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End-of-Life Care and Patient Communication in Critical Care Settings

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End-of-Life Care and Patient Communication in Critical Care Settings

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Disclosure: Financial — Received a speaking fee from Passy-Muir, Inc. for this presentation
Nonfinancial — No relevant nonfinancial relationship exists.

Disclosure Statement

- Passy-Muir, Inc. has developed and patented a licensed technology trademarked as the Passy-Muir® Tracheostomy and Ventilator Swallowing and Speaking Valve. This presentation will focus primarily on the biased-closed position Passy-Muir Valve and will include little to no information on other speaking valves.

Evidence for Communication Support at End-of-Life in the ICU

- ICU treatment ≠ good end of life care
- Communication ability, topic, methods
- Use of augmentative and alternative communication tools
- Symptom communication & management
- Communication with family -- final messages
- Participation in treatment decision making

American Journal of Critical Care 2004; 13 (3)

CE Article

Communication Ability, Method, and Content Among Nonspeaking Nonsurviving Patients Treated With Mechanical Ventilation in the Intensive Care Unit

By Mary Beth Happ, RN, PhD, Patricia Tuite, RN, MSN, Kathy Dobbins, MSN, CRNP, Dana DiVirgilio-Thomas, M.A. and Julius Kitutu, PhD, from University of Pittsburgh School of Nursing (MBH, PT, DD-T, JK) and University of Pittsburgh Medical Center (KD), Pittsburgh, Pa.

- Chart review of 50 randomly selected ICU patients who died
- 72% had evidence of communication during MV
- Most communication (62.9%) occurred when NOT physically restrained
- Topics: (1) pain/discomfort, (2) emotional, (3) physical care needs, (4) symptoms, (5) family
- A few (~4%) described active patient participation in LST decisions

COMMUNICATION ABILITY

- point prevalence studies
  - 18.4% ICU patients[1]
  - 33% AAC candidacy – all hospital patients[2]
- incidence across ICU stay
  - 50% MV patients for > 2 days in ICU [3]
- Take home message → All patients deserve daily assessment for communication ability

[1]Thomas LA, Rodriguez CS. Clin Nurs Res, 2011. **20**(4): 439-47.
[2]Zubow , L. and R. Hurtig, Perspectives on AAC, 2013; **22**(2): 79-90.
[3]Sciulli AM, et al. Council for the Advancement of Nursing Science 2012 State of the Science Congress, Washington, DC.

USE OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

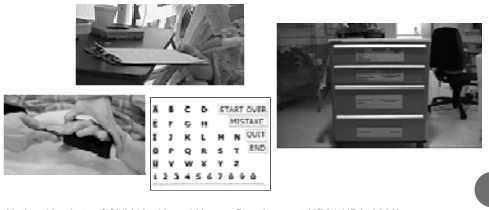
AUGMENTATIVE AND ALTERNATIVE STRATEGIES AND RESOURCES

- Definition (AAC): all communication methods that supplement natural speech including unaided (signing) or aided (writing, typing, communication boards electronic device) techniques.

SPEACS: Study of Patient-nurse Effectiveness with Assisted Communication Strategies

BASIC COMMUNICATION SKILLS TRAINING

- 4-hour **educational program** delivered by SLPs
- **Communication Supplies**



National Institute of Child Health and Human Development (5R01-HD043988)

SPEACS: Study of Patient-nurse Effectiveness with Assisted Communication Strategies

ELECTRONIC COMMUNICATION DEVICES + SLP

- 4-hour Basic Communication Skills training +
- 2-hour introduction to electronic devices +
- Communication Cart
- SLP assesses each study patient
- Matches electronic devices and "low tech" strategies to patient ability - preference
- Confers with nurse & models behaviors
- Writes communication plan
- Daily follow-up

SPEACS STUDY

- Conducted in two ICUs
- Observed 89 patient-nurse dyads
- 4 Video recorded communication observations (total = 356) rated by trained coders
- Achieved communication process improvements

National Institute of Child Health and Human Development (5R01-HD043988)

13

SPEACS-2 Implementation (6 ICUs)

- Nurse Training: 323 ICU nurses trained (>84% eligible)
- Bedside Communication Rounds with SLP: 116
- Communication tools: > 3000 items supplied to 6 ICUs (24 mos)

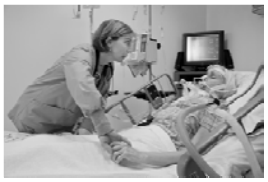
Speech Language Pathologist

Brooke Paull, MS, SLP-CCC

AAC Tools and Techniques

1. Get the patient's attention by touch and eye contact

Face the patient when communicating



Courtesy of Robert Wood Johnson Foundation

2. Assess Oral Movement

- Trial tracheostomy speaking valve if patient meets criteria
- Trach speaking can be used for short periods or important conversations

3. Speak slowly, distinctly with pauses.

- Coach patients to use their tongue and teeth when mouthing words.
- Ask only one question at a time.
- Patient can point to first letter on alphabet board when mouthing words

4. Establish a consistent yes / no code

- Thumbs up for YES, thumb in fist for NO
- Use tagged yes/no questions with patients who are
  - delirious, sedated, confused,
  - or language impaired

5. Meaningful and Mirrored Gesture: Use Gesture Deliberately as You Speak to Patients

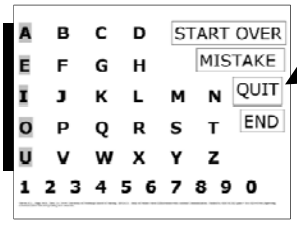
6. Sensory and Positional Aids

- Keep glasses and hearing aids within reach
- Use only felt-tip pens
- Try simple orthotic aids- pen grips
- Clipboards
- Slanted boards with wrist rests

More on Writing….

- Keep legible pages for future reference
- Encourage patients to point to previously used phrases.

7. Communication Boards



Control Phrases verify whether the message was understood correctly, etc.

Photo courtesy of Vidatak, LLC

8. Written Choice Conversational Strategy

(Garrett & Beukelman, 1995)

1) **Ask Wh – Questions. Who, What, Where, How.. about a topic.**
2) **YOU formulate possible answers for patient.**
   - **Write down 3-5 choices — print on the page**
   - **Put a dot in front of each choice - this is a cue for the patient to point**
   - **Review each choice aloud as you point to them**
   - **Then, tell the patient to point to his answer**

3) Circle his answer, say it aloud and <u>confirm it</u>
   - **e.g. "Oh, so you think Obama is a good president?"**

4) Ask follow-up questions as appropriate

Example: "What should we ask your family to bring from home?"

- **Pictures**
- **Glasses**
- **Snacks**
- **Other**

9. Written Key Words

Used to improve comprehension (augmented input)

- CT-Scan at 2:00pm
- Going in your bed
- Portable ventilator
- Medicine for nerves
- I will be with you

10. Personal Electronic Devices

Considerations

- Cleaning
- Mounting
- Securing
- Charging
- Dexterity
- Cognitive "load": focus, executive function, new learning

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Volume 14, Number 4, 2011
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DOI: 10.1089/jpm.2010.0313

Case Discussions in Palliative Medicine

Feature Editors: Eva H. Chittenden and Craig D. Blinderman

Listening to the Voiceless Patient: Case Reports in Assisted Communication in the Intensive Care Unit

Jill V. Radtke, M.S.N., R.N.,[1] Bibiana M. Baumann, M.S., S.L.P.-C.C.C.,[2] Kathryn E. Garrett, Ph.D., S.L.P.-C.C.C.,[2] and Mary Beth Happ, Ph.D., R.N., FAAN[1,3]

Clinical Case Exemplars

- "The Patient Whisperer"

Symptom Communication

Symptom Communication

IF, *Patient report is the "gold standard"*

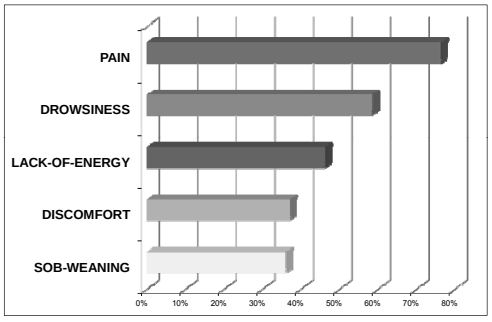
THEN, *How does the nonvocal patient report symptoms?*

National Institute for Nursing Research (K24-NR010244)

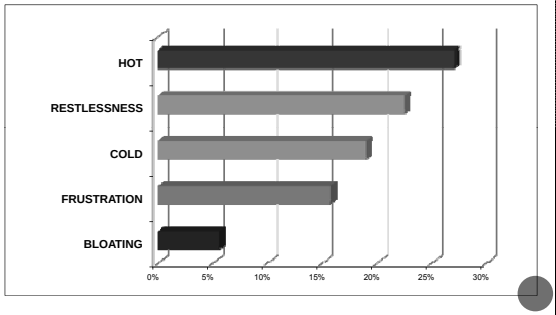
Symptom Communication

- We observed and analyzed symptom communication from video recordings
- Nurses often use physiological or behavioral indictors of pain and other symptoms
- "Cannot speak" is inappropriately equated with "unable to assess," "can't communicate symptoms"

Most Commonly Identified Symptoms



New symptoms



Tate JA, et al. ***J Gerontol Nurs.*** 2013 ;39(8):28-38

Symptom Communication During Critical Illness

The Impact of Age, Delirium, and Delirium Presentation

Take home:
Delirium Makes a Difference!

- Delirium was associated with self-report of pain, drowsiness, & feeling cold
- Patients were significantly less likely to initiate symptom communication when delirious

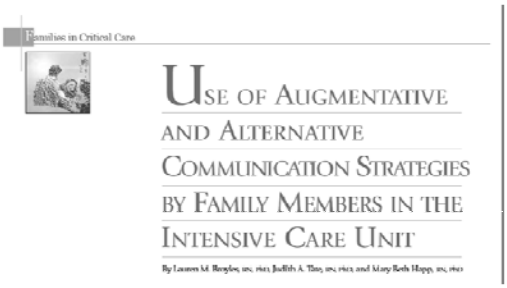
Palliative Care

- Pain and Symptom Management
- Goals of Care Communication
- Family Involvement and Support
- Palliative Care should accompany all levels of care from curative → end-of-life

Family Involvement

My brother died in [an intensive care unit] at age 49 after a prolonged intubation. I know there were many things he tried to communicate through his eyes and the "mouthing of words" but was not successful. He was unable to use his hands and would often become frustrated at his inability to convey what he was trying to communicate. He left 2 teenage children and I often wonder what he would have said to them. [e-mail from a family member]

Broyles, Tate, Happ. *Am J Crit Care* 2012; 21 (2): e21.



- Families were unprepared for /unaware of patient communication
- 44% of families showed some use of AAC
- Writing was most common, communication devices, boards

End of Life Communication

Final Messages to Family

- I love you
- I forgive you
- I'm sorry
- I'm okay
- Good bye

- I'm afraid
- I want to pray
- Music

Chlan LL. et al., *JAMA*. 2013 Jun 12;309(22):2335-44.

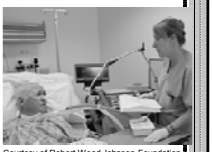
Listening to the Voice of the Critically Ill Patient

- Do we really want to hear what they want to say?
- What are our ethical obligations?
- Should critically ill patients participate in decisions about LSTs? Invasive procedures?
- What level(s) of participation would be appropriate? Under what conditions?
- How should we weigh patient's views when they are not autonomous or fully informed?

Clinical Case Exemplars

- "Opening the Can of Worms"

Barriers to Decisional Participation


Courtesy of Robert Wood Johnson Foundation

- Emotional/psychological stress
- Cognitive impairment[1-4]
  - distorted thought processes
  - delirium
  - diminished problem solving ability
- Communication difficulty

1. Cassell EJ, Leon AC, Kaufman SG. *Annals Intern Med* 2001; 134: 1120-1123.
2. Morandi A, Jackson JC, Ely EW. *Int Rev Psychiatry*. 2009;21(1):43-58
3. Hupcey JE, Zimmerman HE. *Am J Crit Care* 2000; 192-198.
4. Rier DA.. *Soc Health Ill* 2000; 22 (1): 68-93.

Evidence for Decision Making Communication is Mixed

- Studies of LST decision making focus on physician-family communication
  - "shared decision making" excludes patient
- 4-40% patients communicate tx preferences or participate in decisions during critical illness[1-5]
- Chronic ventilator unit, patients as "decision makers" = 45/94 (48%)[6]
  - Patients involved in most (8/13) decisions leading to vent discontinuation.

1. Happ MB, Swigart VA,Tate JA, Hoffman LA, Arnold RM. *Res Nurs Health* 2007; 30: 361-72.
2. Faber-Langendoen K. *Arch Intern Med* 1996; 156: 2130-36.
3. Lynn J, Teno JM, Phillips RS et al. *Annals Intern Med* 1997; 126: 97-106.
4. Smedira NG, Evans BH, Grais LS, et al. *New Eng J Med* 1990; 322:309-315.
5. Cohen S, Sprung C, Sjokvist P, Lippert A, Ricou B, Baras M, et al. *Intens Care Med* 2005; 31:1215-21
6. Ankrom, M., et al. *J Am Geriatrics Society,* 2001. 49: 1549-1554.

Research in Nursing & Health, 2007, 30, 361–372

Patient Involvement in Health-Related Decisions During Prolonged Critical Illness

Mary Beth Happ,[1,*] Valerie A. Swigart,[1] Judith A. Tate,[1]
Leslie A. Hoffman,[1,2] Robert M. Arnold[2,3]

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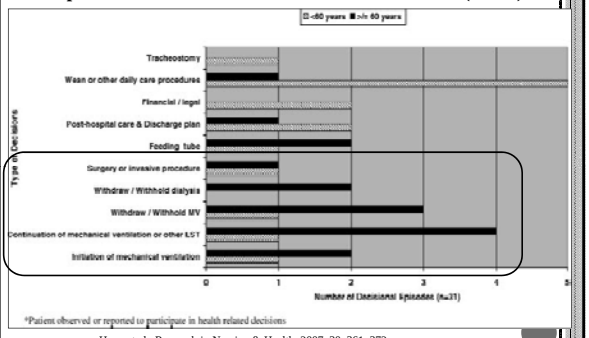
[2]School of Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania
[3]Center for Bioethics & Health Law, University of Pittsburgh, Pittsburgh, Pennsylvania

Accepted 5 December 2006

- Ethnographic study of 30 patients weaning from PMV
- 40% (12/30) were involved in health related decisions

Direct patient involvement in health-related decisions (n =12)



*Patient observed or reported to participate in health related decisions

Happ et al., Research in Nursing & Health, 2007, 30, 361–372

Patient Involvement

- Physicians, APNs, and families solicited patient involvement
- Patient participation was sought despite unclear thinking
- Information sharing was a motivation for including patient
- Patients confirmed or validated decisions already underway
- Ambiguity
- Patients were most independent in treatment refusals

"I'm afraid that I'll be living when I want to be dead."

~ 69 year-old woman with end-stage kidney disease, transplantation complications & failure-to-wean from MV

A Double Edged Sword

"***it was easier to make the decision (to withdrawal MV) when my mother wasn't communicating."***

~ adult daughter of 79 y/o w/ multisystem organ failure, sepsis

Clinical Case Exemplars

- "Let me speak"

Patient Participation in Treatment Decisions Before & After a Program to Facilitate Patient Communication in the ICU

Case exemplar

Greenwall Foundation Kornfeld Program on Bioethics and Patient Care

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Information and Resources

SPEACS website: www.pitt.edu/~speacs
Patient-Provider Communication forum http://www.patientprovidercommunication.org/
John Costello, SLP-CCC
http://www.patientprovidercommunication.org/files/ISAACMessBankpreservelegacyhandoutforweb.pdf
http://www.patientprovidercommunication.org/files/draftmessagebankguidetemplateforweb.pdf
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