

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 Brooke M. Baumann, M.S., S.L.P.-C.C.C.,²
Kathryn L. Garrett, Ph.D., S.L.P.-C.C.C.,³ and Mary Beth Happ, Ph.D., R.N., FAAN^{1,4,5}

Abstract

Communication problems experienced by nonspeaking, critically ill patients in the Intensive Care Unit (ICU) have serious implications for the physical and psychological well-being of patients and the quality of their care. These problems are most profound for those with prolonged critical illnesses who are at the highest risk of dying. Recently, speech language pathologist (SLP) services have been used to provide augmentative and alternative communication (AAC) assistance to this vulnerable group of patients, their caregivers, and medical staff.

Here we present three clinical cases that illustrate the application of AAC strategies across different levels of illness severity and communication impairment for nonspeaking patients in the ICU. Both high-tech communication devices with voice output and low-tech options were used for each patient according to their motor and cognitive abilities. To accommodate fluctuations in patient status and communication needs, multiple AAC strategies were integrated into the communication repertoire and tailored for each case. Medical personnel involved in these cases attributed enhanced communication efficiency, improved ventilator weaning trials, and increased patient engagement to the AAC techniques. This approach has the potential to improve symptom communication and to ease suffering for seriously ill ICU patients with speech limitations.

Introduction

PATIENT COMMUNICATION PROBLEMS can significantly affect care in the ICU, where patients may be unable to speak or communicate effectively due to mechanical ventilation, respiratory compromise, neuromuscular weakness, and/or cognitive deficits. Patients report feelings of frustration, panic, anxiety, dehumanization, and sleeplessness when unable to speak.¹⁻⁵ It is easy to misinterpret and respond incorrectly to their messages about symptoms, treatment preferences, needs, or concerns. Non-speaking patients also are at risk for preventable adverse events, including device disruption, falls, and unnecessary restraint use.⁶ These problems may be most profound for those with prolonged critical illnesses who are discharged to extended care facilities or who die during or shortly after ICU care.^{7,8}

Physicians and nurses are not routinely trained in communication assessment and assistive communication strategies. Communication materials and devices, as well as

individuals competent in using them, are often unavailable on hospital units. A speech-language pathologist (SLP)—someone who is specially trained in augmentative and alternative communication (AAC)—can be a valuable resource for assessment and intervention with critically ill nonspeaking patients.⁹⁻¹²

These three clinical cases illustrate the use of SLP expertise and AAC strategies across a range of patient acuities and disabilities within ICUs. The cases were drawn from two sources: (1) the Study of Patient-Nurse Effectiveness with Assisted Communication Strategies (SPEACS)¹³ and (2) the acute-care speech-language consultation practice of one author (BMB). A three-pronged approach¹⁴ was used to assess each patient for AAC intervention: (1) identifying present and future communication needs; (2) considering candidacy for speech methods; and (3) assessing requisite skills (i.e., cognition, motor skills, language, literacy). Each case was assigned a pseudonym and some identifiable details were modified.

¹Department of Acute & Tertiary Care, University of Pittsburgh School of Nursing, Pittsburgh, Pennsylvania.

²Department of Otolaryngology, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.

³Alternative Communication Therapies, L.L.C., Pittsburgh, Pennsylvania.

⁴Department of Critical Care Medicine, University of Pittsburgh, School of Medicine, Pittsburgh, Pennsylvania.

⁵Center for Bioethics and Health Law, University of Pittsburgh, Pittsburgh, Pennsylvania.

Accepted November 19, 2010.

Case 1: Fluctuating Cognitive and Impaired Motor Function

Background

“Ellen,” 32 years old, was initially hospitalized for an acute myocardial infarction with associated complications of systemic lupus erythematosus and hypertension. Shortly after admission, she delivered a stillborn infant at 20 weeks gestation. She subsequently developed multiple brain infarcts, hemiplegia, mental status changes, and acute respiratory failure. She was intubated, mechanically ventilated, and transferred to the ICU. After two weeks on mechanical ventilation with difficulty weaning, she received a tracheostomy.

Palliative care medicine was consulted for agitation and uncontrolled pain. The palliative care physician became concerned that Ellen’s non-vocal behaviors (e.g., shaking head “no,” thrashing arm) might be attempts to communicate. Consequently, the physician requested an SLP consultation.

AAC Intervention

After assessment (see Table 1), the SLP cued Ellen to convey YES and NO with clear head nods. The SLP then ascertained, through a series of YES-NO biographical questions, that Ellen’s cognitive status was intact.

Next, the SLP presented a series of commonly used topics to Ellen verbally from a “topic” notebook. The patient nodded YES or NO until composing the desired message. For example, Ellen nodded YES to the “hygiene” topic, then selected “hair” (subtopic), and further signaled YES to the specific message of “Comb my hair.” This “partner-assisted scanning” technique¹² was also attempted with an alphabet board (a laminated sheet displaying the alphabet and numbers 1–10). Using this spelling method, Ellen reported her occupation—“secretary”—and job location—“downtown”—by confirming the row of the correct letter and then each letter as the SLP announced it aloud. Because the patient sustained attention only intermittently, interactions required patience and frequent cueing.

The written-choice conversational strategy^{15,16} was also a successful communication method for Ellen. In this technique, the communication partner asks questions, writes possible keyword answers in large print, reviews the selections aloud while pointing to them, and instructs the patient to point (or signal YES-NO) to the most accurate answer, which is confirmed by the SLP circling that choice. Relevant follow-up questions are pursued using the same method. Written choice was used to determine Ellen’s favorite music genre. The SLP then reverted to alphabet-board partner-assisted scanning to arrive at the patient’s favorite artist.

These successful low-tech AAC strategies were reviewed with nursing and posted for staff and family to follow. The SLP also ordered trials with a tracheostomy speaking valve, despite the medical team’s skepticism about its appropriateness for a brain-injured patient. The rationale for a one-way speaking valve is that air must pass over the vocal cords to regain speech. Ellen produced intelligible words using the speaking valve, although long phrases were mostly unintelligible due to severe dysarthria. The SLP, therefore, encouraged integration of low-tech AAC strategies (e.g., partner-assisted topic and alphabet scanning) while coaching

TABLE 1. INITIAL CASE ASSESSMENTS

Assessment parameter	Case 1: “Ellen”	Case 2: “Sarah”	Case 3: “Karen”
Neuro/cognition	Somewhat impaired , cognitively intact with limited sustained attention	Fluctuating , from alert, anxious, cognition intact to somnolent, requiring maximal tactile/auditory stimulation to attend	Intact , alert and oriented, cognition fully intact
Oral-motor	Nonfunctional , few attempts to mouth words, poor articulation, unintelligible	Moderately functional , few attempts to mouth words, imprecise articulation	Functional , but minimal attempts to mouth words
Upper extremities	Compromised , left hemiparesis and left neglect, moderately limited	Moderately compromised , deconditioned, tremulous, elbow support needed for pointing, difficulty grasping writing instrument, poor legibility	Functional , gross/fine motor skills intact; able to write, type, point
Head control	Adequate , but head-nods unclear at times	Adequate , but head-nods unclear at times	Intact , clear, consistent head-nods
Sensory	Intact	Sight compromised , glasses available but ill-fitting (able to read 24 pt font with glasses on)	Sight compromised , unimpaired when glasses on
Breath support for phonation/speaking valve trials	Initially poor phonation with speaking valve, overall intelligibility <25% in conversation	N/A—No speaking valve trials due to deconditioning and medical acuity	Vocal quality poor: 2/10
Language/literacy	English/literate	English/literate	English/literate
Primary communication method/preference before SLP intervention	Gestures —unclear and imprecise, often misinterpreted	None noted —spiral notebook was tied to bedrail, but out of patient’s reach	Writing —notebook filled with patient’s writing at bedside; legible
Communication needs	Immediate medical needs, meaning of gestures	Immediate medical needs, requests for family	Novel messages

the patient to produce loud vocalizations of single-syllable words with the speaking valve.

Outcomes of the AAC Intervention

Shortly after the SLP consultation, Ellen was evaluated by the physical medicine-rehabilitation service, whose members specifically noted the patient's improved communication ability following SLP intervention. Ellen was discharged to an acute rehabilitation hospital, where she received speech language therapy twice daily. Communication strategies initiated in the acute-care phase continued during rehabilitation. Ellen produced moderately intelligible speech after approximately three to four weeks.

Case 2: Fluctuating Cognitive, Moderately-Compromised Motor Function

Background

"Sarah," 28, was admitted to the ICU following a repeat double lung transplant. Her post-operative course was complicated by Methicillin-resistant *Staphylococcus aureus* (MRSA) pneumonia, acute rejection, granulation of lung tissue, and kidney failure. She received a tracheostomy for ventilator dependence.

AAC Intervention

Following assessment (Table 1), the SLP provided an alphabet board for speech supplementation, in which the patient points to the first letter of a word while mouthing it. This strategy was partially successful when Sarah was awake and alert. The SLP then tried several electronic speech-generating devices, but most proved too taxing, given Sarah's short intervals of wakefulness. Finally, a DynaMyte[®] (DynaVox Technologies) was mounted to a tilted table tray in front of the patient for constant access. The touch screen on this device required minimal physical pressure to activate message "buttons." When selected, the message was automatically spoken via synthesized speech. Messages were represented with pictures and words located in folders representing common topics (e.g., "feelings," "help," "people").⁹

The SLP customized folders and messages to prompt specific communication about medical needs. For example, when Sarah indicated, "I have pain," the device then cued her to specify the location and intensity of the pain. Sarah also commonly used the DynaMyte to gain the nurses' attention and to relay her most pressing medical needs or physical discomforts (e.g., "hot," "cold," "blanket"). Novel messages could be spelled out via a touch-screen keyboard on the device, but this proved difficult given Sarah's limited fine motor skills and concentration. Therefore, Sarah continued to rely on mouthed speech, supplemented with an alphabet board.

Outcomes of the AAC Intervention

Sarah's mother expressed the opinion that the device was "great." Her nurse commented that Sarah became "expert" in its operation, and encouraged Sarah to practice using the device to gain independence in communication. By referencing the communication plan developed and posted above Sarah's bed, other nurses became proficient in communicating with Sarah until her death in the ICU several months later.

Although Sarah's level of consciousness and ability to communicate declined markedly in the weeks preceding her death, the AAC intervention helped her communicate frequently and successfully earlier in her hospitalization.

Case 3: Intact Cognitive and Motor Function

Background

"Karen," 39, was admitted to the ICU following an aortic aneurysm repair. Due to difficulty in weaning from mechanical ventilation, she remained in the ICU for two months post-surgery. During her admission, Karen's affect was described as "flat," and she had little energy. At the time of the SLP intervention, she was tolerating tracheostomy mask-weaning trials with a speaking valve in 15-minute increments daily. She did, however, demonstrate intact cognition, spelling, and fine motor skills, in the SLP's assessment.

AAC Intervention

The SLP introduced Karen to mouthing and first-letter spelling with an alphabet board to help conserve her energy (Table 1). Although Karen performed well with this technique, she did not like it. After trying several electronic AAC devices, the patient and SLP selected a Lightwriter[®] (Toby Churchill Ltd.) and tilted tray-table set-up. The Lightwriter features an alphabet and numeric keypad, as well as a two-sided LCD screen that displays the typed message to both the "sender" and receiver. The device also "speaks" the message aloud via digitized speech.

Karen was immediately able to type complex phrases on the Lightwriter. At one point, she facetiously typed, "My husband will say that he liked me better when I wasn't talking." Because her message was conveyed instantly, comedic timing was preserved and the intended humor was well-received.

Within days, Karen used the Lightwriter almost exclusively to communicate. She also learned to store some personal messages (e.g., humor, medical needs) for easy retrieval. First-letter alphabet-board spelling and mouthing was regularly reviewed with Karen for back-up in the event of device failure or patient discharge/transfer.

Outcomes of the AAC Intervention

The patient and her husband expressed satisfaction with the immediacy of communication and freedom to create novel messages with the Lightwriter. The device also provided Karen with a voice (albeit electronic). Medical staff attributed Karen's increasingly prolonged ventilator wean times and improved affect to the diversion provided by the Lightwriter. This improvement may have also been attributable to Karen's increasing control of her situation via augmented communication.

Nurses liked the way that Karen's use of the device allowed them to communicate while completing other tasks. One nurse commented, "[The Lightwriter] was good because I could be doing something while she was typing the message. I didn't even have to face her or be close to read what she pointed to or mouthed. She really likes the device, it's quick, and it's good for her." Shortly thereafter, Karen was transferred to a step-down unit. There, she continued to use the Lightwriter until graduating to a tracheostomy speaking valve.

Discussion

Communication impairment is common among patients in critical care and at the end of life.¹⁷ Communication between ICU patients and caregivers is usually limited to nurse-initiated, informative comments about physical care, symptoms, occasional yes/no questions, or commands.^{18–22} For the cases presented here, AAC interventions provided by the SLP were well-received by patient, staff, and family members. AAC enhanced patient autonomy, normalized communication to the degree possible while non-speaking, and permitted accurate information transfer, particularly in regard to immediate medical needs. AAC interventions also may have had a positive impact on communication efficiency, ventilator weaning, patient affect, accuracy of symptom assessment and treatment, and discharge dispositions.

With AAC, patients could potentially participate in discussions of treatment preference, make decisions about their treatment options, and communicate final messages.²³ For planned surgeries (e.g., lung transplant) or predicted neuromuscular decline (e.g., ALS), patients could pre-record and save messages in electronic communication devices (“message banking”).²⁴ Proactive application of AAC has been used successfully with children and families facing the end of life and is reported to preserve the patient’s voice and sense of self.²⁴

Low-tech AAC strategies, such as supplemented speech, written choice communication, and picture communication boards, can be highly effective, and materials can be printed from a template or purchased in bulk from commercial vendors for minimal cost.¹² Electronic speech-generating devices tend to be more expensive, ranging from \$500–\$9,000 each (see vendor links: <http://aac.unl.edu/AACV11.html>). AAC-based services are available in select hospital-based SLP departments across the country.^{9–12,25} For patients requiring or dependent upon AAC at hospital discharge, a home care or outpatient SLP consultation is recommended, with the possibility of obtaining the patient’s own electronic device. An SLP with AAC knowledge and resources can develop communication strategies, integrate technologies, and train the patient and family to use them.

The ICU patients presented here, all candidates for palliative care consultation services by virtue of prolonged critical illness, symptom burden, grief and loss, and high risk of dying, illustrate varying levels of motor and cognitive ability.¹⁰ Fluctuating cognition and strength pose special challenges in assessment and implementation of AAC strategies in the ICU. Certainly, frequent reassessment of the communication plan and strategy modifications are necessary. We propose that patients exhibiting at least minimum periods of sustained wakefulness and attention be considered for these interventions.

Conclusions

This case series may serve as a model upon which to base communication assessment and AAC strategy implementation for nonspeaking patients in the ICU. While not currently part of routine practice in the ICU, providing communication devices and materials and SLP consultation may offer additional communication support, enhance communication outcomes, and add value to palliative care services in the ICU.

Acknowledgments

Funding source: National Institutes of Health/National Institute of Child Health and Human Development (5R01-HD043988, Improving Communication with Nonspeaking ICU Patients). Additional support: National Institute of Nursing Research (5K24-NR010244).

Author Disclosure Statement

No competing financial interests exist.

References

- Bergbom-Engberg I, Haljamae H: Assessment of patients’ experience of discomforts during respirator therapy. *Crit Care Med* 1989;17:1068–1072.
- Pennock BE, Crawshaw L, Maher T, Price T, Kaplan PD: Distressful events in the ICU as perceived by patients recovering from coronary artery bypass surgery. *Heart Lung* 1994;23:323–327.
- Rotondi AJ, Chelluri L, Sirio C, Mendelsohn A, Schulz R, Belle S, Im K, Donahoe M, Pinsky MR: Patients’ recollections of stressful experiences while receiving prolonged mechanical ventilation in an intensive care unit. *Crit Care Med* 2002; 30:746–752.
- Wunderlich RJ, Perry A, Lavin MA, Katz B: Patients’ perceptions of uncertainty and stress during weaning from mechanical ventilation. *Dimens Crit Care Nurs* 1999;18: 8–12.
- Patak L, Gawlinski A, Fung NI, Doering L, Berg J: Patients’ reports of health care practitioner interventions that are related to communication during mechanical ventilation. *Heart Lung* 2004;33:308–320.
- Bartlett G, Blais R, Tamblyn R, et al.: Impact of patient communication problems on the risk of preventable adverse events in the acute care settings. *CMAJ* 2008;178: 1555–1562.
- Douglas SL, Daly BJ, Brennan PF, Harris S, Nochomovitz M, Dyer MA: Outcomes of long-term ventilator patients: a descriptive study. *Am J Crit Care* 1997;6:99–105.
- Happ MB: Interpretation of non-vocal behavior and the meaning of voicelessness in critical care. *Soc Sci Med* 2000; 50:1247–1255.
- Costello JM: AAC intervention in the intensive care unit: The children’s hospital Boston model. *Augment Altern Commun* 2000;16:137–153.
- Dowden P, Beukelman DR, Lossing C: Serving nonspeaking patients in acute care settings: Intervention outcomes. *Augment Altern Commun* 1986;2:38–44.
- Fox LE, Rau MT: Augmentative and alternative communication for adults following glossectomy and laryngectomy surgery. *Augment Altern Commun* 2001;17:161–166.
- Garrett KL, Happ MB, Costello JM, Fried-Olken MB: AAC in the intensive care unit. In: Beukelman DR, Garrett KL, Yorkston KM (eds): *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore, MD: Paul H. Brookes Publishing Co., 2007, pp. 17–57.
- Happ MB, Sereika S, Garrett K, Tate J: Use of the quasi-experimental sequential cohort design in the Study of Patient-Nurse Effectiveness with Assisted Communication Strategies (SPEACS). *Contemp Clin Trials* 2008;29:801–808.
- Beukelman DR, Mirenda P (eds): *Augmentative communication: Management of severe communication disorders in*

- children and adults, 3rd edition. Baltimore, MD: Brookes Publishing Co., 2005.
15. Garrett KL, Beukelman DR: Changes in the interaction patterns of an individual with severe aphasia given three types of partner support. *Clin Aphasiology* 1995;23:237–251.
 16. Garrett K, Huth C: The impact of graphic contextual information and instruction on the conversational behaviors of a person with severe aphasia. *Aphasiology* 2002;16: 523–536.
 17. Jackson P, Robbins M, Frankel, S: Communication impediments in a group of hospice patients. *J Palliat Med* 1996; 10:79–80.
 18. Hall DS: Interactions between nurses and patients on ventilators. *Am J Crit Care* 1996;5:293–297.
 19. Care to Communicate: An investigation into problems of communication between patients and nurses in intensive therapy units. London: Ashworth P. Whitefriars Press, 1980.
 20. Salyer J, Stuart BJ: Nurse-patient interaction in the intensive care unit. *Heart Lung* 1985;14:20–24.
 21. Hemsley B, Sigafos J, Balandin S, Forbes R, Taylor C, Green VA, Parmenter T: Nursing the patient with severe communication impairment. *J Adv Nurs* 2001;35:827–835.
 22. Happ MB, Tuite P, Dobbin K, DiVirgilio-Thomas D, Kitutu J: Communication ability, method, and content among non-speaking nonsurviving patients treated with mechanical ventilation in the intensive care unit. *Am J Crit Care* 2004; 13:210–218; quiz, 219–220.
 23. Pollens R: Role of the speech-language pathologist in palliative hospice care. *J Palliat Med* 2004;7:694–702.
 24. Costello J: Last words, last connections: How augmentative communication can support children facing end of life. *ASHA Leader* 2009, December 15. www.asha.org/Publications/leader/2009/091215/LastWordsLastConnections.htm. (Accessed July 1, 2010).
 25. Blackstone S: Communication access across the healthcare continuum. *Augmentative Communication News* 2009; 21(2):1–16. www.augcominc.com/newsletters/index.cfm/newsletter_129.pdf (Last accessed January 2011).

Address correspondence to:

Mary Beth Happ, Ph.D., R.N., FAAN
University of Pittsburgh School of Nursing
336 Victoria Building
3500 Victoria Street
Pittsburgh, PA 15261

E-mail: mhapp@pitt.edu