Use of Augmentative and Alternative Communication Strategies by Family Members in the Intensive Care Unit

By Lauren M. Broyles, RN, PhD, Judith A. Tate, RN, PhD, and Mary Beth Happ, RN, PhD

Background
Little is known about communication between patients and their family members during critical illness and mechanical ventilation in the intensive care unit, including use of augmentative and alternative communication tools and strategies.

Objectives
To identify (1) which augmentative and alternative communication tools families use with nonspeaking intensive care patients and how they are used, and (2) what families and nurses say about communication of family members with nonspeaking intensive care patients.

Methods
A qualitative secondary analysis was conducted of existing data from a clinical trial testing interventions to improve communication between nurses and intensive care patients. Narrative study data (field notes, intervention logs, nurses’ interviews) from 127 critically ill adults were reviewed for evidence of family involvement with augmentative and alternative communication tools. Qualitative content analysis was applied for thematic description of family members’ and nurses’ accounts of patient-family communication.

Results
Family involvement with augmentative and alternative communication tools was evident in 44% of the 93 patients who completed the parent study protocol. Spouses or significant others communicated with patients most often. Main themes describing patient-family communication included (1) families being unprepared and unaware, (2) families’ perceptions of communication effectiveness, (3) nurses deferring to or guiding patient-family communication, (4) patients’ communication characteristics, and (5) families’ experience with and interest in augmentative and alternative communication tools.

Conclusions
Assessment by skilled bedside clinicians can reveal patients’ communication potential and facilitate useful augmentative and alternative communication tools and strategies for patients and their families. (American Journal of Critical Care. 2012;21(2):e21-e32)
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 bereaved family member)

Family members are often described as communication partners and spokespersons for patients in intensive care units (ICUs) who are unable to speak because of their need for mechanical ventilation and respiratory tract intubation. Yet as the preceding e-mail note so poignantly illustrates, communication impairment and communication difficulty are sources of distress for family members of critically ill patients.

Supportive interpersonal interaction with family members can be therapeutic for ICU patients who are unable to speak and may ameliorate the stress and trauma experienced by some family members during and after ICU hospitalization. Yet, ICU patients and their families often must overcome significant communication challenges. We know very little about how ICU patients and family members communicate and whether families are comfortable and proficient with the spectrum of augmentative and alternative communication (AAC) tools and strategies. AAC refers to all forms of communication, other than oral speech, that are used to express messages. AAC tools include equipment and aids such as writing implements, alphabet or picture communication boards, or electronic communication devices. In this article, we present results of a qualitative content analysis of data from the parent study, a clinical trial testing interventions to improve communication between nurses and patients in the ICU. Patients’ families commonly express feelings of loss, dismay, and frustration with the critically ill patient’s loss of voice, and prior qualitative research suggests that existing modes of communication between ICU patients and their families are insufficient and unsatisfying. Although nurses routinely advise families to speak to and encourage ICU patients, the involvement of families in assisted communication strategies with non-speaking ICU patients has not been systematically investigated. In studies of families’ bedside presence in the trauma/emergency department and neurological ICUs, family members were noted to model the tone and content of their verbal responses to the patient after the nurse. In our earlier study of weaning from prolonged mechanical ventilation in the ICU, 20% (6/30) of the families were observed to initiate use of assistive communication tools such as writing tablets or “magic slates,” “homemade” communication boards, electronic e-mail devices, and/or individualized signals on their own (M.B.H., J.A.T., V. Swigart, RN, PhD, unpublished data, 2004). Families are traditionally the primary communication partners and facilitators of AAC for persons with communication disabilities in the home setting. The use of AAC tools in patient-family communication in the ICU has not been studied, but is critical to the development of evidence-based interventions to improve communication between family members and critically ill patients.

The purpose of this study was to describe family caregivers’ involvement with assisted communication tools with non-speaking patients under different levels of patient-nurse communication training and intervention in the ICU. Research questions addressed in this study are

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Existing modes of communication between intensive care patients and their families are insufficient and unsatisfying.
1. Which AAC tools do families use with non-speaking ICU patients, and how are they used?
2. What do families and nurses say about family members’ communication with non-speaking patients in the ICU?

Methods

Research Design

We conducted a qualitative secondary analysis of study records—field notes, intervention logs, and brief interviews of nurses—from a clinical trial. The parent study design has been described in detail in previous publications. briefly, the parent study consisted of 3 sequential phases detailed in Figure 1. Ten ICU nurses with a minimum of 1 year critical care experience and no significant speech or hearing deficit were randomly selected to participate in each phase. Eligible patients (1) were 18 years old or older, (2) nonvocal because of oral endotracheal tube or tracheostomy, (3) expected to remain intubated for 48 hours, (4) able to understand English, and (5) had scored 13 or above on the Glasgow Coma Scale. Individuals who were reported to have a diagnosed hearing, speech, or language disability that significantly interfered with communication before hospitalization were excluded. Eligible patients were enrolled and paired with a study nurse when he or she was scheduled to work 2 consecutive day shifts.

Data collection primarily involved the observation and video recording of 4 nurse-patient communication sessions for each nurse-patient dyad enrolled in the study. Field notes were generated while the

Setting and Sample

The parent study was conducted in the 32-bed medical ICU and 22-bed cardiovascular-thoracic ICU at a large, tertiary medical center. Of the 127 patients who were enrolled in the parent study over the 3 different treatment conditions during a 4-year period (2004-2008), 93 patients completed all 4 observational sessions and comprised the sample for identification and quantification of AAC tool use. Narrative study data for all 127 patients enrolled in the parent study were reviewed for evidence of observations or comments about patient-family communication and family members’ involvement with AAC tools. The final analytic sample focused primarily on documents from the 41 patients who had evidence of family involvement with AAC tools (Figure 2), with additional observations or comments about patient-family communication extracted from the documents of the other patients. Identification of these documents is described in the following section.

Procedures

Observational data were collected in the parent study by 1 of 3 trained research assistants using a standardized observation tool established in previous research. Observers wrote detailed field notes documenting salient events pertaining to the setting, patient, nurse, the presence of family visitors, hospital environment or routine, reliability and availability of AAC equipment, and interruptions. Communication content and interactions were documented to supplement and enhance interpretation of the video recording. Nurse debriefing interviews used a semistructured guide. After each session, data collectors began with a grand tour question, “Tell me about your interactions with this patient” followed by questions and probes about specific AAC tools or strategy and the nurse’s opinion about effectiveness of the technique. Nurses were asked specifically about family involvement in AAC communication strategies after the last video-recorded session via the following questions, “Has the family been involved in AAC communication strategies? If so, how? How did they come to learn about [the strategy]?” “Did any messages or strategies come from

Figure 1 Parent study intervention.
the family?" Family members were not interviewed; however, observers recorded naturalistic family comments, particularly those about communication with patients, when they occurred.

An AAC tool was defined as a physical object or device used to transmit or receive messages. We defined family involvement with AAC tools as a family member’s use of or instruction in use of a low- or high-tech communication tool or device during interaction with the patient. Of note, we included the following “unaided” strategies that, in this sample, involved partner (family) assistance or training: intentional eye-blinking systems and partner message scanning by using Yes-No questions. We did not include head nods, gesture, and mouthing words because these are considered unaided communication strategies. Thus, we focused on those strategies that required physical objects, tools, or devices and/or family assistance or training.

For each patient in the initial parent study sample, the first author (L.M.B.) reviewed the source documents in Microsoft Word format to identify and code the presence or absence of any family involvement with AAC, and to identify the specific family member(s) involved by relationship, for example, adult child, spouse/significant other, sibling. A minimum of 5 source documents were available for each of the 93 patients who completed the parent study protocol; these typically consisted of a study enrollment note and field notes for each of the 4 observational sessions. One-third of the patients (n = 31) had evaluation/intervention reports by a speech-language pathologist. AAC tools and devices used by family members were then identified and categorized by the type of AAC tool; multiple uses of the same strategy within a patient’s case were coded only once. Similarly, for each AAC tool used, instances in which family members were the providers of the AAC tool were identified. This primary coding was subsequently reviewed by all 3 authors.

Qualitative content analysis was then applied to the text for simple description of what patients’ families and nurses say about communication between family members and nonspeaking patients in the ICU. The source documents containing evidence of family involvement with AAC or comments about family-patient communication were imported into Atlas.ti (version 5.0, Scientific Software Development, Berlin, Germany) for data management and organization. Initial open coding of the documents was performed by the first author and involved line-by-line examination of the text to identify the attributes...
Table 1. Spouses/significant others (n = 22) and adult children (n = 10) were the family members communicating with patients most often. Other family members using AAC included parents (n = 7), siblings (n = 3), others (n = 4: grandchild, aunt, niece, “caretaker”), and an unknown (n = 1). Six patients had more than 1 family member involved.

Writing (pen and paper) was the family-patient AAC strategy used most often (n = 26 patients). Ten patients used electronic speech-generating devices with family (Table 2). Eleven patients and their families used 2 or more strategies. Novel communication tools and assisted strategies devised or provided by families included intentional, idiosyncratic eye-blinking systems (n = 3 patients), homemade flashcards or message boards (n = 2 patients), a home computer (n = 1 patient), and a child’s toy such as a “Magna Doodle,” or an “Etch-A-Sketch” (n = 2 patients; Table 2).

Main Themes Describing Use of AAC Tools in Patient-Family Communication in the ICU

Five main themes describing family involvement with AAC tools were identified across all phases of the parent study: (1) families being unprepared and unaware, (2) families’ perceptions of communication effectiveness, (3) nurses deferring to or guiding patient-family communication, (4) patients’ communication characteristics, and (5) families’ experience with and interest in AAC tools. Some differences were identified across phases. Although the ineffectiveness of AAC tools was a common complaint of families throughout the study phases, positive comments...
about the effectiveness of AAC tools were concentrated primarily in the intervention phases. Notes from the interventionist (speech-language pathologist) in phase 3 provided a greater emphasis on patients’ communication characteristics. Not surprisingly, evidence of family interest with AAC tools was stronger in the intervention phases.

Unprepared and Unaware. Families were generally unprepared for the patients’ inability to communicate easily and effectively.

The family [members] were unaware of the lack of patient communication prior to surgery. They prepared for surgery via a Web site dedicated to lung transplant patients and they said that although they were prepared for many other things, they were unaware of the communication issue. Had they known, they could have better prepared themselves. [enrollment note]

In other instances, families did not initially recognize patients’ communication capabilities.

The family did not believe that the patient could mouth words. [The researcher] demonstrated her ability. The patient’s son said, “Well, maybe now we can talk to her.” [observation note]

The patient signed his own consent (for study participation) and it seemed as though the family was surprised that he could write. . . [observation note]

Families’ Perceptions of Communication Effectiveness. Families indicated frustration regarding their limited success with naturalistic communication strategies such as mouthing words and writing, and they were aware of patients’ frustration as well. The patient’s daughter said, “I wish I had a better way to understand him. Sometimes it’s so frustrating when he has to repeat over and over. I can’t read his lips.” [enrollment note]

Although families generally had limited success with lip-reading and writing, some experienced moderate ease with these conventional, intuitive strategies.

Sometimes [the husband] understood her [the patient] well and sometimes not. The “sometimes not” was when she mouthed too quickly to be understood. He said that he thought he understood her mouthing more often than not. [observation note]

The [patient’s] mom reads his lips but cannot understand his writing. [nurse interview]

Families’ reported satisfaction with lip reading occurred in the context of having additional, successful alternatives, such as writing, readily available.

The visitors tell me that they are “getting good at lip reading” and can understand the patient fairly well when she mouths words. If not, the patient will write. [observation note]

Her husband stated . . . that when he was unable to comprehend the message she mouthed, he would offer her a tablet and pen to write. He was able to understand those messages for the most part. [enrollment note]

Writing and alphabet boards were not effective strategies for many families, primarily because of edema or limited mobility of the patient’s upper extremity, unavailability of the patient’s glasses, or an existing handwriting style that tended to be illegible.

Table 2
Augmentative and alternative communication (AAC) tools and assisted strategies used by families

<table>
<thead>
<tr>
<th>Tool or strategy</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication/letter boards</td>
<td>8 (14)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Writing (paper/pencil)</td>
<td>26 (46)</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Commercial writing board (wipeable/dry erase)</td>
<td>3 (5)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Writing cuff</td>
<td>1 (2)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Electronic AAC device</td>
<td>10 (16)</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Personal computer</td>
<td>1 (2)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>“Flashcards” or homemade message board</strong></td>
<td>2 (4)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Toy</strong></td>
<td>2 (4)</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assisted strategies</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye blinking</td>
<td>3 (5)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Tagged yes/no, partner scan</td>
<td>1 (2)</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

**Total** 57 10 22 25

*a Percentages may exceed 100% because of rounding. Eleven patients had family member(s) who used more than 1 tool or strategy.
The husband said the [communication] board was already in the room when they arrived the day before. Unfortunately, he said, the patient was too weak to pick out the letters. [enrollment note]

[The patient’s] family said that he had tried to write but because he had no glasses and his writing was so illegible, he became frustrated and did not ask for the paper and pencil . . . [enrollment note]

The patient had been printing notes but found it difficult to hold a pen. His hands were edematous and stiff . . . [enrollment note]

In some instances, family concerns extended beyond mere frustration with communication effectiveness to concerns about the patients’ safety and the vulnerability imposed by the inability to speak.

The family found (the patient) with no call bell in reach. They know that the patient cannot speak; she needs access. [observation note]

Nurses Deferring to or Guiding Patient-Family Communication. Nurses typically deferred to families’ knowledge of and relationship with the patient in planning communication strategies and, sometimes, in interpreting nonvocal messages from the patient. This deference to and reliance on family interpretation was juxtaposed with an uncertainty about the accuracy of family interpretation.

Nurse: They (the family) made their own (communication) cards. They got photographs for him to look at. They’re not doing yes-no questions, and 3 choices [referring to Written Choice technique]. They have a different relationship with him. They’re not as open to the [parent study] strategies, because they know him, and don’t need to use the strategies . . . They’ll try to tell me what he’s saying. It’s not always clear to me that they’re right, but they know him, I’ll take their word for it. [nurse interview]

In other instances, however, nurses expressed concerns about the impact of families’ communication attempts on patients’ clinical progress, particularly with respect to cardiac status and weaning from mechanical ventilation. In these situations, nurses took an active role in directing families’ choice of communication strategies.

Patients and families had minimal familiarity with augmentative and assistive communication strategies.

The nurse goes on to inform the son that the patient is trying to communicate but that she [the nurse] is trying not to have the patient write—just use yes-no questions because the patient is experiencing a number of PVCs [premature ventricular complexes]. [observation note]

RN: [to family visitor] Do not try to make her talk. She is weaning [from the ventilator] at this time and this is the lowest setting she has been on. She has an issue with getting herself upset and is being medicated to keep her calm. She needs to relax. She is doing well right now and this is a good sign. All of us would be anxious if we could not talk. I understand. However, you need to limit your questions to [ones with] yes or no answers. We need to progress to extubation. [observation note]

Nurses recognized that some family members had difficulty communicating with their loved one in the ICU and encouraged them to interact and talk normally with the patient. For example, a nurse encouraged sisters who were having difficulty striking up a conversation with a patient to “pretend that you two are on a bus and discuss something.” In another instance, a nurse facilitated a telephone conversation between a patient undergoing mechanical ventilation and her brother by reading the patient’s handwritten messages to the brother.

Prior Patient Communication Characteristics. Family reports of prior communication and personality styles of patients reflected their expectations of communication content and frequency.

Daughter: Well, he’s not much of a communicator . . . I just mean he doesn’t talk much. [observation note]

[The patient’s] husband stated . . . that she had always been a “talker” and that being unable to communicate was frustrating for both of them. [enrollment note]

[The patient’s] sister feels that the ICU staff hasn’t interacted enough with the patient and this has partially caused the patient’s deterioration in the hospital. She comments to me that the patient is a “big talker,” and this withdrawn, ambivalent attitude is new to her. [enrollment note]

When asked if he used a hammer to pound a nail [a delirium screening question], the patient said he couldn’t but his son could. [The patient’s] son said he was always “cantankerous.” [enrollment note]

Families also reported that limited literacy and preexisting visual/auditory impairments affected patients’
Family members and patients generated creative solutions for overcoming communication challenges.

New care standards require providers to identify patient communication needs and implement a plan to address them.
Families rely on communication strategies that are more familiar and more readily available.

Interventions to improve families’ communication competency may moderate stress levels.

The questions addressed in this study are novel and have not been considered by other research in the field.

Family involvement with AAC strategies will become a more central focus of patient-family centered care and provider-patient communication in the ICU given the release of new hospital accreditation standards by the Joint Commission. These patient-centered communication standards require clinical care providers to identify patients’ communication needs and implement a plan to address and accommodate existing or acquired communication impairments. Additionally, these standards explicitly recommend the use of a mixture of low-, medium-, and high-technology AAC devices and strategies to address the communication needs of patients with sensory or communication impairments and recommend ensuring the availability of these resources 24 hours a day, 7 days a week. (An overview of the Joint Commission initiatives in advancing effective communication, cultural competence, and patient-and family-centered care can be found at: http://www.jointcommission.org/Advancing_Effective_Communication/) The Society for Critical Care Medicine (SCCM) also recognizes that the psychosocial needs of critically ill patients, many of whom cannot communicate, are often overlooked, which compromises the delivery of patient-centered care in the ICU. SCCM draws attention to the benefits of family support and participation in care.

Families are typically unprepared for the communication challenges of critical illness. Resources that families used to prepare for surgery did not describe communication difficulties that result from intubation and mechanical ventilation in the postoperative period. Preoperative consultation with a speech-language pathologist can be effective in planning postoperative communication services for patients who will be temporarily nonspeaking. Assessment by skilled clinicians at the bedside can reveal patients’ communication potential and serve to demonstrate useful assistive communication strategies to their families.

Families’ discomfort and lack of proficiency with communication strategies may add to patients’ feelings of stress and frustration, rather than promoting improved outcomes. No published study has evaluated families’ perception of communication difficulty or the effect of interventions to improve patients’ communication on family caregivers and their communication with critically ill relatives. Clearly, more research is needed to provide evidence-based strategies to aid family caregivers in this setting.

Nurses in this study maintained or assumed that use of yes-no questions was the least stressful method for family-patient communication during weaning from prolonged mechanical ventilation. Although this perspective is consistent with previous qualitative research describing clinicians’ perspectives on family visitation during weaning from prolonged mechanical ventilation, these claims have not been empirically tested or validated. This perspective is also consistent with previous observational studies documenting nurses’ control of the timing, topic, and duration of communication in the ICU. Communication with family members may be more stressful because patients want to communicate novel or emotional messages to family members (such as, “I love you,” “Did you pay the gas bill?” etc) that are not amenable to standard yes-no questions or a “medical needs” topic list.

Family members’ expectations of communication with patients were consistent with past patterns and characteristics of the patient. This finding confirms the importance of an individualized approach to planning for AAC during critical illness and confirms individual variation in communication frequency and AAC tool preference. Additionally, our study results demonstrate that families carry important information regarding limited literacy and pre-existing visual/auditory impairments that are critical to effective AAC planning and strategy selection. The degree to which data on baseline communication function are routinely collected from families of ICU patients receiving mechanical ventilation is unclear; however, this is an area of concern in the new hospital accreditation standards from the Joint Commission.

AAC communication materials were available to patients in the 2 intervention phases of the parent study. However, without direct instruction and ongoing encouragement about how to use communication materials with seriously ill patients who have impaired communication, families often failed to use AAC tools to understand their critically ill loved ones’ messages and instead just “made do.” Families’ limited interest in and use of AAC may have been due to having had limited exposure to various AAC strategies/devices, their potential for enhancing communication, and how to use them effectively. Our data indicate that families tended to
rely on communication strategies that were more familiar and more readily available. Experience with deaf family members and/or American Sign Language did not translate into useful communication strategies during critical illness for patients. Families are likely to benefit from simple instruction and encouragement on how to use communication materials and basic assistive communication strategies in the ICU. Nurses and speech-language pathologists should make sure communication materials are available for family visitation to maximize all communication options for nonspeaking patients and their families.

Use of an existing data sample has several limitations.53-55 As the focus of the parent study involved nurse-patient communication, the data collection strategies were not designed with patient-family communication in mind; this limitation may affect the comprehensiveness and validity of the findings, which should be considered primarily as hypothesis-generating. In addition to the 41 families identified in our study documents, other families may also have used AAC tools but were unobserved by nurses or our research team. That is, our dataset includes only observations at 5 time points over a 3-day period (enrollment and morning and afternoon observations during 2 days of observation) and does not represent the full extent of family involvement in assisted communication. We did not observe patient-family communication that occurred during evening visiting hours. Moreover, because these data were gleaned from a clinical trial in which a variety of communication strategies were available and/or presented to nonspeaking patients, we may have observed more AAC use than is currently typical in ICUs.

Conclusion

Our study suggests that although families experience difficulties in communicating with critically ill, nonspeaking ICU patients, their use of AAC tools and assisted strategies is limited, even when these resources are relatively available. Given these observations and the absence of discussion of the topic in the literature, it is likely that this problem is unrecognized and may contribute to stress among both families and patients. Recent studies show that family members experience psychological symptoms such as anxiety, traumatic stress, and depression during and after a loved one’s critical illness.56-59 Indeed, family members are at risk for posttraumatic stress disorder, particularly if the patient dies.57,58,61 The relationship between patients’ communication difficulty and/or ability during critical illness and families’ outcomes after ICU discharge or death has not been explored. We hypothesize that interventions to improve family members’ knowledge and competency in the use of simple AAC materials and techniques might moderate or alleviate stress for families of patients in the ICU.

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