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\C Augmentative and Alternative Communication

AAC Intervention in the Intensive Care Unit: The Children's Hospital Boston Model

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This paper describes a model for preoperative augmentative and alternative communication (AAC) intervention for patients with planned admissions to the intensive care unit following surgery that render them temporarily unable to speak. Details of preoperative and postoperative interventions and discharge interviews are provided, along with strategies for patient-directed vocabulary selection and digital voice message banking. Anecdotal data present the benefits of preoperative introduction to AAC, as described by patients, family members, and medical staff.

KEY WORDS: intubation, message banking, ventilator dependency, vocabulary selection, voice banking

The inability to communicate, no matter how temporary, has been identified as one of the most frustrating and stressful aspects of an intensive care unit (ICU) admission for patients who are temporarily unable to speak (Dowden, Honsinger, & Beukelman 1986; Fitch, 1987; Fried-Oken, Howard, & Stewart, 1991; Gries & Fernsler, 1988; Hafsteindóttir, 1996; Hudelson, 1977; Jablonski, 1995; Menzel, 1994; Stovsky, Rudy, & Dragonette, 1988; Villaire, 1995; Williams, 1992). This is no less the case when an ICU admission is planned because of a condition such as a disorder of the upper airway or ventilator dependency or because of the need for a surgical intervention such as maxillofacial/orofacial reconstruction, organ transplantation, or an oncology-related procedure. Nursing staff and other critical care providers report that they face substantial challenges in interpreting patients' communication attempts in ICU settings and have identified the prevention of communication breakdowns in the ICU as a priority research topic (Funk, 1989; Lewandowski & Kositsky, 1983; Lindquist et al., 1993; Provine, 1995; Raines, 1993; Spencer, 1985; Stovsky et al., 1988). Hospital staff also report that family members of patients who are temporarily unable to speak experience extreme levels of anxiety, both because of their own inability to communicate with their loved ones and their loved ones' inability to communicate medical and personal needs effectively (Children's Hospital Boston Multidisciplinary Intensive Care Unit staff, personal communication, July 1999).

Traditionally, communication supports for patients in ICU settings who are temporarily unable to speak in the ICU have focused on postoperative bedside assessment and intervention. These interventions include alphabet and picture boards, Magic Slates© or felt-tip pens for written output, eye gaze displays, electrolarynges, small typing systems, and digitized recording systems (Dowden, Honsinger, & Beukelman, 1986; Fried-Oken et al., 1991; Mitsuda, Baarslag-Benson, Hazel, & Therriault, 1992). The success of such interventions may be compromised by patients' (a) inability to process information effectively because of their medical conditions and/or medications; (b) reduced motor and/or sensory status secondary to traction, edema, or the insertion of intravenous lines/tubes; (c) temporary lack of access to glasses or hearing aids; and/or (d) restricted mobility due to the temporary use of restraints that may be necessary during periods of sedation-induced confusion in order to guard against self-extubation or self-removal of other supports. In addition, postoperative interventions rarely allow patients to participate actively in decision making and selection of AAC strategies and techniques.

A reliance on postoperative communication intervention in the ICU is also problematic with regard to learning. Patients who are critically ill process information ineffectively and often experience high emotional distress coupled with a sense of loss of control (Belitz, 1983; Boeing & Mongera, 1989; Castillo, 1974; Connolly & Shekleton, 1991; Frace, 1982; Funk,

1989; Gaynard et al., 1990; Gries & Fernsler, 1988; Honsinger, Yorkston, & Dowden, 1987; Lawless, 1975; Menzel, 1994; Simmons, 1996; Stovsky et al., 1988). Pain, potential changes in motor and sensory status, depression, and the effects of medications further reduce patients' ability to process new information. The results may include confusion, lack of comprehension, misinterpretation, and increased fear and tension (Stovsky et al., 1988; Williams, 1992). Anger, anxiety, fear, insecurity, and interference with sleep may also interfere with new learning in ICU settings (Menzel, 1994). However, some research has suggested that adequate preoperative instruction may decrease the intensity of such emotional reactions and may allow patients to cope more readily with their medical conditions. For example, in a study of the relationship between preoperative parent and child behavior and postoperative pain in toddlers and preschoolers, Christiano and Tarbell (1998) found that "children with the lowest pain scores were given surgery-relevant information in significantly more preoperative intervals than children with the highest pain scores."

As noted previously, patients with specific types of conditions or surgical interventions are often scheduled in advance for admission to the ICU, which allows time for preoperative communication instruction if a temporary inability to speak is anticipated secondary to procedures such as intubation, tracheostomy, and/or mechanical ventilation. A number of factors support such a preoperative model of AAC intervention. First, a preoperative model allows patients to participate in the selection of AAC strategies and techniques during a time when they have relatively good information-processing abilities in less threatening and less uncertain environments (Gaynard et al., 1990). Second, preoperative intervention may facilitate mastery and competence with AAC strategies prior to the patients' becoming temporarily unable to speak. Finally, patients are able to be more active participants in their own care and may experience a greater degree of control postoperatively. Lack of control has been identified by patients as one of the most stressful aspects of the ICU experience (Belitz, 1983; Borsig & Steinacker, 1982; Boeing & Mongera, 1989; Connolly & Shekleton, 1991; Frace, 1982).

The stress and anxiety caused by a temporary inability to speak also reaches beyond patients and profoundly impacts both family members and primary care providers. This is evidenced by the concerns that have been posed frequently to the ICU Psychosocial Team at Children's Hospital Boston (the team includes a psychologist, social worker, child-life specialist, pastoral care provider, speech-language pathologist, and nurse). Family members often raise several common issues with team members, including (a) fear with regard to their critically ill child's inability to communicate basic comfort and personal care needs; (b) fear that their child may feel abandoned and not have a way to ask for his or her parents (Belitz, 1983); (c) concern for siblings' reactions to an admission, which is often compounded by reduced attention from parents; (d) distress over the temporary "loss" of their child's personality; and (e) feelings of frustration and helplessness because of their inability to prepare the child for surgery or care for the child postoperatively in the medical environment (Rothstein, 1980). In addition, parents often find themselves dependent on health care staff and, in some cases, unable to protect or even comfort their child who must endure painful but necessary procedures (Meyer, Snelling, & Myren-Manbeck, 1998).

The inability to speak is frustrating not only for the patient and his or her family but also for the nursing staff, and can adversely affect the delivery of nursing care (Appel-Hardin, 1984; Cronin & Carrizona, 1984). At least one study has suggested that nurses' communication with patients is positively correlated with patients' ability to communicate and give feedback (Ashworth, 1984). However, because of their other responsibilities, staff must often limit the amount of time they are able to spend interpreting a patient's attempts to communicate. Nurses often describe situations in which they feel disappointed and frustrated with their inability to interpret a patient's message, which may result in the patient becoming angry or anxious and ultimately abandoning the attempt to communicate (Ashworth, 1984; Hall, 1996). This, in turn, may lead to adverse emotional reactions on the part of the patient during the postoperative recovery period (Ashworth, 1984; Nagle, Gangola, & Picton-Robinson, 1971). Thus, providing ICU patients with communication devices and methods that are minimally frustrating and maximally useful is an important but challenging goal for nursing and other support staff in ICU settings (Connolly & Shekleton, 1991).

THE CHILDREN'S HOSPITAL BOSTON MODEL OF PREOPERATIVE AAC INTERVENTION

At Children's Hospital in Boston, a unique model of AAC intervention was introduced in May 1994. The goal of the model was to address many of the aforementioned problems experienced by ICU patients and their families by providing them with effective communication tools and meaningful vocabularies. The model includes several components: (a) providing a preoperative introduction to both aided and unaided AAC strategies; (b) selecting vocabulary preoperatively through a patient-generated and clinician-guided process; (c) "voice banking" selected messages for use with voice output communication aids (VOCAs) after surgery; (d) introducing preplanned AAC strategies postoperatively; (e) teaching family, staff, and patient to use the AAC strategies as needed; and (f) conducting discharge interviews with patients and/or their families, if possible. These components are summarized in Table 1.

TABLE 1: **Overview of the Children's Hospital Boston Model of AAC Intervention in the Pediatric ICU**

Preoperative intervention components
Patient expectations/education
Initial introduction to communication tools
Vocabulary selection
Brief review of sensory, motor, and literacy skills
Introduction to symbols
Review of mounting/positioning options
Voice and message banking
Postoperative intervention components
Bedside screening of awareness, sensory, and motor skills
Mounting of AAC system
Assessment of functional use of communication tools
Family and staff inservicing
Discharge interview
Interview with patient
Interview with family
Interview with medical staff
Dissemination of a formal questionnaire (pending)

Referral

Patients are referred to the speech pathology service for preoperative AAC instruction through a variety of sources. These include specialty service teams (e.g., craniofacial surgery, plastic surgery, tracheostomy, and organ transplant teams), attending physicians and residents, ICU nursing staff, preoperative clinic nursing staff, and staff from specific disciplines (e.g., otolaryngology, neurology, respiratory therapy, radiology, social work, child life, psychology, psychiatry, and pastoral care). In addition, during weekly ICU psychosocial rounds, patients who have already been admitted to the ICU are identified for communication training prior to upcoming medical interventions that will result in a temporary inability to speak (e.g., tracheostomy). Since 1994, more than 100 patients ranging in age from 2.8 to 44 years of age have participated in this model. Many of these patients experienced a temporary inability to speak during a previous hospitalization and based their selection of AAC approaches and vocabulary on their previous experiences.

Preoperative Instruction

During preoperative instruction, patients are introduced to a variety of AAC techniques, including picture displays, alphabet displays, eye gaze displays, and simple VOCAs using both direct selection and scanning modes. Multiple AAC options are introduced to each patient since it is unlikely that any single technique will meet all of their needs during all phases of postoperative recovery (Dowden et al., 1986; Fried-Oken et al., 1991). Usually, patients are scheduled for outpatient preoperative instruction from between 24 hours to several months prior to their planned surgeries; however, bedside instruction is conducted if the patient has already been admitted to the medical center. In a few instances in which patients were not referred for preoperative visits, instruction was provided in the operating room prior to sedation. In all cases, patients choose whether family members are present during preoperative instruction.

General Patient Expectations/Education

All preoperative instructional meetings begin with a general interview to determine the patient's understanding of the planned procedure that will result in a temporary inability to speak. Typically, this meeting is scheduled as the last meeting of the patient's preoperative visit to ensure that he or she has already been provided with adequate medical and procedure-specific information. Patients who have previously experienced a temporary inability to speak in the ICU are often able to articulate clearly their frustrations, anxieties, and wishes relative to communication supports. For others, a general overview of what it may be like to be unable to speak is provided, and related concerns that are anticipated, such as temporary blindness and limited motor function, are also discussed, as appropriate. During this initial interview, patients and families may ask questions about related medical information that was presented by other disciplines earlier in the day. These questions often relate to topics such as suctioning (defining and explaining the process), postoperative eating and/or drinking, the length of the recovery process, and the ICU experience in general. Information is provided and/or referrals are made back to other preoperative team members, as appropriate.

Initial Introduction to Communication Aids

Following a discussion of general expectations, patients are briefly introduced to a variety of communication aids that are available for use in the ICU. In the past, these tools have included the Message Mate 40/600 (Words+, Inc.), DynaMyte (Dynavox, Inc.), LINK (Assistive Technology, Inc.), Cheap Talk 8 and Cheap Talk switch module (Enabling Devices), One-Step switch (Ablenet, Inc.), topic-specific communication displays, and alphabet displays. Currently, the pool of assistive devices has been reduced to include only the Message Mate 40/600, the LINK, and the One-Step switch; these changes were made over time on the basis of patient preferences, device reliability in the ICU environment, and ease of use. (See Appendix A for the addresses of the vendors of products referenced here.)

Vocabulary Selection

Once patients and families understand the range of potential communication aids, they are asked to identify appropriate vocabulary for the ICU. The vocabulary selection process varies in length; some patients are able to complete it during a single preoperative visit, whereas others prefer to focus on vocabulary selection over several months following the initial visit. In an effort to maintain a patient-directed focus, minimal explicit instruction is provided during initial vocabulary selection. Rather, patients are asked either to imagine what it will be like to be unable to speak, based on the knowledge gained from preoperative teaching, or to reflect on their experiences in this regard during previous hospitalizations. Each patient and family member is asked to generate messages that he or she thinks may be appropriate. Following this "free flow" selection of vocabulary, the AAC clinician typically provides explicit guidance and instruction to encourage patients to select a maximum of 30 to 40 messages from the available pool. Patients are especially encouraged to select at least some vocabulary items that represent their personalities, personal interests, and sense of humor. Gries and Fernsler (1988) noted the importance of person-specific vocabulary in research indicating that patients who were temporarily unable to speak felt that the inability to communicate their true personalities strongly contributed to their stress in the ICU.

Brief Review of Sensory, Motor, and Literacy Skills

Following vocabulary selection, a baseline description of the patient's vision and hearing is established through interviews. If corrective lenses or hearing aids are typically required on an ongoing basis for functional interaction, this information is documented for ICU nursing staff, who are also advised to make these aids available postoperatively whenever possible. Postoperative vision and hearing accommodations are also arranged at this time, as needed; these may include removing the arms of eyeglass frames when excessive facial swelling is anticipated or ensuring that an auditory trainer/amplifier is available to persons with preexisting hearing impairment who may be unable to wear regular hearing aids after surgery.

A variety of symbol displays are then introduced to determine the patient's baseline motor status with regard to target size and range of motion. The patient's ability to apply sufficient pressure to activate the speech output of a VOCA is also assessed during this phase. Patients who present preoperatively with low muscle tone or who have known weakness in the finger and wrist joints are assessed for their ability to apply sufficient pressure to activate a membrane keyboard from a reclining position.

To explore the potential of literacy supports for communication, a brief screening of the patient's alphabet knowledge and/or first-letter-of-word spelling ability is next completed with all patients over 5 years of age. Patients and family members are asked to describe the person's ability to use the alphabet to spell novel words, and two types of letter displays (QWERTY and ABCD) are also introduced. Patients are asked to identify a preferred alphabet organizational scheme and are provided with opportunities to practice using it. Key strategies for efficient letter board use, such as the use of specific targets for "space," "end word," "backspace," and "start over," are also taught at this time.

Finally, for patients with functional literacy skills, a general topic cue display is reviewed along with the strategy of using first-letter cues. The topic cue display contains 8 to 10 written words representing topics that are typically related to an ICU admission, such as emotions, pain, breathing, positioning, personal needs, and family. Custom topics such as prayers, stuffed animals, or other personal interests may also be added. Patients are taught how to use this display to introduce a topic and how to then provide initial letter cues for specific words within a topic using the alphabet display. The message "Get the letter board" or "Get the paper and pen" is also added to the VOCAs of patients who are literate.

Introduction to Symbols

Once vocabulary words and phrases have been selected and an organizational scheme for vocabulary has been determined, symbols are selected for each patient. All children under 10 years of age are introduced to the Wong-Baker Faces Pain Rating Scale (Wong, 1995) so that they are familiar with a symbol-based strategy for communicating pain intensity. Picture Communication Symbols (PCS; Johnson, 1994) are typically used for all patients because they are readily available through the Boardmaker™ software program (Mayer-Johnson, Inc., 1995). (Custom symbols unique to the ICU setting, such as those for nasogastric tubes and oral intubation, have been created in Boardmaker and stored for ongoing use). With clinician guidance, patients are encouraged to create their own communication displays and overlays using the Boardmaker software during the preoperative visit. Because it is difficult postoperatively for many patients to visually focus on a written display, PCS are incorporated into communication displays for both literate patients and for those who cannot read or spell. The final communication display(s) are printed prior to the end of the preoperative visit so that patients can take them home, familiarize themselves with the symbols and the layout, and practice using them prior to surgery.

Alternative Access Strategies

A variety of alternative access strategies are reviewed during the preoperative visit so that patients are prepared for both anticipated and unexpected postoperative outcomes with regard to their motor status. In some cases, a patient's motor or sensory status can be expected to be affected temporarily following surgery. For example, patients with craniosynostosis who have craniofacial surgery and attachment of facial distraction devices for midfacial advancement may be unable to see postoperatively because of extensive facial swelling. Or, patients with extensive facial surgery may have their eyelids taped shut postoperatively in an effort to maintain minimal mobility of the facial region and thus maximize recovery. In other cases, unexpected postoperative changes in motor or sensory status may occur. For example, a decision may be made during plastic surgery to harvest a tissue graft from the shoulder or back, resulting in limited mobility of the upper extremities for direct selection postoperatively. Similarly, a postoperative decision may be made to immobilize both arms to accommodate intravenous or arterial lines, making direct selection impossible.

Table 2 summarizes the range of alternative access techniques that may be reviewed at the initial preoperative meeting. Specific techniques are introduced to each patient, depending on the scheduled operative procedure. For example, a patient for whom a postoperative vision impairment is a certainty is not introduced to vision-based techniques such as eye gaze. Similarly, a patient whose surgery does not involve the face or head (and for whom excessive facial swelling is not expected) is not introduced to auditory scanning or tactile direct selection since these techniques will probably not be necessary.

All patients are introduced to an adapted nurse call system and/or have a nurse call message stored in their VOCAs. Although nurses in the Children's Hospital ICU are rarely more than a few feet away from their patients, it is imperative for patients to feel confident that they can readily gain nurses' attention. Urden (1997) reported that patients who are temporarily unable to speak experience additional stress when standard nurse call systems, which direct patient calls to a central desk in the ICU and result in attendant responses over an intercom, are in use.

Options for Mounting/Positioning VOCAs

Once they have become familiar with various VOCAs and their potential postoperative benefits, patients are often concerned that they may not have ready access to the VOCA in the ICU or that it may not be available to them as they change position in bed. Patients are assured that the VOCA will be available regardless of how they are positioned and they (and their family members, if appropriate) are shown how to use the Universal Mounting Arm (Ablenet, Inc.) and Dual Lock Fastening System (F & F, Inc.) that will be used to mount the VOCA at the ICU bedside. Family members practice positioning and repositioning the mounting arm at this time and are also shown how to change the position of the VOCA to accommodate the patient's motor/sensory and position needs.

Voice and Message Banking

During this phase of the preoperative visit, the patient's own voice is digitally recorded into a VOCA to ensure that the communication techniques used postoperatively closely reflect his or her needs and personality. This process of creating a digital vocabulary archive using a patient's own voice in anticipation of a temporary loss of speech is known as "voice banking." In some cases, a patient's preoperative speech may be compromised or unintelligible due to poor respiratory support or orostructural anomalies. When this occurs, the patient may identify a proxy speaker of the same gender and age range to record messages in the voice bank.

Voice banking has numerous potential benefits for all concerned. For the patient, it enables communication in his or her own voice, tone, and intonation pattern, which helps to preserve a part of his or her personality during the experience of being temporarily unable to speak. This may help to counteract the sense of depersonalization that patients often experience in the ICU (Gries & Fernsler, 1988; Salyer & Stuart, 1985). In addition, voice banking enables patients to project their emotions and beliefs clearly and directly. For example, one 17-year-old candidate for lung transplantation decided to bank the phrase "Yeah, right!," said with great sarcasm, to reflect her belief that medical staff may not always be sincere when they indicate that "This will only take a moment." Voice banking also allows patients to connect emotionally with significant others and to maintain personal relationships by communicating seemingly whimsical or nonsensical messages. The true meanings of such messages can be understood only through intonation and vocal nuance, combined with shared knowledge that is often unique to specific communication partners, rather than their actual semantic content. Finally, voice banking assists patients to take an active role in vocabulary management and in their own postoperative care.

For the parent of a child who is temporarily unable to speak, voice banking provides the comfort of hearing the child's voice during a period of critical illness. In addition, the process of archiving messages provides parents with a concrete way of assisting their child to prepare for surgery and potentially reduces their feelings of helplessness and frustration. ICU staff at Children's Hospital Boston have also suggested that voice banking enables them to form more per-

TABLE 2: **AAC Access Techniques Reviewed at Initial Preoperative Meeting**

Strategy	*Description*	*Rationale/Use*
Unaided yes/no response	Patient identifies preferred alternative mode of indicating yes/no Family is taught to rephrase questions for yes/no responses	Patient may be unable to nod/shake head to indicate yes/no secondary to rigid fixation of cranium or other postsurgical motor restrictions
Adapted nurse call system	Patient is introduced to switches that are alternatives to the standard call switch and may be accessed at various control sites Patient is introduced to the One Step switch and remote access options and records the message "Nurse, I need you"	Patient may be unable to access standard call system secondary to motor restrictions Patient may not be confident of his/her ability to gain attention immediately while unable to speak
Tactile direct selection	The concept of tactile landmarks is introduced Patient and clinician create a tactile display and patient is then provided with opportunity to practice "blind" message selection with the selected custom vocabulary	Patient may be unable to see temporarily after surgery
Eye gaze direct selection	Patient and family are instructed to use an accurate eye gaze technique, i.e., look at a symbol, word, or alphabet letter on a display and then glance at the communication to confirm the selection Patient is familiarized with the use of commands such as space, new word, end, and start over Communication partners are instructed to verbally confirm each selection and write down the message	Patient may not demonstrate a consistent and reliable motor response for either direct selection using the hand or single-switch scanning
Visual assisted scanning	Partner-assisted scanning is introduced Clinician provides education regarding potential confirmation strategies such as eye blinking, eyebrow movement, lip movement, thumbs up, etc. Patient identifies confirmation strategy he or she will use Family is taught about timing considerations and message confirmation	Eye gaze selections may not be reliably or consistently interpreted by communication partners
Single-switch scanning	Linear and row-column single-switch scanning are reviewed using a VOCA Patient practices various scanning techniques using a VOCA with programmed custom vocabulary	Patient may be unable to direct select from the VOCA
Auditory scanning	Custom vocabulary is selected and stored Auditory scanning is introduced with the VOCA Patients practice "blind" message selection using the VOCA	Patient may have temporarily impaired vision and may be unable to direct select from the VOCA

sonal connections by helping them to know the children as people, not just as patients.

The voice banking process is quite simple and straightforward. The patient is instructed to speak each message clearly, with the same intonation that he or she would use in the actual situation. Some patients appear to find the process quite entertaining, which may enable them to remember the selected vocabulary items and their locations more readily postoperatively. Patients are provided with opportunities to approve or re-record every message. The clinician also provides coaching as needed with regard to articulation and/or pause times to ensure that each message will be understood by communication partners in the ICU. Messages are re-recorded until both the patient and the clinician are satisfied with them.

When a surgical intervention is scheduled within 24 to 48 hours after the preoperative visit, the communication tools developed during the preoperative visit are made available to patients immediately so that they can become familiar and comfortable with them. Under some circumstances, patients may be allowed to take their VOCAs home for a period of time to allow for maximum familiarization. When this occurs, the patient and family members are taught how to add, delete, and change stored vocabulary in the VOCA in case new messages are identified during the time period between the preoperative visit and the surgical date.

Postoperative Bedside Intervention

After surgery, patients typically spend a brief period of time in the post-anesthesia care unit (PACU) before transferring to the ICU. Typically, the communication tools are brought to the bedside in the ICU, but they may be introduced in the PACU if the patient must remain there for some time. Introduction of communication supports occurs only after the medical team has determined that the patient is stable, since the supports may be contraindicated while the patient is required to remain immobile, concentrate on breathing, and relax. At the bedside, the patient's level of alertness is first assessed by the nurse and the medical team; this includes assessment of his or her neurologic status, ability to attend to a communication partner, ability to follow simple directions, and ability to be comforted.

Because the ICU medical staff at Children's Hospital Boston have, over time, acquired an appreciation of the benefits of effective independent postoperative communication, it is common for them to page the speech-language pathologist to initiate the communication intervention once a patient is determined to be medically stable. In other cases, the speech-language pathologist may be called at the urging of family members who participated in the preoperative training. Sometimes, a patient may arrive in the ICU from the PACU in the late evening or early morning hours; if this is planned in advance, the speech-language pathologist leaves the communication tools in the ICU in anticipation of the patient's arrival. Since the ICU nursing staff have become quite familiar with the AAC tools and techniques, they are able to attach the required communication device(s) to the bedside once the patient is stable. This bedside staff support is crucial because patients expect to have their communication tools readily available to them when they awake in the ICU. In other instances, a patient may choose to have a family member keep the communication tools during surgery and to then provide them at the bedside in the ICU.

Prior to introducing the AAC techniques at the bedside, the speech-language pathologist briefly reassesses the patient's awareness, motor skills, and sensory skills. The communication device is then introduced and the patient is asked "Do you remember this?," or, if the patient is unable to see postoperatively, the clinician may state "I have your communication device here. Do you remember setting this up before your surgery?" The communication device is then mounted on the bedside and the patient with unencumbered vision is asked to confirm that the display is within his or her visual field. Patients who were able to use direct selection preoperatively are encouraged to try to touch specific targets on the display. This allows for a quick screening of the patient's direct selection and visual scanning skills with regard to specific targets. Patients for whom temporary visual impairments were anticipated preoperatively are asked to locate specific targets on their displays using the tactile markers that were selected preoperatively, or auditory scanning may be introduced, if this access technique was selected. Patients who are unable to use direct selection are introduced to single-switch scanning, and a motor access site for consistent and reliable switch activation is established. Depending on the patient's motor status, various switches such as the Jellybean, Spec, or string switch (Ablenet, Inc.), the Micro Light or Plate switch (TASH International, Inc.) or the Sensor switch (Don Johnston, Inc.) are investigated for use. It is at this juncture that the need for a versatile VOCA becomes most critical since the patient's condition may vary from what was anticipated. For example, a patient who was expected to have intact direct selection skills may present postoperatively with reduced motor skills that necessitate single-switch scanning, or a patient for whom single-switch row-column scanning was anticipated preoperatively may present with a temporary visual impairment that necessitates auditory scanning. Following the bedside assessment, the patient is engaged in a communication exchange to establish functional use of the communication tools, and staff and family training is provided at the bedside, as needed.

Discharge Interview

A formal discharge interview process was not initially included in the intervention model. However, numerous patients and families have been interviewed informally regarding the strengths and challenges of the AAC model, and feedback from the medical staff has also been solicited regularly. A formal questionnaire designed to probe the efficacy of this model in a more structured format is currently under development. Once it is completed, this tool will be distributed to patients and families who have participated in the preoperative AAC program.

RESULTS

When the Children's Hospital Boston preoperative AAC model was implemented in 1994, we hoped that having patients and their families involved in selecting and creating AAC techniques would have a positive impact on their ICU experience. We also hoped that the medical staff would benefit from an increased efficiency of patient communication. However, feedback about the model has suggested benefits that go far beyond what we had anticipated and include psychosocial benefits for both patients and their families as well as reports of enhanced quality of care from medical staff.

Although more than 100 patients have participated in this intervention model, feedback data were not recorded for all patients from the outset. Table 3 summarizes the ages, medical diagnoses, medical interventions, and communication strategies used postoperatively by 43 patients for whom these data were available. Although many patients had multiple diagnoses and interventions, the most common were surgeries related to craniofacial anomalies (32%), intubation or tracheostomies for airway management (19%),

TABLE 3: **Sample of Participants in the Children's Hospital Boston Model Who Participated in the Discharge Interview**

Patient	*Chronological Age*	*Medical Diagnosis*	*Medical Intervention*	*Postoperative AAC Tools*
JC	13	Cystic fibrosis	Lung transplant	Message Mate, QWERTY display, writing tablet
RA	13	Hemifacial microsomia	Jaw reconstruction, rigid fixation	Message Mate, QWERTY display
CM	8	Apert syndrome	Midfacial advancement and fixation	Message Mate
KD	13	Tracheoesophageal malformation	Tracheoesophageal reconstruction	Message Mate, writing tablet
KS	12	Cystic fibrosis	Lung transplant	Message Mate, QWERTY display, writing tablet
AB	7	Ewing's sarcoma of the mandible	Total mandibulectomy, mandibular reconstruction, tracheostomy	Message Mate, ABCD display
AT	19	Muscular dystrophy	Respiratory distress/tracheostomy/ventilation	Message Mate, QWERTY display
MP	23	Cystic fibrosis	Lung transplant	Message Mate, QWERTY display, writing tablet
CR	5	Retrognathia with mandibular asymmetry, jaw hypomobility	Mandibular osteotomy, rigid fixation, tracheostomy	Message Mate, symbol communication board
TS	18	Restrictive lung disease, acute respiratory disease	Tracheostomy	Message Mate, writing tablet
DS	18	Rhabdosarcoma/angiofibroma of nasopharynx	Resection of tumor	Message Mate, writing tablet
LS	16	Maxillary hypoplasia	Midfacial advancement, rigid fixation	Message Mate, QWERTY display
JS	10	Crouzon syndrome	Midfacial advancement, rigid fixation	None
TT	16	Apert syndrome	Midfacial advancement, rigid fixation	Message Mate, QWERTY display
FV	14	Angiofibroma of nasopharynx	Resection	Message Mate
WF	16	Cardiac myopathy	Tracheostomy	Message Mate
SW	10.5	Rhabdosarcoma of mandible	Resection	Message Mate

Continued

TABLE 3: **Continued**

Patient	Chronological Age	Medical Diagnosis	Medical Intervention	Postoperative AAC Tools
IC	13	Carcinoma of epiglottis and neck	Radiation treatment, resection, tracheostomy	Message Mate, LINK, writing tablet
BL	18	Severe bilateral facial microsomia	Midfacial advancement, rigid fixation	Message Mate, QWERTY display
AL	13	Crouzon syndrome	Midfacial advancement, rigid fixation	Message Mate
AD	16	Aggressive juvenile ossifying fibroma of left maxilla	Left posterior maxillectomy	Message Mate
KG	8	Hemifacial microsomia	Jaw reconstruction	Message Mate
DB	17	Cystic fibrosis	Lung transplant	Message Mate, QWERTY display, writing tablet
RM	5.7	Midfacial hypoplasia	Midfacial advancement	Message Mate
AM	11	Cervical-facial-laryngeal venous malformation	Sclerotherapy, tracheostomy	Message Mate, QWERTY display, LINK
JH	6	Venous malformation of tongue	Sclerotherapy, tracheostomy	Message Mate, symbol communication display
JA	23	Respiratory distress/pulmonary nodules	Intubation, other treatment	Message Mate
LA	18	Respiratory distress, history of Arnold-Chiari malformation	Tracheostomy	Message Mate
CB	9	Congenital venous malformation of lower face, neck, pharynx	Sclerotherapy, tracheostomy	Message Mate, writing tablet, symbol communication display
WC	20	Renal failure	Renal transplant, intubation	Message Mate, writing tablet
LD	13	Subglottic stenosis, bilateral vocal fold immobility	Laryngotracheal reconstruction	Message Mate
GC	23	Recurrent facial sarcoma	Resection	Message Mate
NJ	6.8	Rhabdomyosarcoma of the pharynx	Tracheostomy for airway management during radiation	Message Mate
JW	35	Lymphatic malformation of oropharynx	Sclerotherapy	Message Mate, writing tablet
AK	2.8	Congenital subglottic stenosis and laryngeal malformation	Larnygotracheal reconstruction	Message Mate, symbol communication display
JA	13	Nager's syndrome	Mandibular reconstruction	Message Mate, QWERTY display
RD	4	Pfeiffer's syndrome	Midfacial advancement	Message Mate, symbol communication display
DC	20	Cranial metaphyseal dysplasia, cervical spine enlargement	Transoral resection of C1 body, intubation	Message Mate
MS	26	Pulmonary fibromatosis, status post acute lymphocytic leukemia and bone marrow transplant	Lung transplant	None
RE	12	Cystic fibrosis, status post lung transplant 24+ months, airway compromise	Intubation	Message Mate, QWERTY display, writing tablet
KF	24	Cystic fibrosis	Lung transplant	Message Mate
JR	44	Venous malformation	Laser treatment, tracheostomy	Message Mate, QWERTY display, writing tablet
DP	26	Muscular dystrophy, pneumonia	Intubation	Message Mate

tumors of the face or airway (16%), lung transplantation(s) (15%), compromised airways secondary to venous malformations (11%), and tracheolaryngeal or esophageal reconstructions (7%).

In the sections that follow, outcomes and examples of feedback from patients and their families with regard to various aspects of the intervention model will be summarized and discussed.

Preoperative Intervention

To date, almost all patients have had at least one family member present during preoperative instruction, although several adolescent patients invited their parents to leave during one or more portions of this training (e.g., vocabulary selection, voice banking). Preoperative instruction typically occurred 24 to 72 hours prior to the planned surgical intervention. The exceptions involved individuals who were awaiting lung transplantation, since the accepted protocol for cadaver transplantation requires that emergency surgery be scheduled as soon as healthy donor organs are harvested. Thus, preoperative instruction was provided for those patients as soon as the need for transplantation was identified, which ranged from 2 to 18 months prior to their actual transplant dates.

Patient Expectation/Education

During their preoperative visits, patients were encouraged to discuss their expectations of the postoperative experience and were provided with relevant information. This was often the first time that patients who had not previously had surgery that resulted in an inability to speak seriously considered what this inability might be like for them and for their families. For example, following this discussion, KD (age 13) stated:

> *It made me really think about what it is going to be like, so I won't be surprised after surgery.*

The benefits of the initial discussions were also noted by families. For example, when discussing his impressions of his 6.5-year-old daughter's postoperative communication, AB's father commented that:

> *The first thing she said on the ICU was 'I need to be suctioned.' She wouldn't have even known how to tell us she needed her mouth cleaned out or even know that it was an option if we hadn't talked [preoperatively] about what suctioning is and when you ask for it.*

Initial Introduction to Communication Tools

The Message Mate 40/600 mounted on the Ablenet Universal Mounting Arm has been available to all patients participating in this model. The features of this device that have made it an excellent match for patients' preoperative and ICU needs include (a) simplicity of message storage and editing, (b) the high quality of the device's digitized speech, (c) flexibility of access options ranging from direct selection to single switch auditory scanning, (d) compact size, (e) durability, and (f) ease of editing the display. A more sophisticated and powerful VOCA with a dynamic display was introduced to patients as an option during the initial phase of implementation of this model but was eliminated from the ICU phase because 100% of patients involved in preoperative training declined it. Patients and their families cited many reasons for rejecting the more sophisticated technology, including fears of confusion, accidental activation of messages, more complex programming demands, and potential problems with implementation immediately after surgery. In fact, one 9-year-old boy with severe apraxia of speech who already used a portable dynamic display device also decided not to use his VOCA in the ICU postoperatively and instead selected a simpler VOCA with a static display. However, some patients did use dynamic display technology once they left the ICU if their inability to speak extended into the acute care phase of recovery.

Vocabulary Selection

According to patient selection patterns, it appeared that approximately 40 vocabulary items were adequate to meet most patients' communication needs during the postoperative period. The 40-target grid from the Message Mate was used as a guide during vocabulary selection, and no patients indicated a need for more space. On average, patients and their families selected between 25 to 30 messages for inclusion on the grid. Many also reserved at least two spaces on the display for unanticipated messages that could be added postoperatively by a proxy speaker.

A preliminary analysis of patient-generated vocabulary displays revealed three major word categories: medical, personal comfort, and psychosocial. The primary personal comfort messages related to personal needs, positioning, and statements or directives. The psychosocial vocabulary included messages classified as social, emotional, comfort, control, sarcasm and humor, clarification, leisure/entertainment, and questions. Appendix B details the 12 distinct categories of messages that were evident from this analysis and example messages in each.

Many patients and family members commented on the vocabulary selection process and its impact on them after surgery. For example, DP, a 26-year-old man with Duchenne muscular dystrophy, was in the ICU with respiratory distress secondary to pneumonia. In anticipation of being intubated for ventilator support, DP and his mother, with assistance from the speech-language pathologist, identified and stored

vocabulary in a Message Mate. DP had previously experienced an inability to speak in the ICU without the benefit of communication supports. When DP suggested including the message "I am thirsty," his mother disagreed and reminded him that the nurses would not be able to give him anything to drink. DP responded:

I know I am not going to be able to drink. I've been here before. Communication doesn't always have to make something happen, but I have to be able to try.

DP then proceeded to record three consecutive messages: "I am thirsty," "I am really thirsty," and "I am really, really thirsty." Similarly, MP, a 23-year-old man who had also experienced a nonspeaking condition during a previous hospitalization, noted that:

I can keep telling you how hungry I am even though I can't eat, so I don't have to keep it to myself.

MS, a 26-year-old woman who was a lung transplant recipient, reflected on the relief she derived from being able to select her own vocabulary:

Before I had this [in previous hospitalizations], I was so afraid they might give me a medicine I was allergic to. This time, I had it stored in the box [i.e., the VOCA] and I could ask them what they were giving me and tell them what I am allergic to. I was much more relaxed knowing the box was there with my messages in it.

When patients began the process of identifying vocabulary, they often selected messages related to control. As can be seen in Appendix B, common control messages included "Stop!," "Come back in a few minutes," and "Leave me alone." Reflecting afterwards on the power of being able to exert control, a 9-year-old patient said:

I liked that I could tell them all to wait a few minutes, and they really did!

Similarly, the first message identified by ER, a 7 year old who was preparing for craniofacial surgery and who had been hospitalized previously, was "Don't touch my IV." He explained:

People just move the IV around. But it is in my arm with a needle and it really hurts!

Another common control theme in feedback reports was related to patients' ability to access assistance when needed. A 20-year-old patient reflected on his need to know that staff would respond to him, regardless of the frequency with which he called them:

I couldn't sleep until I knew that the nurse would come every time I needed her, so I kept on hitting the 'Nurse, I need you' message to see if she would come.

Interestingly, nursing staff reported that, when patients used their VOCAs to exert control, it often made their jobs easier:

It let me relinquish some of the control to her because I knew she could tell me to wait a few minutes longer, so I could offer the option.

It took the guesswork out of it. He could tell when he needed me or tell me to leave him alone when he wanted to rest.

She told me to close the curtain sometimes, and other times wanted it open. I didn't have to guess how overloaded she was or how much socialization she wanted, because she told me!

Without the board, I have to be looking right at him to know he is trying to tell me something. With this [VOCA], he can tell me something very easily while I am checking his pump or doing something else.

Related to control is the ability to gain comfort when fearful or agitated. Patients as young as 7 years of age selected vocabulary that allowed them to elicit comfort from others or to provide comfort to themselves. For example, AB, age 7, selected the message "Hold my hand" for storage in her VOCA. One of her nurses commented that:

She told her dad 'Hold my hand,' and you could see how much better it made her feel [when he did].

Another of AB's nurses observed that:

Her dad programmed a message in the box [i.e., the VOCA] to her so she could push the button to hear him talk to her whenever she wanted. It was a way of self-comforting.

One 19-year-old patient with muscular dystrophy recorded the message "I am okay" and then proceeded to use it repeatedly while he was intubated and in the ICU. Initially, medical staff and family members were confused by his frequent and unsolicited use of this message; however, it became clear over time that he was comforting himself by repeating it, not using it to inform others of his status. Another comfort-related technique was evidenced by JA, a 13-year-old boy who selected "Tell me a puppy story" for inclusion on his VOCA. When asked to explain this, he indicated:

Stories about my dogs distract me from what is going on around me.

In addition, some patients chose to comfort themselves by "venting" their anger, as noted by a nurse who was frequently the target of "VOCA yelling" by one such individual:

It allowed him to vent his anger. Every time we would do a procedure he would say 'I hate you' and 'This sucks,' and it would make him feel better. I was glad to hear it every time he pushed the buttons because at least he was clearly expressing how he felt, which made him feel better.

Patients also selected vocabulary that was personal and often represented issues that were of paramount importance to them but may not have been recognized as such by others. For example, one 8-year-old girl insisted on storing the message "Don't let Frank in my room," fearing that, during her hospitalization, her younger brother would play in her bedroom without permission. A 7-year-old girl stored the message "No fair!" so that throughout her hospital stay she could protest the fact that her siblings had the pleasure of staying with their grandparents. JH, age 6, was very concerned that his job as the family dog feeder would be carried out properly in his absence and stored the question "Who is feeding the dog?"

Brief Review of Sensory, Motor, and Literacy Skills

Most of the sensory changes that occurred during the postoperative period were anticipated successfully and supported appropriately. For example, hospital opticians regularly modified eyeglass frames when excessive facial swelling was anticipated, and the audiology department stocked additional auditory trainers and amplification systems so that they would be readily available in the ICU if they were needed. Adaptations related to sensory concerns were needed for approximately 3% of patients; of these, approximately half had craniofacial surgeries with related facial swelling that compromised vision. One such patient reflected on the preoperative training by proudly stating:

I know where all the messages are without even looking, which is good since I won't be able to see after surgery.

He then proceeded to close his eyes, move his fingers across the tactile markers he had placed on the VOCA display, and direct the message "Thank you" to the speech-language pathologist.

Regarding motor access, the majority of patients who have participated in this program to date have been able to use direct selection of targets less than 1 inch square on Message Mate 40 overlay (the smallest targets were spaced 0.75 inches apart for two patients with Apert syndrome and syndactylism, to allow for accurate direct selection). Only seven patients in the sample used single-switch scanning during some part of their postoperative recovery. Of these, two patients with muscular dystrophy were single-switch scanners prior to ICU admission, and the remaining five patients made the transition to direct selection as their postoperative motor and sensory status improved. Interestingly, several other patients might have used single-switch scanning for brief periods of time postoperatively but chose instead to have their family member use partner-assisted scanning with their Message Mate overlays. These patients then made the transition to direct selection, often within hours of beginning to communicate postoperatively.

Some of the comments regarding the preoperative training with regard to motor access included:

When I was so upset and uncomfortable, I don't think I could have learned to use that switch to scan; so it is really good that I learned to use it before the surgery.

Another patient stated:

The way I was feeling, it would have been really hard to learn and understand all that stuff after my surgery, and I never could have gotten the information from the doctors that I needed to have.

Introduction to Symbols

To date, no literate patient has refused to include PCS with the printed word gloss on the VOCA overlay. In fact, two patients who had been previously hospitalized in the ICU remarked that they believed that PCS would be easier to see and to understand immediately after surgery than would written words alone. In addition to using the Boardmaker software to select symbols and create individualized overlays, several patients have also chosen to draw their own, unique symbols.

Voice and Message Banking

The impact of voice and message banking has been quite significant for patients, family members, and the ICU medical staff. During the preoperative visit, while engaged in the voice banking activity, many patients made comments such as the following:

I'm gonna yell the next message so everyone knows I'm mad. (KD, age 13)

Oh, that one sounds good, it sounds like I'm really scared. (AB, age 6.5)

The nurses spend so much time taking care of me. I want them to know me as a person—this way [with the Message Mate] they will hear my voice and know my sense of humor. (KF, age 24)

Parents reported that hearing the voice of their critically ill child had a very positive emotional impact on them while in the ICU:

I knew she was still there, even though she looked so sick, because it was her voice. It was not only her needs that were met, but it was my need to hear my daughter talk to me. It was a really nice thing. (mother of AB)

I know that she is going to be able to talk again, but I can't describe how important it is to me to hear my daughter's voice talking to me. She looks so sick, but I know that even though they removed her mandible, they left her personality. (father of AB)

I knew that he would need the device to talk, but I think I am getting more benefit out of it [than he is] because I can hear his voice talk to me! (mother of AK)

Nursing staff have also commented that voice banking allowed them to better know their patient's personality and provided them with a greater appreciation of the person behind the patient:

I would hear his voice, and it would make me smile ... it's like I knew him better.

When you hear the voice of the patient, it gives you so much more of a connection with the person.

Hearing his little voice say 'Thank you' every time I did something melted my heart. It wouldn't have been the same if it was somebody else's voice or just a picture board.

Postoperative Intervention

Of all of the patients who have participated in this model, only a small number have not used any of the AAC tools that were introduced preoperatively. One such patient was MS, a 26-year-old woman who received a lung transplant and made such rapid progress that she was extubated within hours of her surgery. During the period of time between the PACU and the extubation, she was too sedated to engage in communication. Another such patient was JS, a 10-year-old girl who had a midfacial advancement and who was highly agitated and virtually inconsolable postoperatively. In order to support an optimal recovery, she remained sedated throughout her treatment in the ICU until she was stable enough to extubate. These two patients were typical of the few who did not use AAC postoperatively.

Regarding positioning of the VOCA postoperatively, one patient commented:

I got anxious when they moved the rail of the bed down and the speech box moved out of view. As long as I could see it there, I felt more relaxed.

Similarly, AT's father reported that, when the Message Mate was moved out of his son's reach or when the switch was moved away from his toe (AT's access site) during repositioning, AT became visibly anxious. His father noted the importance of having the VOCA and switch positioned properly at all times.

Discharge Interviews

Interviews with patients prior to discharge revealed multiple benefits to this model of intervention. Contrary to previous reports in which patients have reported feeling depersonalized and feeling like they were "worked on" rather than "worked with" (Belitz, 1983), many patients reported that they felt that they had had a real role in their own care:

It was one thing I could do that I knew would be there after surgery to help me get through this. (DC, age 20)

Similarly, AT reported that he knew that he was respected as a person because he could tell his nurse or doctor something and they would respond:

I knew exactly what to tell you [when I felt like my lungs were full], since we went over everything before the surgery and I knew the doctor would listen to me.

In commenting on the use of the VOCA, JW, age 34, commented:

To some extent, it provided a degree of fun and made what could have been a miserable experience a bit better.

After they no longer needed their VOCAs, several patients provided feedback regarding vocabulary they wished they had included. Examples of such messages included "When will the tube come out?" and "Mom, stop kissing me!" One patient who had a temporary visual impairment postoperatively suggested that the Message Mate overlay surface should have a slight indentation at each target, since this would have made it easier for him to navigate the display without sight.

Family members, especially parents, made numerous comments during the discharge interview. One of the most common themes was that the preoperative intervention model allowed them to prepare for their child's surgery:

It was something that we could do as a family to prepare. (father of SW)

It gave me something concrete to do to prepare her for surgery. We could have taken her to the Aquarium or had a special dinner. But this was meaningful and was a part of getting her through the whole experience. (mother of AB)

It was great because his sister really helped him select vocabulary and she was the designated recorder if some-

thing needed to be added after surgery. It gave her a role in her brother's recovery. (mother of JA)

Parents also reported that they experienced great comfort in the fact that their child could communicate in their absence:

I know that I can go for a cup of coffee or go to the bathroom, and she can communicate an emergency need. Without this [VOCA], I would be afraid to leave her side because someone else might not be able to figure out [what she is trying to communicate] the way I could. (mother of NJ)

When reflecting on her role as a care giver during her daughter's hospitalization, KB's mother stated:

As a parent you feel so helpless, and all you want is to do something to make your child feel better. It is so frustrating not being able to do anything but look at her. When she used the device to tell me she was cold, I could make her feel better and that made me feel so much better.

Parents also commented on their perception of a higher standard of care because of the VOCA:

This [model of intervention] is an example of the caliber of the institution. It makes us know that we did the best job we could as parents. It was a tough decision to have this surgery and if we had chosen another medical center, we don't know if this would have been available. (father of AB)

ICU medical staff have also noted multiple benefits related to the preoperative intervention model. Several nurses have suggested that patients' ability to select vocabulary to reflect their interests enhances the ability to form relationships postoperatively:

I could talk with her about nonmedical stuff because I saw on the board that she had a way of chatting with me. So we talked about our cats.

An attending physician commented:

I heard him say, 'It is nice to see you,' and I couldn't believe that anyone would say that to me under the circumstances. It really showed me something about the child I would not have known.

Nurses also noted patients' ability to efficiently communicate urgent needs:

He can tell me something he is worried about immediately, and I can respond. Otherwise, he would just be lying there stewing in his anxiety without being able to tell me.

She came back from the OR, and she immediately told me she needed to be suctioned. We got up all this gunk from her lungs, and otherwise we wouldn't have known she needed it until she was in distress.

She could say, 'I am in pain,' and then we could ask the right questions to figure out how to comfort her.

In the same vein, one physician commented:

If he had not told me that he felt like his lungs were full, I never would have known and he would have been lying there thinking he was really in trouble and nobody knew. We were able to immediately reassure him by telling him his scan was fine and then gave him more medical information.

It is interesting to note that the intervention model continues to change in subtle ways as patients, families, and medical personnel offer feedback and suggestions. Most notably, patient feedback has led to a redefinition of what "success" of the model can mean. Initially, we assumed that success and patient satisfaction would be directly related to the frequency with which the communication tools were employed postoperatively (Dowden, Beukelman, & Lossing, 1986; Fried-Oken et al., 1991). However, even those patients who did not use any of the preoperatively introduced communication strategies after surgery reported that they derived considerable comfort from the mere fact that the strategies were readily available. For example, MS (age 26) reported:

Even though I never used the talking box, it was the fact that I knew it would be there on the other side of surgery that made me feel so good. I would have been even more anxious going in to the surgery but I knew that I would be able to communicate the things important to me.

Many patients and family members who have participated in this model and who foresee additional planned surgeries that will result in temporary speechlessness have requested that AAC strategies be available to them for their return hospitalizations:

It was so important to me. If I ever need to be intubated again, I want to make sure we set this up first. (JW, age 34)

We don't want to come back for the next phase of surgery unless we have this available for him again. (mother of CM)

CONCLUSION

Overall, patient reports of their ICU experiences within the Children's Hospital Boston model have differed considerably from those reported previously in the literature. During discharge interviews, none of the patients who participated in this model reported feeling exhausted in their attempts to communicate (Hafsteindóttir, 1996), isolated (Belitz, 1983; Villaire,

1995), out of control (Stovsky et al., 1988), or afraid and anxious because of communication breakdowns (Borsig & Steinacker, 1982). Furthermore, in contrast to previous reports of patients' inability to recall preoperatively introduced communication strategies (Hafsteindóttir, 1996), it appears that the vast majority of the patients participating in the Children's Hospital Boston model had minimal difficulty in this regard. This may be because the model emphasizes their intimate and active involvement in the development of individualized AAC tools.

A preoperative model of AAC intervention that addresses the anticipated communication needs of patients who will be temporarily unable to speak in the ICU appears to be appropriate and beneficial as a clinical strategy for all concerned. Anecdotal reports related to this intervention model suggest that it has substantial benefits for patients, family members, and medical staff. In particular, we believe that involving patients and their family members in the vocabulary selection and voice banking processes is critically important, and that this involvement often results in more functional and sensitive postsurgical care. However, although our clinical experiences include anecdotal reports of positive changes in oxygen saturation levels, cardiac rates, and overall patient comfort when effective AAC is available, it is clear that systematic research is needed to investigate the extent to which the benefits of this model are actually related to short- and long-term outcomes. Additional research should also focus on issues of pain management and ICU recovery time, as well as to the quality, content, and quantity of postoperative message exchanges using vocabulary that has been self-selected preoperatively.

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APPENDIX A

Products Referenced

Products	*Vendor*
Boardmaker™ software	Mayer-Johnson Company P.O. Box 1579 Solana Beach, CA 92075-7579, USA Tel: 858-550-0084 www.mayer-johnson.com
Cheap Talk 8 Cheap Talk switch module	Enabling Devices Toys for Special Children 385 Warburton Avenue Hastings on Hudson, NY 10706, USA Tel: 800-832-8697 www.enablingdevices.com
DynaMyte	Dynavox Technologies 2100 Wharton Street Pittsburgh, PA 15203, USA Tel: 800-344-1778 www.dynavoxsyst.com
LINK	Assistive Technology, Inc. 7 Wells Avenue Newton, MA 02459, USA Tel: 800-793-9227 www.assitivetech.com
Jellybean switch Specs switch String switch Universal Mounting Arm One-Step switch	Ablenet, Inc. 1081 Tenth Avenue, SE Minneapolis, MN 55414-1312, USA Tel: 800-322-0956 www.ablenetinc.com
Message Mate 40/600	Words+, Inc. 1220 West Avenue J Lancaster, CA 93534, USA Tel: 800-869-8521 www.words-plus.com
Dual Lock Fastening System	F&F, Inc. 330 Tacoma Street Worcester, MA 01605, USA Tel: 888-696-1020
Micro Light Plate switch	TASH International, Inc. Unit 1, 91 Station Street Ajax, ON, L1S 3H2, Canada Tel: 800-463-5685 www.tashint.com
Sensor Switch	Don Johnston, Incorporated P.O. Box 639 Wauconda, IL 60084-0639, USA Tel: 800-740-7326 www.donjohnston.com

APPENDIX B

Examples of Patient-Selected AAC Messages for the ICU

Personal Needs

I need to go to the bathroom.
I want to eat.
I want a drink.
I want ice chips on my lips.
Please put a wet cloth on my mouth.
Please brush my teeth.
I am really thirsty!
Please cover me up.
Put on my glasses.
Wipe my nose.
I need my hearing aid.
I am hot/cold.

Social

Thank you.
I am sorry.
I appreciate it.
You are nice.
What is your name?
I love you.
I am glad you came to see me.
How is _____?
Please talk to me.
God bless you.

Control

Leave me alone.
Come back in a few minutes.
Stop!
Go away.
I don't want that.
I want privacy.
No!
Wait 5 minutes.
I am 12 years old and do not like watching Barney!
Turn the lights off.

Positioning

Please move the bed up/down.
I am uncomfortable.
I want to turn over.
I want to sit in the chair.
I want to go to bed.
Place a pillow under my legs.
Roll up towels and put them under my right shoulder.
Bring my left knee over to my right hip.

Statements/Directives

Nurse, I need you!
I want to see the doctor.
Tell me what is going on.
Don't touch my IV.
Don't move me.
I want to go to the floor.
Turn the lights on/off
Open/close the curtain.
Be careful you don't unplug that!

Sarcasm

What are you looking at, Doogie?
Go jump in the lake!
You are a turkey!
I think I just heard them page you, doctor.
Give me a break!
Duh!
Yeah, right!
I love this place!

Clarification

What did you say?
I don't understand.
Huh?
Say it again.
Explain that, please.

Questions

How am I doing?
When can I go home?
When can the tube come out?
When can I eat?
When can I drink?
Who are you?
What are you doing?
Will it hurt?
Where is my mother?
Am I going to die?
I have a question.
Who is feeding the dogs?

Medical

I need to be suctioned.
I need to throw up.
I need to cough.
I am in pain.
I want medicine.
Something doesn't feel right.
I feel sick.
It hurts.
My breathing feels weird.

Emotions/Feelings

I am afraid.
I am mad.
I'm okay.
I am not stupid.
This sucks.
I hate/love you.
I am tired.
I am afraid I will be like this forever.

Leisure/Entertainment

I want to watch TV.
I want to listen to music.
I want my Walkman.
I want to watch a video.
Can I go to the playroom?
I want to draw.
Please turn the volume up/down.
Can I look at my photos?
Please read to me.

Comfort

Please don't leave me.
Hold my hand.
Rub my head.
Stay with me.
Get in bed with me.
Read me a story.
Keep talking to me.
I am going to be fine.
I am okay.
Tell me a puppy story.
Talk about anything.
Visualize with me.
Pray with me.