alphabet board
  - Customized communication boards
- MessageMate 40
  - 40 identified messages
  - Column-Row, single switch scanning
  - Joking around

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**Case Study: Rob 6/25**

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**Case Study: Rob 7/18**

- **Clinical Status:**
  - Maintained mental status
  - Increased frustration
  - Continued pain management – sedation varies

- Continued use of previously provided materials
- Dynavox Maestro
  - Need for broader, more diverse communication
  - Rolling Mount
  - Single Switch Scanning
Case Study: Rob 7/18

Clinical Status:
- Maintained mental status
- Increased frustration
- New pain management plan
- Continued use of previously provided materials
- Dynavox Maestro
  - Need for broader, more diverse communication
  - Rolling Mount
  - Single Switch Scanning
- Communication Book: paper copy of Dynavox pages

Case Study: Rob 8/7

Case Study: Rob 8/16-8/22

- Transfer back to ICU
- Increased work of breath and ICU airway management
- Accessing Dynavox and low-tech AAC
Case Study: Rob  9/5

- Clinical Status:
  - Back in BMT unit
  - Maintained mental status
  - Continued pain management
  - Rash 
  - Rash discomfort
  - Continued use of previously provided materials
  - Dynavox Maestro
  - Communication Book – most helpful due to rash and discomfort
  - SBS
  - Jokes
  - Gain attention at night with foot

Case Study: Rob  10/8

- Clinical Status:
  - Pain management stabilized
  - Rash subsided
  - Slow progressive decline in motor and cognitive function
  - Ready for discharge to inpatient rehab

- Disease progression =
  - Decreased access to Dynavox
  - Intermittent access to MessageMate (memorized)
  - Increased use of low-tech AAC; partner assisted communication

“It can make a big difference”

Costello, J. Last words, last connections: How augmentative communication can support children facing end of life. The ASHA Leader, 10, 6-11.


