Augmentative Communication and the Communication Vulnerable Patient: Changing Role of the Speech Language Pathologist

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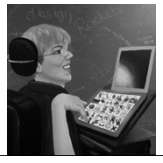
Augmentative Communication Program

Outpatient (Waltham campus)

Inpatient (Longwood campus)



Inpatient
Augmentative
Communication
Closet

Augmentative Communication Program

***Based in part on*:**
Costello J., Patak L., Pritchard J., *Communication vulnerable patients in the pediatric ICU: Enhancing care through augmentative and alternative communication.* Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary 3 (2010) 289–301

*** AAC-RERC sponsored issue**

Agenda

- **Introduction to Augmentative and Alternative Communication in the hospital setting**
- **Communication Vulnerability and risks to care**
- **Historic and CHANGING Role of the SLP in the hospital setting**
- **Children's Understanding of illness, pain and discomfort**
- **Cycle of Stress**
- **Patient Profile and clinical considerations**
- **Very brief overview of Domains of Assessment for ICU/Acute care**

Because we have such a diverse audience with varied AAC experience:

Brief Introduction to AAC in the Hospital Setting

Historically pediatric ICU/acute care:

- Patient communication challenges typically not formally addressed
  - Patient nods, mouth words, gestures
- In few instances:
  - Alphabet board
  - Picture boards
  - Small typing systems
  - Paper and pen
  - Magic slate
- In exceedingly rare instances:
  - Voice output communication aids
  - Other assistive technology

What strategies (if any)are used when a patient can not speak?

Nurses rely on lip reading

Have a familiar family member interpret

Gestures

Pen and paper

Alphabet board

Hand drawn pictures

Medical staff ask yes/no questions*

If a patient IS successful with communication in ICU interactions are:

- Basic communication
- Do not involve patient ideas, questions or other messages
- Usually patient's ability to communicate is either minimal OR Non-existent

Patients who can not speak in the ICU/ acute care report:

- Fear and exhaustion (Hafsteindottir 1996)
- Isolation (Beliz 1983)
- Lack of control and stripped of self (Stovsky 1988)
- Fear and anxiety (Borsig & Stenacher 1982)
- **Frustration, sleep disturbances (Patak, Gawlinski, Fung, Doering & Berg 2004)**

- **Communication difficulty with mechanically ventilated (MV) patients - related to illness severity, anger (Menzel, 1998)**
- **Greater difficulty communicating with family than with nurses (Menzel, 1998)**
- **Under-recognition & high levels of pain reported in MV patients**
- **RNs/MDs more likely to communicate with patients who are more responsive.**

What is (typically) the role of the Speech-Language Pathologist in the Intensive Care and Acute Care Unit (vs Rehab units)?

Feeding and swallowing

Why is this?

- Funding/reimbursement
- Available FTE
- Institutional structure/culture
- Knowledge barriers of SLP staff*

* professional preparedness

Communication Vulnerability: Who does it impact?

- Patient
- Family
- Staff

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

*Serious communication disabilities in hospitalized patients, Ebert, D. *N Engl J Med*. 1998

Patients with communication vulnerability

- **Congenital conditions**
- **Acquired conditions**
- **Degenerative conditions**
- **Condition related to medical intervention (surgery)**
- **Condition related to medical treatment**

VIDEO

Communication Vulnerability: Who does it impact?

Patient

- Loss of control, stripped of personality, sense of self, (Costello, 2000)
- inability 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)

VIDEO

VIDEO

Independent (with added recovery)

VIDEO

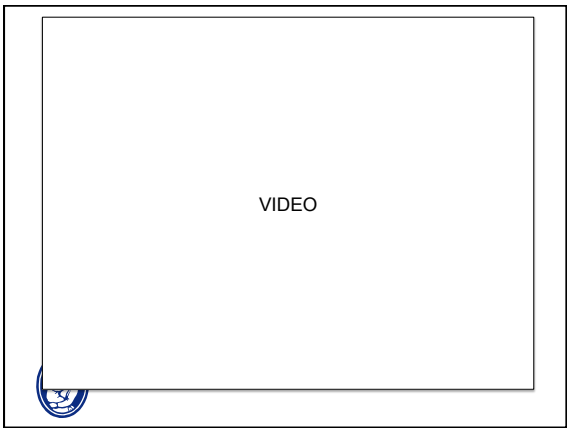
VIDEO

location of pain

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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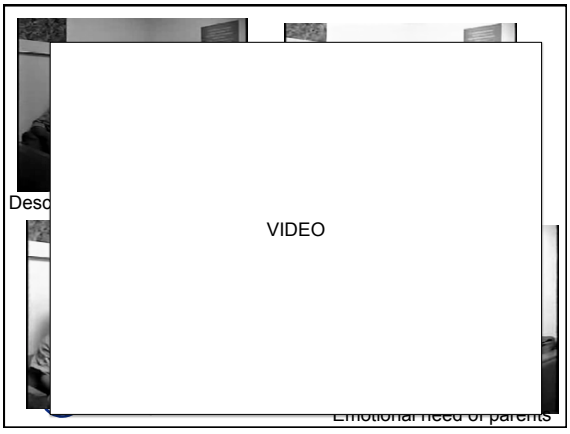
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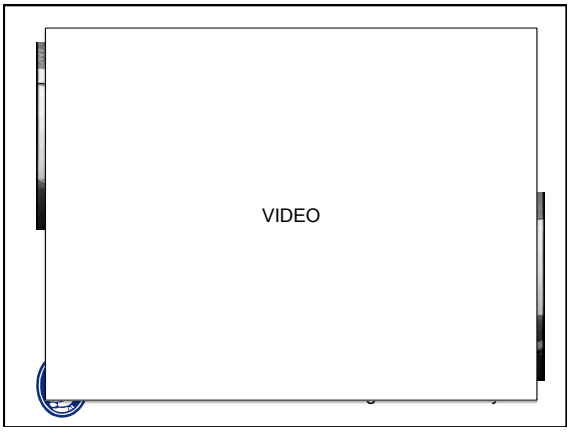
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Communication Vulnerability: Who does it impact?

Staff

- Delivery of nursing care
- Nurses typically do not have time to "figure out" what patient is trying to communicate.
- 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)

Medical Staff

- The
- Bec
- Nur

VIDEO

Communication Vulnerability: Impact on staff

1. Quality of care issue "all patients who described good communication with their providers told us they were treated in a caring, concerned and respectful manner"
   -Duclos, et. Al. 2005 International Journal of Quality in Health Care v 17 # 6 page 483

2. Patients inability to communicate has a negative impact on the nurse/doctors tendency to communicate with them, (Ashworth, 84)

VIDEO

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
- 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
- Phsychiatric 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
- 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

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 communicates and 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
- Pre- and Post-op Process

Why is there FINALLY so much more focus on Communication Vulnerability?

In the United States,

-The Joint Commission sets standards of care for hospitals and health care providers

-2012 introduces changes to hospital standards for accreditation that address "communication vulnerability"

SOLUTION (end goal):

➢Health Care institutions are urged to **develop hospital systems** to achieve effective patient-provider communication across the care continuum.

➢Institutions *must* **provide readily available resources and interventions at the bedside** to support patient-provider communication.

➢Bedside **charting** *must* **include communication assessment**, **provision of** effective communication **resources and interventions**, establishment of **communication goals** that include the patient's input when possible, and an **evaluation of the effectiveness of resources and interventions provided.**

SOLUTION (end goal):

➢Institutional **guidelines need to include performance expectations** in order for care providers and clinical practice to achieve effective patient communication whenever possible, especially with communication-vulnerable patients.

➢Revise **staff training and education curricula to increase awareness** of communication-vulnerabilities and the know-how to best use resources available at the bedside.

➢Revise the **referral process** to trigger doctors and nurses to **prompt referrals** to communication specialists and language services **whenever patient communication is not successfully addressed** with the resources and interventions that are readily available at the bedside.

WHAT IS "EFFECTIVE COMMUNICATION"?

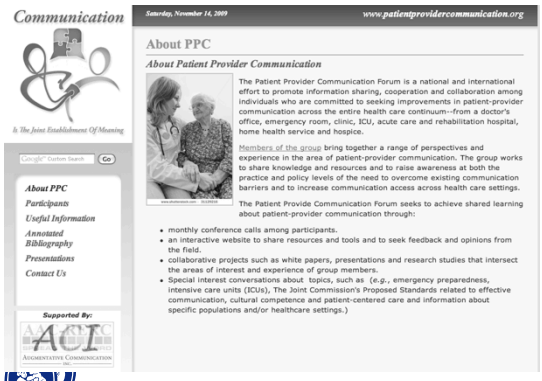
"the successful joint establishment of meaning wherein patients and healthcare providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood"

(The Joint Commission, 2010b, p. 91).

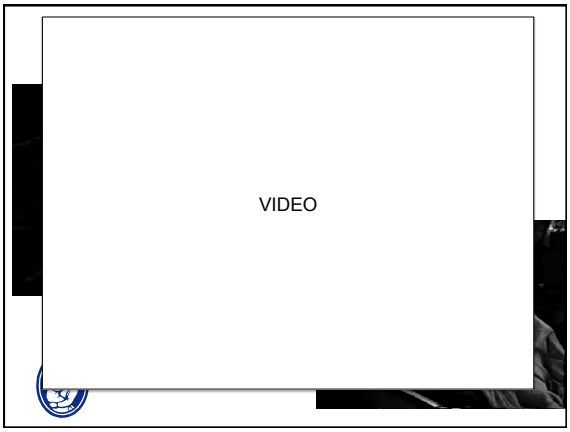
So, to review: COMMUNICATION VULNERABLE PATIENTS

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**



http://www.patientprovidercommunication.org/



Poor Communication Impacts Patient Safety

Communication vulnerable patients are at increased risk for:

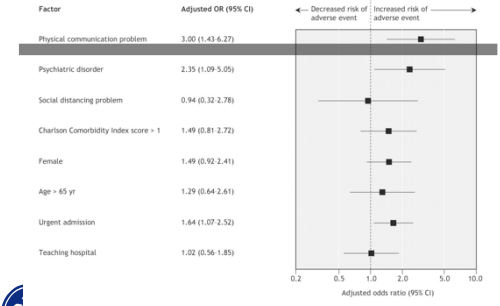
- Serious medical events (Cohen et al., 2005)
- Sentinel events (The Joint Commission, 2007)
- Poor medication compliance/ adherence (Andrulis et al., 2002; Flores et al., 2003)

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"

Figure 3: Odds ratios (ORs) and 95% confidence intervals (CIs) for factors associated with preventable adverse events, adjusted for age, sex, Charlson Comorbidity Index score, admission status and type of hospital



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CMAJ·JAMC

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.

Toddlers and preschoolers (2-5 yr)

Communication needs:

At this stage, children may view procedures as punishment for bad behavior

This makes it particularly important to communicate: fear, anxiety and solicit parents and loved ones for comfort, explanation and protection

Children's reaction to pain

School age (6 - 12 years)

- Can tell the location of pain
- know that illness is caused by germs and believe that staff's response depends on how well they express pain

Brewster, Arlene B. Chronically III Hospitalized Children's Concepts of Their Illness
PEDIATRICS Vol. 69 No. 3 March 1982, pp. 355-362

School age (6 - 12 years)

Communication Needs:

Children need to be able to effectively communicate matters of comfort and pain

Children's reaction to pain
Adolescents (13 and older)

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

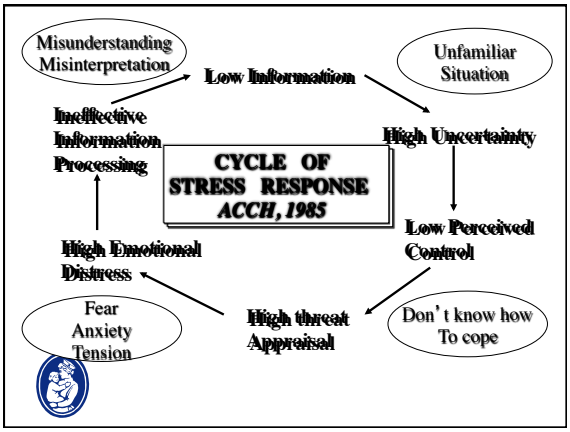
Perrin, Ellen C., Gerrity P. Susan, There's a Demon in Your Belly: Children's Understanding of Illness PEDIATRICS Vol. 67 No. 6 June 1981, pp. 841-849

Adolescents (13 and older)

Communication need:

At this more mature stage, a child may be particularly anxious to be able to ask questions, interact with staff and understand the intent of intervention.

CYCLE OF STRESS RESPONSE
ACCH, 1985



Impact of communication vulnerability:
Impact on the child

challenges and needs of patient
» Powerlessness
» Loss of Control
» Disconnection from loved ones
» Inability to participate in own care
» Inability to ask questions, express needs, fears,PERSONALITY, etc.

VIDEO

VIDEO

CHANGING ROLE: REVISITED
What does this mean for the Speech-Language Pathologist?

An increased demand for expertise in AAC with acute and intensive care patients

This will require increased training to prepare SLPs to provide AAC services for patients who are communication vulnerable in the medical setting.

There will be an increased need for AAC tools and strategies to be readily available for assessment and intervention.

Profile/Phases of Communication Vulnerable Patient

Phase 1: Emerging from Sedation

Phase 2: Increased wakefullness

Phase 3: Need for Broad and diverse communication access

Phase 1 Emerging from Sedation

- **Yes - no - I don't know**
- **Call for nurse/modified nurse call**
- **Gain attention of loved ones/staff with simple voice output**

Phase 2 Increased wakefulness

- **Require all of phase 1 strategies**
- **Require more relevant vocabulary**
- **Picture boards**
- **Alphabet boards**
  - **ABC**
  - **QWERTY**
- **Multi-message voice output devices**
- **Digitally recorded messages ******
- **Voice amplification**

Phase 3
Broad and Diverse Communication Access

- All options from phase 1 and 2
- Generative communication with alphabet and sophisticated page sets
- Word and grammar prediction
- Encoding strategies
- Music and video files
- Internet access
- telephone

Impact of AAC

Patients taught to use communication tools such as picture boards, word boards or simple communication devices, reported improved satisfaction and comfort when compared to care without communication support

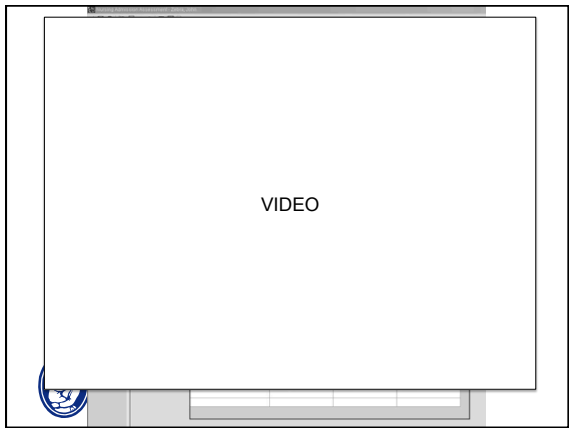
(Patak et.al 2007, Costello 2000, Stovsky, Rudy & Dragonete, 1988)

First: getting the referral

KEY:

staff recognizing communication vulnerability and then recognizing that it is NOT alright

*** Huge opportunity for nurse /staff training by SLP**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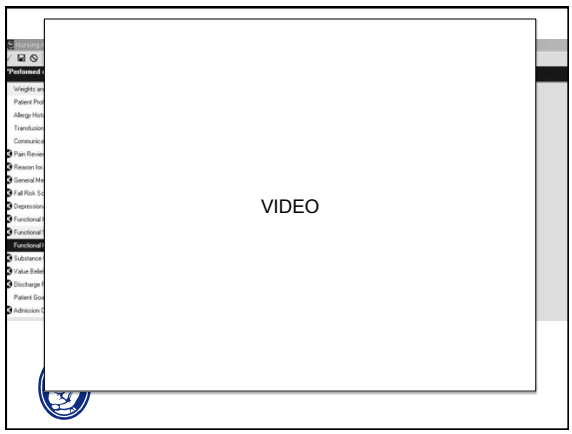
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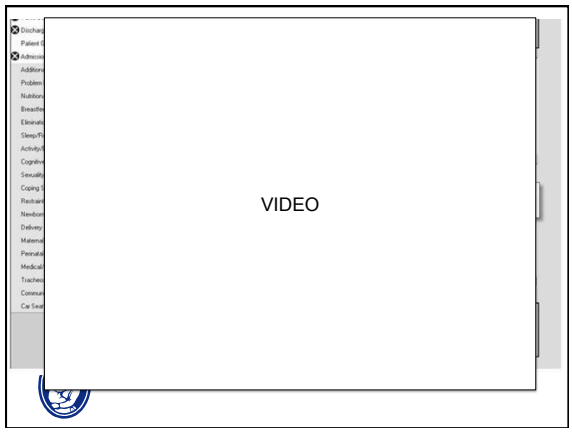
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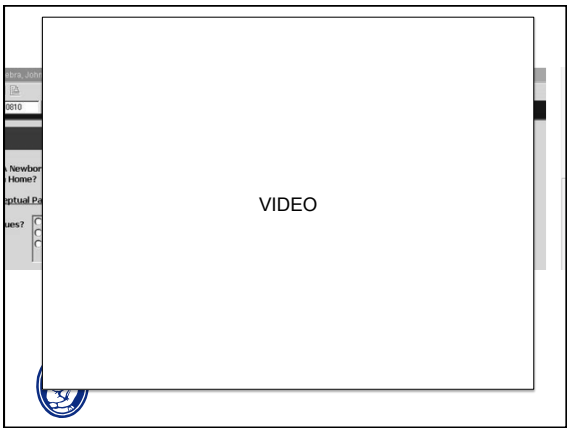
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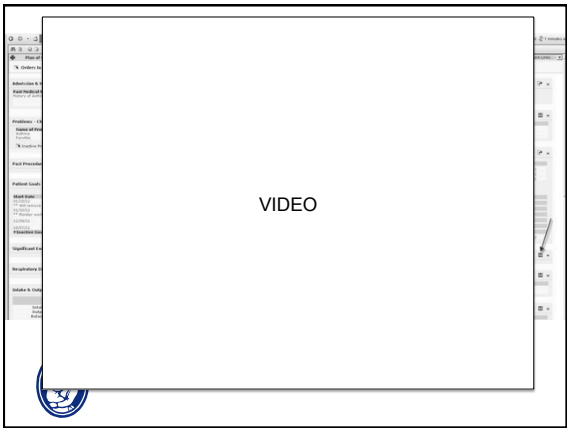
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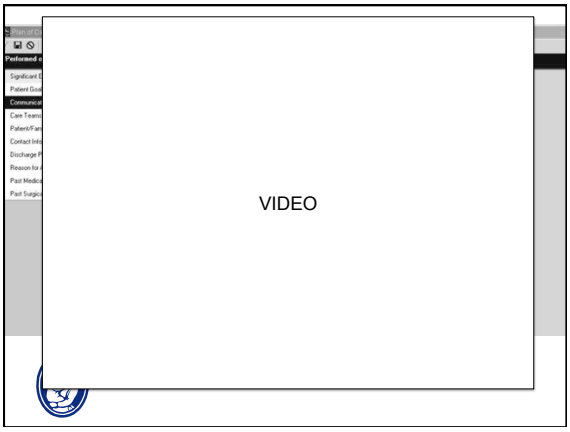
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Referral source

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

Many hospital admissions may have a known/expected non-speaking condition

Who might have a Temporary Nonspeaking condition?

STAY TUNED FOR DISCUSSION ON MESSAGE BANKING!!!!

Questions to ask/consider at admission

questions to ask:

- Does the patient currently have difficulty communicating and participating in the admission process?
- Does the patient have an existing augmentative communication device or strategy that he/she employs for expressive and/or receptive language?
- Is a process or procedure during hospitalization expected to induce communication vulnerability?
- Will hospitalization make the use of current and needed vision or hearing aids not possible?

Whirlwind review:

Assessment Domain
CORE Assessment considerations
Impact on system selection and feature matching.

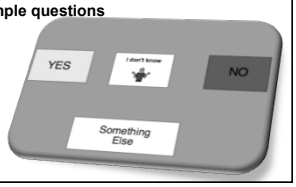
May be a VERY dynamic process with status changing regularly

Cognitive status:

- **Alertness**
- **Awareness**
- **Orientation**
- **Pre-morbid status**

Cognitive Assessment considerations:

- **Often status is first reported by bedside care providers**
- **Observe patient's wakefullness and fatigue (impact participation and length of assessment)**
- **Patient's ability to follow simple directions**
- **Patient's ability to respond to simple questions**
- **(yes/ no / don't know response)**



Cognitive Assessment considerations:

- **Potential presence of delirium**
- **Impact of medications (example**
- **Quality and quantity of sleep**
- **Potential presence of dementia**

Feature match/intervention considerations

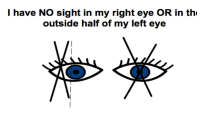
- **Will determine if assessment happens over time, postponed or continued.**
- **May need to re-assess often and adjust recommendations frequently**
- **May require range of supports to be used at different times of day**
- **Will impact complexity of instructional language and strategies introduced**
- **May suggest selection of memory book or orientation strategies through visuals, visual schedule**
- **Use of symbols versus written word**

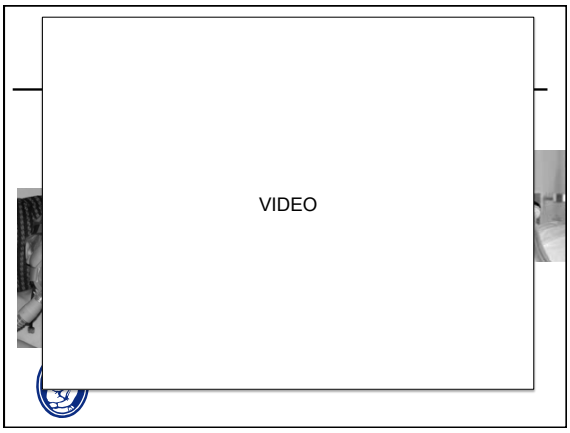
Sensory domain:

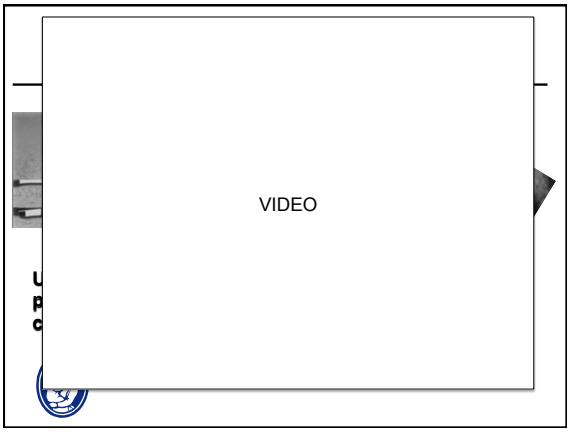
- Vision
- Hearing
- Comparison to pre-morbid status?

Sensory Assessment considerations

- Does s/he where glasses? If yes, are they here?
- Does s/he have hearing aids? If yes, are they here?
- If physical status will not support glasses or hearing aids (swelling, incision site, etc.), what accommodations can be made
- Have C.I.? Available?







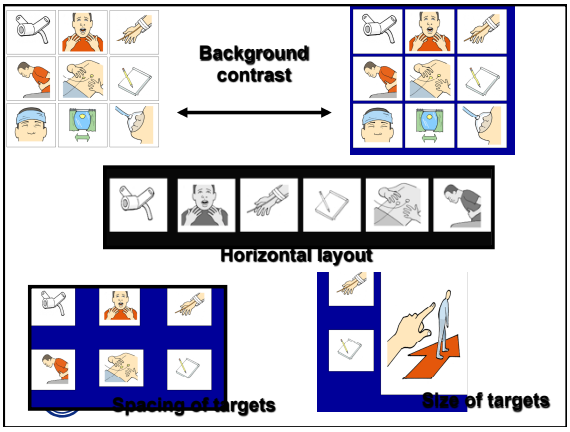
Feature match/intervention Considerations (sensory)

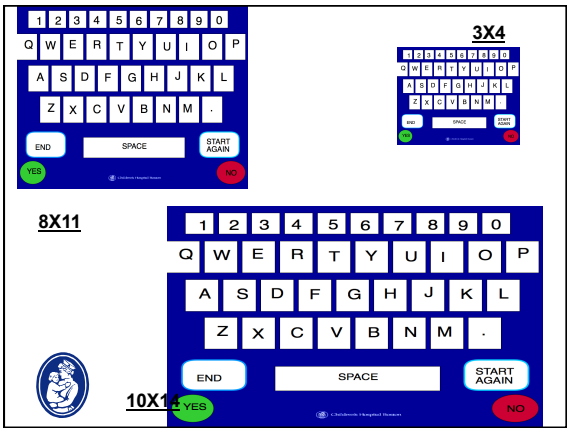
- Consideration for communication with family/friends via phone:
  http://ip-relay.com OR TTY
- Use of web cam/Skype video for sign communication with family/friends

VIDEO

Feature match/intervention Considerations (sensory)

- Symbol set/representation selection
- characteristics of text
- Size of targets
- Color contrasts
- Complexity of layout
- Use of symbols versus text
- System that supports keyguard
- System that supports tactile markers





Motor Domain

- Use of gestures/pantomime
- Control/access
- Physical positioning
- Direct selection (hand, eyes, other?
- Ability to write/draw

Assessment considerations

- Ability to point with hand
- Ability to point with eyes
- Ability to point with head light
- Use of splints to support pointing
- Indirect access through scanning
- Indirect access through partner assist
- Access changed by positioning?

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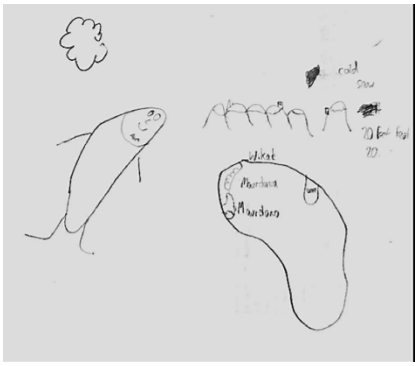

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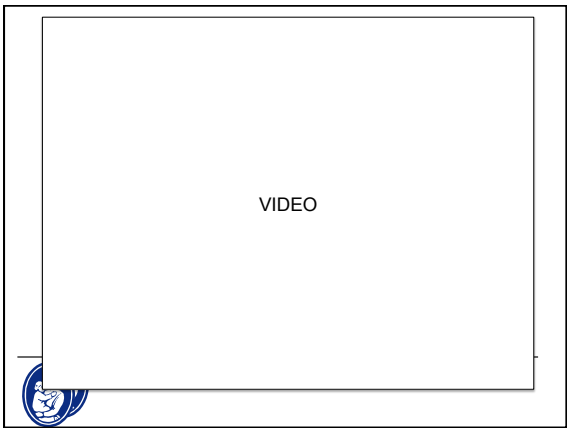
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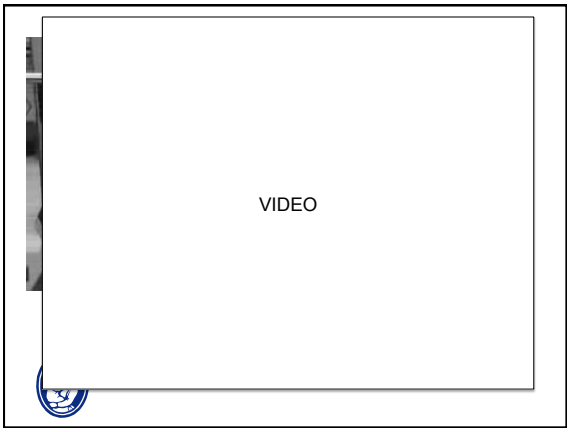
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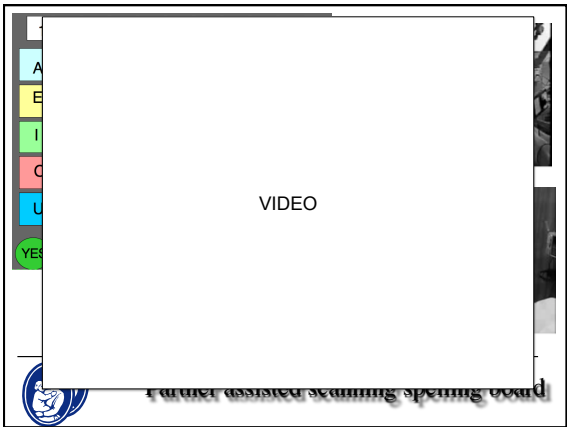
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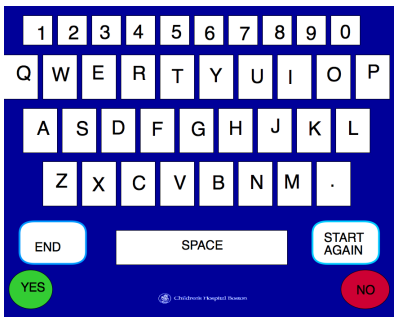

Direct selection spelling board

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A
"

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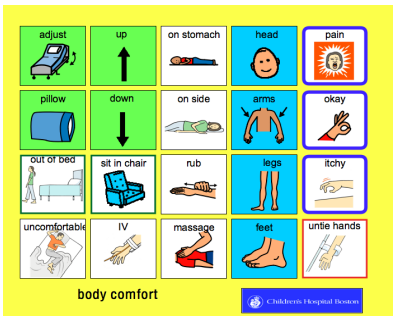
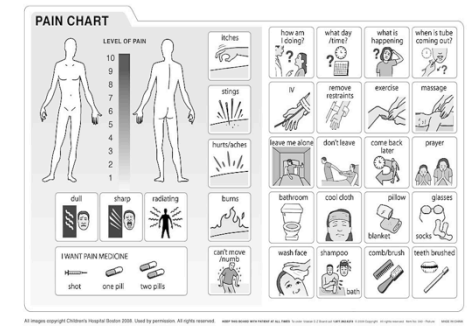


http://www.vidatak.com/



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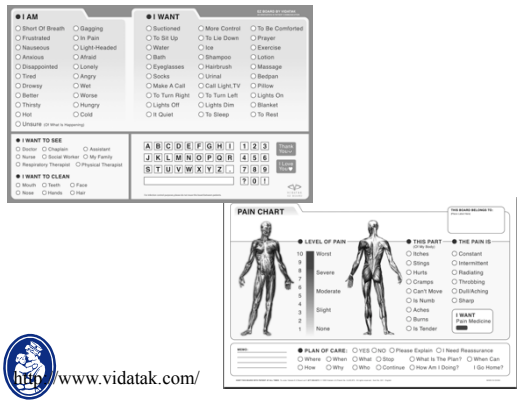
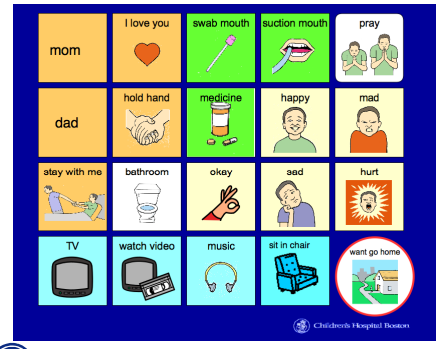


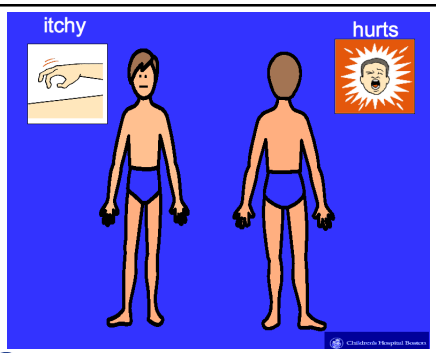
http://www.vidatak.com/

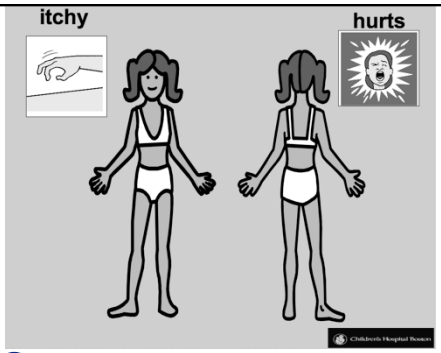
VIDEO

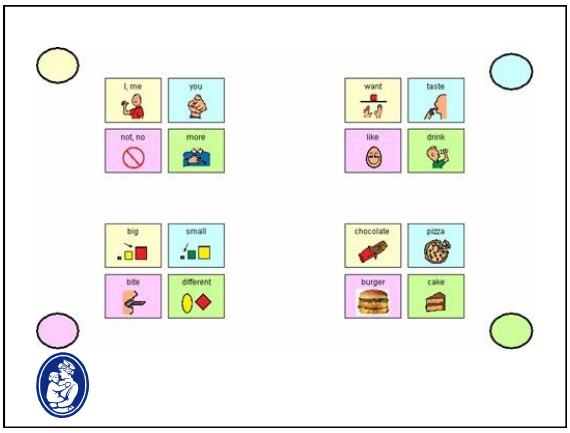
come back later
uncomfortable
fix pillow
swab mouth
lips dry
hold hand
stay with me
light on
light off
washcloth on head
suction mouth
I love you
cold
hot
open curtain
close curtain
bathroom
When tube out mouth
television
listen to music
read book
leave me alone


mom
I love you
swab mouth
suction mouth
pray
dad
hold hand
medicine
happy
mad
stay with me
bathroom
okay
sad
hurt
TV
watch video
music
sit in chair
want go home
Children's Hospital Boston

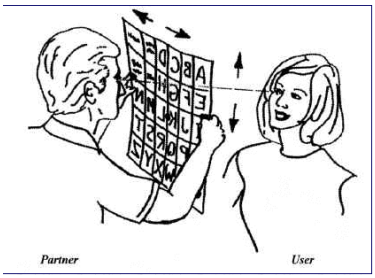
I'm bored, I want to....
Children's Hospital Boston
cart
car
draw color
playroom
wagon
watch video
watch TV
paint
read book
watch DVD
change channel TV
Nintendo
computer
game
out of bed
Play/playroom


itchy
hurts
Children's Hospital Boston


itchy
hurts
Children's Hospital Boston



Eye Linking



Resource:http://www.cini.org

VIDEO

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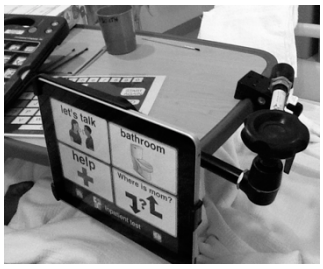

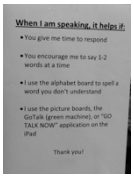

positioning

- Cuff inflation may vary by positioning and impact need for AAC vs. ability to use speech.
- Access skill may change with physical positioning (in bed/in chair) and require different strategies or mounts
- Medical procedure may impact positioning which will impact feature match
  - Example: spinal fusion/rod insertion
  - reconstruction surgery with tissue graphing

Language Comprehension Domain

Native language?
Comprehension
Ability to follow directions
Able to answer yes/no questions

Feature match/intervention Considerations (language)

Post how patient indicates yes/no in obvious space in room

- Examples: thumbs up/down
- Squeeze eyes or blink eyes
- Squeeze hand once or twice

Feature match/intervention Considerations (language)

- Use of visuals (symbols, photos, text)
- Intervention may focus on simple single message output devices
- May focus on strategies to support control and impact on environment

Feature match/intervention Considerations (language)

- ALWAYS use QUALIFIED MEDICAL INTERPRETER services when patient does not speak English/uses ASL
- Use of digitally recorded communication aids for communication in native language and English (approved by qualified medical interpreter)

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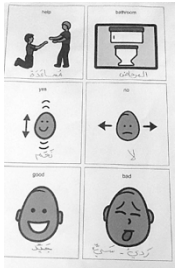
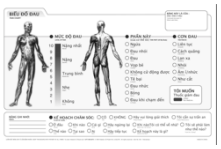


Collaboration with Interpreter servies

Communication Boards with Language Translation



Vietnamese

Spanish

Feature match/intervention Considerations (language)

Selection of tools/strategies with transparent organization versus requiring meta understanding of navigation/organization *

* may change rapidly with medical status change

Selection of sophisticated tools and integrated features for environmental control, web access, etc.

Literacy Domain Feature Match considerations

- Use of written words
- Use of alphabet for generative communication
- Encoding strategies
- Use of keyboard based systems
- Keep pen and paper at bedside along with easily accessible strategy to request (simple voice output tool)

Literacy Domain Feature Match considerations

- Use of cell phone/text messaging for communication
- Use of letter cues/topic cues
- ***Note: good decoding skills and reading comprehension does not mean patient has good encoding skills
  - May be able to use canned text but not generate novel text.

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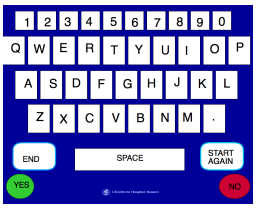
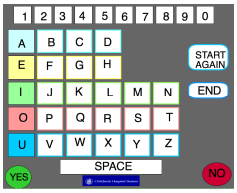


Feature Match: QWERTY vs Alphabetical



VIDEO

Boogie Board

VIDEO

Letter Cue board

THE WORD BEGINS WITH…..

Q	W	E	R	T	Y	U	I	O	P
A	S	D	F	G	H	J	K	L	
Z	X	C	V	B	N	M	*Start again*		
br	cr	fr	gr	tr	pl	str	*Next word*		
bl	cl	fl	gl	sw	dw	tw	*End*		
sl	sc	sk	sm	sn	sp				
sw	squ	spl	spr	scr					

Topic Cue board

People	**Food**	**Emotions**
Places	**Colors**	**Questions**
Animals	**Entertainment**	**Body**
School	**Home**	**Community**

VIDEO

Speech Production

- Moderately compromised intelligibility?
- Severely compromised intelligibility?
- Type of intubation/ cannula ?
- Impacted by cpap/bipap mask and type of mask?
- Impacted by fixation or other hardware?

Voice Amplification or use of Electrolarynx

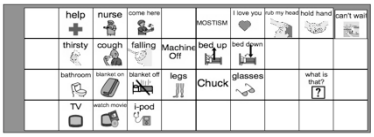
Vocabulary Selection

- Patient needs
- Patient personality
- Patient's developmental status
- Patient interest
- Address medical, personal and pyschosocial needs

Comparison of MessageMate

KYLE

PATRICK



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Domain of Assessment: Environmental

- Lighting
- Noise (including noise from vent and other medical equipment)
- Available real estate/furniture for Mounting/ access
- Nurse route of access maintained

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