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

Addressing the Needs of Patients who are Communication Vulnerable

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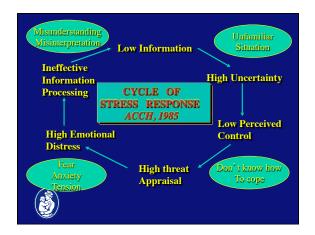
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- Program History
- Model of Intervention







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 The Control of the State of Stat

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)

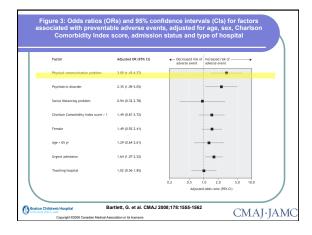
Risk for Serious Medical Events

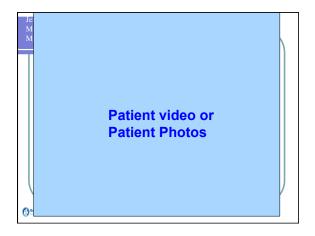
- Communication-vulnerable patients are:
 - Higher rates of hospitalization
 - Higher rates of drug complications
 - Highest use of resources to provide care
 - Lowest levels of satisfaction with care
 - Increased risk of delayed care
 - Increased risk of malpractice
 - Increased length of hospital stay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

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

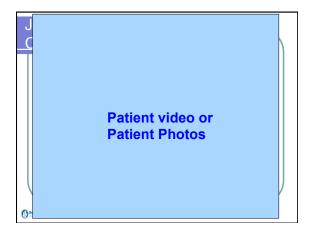
- "The presence of physical communication problems was significantly associated with an increased risk of experiencing a preventable adverse event"
- "We found that patients with communication problems were three times more likely to experience preventable adverse events than patients without such problems"

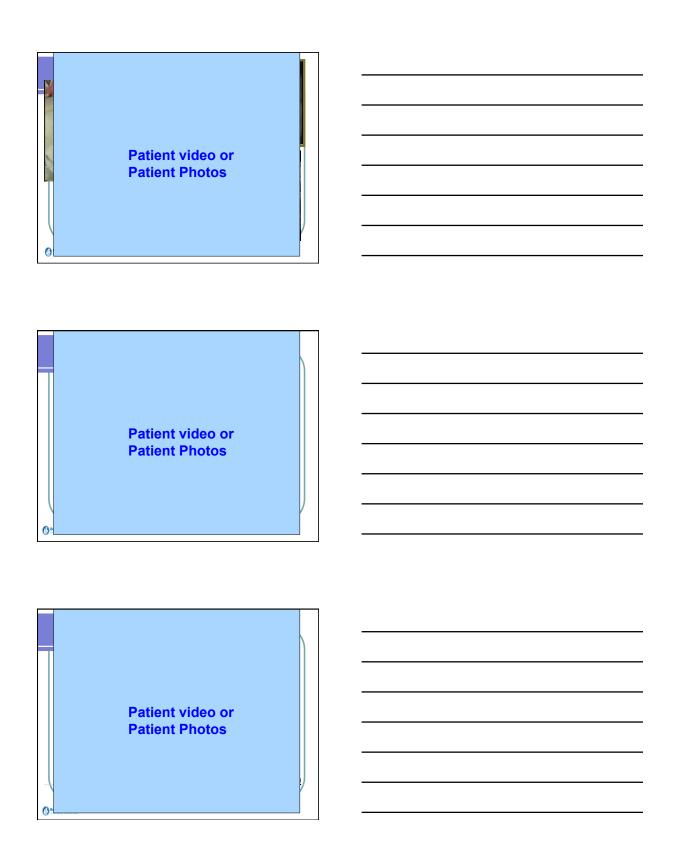
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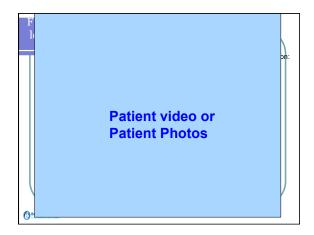


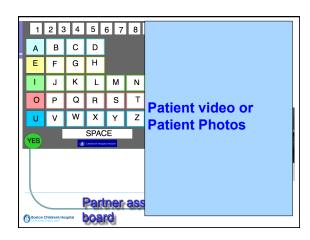


Changes to THE JOINT COMMISSION hospital standards for accreditation that address "communication vulnerability" in 2011 (measured as of 2012 July). Increased focus nationally and internationally on the impact of communication vulnerability on patient care. Increased focus on the Joint Commission International Standards of Care



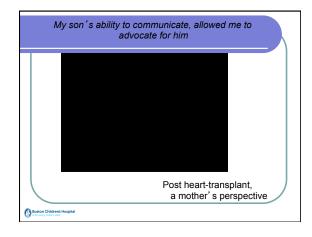








Guidelines for admission to Pediatric ICU American Academy of Pediatrics and the Society of Critical Care Medicine Pediatrics, V 103, No. 4 April 1999 • Severe or potentially life threatening (Endotracheal intubation and potential mechanical ventilation) • Pulmonary or airway disease • Severe, life threatening or unstable cardiovascular conditions • Neurological conditions or seizures • Hematology/oncology disease: (tumors or masses compressing airway) • Endocrine/metabolic disease



Importance of communication and potential impact or patient outcomes is recognized by:

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

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Roadmap 'Guide' to help facilities implement standards D. 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."

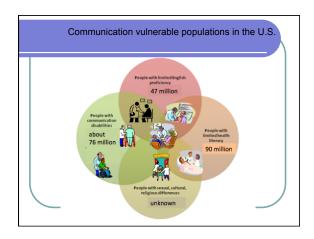
effectively communicates with patients when providing care_treatment_and_services: ..." Patients may have hearing or visual needs... or be unable to speak due to their medical condition or treatment. Additionally, some communication needs may change during the course of care. Once the patient's communication 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..." Advancing Effective Communication Cultural Competence, and Patient- and Family-Centered Caro A Roadmap for Hospitals

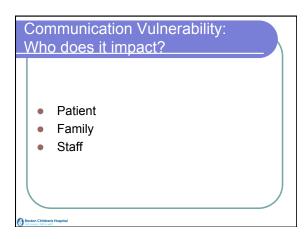
COMMUNICATION VULNERABLE PATIENTS

Individuals with

- 1. Pre-existing hearing, speech, cognitive disabilities who may (may not) have access to communication tools/ supports
- 2. Recent communication difficulties occurring as a result of their disease/illness/accident/event
- 3. Communication difficulties that occur as a result of medical treatment (e.g., intubation, sedation)
- 4. Linguistic differences
- 5. Limited health literacy
- 6. Limited ability to read/write
- 7. Cultural differences







Communication Vulnerability: Who does it impact? Patient Loss of control of environment, sense of self,

- 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)



Communication Vulnerability: Who does it impact?

- 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)

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Communication Vulnerability: Who does it impact?

- 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)

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Communication Vulnerability: Who does it impact? Patient Population Communication vulnerable at baseline Acute onset of communication

 Acute onset of communication vulnerability

At risk for communication vulnerability

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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

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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
 - Phsychiatric disorder
 - Decreased motor skills needed to effective use and access the nurse call system

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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

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Role of the SLP

- 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

 - 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 Boston Children's Hospital Feature Matching in the Acute Care Setting: Quick Considerations Cognitive status Alertness Awareness Orientation Impact of medications/sleep/delirium/time of day Vision Hearing Boston Children's Hospital 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 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 Boston Children's Hospital 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 Boston Children's Hospital 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 ■ Phase 2: Increased wakefulness Phase 3: Need for broad and diverse communication access (Costello, Patak, and Pritchard, 2010) Boston Children's Hospital

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'



Phases of Communication Vulnerable Patient

- 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

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

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Phases of Communication Vulnerable Patient

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

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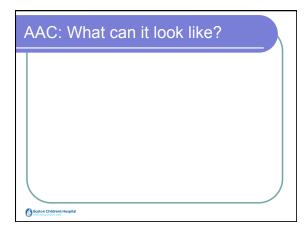
Key Components to Successful Intervention:

- 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

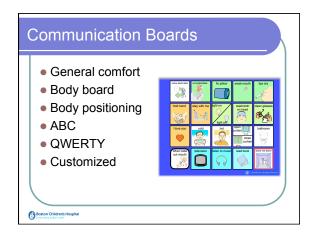
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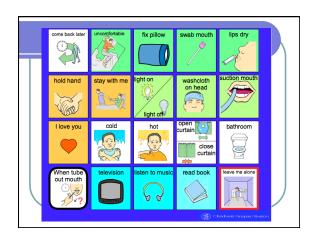
Areas to focus: Universal awareness of patient-provider communication Consistency in provider awareness for identifying and addressing patient communication needs. Addressing communication vulnerability at all points of care Inability to speak Inability to see/hear Understand the language Inability to physically access the nurse call

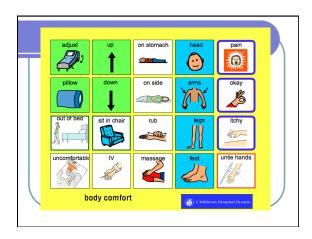
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"I can understand what you are saying. Please speak directly to me." "I blink once for YES and twice for NO" Please write when speaking with me. Use the dry erase board or typewriter"

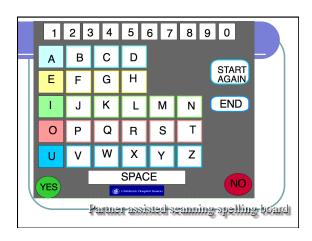


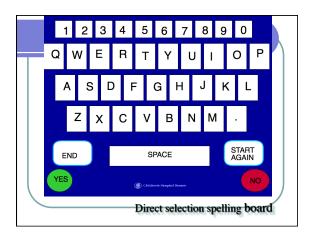


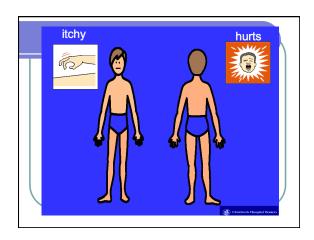




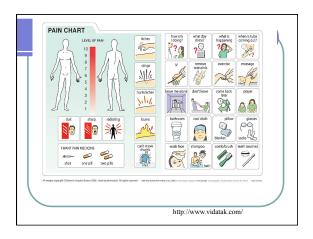


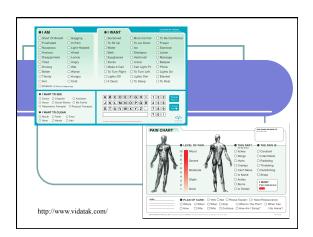


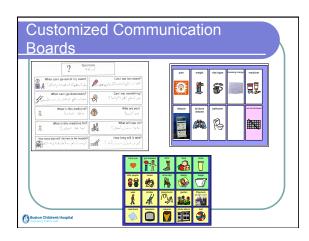


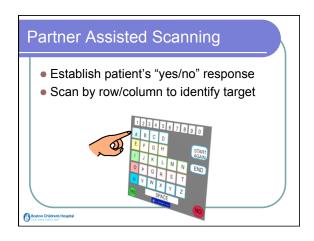




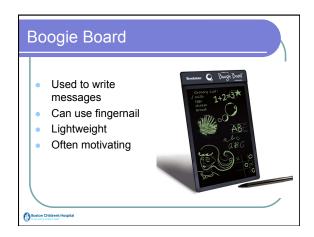




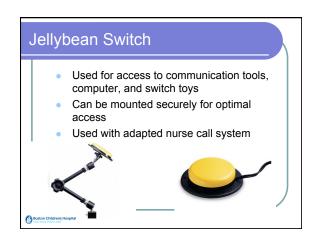




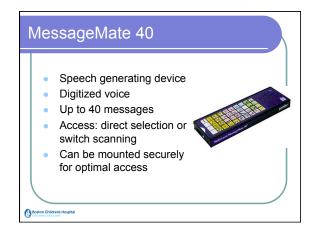


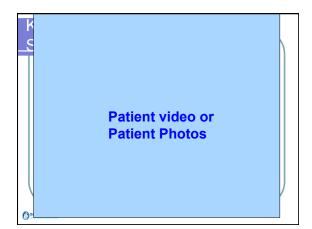


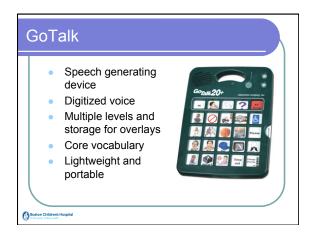


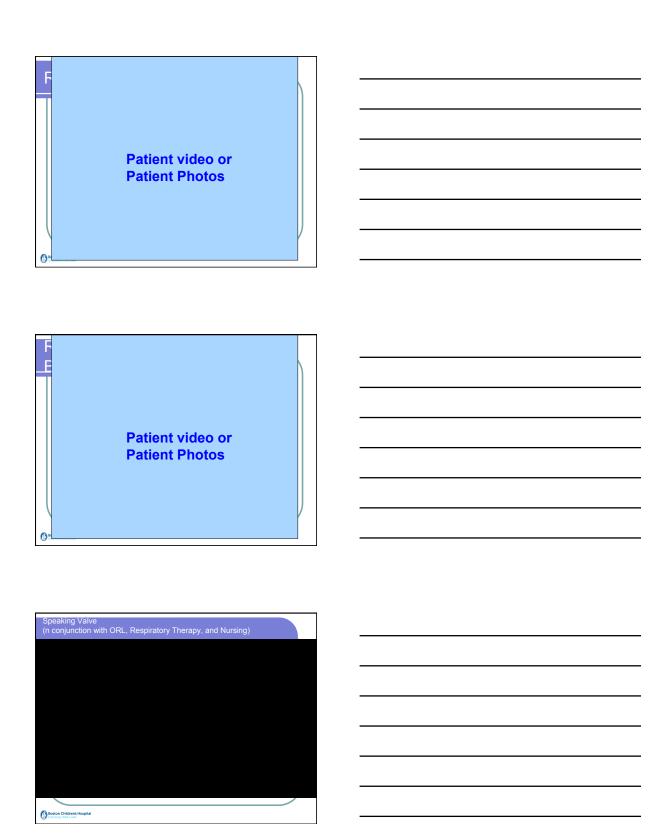


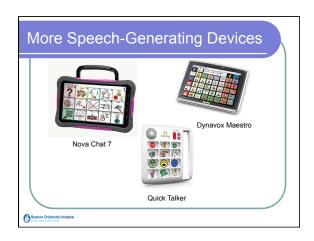






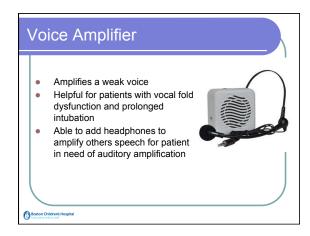


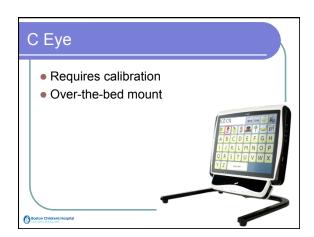








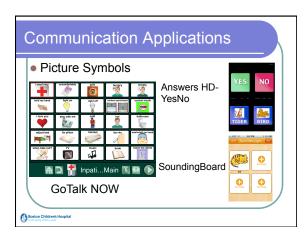


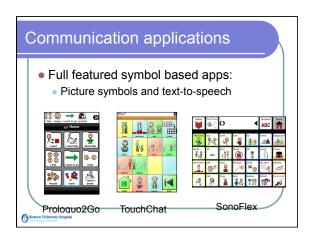




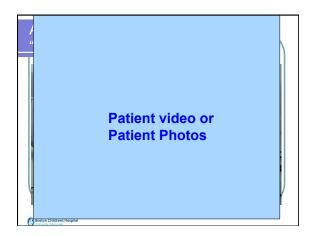


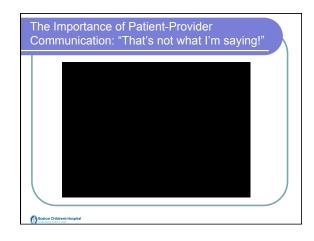




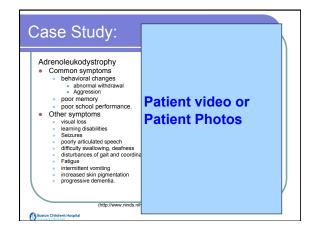








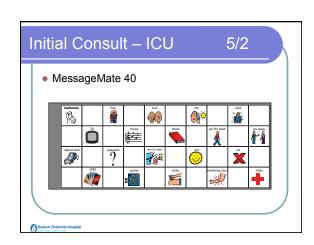
Age: 11 years Diagnosis: Cerebral Adrenoleukodystrophy X-linked Mismatched Bone Marrow Transplant on June 2, 2011 "Adrenoleukodystrophy, or ALD, is a genetically determined neurological disorder that affects 1 in every 17,900 boys worldwide. The presentation of symptoms occurs between the ages of 4 and 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."



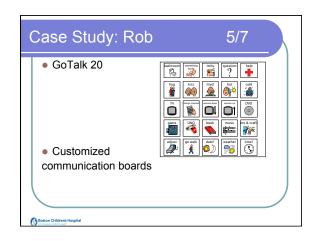
Case Study: Robert Treatment Bone marrow transplants can provide longterm benefit to boys who have early evidence of X-ALD, but the procedure carries risk of mortality and morbidity Rare Case Study: Robert Robert's Baseline Skills: Typical development Quiet disposition Bolivian Primarily Spanish speaking Understands English Initial Consult Recommended by Child Life Specialist Transfer to ICU

Altered motor function, dysphagia, and dysarthria Speaking few words Typically one word utterances Reduced intelligibility Benefits from prompting by family members Motor 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

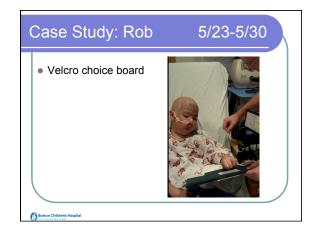


Case Study: Rob 5/7 Clinical Status: Transfer to BMT unit Speech slowly improved followed by decline Frequently fatigued Decreased coordination of tongue, jaw, and lips Frustrated by inability to speak Hand tremors GoTalk 20 – keyguard, larger targets, easier access Customized communication boards



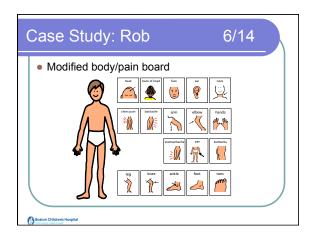
Case Study: Robert 5/14 Clinical Status: Brief awake periods Infrequently engaged Increased motor deficits: strength and coordination, hypotonic Partner assisted auditory-visual scanning GoTalk overlay Communication Boards Visual Cue Cards Orientation, receptive language

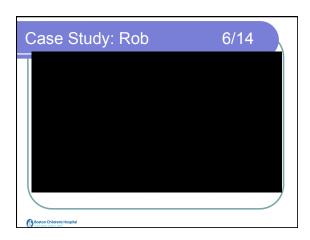
Case Study: Robert 5/23-5/30 Clinical Status: Mental Status: waxes and wanes Medical Plan: Weaning Medication Motor Skills: significantly reduced Some approximated verbalizations? (i.e. "I love you") BORED Velcro choice board – 2-4 pictures at a time Yes/No/I don't know Powerlink Timer, cassette player,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

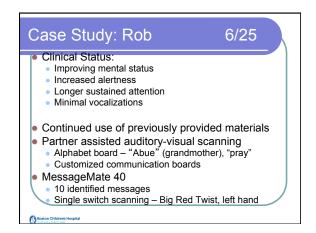


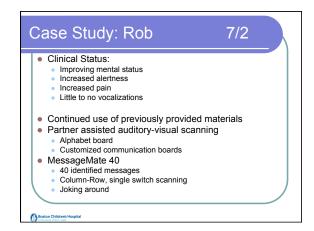
Case Study: Rob Clinical Status: Increased alertness x2 days Increased vocalizations and laughter Mother noticed increased movements of his tongue in an apparent attempt to formulate words. Complaining more (parents pleased) Velcro choice board – increased # of choices Yes/No/I don't know board + speech-sound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

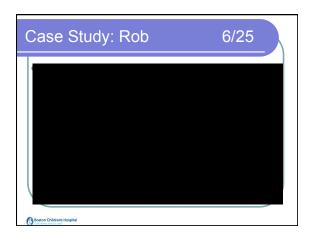
Case Study: Rob Clinical Status: Gestures: raise left arm for "yes" Increased pain Modified body/pain board – some reaching/pointing Velcro choice board Yes/No/I don't know Powerlink Timer, cassette player, switch interface Partner assisted auditory-visual scanning

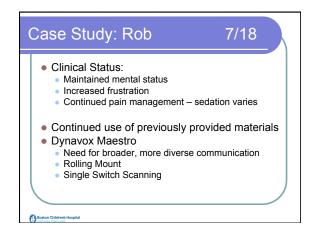


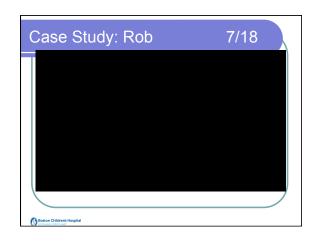










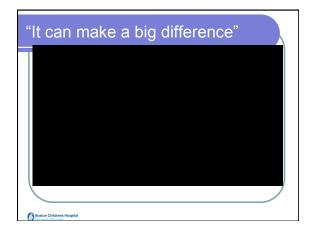


Case Study: Rob Clinical Status: Maintained mental status Increased frustration New pain management plan Continued use of previously provided materials Dynavox Maestro Need for broader, more diverse communication Rolling Mount Single Switch Scanning Communication Book: paper copy of Dynavox pages

Case Study: Rob 8/16-8/22 Transfer back to ICU Increased work of breath and ICU airway management Accessing Dynavox and low-tech AAC

Case Study: Rob • Clinical Status: • Back in BMT unit • Maintained mental status • Continued pain management • Rash → discomfort • Continued use of previously provided materials • Dynavox Maestro • Communication Book – most helpful d/t rash and discomfort • SBS • Jokes • Gain attention at night w/ foot

Case Study: Rob 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



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	Bartlett, G., Blais, R., Tamblyn, R., Clermont, R.J., & MacGibbon, B. (2008) Impact of	1			
ľ	patient communication problems on the risk of preventable adverse events in acute				
•	care settings. Canadian Medical Association Journal. 178 (2). Costello, J. Last words, last connections: How augmentative communication can support children facing end of life, The ASHA Leader 15 (2009), 8–11.				
•	Costello, J. Augmentative Communication in the Intensive Care Unit: The Children's				
	Hospital Boston Model, Augmentative and Alternative Communication 16(3) (2000), 137–153.				
•	Costello, J. Patak, L and Wilson-Stronks, A. AAC and communication vulnerable patients: A call to action, American Speech and Hearing Association Annual Conference, Chicago, Illinois, 2008.				
•	Costello, J, Patak, L and Pritchard, J. Communication vulnerable patients in the pediatric ICU: Enhancing care through augmentative and alternative communication Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 3 (2010)				
	289–301				
(care settings: Intervention outcomes, Augmentative and Communication 2 (1986),				
	38–44.				
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0	Dowden, P., Honsinger, H and Beukelman, D Serving non-speaking patients in acute care settings: An intervention approach, Augmentative and Alternative Communication 2 (1986),				
0	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32.				
	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32. Ebert, D., Communication disabilities among medical inpatients, New England Journal of Medicine 3 (1998), 339–272. Fried-Oken, M. Howard, J.M. and Stewart, S.R., Feedback on AAC Intervention from adults who are temporarily un-able to speak, Augmentative and Alternative Communication 7				
	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32. Ebert, D., Communication disabilities among medical inpatients, New England Journal of Medicine 3 (1998), 339–272. Fried-Oken, M. Howard, J.M. and Stewart, S.R., Feedback on AAC Intervention from adults who are temporarily un-able to speak. Augmentative and Alternative Communication 7 (1991), 43–50. Garrett, K., Happ, MB, Costello, J and Fried-Oken, M AAC in the ICU, in Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, D.				
•	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32. Ebert, D., Communication disabilities among medical inpatients, New England Journal of Medicine 3 (1998), 339–272. Fried-Oken, M. Howard, J.M. and Stewart, S.R., Feedback on AAC Intervention from adults who are temporarily un-able to speak, Augmentative and Alternative Communication 7 (1991), 43–50. Garrett, K. Happ, MB, Costello, J and Fried-Oken, M AAC in the ICU, in Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, D. Beukelman, K. Garrett and K. Yorkson, eds., Paul H. Brookes Publishing Company, Maryland, 2007				
	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32. Ebert, D., Communication disabilities among medical inpatients, New England Journal of Medicine 3 (1998), 339–272. Fried-Oken, M. Howard, J.M. and Stewart, S.R., Feedback on AAC Intervention from adults who are temporarily un- able to speak, Augmentative and Alternative Communication 7 (1991), 43–50. Garrett, K. Happ, MB, Costello, J and Fried-Oken, M AAC in the ICU, in Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, D. Beukelman, K. Garrett and K. Yorkson, eds., Paul H. Brookes Publishing Company, Maryland, 2007 Karlsson, et.al. The lived experiences of adult intensive care patients who were conscious during mechanical ventilation Intensive and Critical Care Nursing (2012) 28, 6-15				
•	settings: An intervention approach, Augmentative and Alternative Communication 2 (1986), 25–32. Ebert, D., Communication disabilities among medical inpatients, New England Journal of Medicine 3 (1998), 339–272. Fried-Oken, M. Howard, J.M. and Stewart, S.R., Feedback on AAC Intervention from adults who are temporarily un- able to speak, Augmentative and Alternative Communication 7 (1991), 43–50. Garrett, K. Happ, MB, Costello, J and Fried-Oken, M AAC in the ICU, in Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, D. Beukelman, K. Garrett and K. Yorkson, eds., Paul H. Brookes Publishing Company, Maryland, 2007 Karlsson, et.al. The lived experiences of adult intensive care patients who were conscious during mechanical ventilation Intensive and Critical Care Nursing (2012) 28, 6-15				