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Acute Care of the Elderly Column




Elizabeth Capezuti
PhD, RN, FAAN

Sarah Hope Kagan
PhD, RN, FAAN

Mary Beth Happ
PhD, RN, FAAN

Lorraine C. Mion
PhD, RN, FAAN

Partnering with speech language pathologist to facilitate patient decision making during serious illness

Tami Altschuler[a], Mary Beth Happ[b,*]

[a] NYU Langone Medical Center - Tisch Hospital, New York City, NY 10016, United States
[b] The Ohio State University College of Nursing, Columbus, OH, United States

Professional organizations, such as the Society of Critical Care Medicine, promote guidelines to include patients and families in shared decision making in the acute and critical care setting.[1] Older adults, however, often have pre-existing or acquired communication impairments during hospitalization that result in their exclusion from treatment decision making communication or the assumption of a passive role in the process. Augmentative and alternative communication (AAC) approaches can be broadly thought of as any non-speech form of communication. This may include unaided supports such as the use of gestures or head nodding in response to questions to high technology speech generating devices. Patients who are unable to speak due to mechanical ventilation or neurological conditions who use AAC are empowered to participate in their own care and make decisions about their treatment options.[2]

In this paper, we present a clinical case exemplar of communication assessment and AAC use with a critically ill, older adult to illustrate the assessment and communication support necessary to facilitate authentic and accurate patient involvement in treatment decision making.

Mr. Moore (pseudonym) was am older adult - admitted to the ICU in hypovolemic shock after a motor vehicle accident. His hospitalization course was complicated and prolonged. He was intubated, receiving mechanical ventilation for respiratory failure, alert and cognitively intact. The medical team met with him at the bedside multiple times for life sustaining treatment decision making as he was unable to safely wean from mechanical ventilation and the medical team anticipated lifelong ventilator dependency with tracheostomy placement. Mr. Moore was informed of the reason for tracheostomy as well as the risks associated with undergoing this procedure given recent cardiac events. He was instructed to raise one finger if he chose a palliative extubation without further life sustaining treatment or raise two fingers if he chose a tracheostomy with the possibility of transitioning to a long-term acute care hospital. Mr. Moore averted his eye gaze and bit on the endotracheal tube, refusing to make a decision. At that point, the team turned to his wife to serve as decisional surrogate and involved the speech language pathologist (SLP) for communication assessment and AAC consultation.

During the SLP's initial evaluation, Mr. Moore attempted to communicate by mouthing words around the endotracheal tube, however this was unreliable given the limited range of motion of oral musculature with the tube. Moreover, this method is highly dependent upon the communication partner's ability to lip read, a highly specialized skill. A yes/no response was established with eye signals (upward eye gaze shift for "yes" and forced eye closure for "no"). Mr. Moore demonstrated bilateral upper extremity weakness and was unable to access a communication board with direct selection. His history of macular degeneration was an additional challenge, however, his glasses were at the bedside and visual acuity was intact for a large, clear, plastic alphabet board. Mr. Moore was able to spell out words by shifting his eye gaze to the targeted letters on the board. The commercially available board was arranged with vowels on the left margin for ease of visual organization (Fig. 1). To establish reliability with this method, he was initially asked to spell out words/phrases to

* Corresponding author.
E-mail address: happ.3@osu.edu (M.B. Happ).

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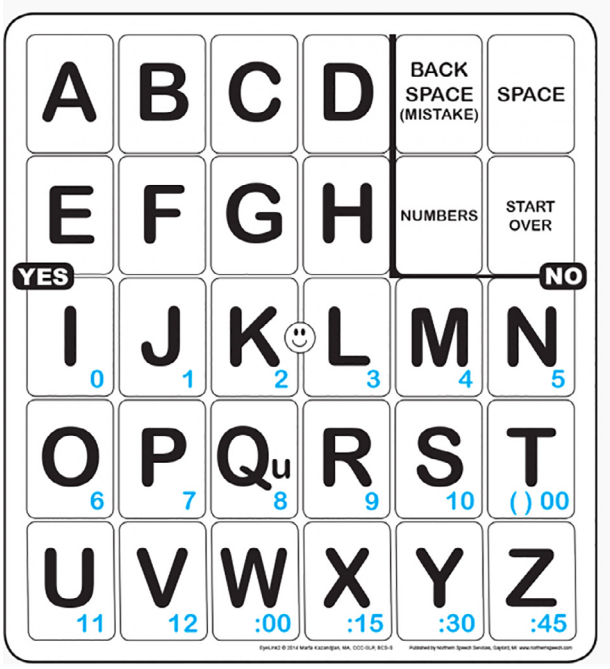

Fig. 1. Eye Gaze Letter Board Eyelink2 by Northern Speech Services, (Gaylord, MI).

personally relevant and factual questions, such as "What is your wife's name?". Subsequent therapy sessions included the medical team, palliative care team, his son, and the SLP for further discussion about treatment decisions.

Mr. Moore asked relevant questions about quality of life, communication, and nutrition options with tracheostomy. He received additional education and explanation about tracheostomy and the benefits and risks of the procedure, including the use of a visual model of a tracheostomy to improve understanding (Fig. 2). After two of these education and discussion sessions with the medical team, SLP, and wife, Mr. Moore decided to pursue a tracheostomy. His wife endorsed her husband's decision and stated that he demonstrated the ability to make his own decisions. Once Mr. Moore was able to use the tracheostomy speaking valve, he expressed frustration with the decision-making process, his communication difficulty, and the burden that was placed on the son. "I feel like you saved my life. They kept asking me to raise one finger or two fingers. I wanted someone to ask me to raise three fingers if I needed more time to figure things out."

Fig. 2. Tracheostomy Model Tracheostomy Tube Observation Model (T.O.M.) by Passy-Muir, Inc. (Irvine, CA).

In Mr. Moore's case, well-intentioned clinicians established a simple yes-no signal communication system to engage a decisionally capable chronically critically patient in a decision about tracheostomy placement to continue life sustaining treatment. A consistent and reliable yes-no signal is an important first step in establishing an AAC system with a patient who is unable to speak. However, the clinicians did not provide a communication system that allowed Mr. Moore to opt out of the yes-no dichotomy (e.g., "neither" "something else"), to generate novel messages or ask questions about the decisional choices or to communicate feelings and concerns. They also did not use augmented input when initially explaining the tracheostomy procedure, benefits, risks, expected outcomes and long-term prognosis. Procedural explanation boards, written key words, diagrams, and models offer dynamic supports to enhance deeper level of understanding, assimilate concepts, and facilitate increased patient participation.

Mr. Moore's initial nonresponse to the yes-no question regarding the tracheostomy could be interpreted as decisional ambiguity or an inability or unwillingness to participate in treatment decision making. Instead, the communication was one-sided. The clinicians controlled the content and the questions. When communication impaired older adults withdraw from health care interactions, lose attention, or become frustrated (sometimes to the point of agitation), it is easy to assign neuropsychological meanings such as depression, delirium, or dementia. And while those are all real possibilities, a more comprehensive assessment and communication approach are warranted.

SLPs have a unique role and responsibility in addressing the abilities of patients with complex communication needs. They are educationally and clinically prepared to establish an effective communication system across the spectrum from no technology (gestures, pointing) to high technology (speech generating devices) with consideration of each patient's sensory, motor, and cognitive functions. SLPs are readily available at most hospitals either in-house or through a consultation service. While acute-critical care SLP services are more typically focused on assessing and treating dysphagia, the inclusion of patient-provider communication as best practice is emerging nationally and is responsive to The Joint Commission hospital accreditation standards.

Nurses are often the most frequent communication partners for patients and it is crucial for the SLP to provide training on the most effective communication strategies and the individualized communication systems established for their patients. Critical care nurses who participated in basic communication skills training and received access to AAC tools and SLP consultation reported improved knowledge, satisfaction, confidence, and comfort in communicating with nonvocal ICU patients.[3,4] These basic skills guide the nurse in applying patient neurocognitive and motor assessments to better understand the older adult patient's communication support needs. Communication training programs are recommended to partner nursing and SLPs for optimal everyday bedside practice as well as individualized "on the spot" assessment and implementation of the unique communication needs of patients.

Nurses can engage SLPs on systems and individual levels in the following ways:

1. Collaborate with hospital SLP service to include SLPs as full members of the interdisciplinary team (rather than specialty consultations) in ICU liberation, early rehabilitation and palliative/end-of-life care initiatives.
2. Partner with the hospital SLP service to obtain and maintain necessary AAC materials for patient communication support.

3 Implement basic communication skills training programs in collaboration with an SLP "champion".
4 Initiate consultations with the hospital SLP service for communication assessment and support in individual cases where patients with impaired communication require assistance to communicate beyond 'yes/no'.

Importantly, SLP consultation should occur prior to the need for decision making discussions with patients about life sustaining treatments to allow ample time for the patient and clinicians to learn and/or make adjustments to the communication system.

To date, published data on patient participation in decision making about life sustaining treatment during mechanical ventilation in the ICU is relatively sparse. European physicians surveyed in the ETHICUS study reported that ICU patients were involved in 4% of life sustaining treatment discussions.[5] However, study reports do not specify what proportion (if any) of the mechanically ventilated patients participated in decision-making. More recently, a 1-day point prevalence study across nineteen ICUs in France showed that attending physicians designated significantly more ICU patients as having decision-making capacity ($n = 92/206$; 45%) than did a quantitative measure ($n = 34/206$; 17%).[6] The investigators did not, however, specify the proportion of mechanically ventilated patients who were deemed to have decision-making capacity. There have not been similar studies conducted in the U.S.

Qualitative research and case reports provide specific examples of patient involvement in life sustaining treatment decision making during mechanical ventilation. For example, a qualitative study of ICU patients weaning from prolonged mechanical ventilation documented patient participation in 31 different care and treatment decisions in 12 of the 30 cases (40%) observed. Older patients (≥60 years of age) were involved more frequently in decisions to withdraw, withhold or continue life-sustaining treatments ($n = 9$) than their younger counterparts ($n = 2$).[7]

In a published case report, clinicians ascertained the values and treatment preferences of a mechanically ventilated ICU patient through the use of a professional lip reader-translator. This information was then considered in end-of-life care and life sustaining treatment decision making for the patient who was decisionally incapable.[8] In a second published case, AAC techniques were used to determine decisional capacity of a young woman with a high cervical spine injury and, subsequently, the patient's authority to make life sustaining treatment decisions was upheld.[9] Patients with advanced motor neuron disease, such as amylotropic lateral sclerosis, may use eye tracking computer systems to participate in communication about their care and treatment decision making.[10]

Berning and colleagues developed and tested a picture board communication tool for spiritual care assessment and communication with nonvocal ICU patients.[11] Although the spiritual care tool does not address treatment decision-making, the study showed that the specialized AAC tool is feasible to use with non-delirious mechanically ventilated patients. Importantly, more than a quarter of study participants died in hospital suggesting a potential opportunity for supporting patient participation in treatment decision making.[11]

While our case exemplar is centered in the ICU, the communication assessment and AAC supports are applicable to older adults with a range of communication impairments throughout the hospital setting. Decision making about life sustaining treatments is difficult – a complex and emotionally charged dynamic with serious, often irreversible, consequences. We have little evidence on the best, most ethically responsible, approaches to engage seriously ill patients in the treatment decision making process.[12] Mr. Moore's case and the information presented here are intended to show that communication support guided by expert SLP consultation and competent use of AAC by bedside clinicians are essential components in responsible shared decision making with communication impaired older adults in the acute – critical care setting.

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Ms. Altshuler is the Clinical Specialist in Patient-Provider Communication, Department of Speech-Language Pathology, Rusk Rehabilitation, NYU Langone Health, NYU Langone Medical Center - Tisch Hospital.

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