AAC in Pediatric ICU and Acute Care Settings: A Requirement for Best Patient Care Rachel Santiago, MS, CCC-SLP John Costello, MA, CCC-SLP Boston Children's Hospital Boston, MA Boston Children's Hospital Boston Children's Hospital

Disclosures

- Rachel Santiago is a full time salaried employee at Boston Children's Hospital
- John Costello is a full time salaried employee at Boston Children's Hospital

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Welcome to Boston!







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A little about us... Rachel Santiago: Speech-Language Pathologist Clinical Coordinator, Inpatient Augmentative Communication Program Speech-Language Pathologist Director, Augmentative Communication Program; Pediatric ACP and ALS Programs Michelle Howard: Speech-Language Pathologist, Inpatient Augmentative Communication Program Boston Children's Hospital **AGENDA** · Define communication vulnerability & research discussion · Common barriers to successful AAC in ICU/acute care · Patient profiles · Phases of communication need · Children vs. Adults: Child and Pain · Trends and patterns of care · Domains of assessment · Bedside intervention: Tools and strategies Boston Children's Hospital 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

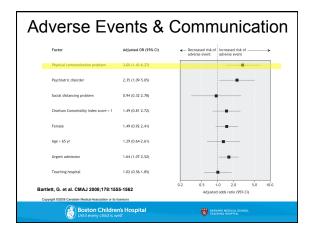
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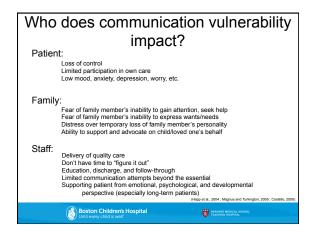
Who is communication vulnerable? 1. Pre-existing hearing, speech, cognitive disabilities Recent communication difficulties due to disease/illness/accident/event Recent communication difficulties due to medical treatment (e.g., intubation, Linguistic differences Limited health literacy Limited ability to read/write Cultural differences/mismatch Boston Children's Hospital HARVARD MEDICAL SCHOOL TEACHING HOSPITAL Why Do We Care? Joint Commission Standards: - Identify needs - Address needs · Patient-satisfaction scores · Research shows poor communication affects patient outcomes · Minimize adverse events resulting from poor patientprovider communication Boston Children's Hospital Until every child is well Join Commission on Communication Vulnerability Effective communication is: "The $\underline{\text{\bf successful joint negotiation}}$ of meaning wherein patients and health providers exchange information, enabling patients to participate actively in their care from admission through $\underline{\mbox{\bf discharge}}$ and ensure that the responsibilities of both patient and providers are understood. To truly be effective, communication requires a two-way process (receptive and expressive) in which messages are negotiated until the

information is correctly understood by both parties."

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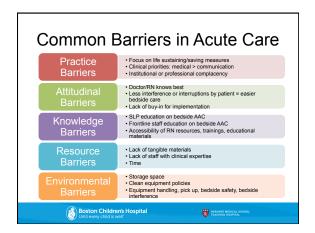
Research · Patients with access to communication supports: - Receive less sedation - Transition more quickly - Have increased satisfaction with health care - Feel more in control · Communication vulnerable patients are at increased risk for: - Serious medical events (Cohen et al., 2005) - Sentinel events (The Joint Commission, 2007) - Poor medication compliance/adherence (Andrulis et al., 2002; Flores et al., 2003) Patients meeting criteria for AAC/AT needs not always receiving services (Zubow and Hurtig, 2013) Greatest need in ICU Boston Children's Hospital HARVARD MEDICAL SCHOOL TEACHING HOSPITAL





Barriers Why is bedside AAC not a formal, required, or standard service at all hospitals?





What is commonly done to address communication vulnerability?

- · Lip reading (by patient, by staff)
- · Reliance on family/caregiver to interpret
- Gestures
- · Pen/paper
- · Alphabet board
- · Hand drawn pictures
- · Yes/no questions
- · Non-English speakers
 - Ad hoc interpreters
 - Interpretation applications and software



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Problem... Family/caregiver burden Guessing (and guessing wrong) - Potential for miscommunication is high Ad hoc interpreters: (Napoles, et al. 2015) - Not bound by HiPPA - Higher risk of errors - Filtered information Reduced access to the nurse-call system - Alternative methods may be available but not appropriate or reliable Weakness or motor impairment - * Reduced ability be access 'standard' communication strategies Yes/No questions: - Limits patients' participation and direction of care - Often not provided with an option to indicate "1 don't know," "Maybe," "I need more information: - Speaking beyond the immediate needs of patient is low



Patient-Provider Communication at the Patient-Level (Patale of al., 2009) Assess the Patient's Communication Need Refer to Communication Specialist Select a Communication Intervention Evaluate the Effectiveness of the Intervention Figure 1. Diagram of formalized process to manage patient-provider communication at the patient-level

Patient Profiles:

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



Patient Profiles

- Communication Vulnerable at Baseline
 - Baseline speech, language, and/or communication deficits
 - Patients who use AAC or AT outside the hospital environment
 - Intellectual disability
 - · Tracheostomy or other form of mechanical ventilation
 - Language difference / Non-English speakers
 - Baseline motor skills that impact use and access to nurse call system



Role of the SLP Communication Vulnerable at Baseline Assist with adding medical related vocabulary to patients 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 Boston Children's Hospital **Patient Profiles** Acute onset of Communication Vulnerability Intubation or other form of mechanical ventilation New tracheostomy Medical procedure, treatment, or device that impedes a patient's ability to effectively speak Brain injury, aphasia Aphonia, dysphonia or new onset vocal chord paresis Dysarthria, unintelligible speech Altered mental status; sedation Psychiatric disorder Decreased motor skills needed to effective use and access the nurse call system Boston Children's Hospital Role of the SLP Acute onset of Communication Vulnerability Evaluate current communication skills/bedside Design and construct supports to meet needs (refer to phases) Mount, train partners Periodic reevaluation and modification or enhancement of communication supports as needed Explore optimal access options Set up adapted call button

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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

Communication Vulnerability: Who does it impact?

- At risk for communication Vulnerability
 - · Risk for intubation or other form of mechanical ventilation
 - · Pre-tracheostomy
 - Anticipated medical procedures or treatments
 - Degenerative condition
 - Positional restrictions





Role of the SLP

- At risk for communication Vulnerability
 - BCH Model of Preoperative AAC
 - 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

 - Preservation of personality

 - Message Bank when possible School based/community based instruction and pre-planning
 - Vocabulary selection
 - Message banking Creating materials





Phases of Communication Need

- Phase 1: Emerging from Sedation
 - Gaining attention
 - · Nurse-call
 - Bedside
 - Answering simple questions
 - YES NO I DON'T KNOW





Phases of Communication Need • Phase 1: Emerging from Sedation Lean matter: your question: YES - undown a such the yet with the first with and affer year law leaves and the year of the first year of the firs

Phases of Communication Need

- Phase 2: Increased wakefulness
 - Everything from phase 1 and...
 - More relevant vocabulary
 - Picture boards
 - Alphabet boards
 - Multi-message voice-output communication
 - Voice amplification

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Phases of Communication Need • Phase 2: Increased wakefulness PAIN SCALE PAIN SCALE AND SCALE

Phases of Communication Need

- Phase 3: Broad and diverse communication
- Everything from phase 1 and 2 and...
- Generative, robust communication
- Encoding strategies
- Internet access and mobile communication
- Phone or video chat access
- Environmental control (beyond nurse-call system)
 - Tablet
 - Computer
 - Leisure activities





Phases of Communication Need Phase 3: Broad and diverse communication



Feature-Matched Assessment:

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





Assessment Domains

- · At each phase of comm. need
- Monitor for changes by reassessing across various domains
- · Monitor for increased communicative functions



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Domains of Assessment:

- 1. Cognition
 - Alertness/awareness
 Sedation

 - Baseline status
- Speech and Language Skills
 Use of speech, symbols, text, and communication displays
- Sensory
 Vision

 - Hearing
 - Anticipated swelling/incision sites

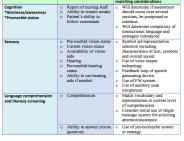
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- 4. Respiratory Status
- 5. Gestures

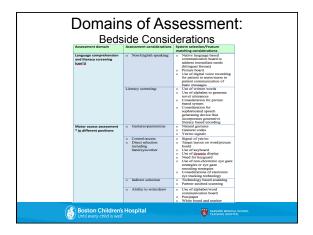
- 6. Sign Language
- 7. Literacy
- 8. Vocabulary selection
- 9. Medical Status
- 10. Motor Skills
- 11. Team members &
- Communication Partners
- 12. Patient motivation & buy-in

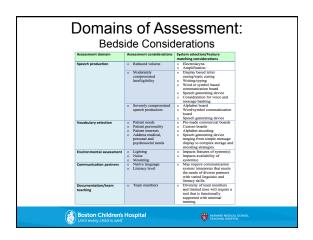


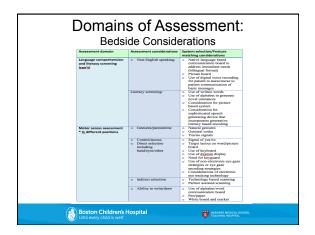
Domains of Assessment: **Bedside Considerations**











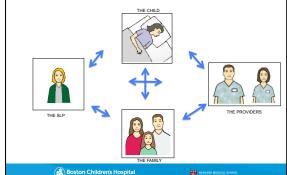
Communication Vulnerability Can Impact All Patients

BUT our treatment is not the same for all patients





Children are NOT small adults



Basic Tenets (A-B-C-D-E-F) to Approaching the Child's Bedside

- Assure
- Bring
- Control
- Direct
- Emotion and Personality
- Fun







A-B-C-D-E-F

- Assure In a hospital setting, a child is constantly on guard for the clinician who will invade their personal space and introduce an unwanted procedure
- Bring materials and tools with you to the first visit. For many children, 'seeing is understanding'
- Control. Children need to feel a sense of control in the hospital.

estella Cantinga & Blackstone (2015





A-B-C-D-E-F

- Direct attention to the child. While your behavior will ultimately be directed by the child's behavior, your attention should always be to the child first
- Emotion and personality hospitalization is a very emotional experience. Loneliness, isolation, separation, anxiety, sorrow, etc. The reflection of personality is essential and is key to successful development and implementation of communication strategies
- Fun. Children understand their world and cope through play.
 Despite potentially life threatening medical circumstances, you must be ready to focus on fun

Costello, Santiago, & Blackstone (201)





Intensive Care Unit Experience: through the Eyes of a Child



Children's reaction to pain

Toddlers and preschoolers (2-5 yr):

- Experience pain but can not always identify the source or location
- 'Magical thinking' may lead child to believe their pain is punishment for real or imagined misbehavior... they believe the pain is someone' s fault.



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Children's reaction to pain

Toddlers and preschoolers (2-5 yr):

- · Communication needs:
 - Children may view procedures as punishment for bad behavior

 - Important to:
 - Express Fear
 Express Anxiety
 - Solicit parents and loved ones for comfort
 Seek explanation and protection











Children's reaction to pain

School age (6 - 12 years)

- · Can tell the location of pain
- · Understand illness is caused by germs
- Believe staff's response depends on how well they express pain
 - Some children may withhold expression of pain to avoid RN interventions

Brewster (1982)



Children's read School age (6	
Communication nee Children need to be able to matters of comfort and pail Where? How much? What kind? (Nausea vs. ac.) What do I need now?	o effectively communicate in
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Children's reaction to pain

Adolescents (13 and older)

- · Begin to understand:
 - There are multiple causes of illness, that the body may respond to many different factors and illness is caused by physical weakness or susceptibility.
 - Different interventions may be needed to address illness and that staff act with necessary intent and empathy.





Children's reaction to pain

Adolescents (13 and older)

- Communication need:
 - At this more mature stage, a child may eager to ask questions, interact with staff and understand the intent of ntervention.

 Will be okay?

 What is the plan?

 What is that medicine for?

 Will this but or make me nauseous?

 How long will I need to take this medication?









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Trends and Patterns of Care Across pediatric caseload	
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Objective	
To analyze trends in AAC service delivery in patients referred for augmentative and alternative communication	
consultation in the pediatric intensive care and acute care settings.	
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Until every child is well Tracesses-osiens.	
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Methods	
Metrious	
IRB approved retrospective review	
Reviewed EMRs and billing data of patients followed by	
a single speech-language pathologist in the Inpatient Augmentative Communication Program between	
December 2015 – May 2016 (n=168)	
Data was entered into the RedCap data collection offware and applying the second control of the secon	
software and analyzed	
*n=168 does not represent actual total volume Santiago, Howard, Costello, & Rahbar (2017	7
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Methods

- Information gathered and analyzed included:
 - Patient variables (age, baseline diagnosis, baseline communication status)
 - Admission variables (i.e. date, reason for admission, admitting department, etc.)
 - Assessment recommendations
 - Intervention recommendations

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Results

- 168 unique patients were seen during the 6-month time frame for assessment
- · 540 patient encounters
- 112 patients (67%) were seen for follow-up intervention encounters
- Mean number of follow-up encounters = 3.84 sessions

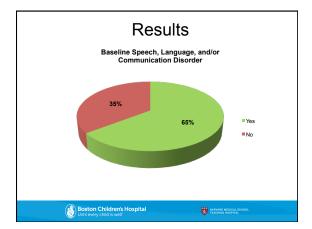
Patient ages ranged from 1 month - 32 years

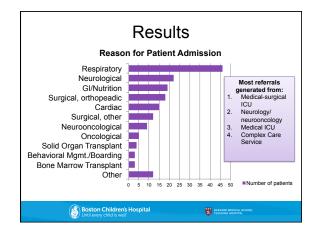
Santiago, Howard, Costello, & Rahbar (2017)

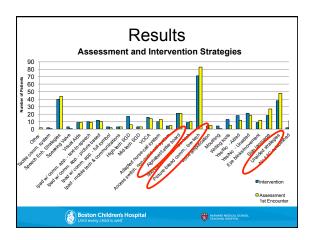
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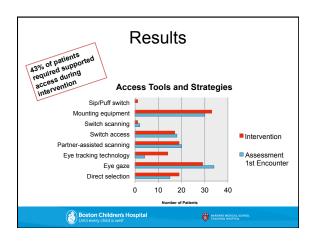
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Discussion Demographics: Over half of referred patients had a noted baseline communication impairment Broad age range, with average of 11.82 years High % of patients admitted with respiratory complications Assessment Considerations: Low-tech picture-based communication boards most recommended along w unaided strategies - Half of patients required supported access strategies during first encounters Intervention Considerations: High tech strategies typically recommended during follow up encounters, if recommended at all - >1/2 patients w/ follow up visits required new or modified AAC strategies

Limitations

- · Retrospective review
- · Single clinician caseload
- · Referral bias

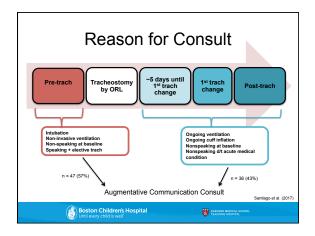


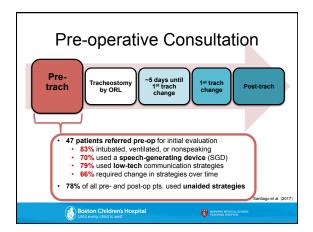
Conclusions

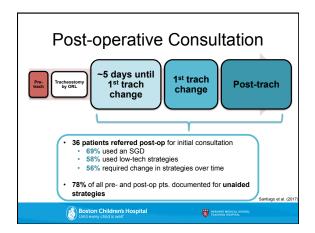
- · Low-tech goes a long way!
 - Unaided and aided strategies should be explored
- · Foundation of knowledge in AAC
- · Access is key
- Be prepared, especially in the ICU
- Communication enhancement is DYNAMIC!

		Santiago, Howard, Costello, & Rahbar (201
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Trends and Patterns of Care Pediatric Patients Undergoing Tracheostomy	
Boston Children's Hospital Until every child is well Until every child is well	
Objective	
For pediatric patients undergoing tracheostomy,	
To describe an approach to service delivery throughout the recovery continuum and,	
To identify trends in bedside AAC assessment and intervention recommendations	
Santiago et al. (2017) - manuscript in process Boston Children's Hospital Until every child is well' White Process Records (Records)	
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Methods	
Chart reviewed all patients who underwent tracheostomy and were followed by the Inpatient Augmentative Communication Program (ACP) between 2013-2016 (n=83)	
Looked at:	
Timing of first evaluation (i.e. pre-operative or post-operative consultation)	
Types of recommendations (i.e. tools and strategies)	
Santiago et al. (2017)	







Limitations -Referral bias -Retrospective review -Single clinician caseload HARVARD MEDICAL SCI TEACHING HOSPITAL Recommendations · Refer early when able · Availability of varied SGDs for assessment and intervention · Provision of low-tech and unaided strategies is key - SGDs are not always the answer · Communication needs may change over time • Follow-up throughout the recovery continuum Boston Children's Hospital Trends and Patterns of Care Early Mobility - ICU Patients with Prolonged Bedrest

Early Mobility Protocols

- · Typically aim to:
 - Improve patient quality of life
 - Decrease hospital acquired conditions
 - Improve functional outcomes
- · Involves gradual introduction of safe, developmentally appropriate activities
 - Mobility & early activity
 - Predefined screening process





Early Mobility

- · Early Mobility at BCH:
 - Johns Hopkins PICU Up!™ Program
 - Multidisciplinary effort that launched January 2017
 - Strong early mobility efforts exist, but areas for improvement



- Areas for Improvement:

 - Consult services within a scheduled timeframe Engage bedside staff/parents in routine activities
 - Clear guidelines for inclusion/exclusion criteria
 - Improve interdisciplinary communication of mobility goals





Subcommittees

- · Culture and Education Group
- · Barrier Identification Group
- · Safety Guidelines Group
- · Measurement Group
- · Intervention Group





PICU Up! Levels · Levels w/ Tiered Activity Plans/Guidelines - Based on inclusion/exclusion criteria, severity of illness, behavioral state (SBS score) Level 1 – SBS -3 to -2 • Level 2 – SBS -1 to +3 Level 3 – SBS -1 to +3 • Parallels the "Phases of Communication Need" (Costello, Patak, & · Will better capture consult orders for services - (PT, OT, Aug. Comm, Feeding, Child Life, Psych, etc.) Multidisciplinary approach w/ increased family & bedside staff involvement Boston Children's Hospital HARVARD MEDICAL SCHOOL TEACHING HOSPITAL Palliative Care & End of life Introduce broad range of AAC tools and strategies to support: √Expression of needs √Social connectedness √Comfort √Nurse call Boston Children's Hospital Palliative Care & End of life Goals for the SLP · Support and enable: participation in daily care/decision making - express emotional state - discuss illness or concrete experience related to illness - expression of self - opportunities for control - social connectedness and emotional closeness - reflection/contemplation of positive life events - expression of legacy

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Palliative Care & End of Life Lessons Learned:

- A simple message can create a powerful connection (for patient and family), especially in the last days or hours of life
- Continued ability to communicate a simple message, even when intentionality is in question, can contribute to the legacy of emotional connection with loved ones

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Palliative Care & End of Life Lessons Learned:

- Communication needs and goals change with disease progression
- · Try to anticipate course of changing needs
 - Better to pre-plan and not need it, then need and not have it
 - Message banking (when able)
 - Tools with varied access options
- At each stage, make sure that maintaining 'the person' is foremost.

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Palliative Care & End of Life Lessons Learned:

<u>Always remember</u> that the person with a life threatening illness is not the *only* person affected by loss of communication skill.

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Communication Kits

Productivity, time, and management issues may prevent SLPs from seeing all patients in need

- Some hospitals train front line staff (RNs, physicians, child life specialists, etc.) to support early communication
- · Caution:
 - Staff education on "communication readiness"
 - Just because patient can't use communication kit DOES NOT mean patient isn't a candidate for AAC!





Communication Kits

- · Provide education and in-service trainings
 - Aided AND Unaided strategies
 - Decision trees to guide selection of appropriate tools and strategies
- When to consult SLP for further assessment as needed
- Communication toolkit:
 - Include inventory list
 - Include sign-out and sign-in sheet
 - Include descriptions of each tool and how to present (with special consideration for patients with reduced mobility, vision, and hearing)





Communication Kits

- · Communication boards
 - Pictures
 - Alphabet
 - Alphabet
 Varied displays (eye gaze, partnerassisted scanning, direct selection) Adapted nurse-call acces
 Simple mounting supports:
- Non-English supports
- Bilingual visual aids
- Writing tools

 Clipboard, pen/paper

 Dry erase board Boogieboard
- Sensory aids
- Voice amplifiers
- - (Personal glasses)*



 Tools to 	gain attention
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- Voice-output communication aids
- Chimes
- Adapted nurse-call access
- Switch arm
- Tabletop or bed mount
- Instructions



Communication Tools and Strategies

- · Custom tools and strategies
 - Usually with referral or formal consultation with inpatient augmentative communication specialist
- Pre-made; Ready-to-go tools
 - Accessible by front-line staff
 - "Communication Toolkit"
 - Later consult specialist for more in-depth assessment and intervention





Communication Systems Are...

- Multimodal, not a single strategy
 - Not 'one size fits all'
- May require modifications and reassessment based on patient status
 - May include a wide range of vocabulary & messages based on MANY factors





Aided vs. Unaided Communication 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



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Access Considerations - How will the patient access their existing or new communication system? - Baseline skills and needs - Anticipated effects or surgery or medical event (i.e. IV boards, incision sites, halo traction) - Anticipated environmental considerations (i.e. lay supine 48 hrs post op, nurse-call wall adapter) - Sedation - Weakness

Environmental Considerations

- How will implementation of tools, materials, and/or strategies affect cares and vice versa?
 - Space
 - Placement
 - Positioning
 - Physical Therapy
 - Impact of medication
 - Eye gaze
 - Blurry vision
 - Generalized weakness
 Physical restraints
 - Signage!







Tools and Strategies



This is *not* an exhaustive list of aided tools! Keep in mind... there's more out there!

Tech is changing every day!



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Bedside Signage

- · May be
 - General, premade signage
 - Custom
- · Purpose:
 - Baseline communication strategies/ preferences
 - Helpful communication tips
 - Equipment set up
 - Presentation of materials

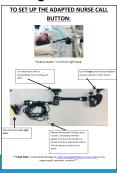




Sample Bedside Signs

- "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"





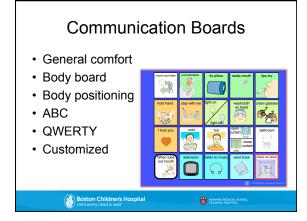


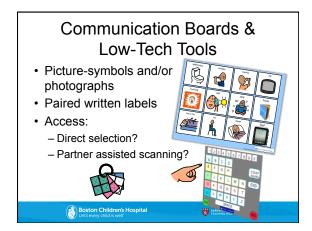
Yes/No/I don't know • Pre-established, unaided strategies - Eye blinks - Gestures (thumbs up/down) - Eye gaze towards partner's hand (right hand = yes, left hand = no, look up = I don't know or Something else) • Picture boards/cards

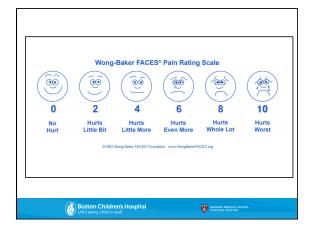








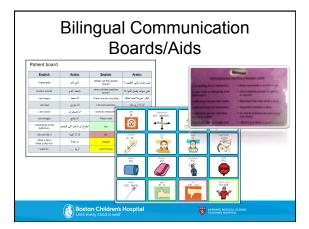




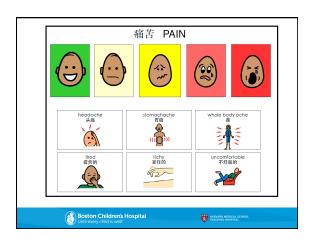
Communication Enhancement: Non-English Speakers

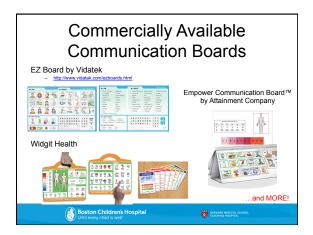
- Support "closed loop" communication
- Bilingual materials and tools = ideal
- · Collaboration with interpreter services for:
 - Digitized voice recording
 - Translated written messages
 - Culturally sensitive visuals



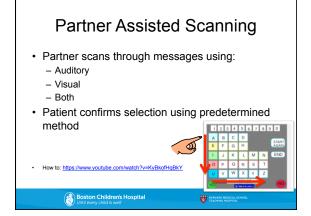














Voice Output Communication

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







Speech-Generating Devices High-tech

- · Digitized or Synthesized voice
- · Access:
 - Physical direct selection
 - Eye gaze
- Single or multi-switch scanning
- Mounting:
 - Rolling mount
 - Bedside mount
 - Wheelchair mount



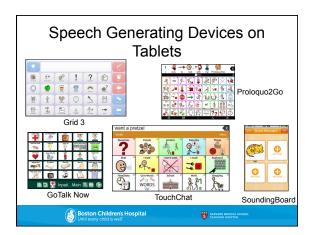


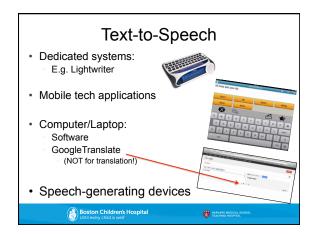
Speech Generating Devices High-tech, Mobile-tech

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











Voice/Sound Amplification Amplifies a weak voice Helpful for patients with vocal fold dysfunction and prolonged intubation Amplification dt hearing loss in absence of hearing aids Transdermal microphones: great for BiPap Pocketalker for patients hard of hearing

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