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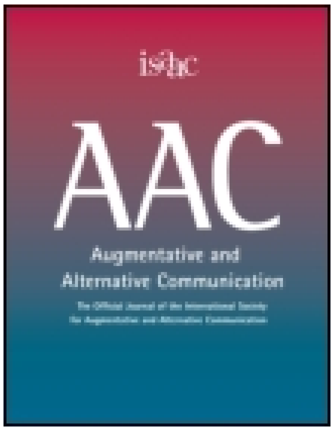

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Feedback on AAC intervention from adults who are temporarily unable to speak

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Feedback on AAC Intervention from Adults Who Are Temporarily Unable to Speak

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The purpose of this study was to assess through retrospective patient interviews the effectiveness of augmentative and alternative communication (AAC) interventions in acute care medical settings. Five adults with temporary severe expressive communication disabilities in the Intensive Care Unit (ICU) due to Guillain-Barre syndrome or botulism were interviewed. Each adult used AAC techniques during the acute phase of their illness when oral speech was not functional. Interviews centered around: the AAC techniques that were introduced in the ICU; reactions of communication partners to AAC approaches; fears and frustrations with speechlessness and AAC approaches; successes and failures of augmented communication; and suggestions for future AAC intervention. Satisfaction with aided expression was reported for about 85% of the interventions. These adults suggested that multiple, simultaneous techniques are most useful. They requested inservice training of all ICU staff with AAC techniques. They considered family training and acceptance of communication alternatives as crucial to success. Nonelectronic approaches were preferred over electronic approaches. Continual patience was one of the most important intervention requirements for the temporary user.

KEY WORDS: acquired disorder, adults, feedback, Guillain-Barre Syndrome, intervention, temporary nonspeaking condition

> When they put the tubes in, you get to the point of being helpless and you feel a need to communicate and talk to someone. You can't move. And you can't talk. And you want to say things. And you think, 'Now I'd like to ask some more questions. You explained to me what's going on. But no, I want to know more now. What's going to happen?' And all you can do is just lay there. That's when you really, really get spooked the most. (MS)

Patients in the intensive care units (ICUs) of hospitals often require augmentative and alternative communication (AAC) approaches for short periods of time. They are temporarily unable to speak and need a means to express basic needs efficiently and effectively until their speaking abilities are restored. Initially, most patients in the ICU are too ill to communicate and are medicated to a degree that affects their alertness, attention, and cognition. Expressive communication is often impossible and, many times, not a lifesaving priority. However, after the acute illness is controlled, many patients with intact cognitive-language skills experience a short-term severe expressive disability, and are in urgent need of a communication system. AAC approaches offer patients a way to express themselves throughout the illness until oral motorskills return.

The abrupt onset of the severe expressive disabilities may result from neurologic disease, traumatic injury, musculoskeletal disorders, or the introduction of lifesaving equipment that prevents natural speech production. The diseases that produce temporary speechlessness in adults include Guillain-Barre syndrome, botulism, cardiopulmonary insufficiency (Vanderheiden and Yoder, 1986). Paralysis of the craniofacial nerves, clinically resulting in severe orofacial weakness, facial diplegia, dysarthria, and dysphagia, is present in a number of acute neurologic diseases. The dysarthric symptoms may include reduced movement, speed, motor strength, and coordination of speech musculature. Spinal cord injuries, closed head injuries, and postoperative conditions that require intubation, tracheostomy, or mandibular wiring may interfere with natural speech production as well. Finally, if respiratory failure results, intubation tubes through the pharynx, larynx, and trachea for ventilator dependency may be needed. Speech is impossible unless a cuffed tracheostomy tube is used. For more details about the disease states causing speechlessness in adults, see Beukelman and Garrett (1988).

The main purpose of expressive communication augmentation in the intensive care setting is to provide the patient with a means to express basic physical needs or vital information, and to increase the amount of interactions between the patient, ICU staff, and family members to reduce isolation and fear (Lawless, 1975;

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Mast, 1986). Ashworth (1978) reported a study from five well-established intensive care units showing that the amount of interaction between nurses and patients with endotracheal tubes was small, particularly if the patient was unable to respond. One patient was spoken to only once in 4 hours. Ashworth wrote that 32% of the verbal communication to nonspeaking patients was "short-term informative (e.g., "I'm just going to suction you out"); 18% was "command or request" (e.g., "Just lift your arm up"); and 21% was "questions" most of which were related to physical care. Only 7% were "longer informative, teaching, or orienting" interactions. Budd and Brown (1974) found that the latter interactions actually reduced ICU delirium in postcardiotomy patients and shortened length of stay in intensive care.

Although the introduction of communication alternatives in the ICU is appropriate and, in many cases, crucial for the nonspeaking, cognitively intact patient, there are few descriptions or empirical studies about which techniques are most useful and when, in the patient's care schedule, intervention is most timely and efficacious. A number of articles have been written by ICU nurses that describe successful techniques that facilitated expression (Presley, 1980; Schreiber, 1979). Presley (1980) wrote,

> Cyrus didn't have any way of expressing his anger. He couldn't scream, was too weak to kick, and was too uncoordinated to even write curses on paper. He needed to release his anger somehow. So we tried our first unconventional idea-we gave him a rubber-shod hemostat and told him to bang on the bedrails whenever he felt angry or needed something. Within a half hour, he was banging all the time. And by the end of the shift, we were ready to lynch the nurse who'd first suggested giving Cyrus the hemostat. But we endured the racket — if banging on his bedrails would help, we'd learn to cope with it. (p. 84).

Schreiber (1979) described the communication technique used by a patient with Guillain-Barre syndrome who retained some movement of her feet.

> Our first job was finding a way to communicate with Mrs. Savage, and, since none of us had ESP, we knew we'd have to learn foot language. We thought, If we make her right foot the 'yes' foot, and her left foot the 'no' foot, we can ask her questions and she can answer us. But first, she needed a way to get our attention. I bought a string of Indian brass bells, and using umbilical tape, fastened one bell to each of her feet. (p. 47).

AAC specialists also are beginning to describe intervention for the temporary nonspeaking adult in the ICU. Dowden, Honsinger, and Beukelman (1986) presented their systematic approach for evaluating and selecting AAC systems for adults in the acute care setting. Dowden, Beukelman, and Lossing (1986) described the demographic data for 50 nonspeaking patients from the acute care units of the University of Washington Hospitals over a 2-year period. The authors found that most patients fell into 4 etiology groups: cardiopulmonary insufficiency, spinal cord injury, degenerative diseases, and closed head injuries. They concluded that most nonspeaking patients in the ICU require multiple simultaneous approaches to meet their communication needs, and that the approaches change with the patient's resolving cognitive status and oral motor skills. Beukelman and Garrett (1988), in their presentation of adult acquired communication disorders, discuss AAC for patients with Guillain-Barré syndrome, spinal cord injury and respiratory insufficiency. They point out that a range of approaches is required for the Guillain-Barré patient in a short time span due to the rapidly changing course of the disease. In fact, their case presentation lists three different AAC approaches used by a patient within an 8-week period.

Now that efforts are underway to systematize AAC intervention in the acute care setting, specific information on the efficacy of introducing various AAC techniques to temporarily nonspeaking patients is needed. AAC professionals must begin to evaluate the effectiveness of intervention. Beukelman (1986) discusses three reasons why evaluation of intervention is important: to determine if intervention programs are to be maintained or modified; to determine if changes are necessary in the design and function of AAC aids and techniques; and to assess the clinical performance for agency administration. Blackstone (1989) concurs that clinicians must measure the effects of intervention to monitor progress to modify intervention strategies; to determine outcomes; and to provide required documentation. One variable that is used by expert clinicians to measure effectiveness is consumer satisfaction and user feedback (Blackstone, 1989). The adult who relied on AAC approaches for a temporary nonspeaking condition and now uses natural speech can supply important information to evaluate the effectiveness of AAC intervention.

Unfortunately, there are no published reports on feedback of AAC intervention by the temporary AAC user. Most of the first-hand critiques of AAC intervention are written by individuals with congenital nonspeaking conditions (Viggiano, 1981; Kissick, 1984; Smith-Lewis & Ford, 1987). The cognitively intact adult who requires AAC for a limited time span can describe how effective the AAC was. The adult who has experienced successful communication with speech can critique AAC in a unique way and provide new and important insights about AAC techniques and intervention procedures. Professionals can rely on the expertise of these users to provide keen insights into aided and natural expression.

This study elicited feedback on the effectiveness of AAC intervention from cognitively intact adults who relied on AAC approaches during their temporary severe communication disability. The goals of the study were twofold: (1) to determine if the AAC techniques that were used by the temporary nonspeaker were effective from the user point of view, and (2) to respond to suggestions for AAC techniques and intervention strategies that are offered by the temporary nonspeakers.

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METHOD

Subjects

Five adults (3 men and 2 women) who used AAC approaches during their temporary nonspeaking conditions volunteered as subjects. They ranged in age from 17 to 68 years (mean age 45 years). All adults were native English speakers and reported no known neurologic or hearing problems, other than their presenting illnesses. Four subjects presented with Guillain-Barre syndrome, and one presented with botulism. The length of the nonspeaking condition varied from 14 to 90 days, with a mean duration of 41 days. This duration also corresponds to the amount of time that the subjects were admitted to the intensive care units. Table 1 describes the five subjects.

A brief medical history of each subject is presented, based on information elicited from the interview.

Alec K. is a 35-year-old father of 3 children, and is a part-time bus driver. He noticed some tingling in his arms and legs as his illness began, and he progressed from healthy to paralyzed within 5 days. He was diagnosed with Guillain-Barre syndrome and admitted to the hospital ICU on day 6. He remained in the ICU, respirator bound, for 2 weeks. Prior to ventilation, Alec reported that his vocal folds were paralyzed, that he could not swallow, but that whispering was possible. Alec retained minimal hand movement while he was on the respirator. Seven weeks post onset, he was admitted to inpatient rehabilitation.

Rose E. is a 57-year-old homemaker and retired post office employee who presented with Guillain-Barre syndrome. She reported that she first noted problems with swallowing, which progressed within 2 days to a total loss of motor function. Rose had a rapid progressive loss of ventilation function, requiring intubation and ventilator support within 2 days after hospital admission. She required a tracheostomy and nasogastric tube feeding at that time, as well. Rose remained ventilator dependent for 2 months. The tracheostomy, nasogastric-tube feedings, and supplemental oxygen were continued for another 2 weeks. She retained some minimal movement of her feet during the entire illness. Rose was transferred to the inpatient rehabilitation unit 7 weeks post onset of the disease.

Mike S. is a 46-year-old male who presented with Guillain-Barre syndrome. Mike reported that he progressed from "healthy and hardy" to "completely down and out" in 5 days. He noticed progressive weakness of his hands and legs following an upper respiratory infection. He retained voice control until he was placed on a respirator in the ICU. A nasotracheal tube and ventilatory assistance were started 4 days post onset. Because of dysphagia, a nasogastric tube was placed on day 4 as well. He remained on the ventilator for 10 days, and received nasogastric tube feedings for 19 days. Mike stated that he retained some head movement for nodding and some tongue and lip movement for smacking his lips and clicking his tongue during the illness. He was admitted to inpatient rehabilitation 1 month post onset.

TABLE 1: **Subject Descriptions**

Name	*Age (in years)*	*Diagnosis*	*ICU stay (in days)**
Alec K.	35	Guillain-Barré	14
Mike S.	46	Guillain-Barré	10
Rose E.	57	Guillain-Barré	60
Deb T.	15	Guillain-Barré	30
Vic B.	64	Botulism	90

*The number of days in the ICU also corresponds to the length of time that the subjects used AAC techniques.

Deb T. is a 15-year-old, single female who contracted Guillain-Barré syndrome during her first pregnancy (22 weeks gestation at diagnosis). Deb first noticed tingling in her feet and knees, numbness on the right side of her face, and problems with swallowing. She reported that she was able to speak until placed on a respirator in the ICU, 5 days after admission. A nasogastric tube for feeding was required during the first week also. Deb remained ventilator dependent for 1 month. She was dysphonic with a diagnosis of bilateral vocal fold dysfunction after extubation. No treatment was suggested at that time, however, since the paresis may have been a result of the Guillain-Barré syndrome rather than intubation. Improvement in quality of speech was seen prior to discharge, although volume still remained low. Deb said that she retained some movement of her left hand during the illness. She entered inpatient rehabilitation 2.5 months after the disease began.

Vic B. is a 64-year-old retired farmer who presented with botulism. Vic complained that loss of vision was his first symptom and that he progressed quickly to a loss of all motor function. He retained some movement of his right hand. Vic was respirator bound and remained in the hospital for 3 months. He did not receive rehabilitation after the illness.

Medical Aspects of the Severe Communication Disabilities

In order to intervene effectively in the ICU, an AAC clinician must have a working knowledge of the natural course and characteristic communication problems of acute disease. Since the subjects in this study presented with Guillain-Barré syndrome and botulism, short clinical descriptions of each disease follow. Symptoms that may lead to sudden onset, severe expressive communication disabilities are presented.

Guillain-Barré syndrome, also referred to as Landry-Guillain-Barré disease, is an acute demyelinating polyneuropathy. It occurs in about 1.7 cases per 100,000 people (or about 3,500 cases per year in North America) and is among the most common neurologic causes of admission to the ICU (Ropper & Kennedy, 1988). The

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disease is characterized by the acute onset of a symmetrical ascending paralysis that extends from the legs to the trunk, arms, and cranial nerves. It is described as an areflexic motor paralysis with mild sensory disturbances. Paralysis of the cranial nerves is frequent, with a facial diplegia occurring in 85%, and dysarthria or dysphagia presenting in 50% of all cases (Merritt, 1979). Treatment includes ventilation in about one-third of all cases, plasmapheresis within the first 2 weeks of the illness, and general good attention in the ICU (Asbury, McKhann, & McDonald, 1986). If respiratory failure occurs, the average period on a ventilator is 50 days, with a 108-day period of hospitalization (Adams & Victor, 1981). The introduction of AAC approaches may be necessitated by ventilator dependency, severe orofacial weakness or paralysis, and dysarthria. AAC is beginning to be recognized as a beneficial intervention by ICU neurologists. Ropper and Kennedy (1988) write,

> Use of newly available electronic keyboard devices with touch-triggered buttons has greatly eased the burden of communications for these and other intubated or paretic patients. We have found a useful device that moves acursor on a screen by means of a chin- or lip-operated lever. (p. 262).

Botulism clinically resembles Guillain-Barré syndrome though the causes are very different. Botulism is an infection of the nervous system caused by the organism *Clostridium botulinurn,* which when ingested produces a toxin that causes widespread muscle weakness. The disease often occurs when someone eats uncooked canned food that has not been sterilized properly. Initial symptoms occur 12 to 48 hours after ingestion and include ocular motor problems, weakness of the jaw muscles, dysphagia, and dysarthria (Merritt, 1979). Weakness of the trunk and limb muscles follows. In both botulism and Guillain-Barré syndrome, mental status generally remains intact and the patient is cognitively alert once the acute illness subsides. For both diseases, AAC is needed if the patient is ventilator dependent, has a tracheostomy, or presents with significant orofacial muscle weakness.

Procedure

Data were collected in an interview format. Each patient participated in a videotaped discussion with the speech-language pathologist who intervened in the ICU. The interviews occurred when the individual was medically stable and had recovered speaking abilities sufficiently to participate in a lengthy discussion. The discussion lasted approximately 1 hour and was held in a quiet treatment room or the subject's hospital room. Whenever possible, spouses or primary communication partners were included in the interviews.

An interview questionnaire was devised that addressed seven intervention issues (Table 2).

TABLE 2: **Seven Categories for Interview Questions**

1. Description of illness
2. Description of AAC intervention (what approaches were used)
3. Communication partners' reactions to AAC approaches
4. Successes with AAC approaches
5. Failures with AAC approaches
6. Fears and frustrations with speechlessness and AAC approaches
7. Suggestions for future AAC intervention (recommendations for clinicians and tips for temporarily nonspeaking patients)

Questions centered around descriptions of severe expressive disabilities before the introduction of AAC and reactions by the patient and communication partners; evaluations of each AAC technique used; recommendations for more effective techniques and intervention; and suggestions for other nonspeaking patients.

RESULTS AND DISCUSSION

The results of this retrospective study include the comments of five adults who relied on AAC techniques for sudden onset severe communication disabilities. Information gleaned from the interviews is compiled and reported below, along with selected quotes from the five patients.

The Effectiveness of AAC Techniques in the ICU

During the course of the interviews, each patient described the various AAC techniques that they had tried. Some techniques were developed by the patient and family. Others were introduced by the speech-language pathologist. Table 3 lists the techniques that were reported for each patient.

Every patient reported the use of a yes/no system with either a head shake, thumbs up/down or eye movement. Lip reading or mouthing of words was attempted by all five patients as well. Four of the five patients had some residual hand or foot movement to activate a switch or to form manual messages (signs, gestures, or letters written on a hand). Low-tech devices were commonly presented. An alphabet board with direct selection or dependent auditory scan was introduced to four of the five patients. A Magic Slate[1] board was reported by one patient. Use of the nurse call system with an appropriate switch was reported by three patients. Electronic devices were reported in two interviews. A minimum of five and a maximum of nine AAC techniques were introduced to each patient, reinforcing the Dowden, Beukelman, and Lossing (1986) statement that multiple simultaneous approaches are needed by patients in the acute care setting.

Satisfaction with individual AAC approaches, operationally defined here as repeated use by patients and

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[1] Magic Slate is the name of a product sold as a toy. It consists of a sheet of plastic which rests against a piece of coated cardboard. When pressure is applied to the plastic, a temporary mark is left. A stylus is used to "write" or draw on the slate. Messages are erased by lifting the plastic, which clears off all marks.

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TABLE 3: **Augmentative Communication Techniques Used by Five Temporarily Nonspeaking Patients**

Mike S.	*Alec K.*	*Deb T.*	*Rose E.*	*Vic B.*
Yes/No with eyes	Yes/No with thumbs	Yes/No with eyes	Yes/No with headshakes	Yes/No with headshakes
Mouthing words	Mouthing words		Mouthing words	Mouthing words
Lip smacking	Whispering			
Tongue clicking	Eye pointing around room		Rattling footboard of bed	
Facial expressions	Draw letters in hand			Facial expressions
	Finger pointing	Manual signs for emergent needs		Hand gestures
Nurse call with eyebrow wrinkle switch	Verascan with thumbswitch	Scanwriter with pedal switch at left hand	Nurse call with pillow switch at hand then foot	Nurse call
Alphabet board—Eye gaze system	Alphabet board—dependent auditory scan	Alphabet board—direct selection	Alphabet board—dependent auditory scan with frequency of letter layout	
	Alphabet board—direct selection			Wrote on shirt sleeve with finger
Phrase Board	Magic Slate board[1]	Direct selection typewriter	Phrase board—dependent auditory scan for emergent needs	Phrase board—direct selection
			Phrase board—hierarchical topic branching with dependent auditory scan	

[1] Magic Slate is the name of a product sold as a toy, which consists of a sheet of plastic which rests against a piece of coated cardboard. When pressure is applied to the plastic, a mark is left. A stylus is used to "write" or draw on the slate. Messages are erased by lifting the plastic.

reported success in aided expression, was reported in about 85% of the interventions. The two techniques that were repeatedly judged by the patients to be unsuccessful were the phrase board and electronic devices.

Patients reported that the messages on the phrase boards were too limiting. With regard to electronic devices, the motor requirements of the scanning electronic device were often too complex. The learning requirements were too high for patients with shortened attention spans or reduced cognitive capacity because of illness or medication. Alec stated that the limited number of messages on an electronic scanning device and the difficulty with switch control precluded success.

> It was a useless tool to me. There were two problems. First, the words that you put on the thing are limiting and then, there is always a mechanical problem of getting the light to stop when you want it to. It took too much effort to learn how to hit the switch right. And once you did, you needed different words anyway. With so many things sitting right around your bed, you need something that is always there, easily accessible, reasonably easy to understand and use. The machines don't fit that bill at all.

For most patients, low-tech devices were preferred. Alec preferred the Magic Slate:

> Yes, it's that little kid's toy. You can write on it and you can lift it up and erase it and write on it again. I used that a lot. You can write big letters and have sentences real quickly, much quicker than the alphabet board, much quicker than with your hand. That was an excellent tool. In fact, I think that magic board was my preference over everything. You could communicate quickly and say what you wanted to say. You can write your letters and separate your words, like in normal writing. And it was much quicker and easier to understand by other people. I think they probably like it the best, too. So the Magic board was the best one, once I could start using my hands again. When I was unable to use my hands, of course the alphabet board was the best, assuming that the other person understood how to use it, which many didn't.

Four out of five patients stated that the alphabet board was the aid of choice. Both direct selection and dependent auditory scanning techniques were used with the boards. A quick and proven training program for alphabet board use that includes simple, direct instructions needs to be established, however. Clinicians often take the alphabet board approach for granted, since it is so much easier than other techniques. They sometimes forget that even the alphabet board approach is totally foreign to patients and their families, and is a new, unnatural way of communicating that must be taught thoroughly. This point was emphasized by Alec.

> The alphabet board was wonderful, except that nobody else knew how to use it. The rules were too long and complicated. First of all, there were not any set rules written down and when somebody did write down rules they were too many. Half the people didn't know how to use the board, and they were staff. And a couple of people, like my mom, had difficulty using it. It was too complicated, too many rules. Most people think on a level of a sixth grader in daily life. And a sixth grader would have been frustrated reading all those rules.

The dependent auditory scanning was also successful for patients. But, again, criticisms about its complexity were heard and can easily be addressed by our profession.

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> If they had put 'end of word' up in the upper left hand corner of my scanning alphabet board instead of down in the lower right hand corner, we could have used it without going through the whole process and working your way over. Someone was saying that things you use frequently should be at the top row instead of down towards the bottom where you have to hunt for them. They should be easily accessible. I also thinkthat you should have a main set of rules for using the alphabet board. It should have said, 'Always use a pad to write down your letters as Alec is spelling them out.' I think that would have solved a big problem. A simple way of explaining how the board works, like 'Always start at the top, on the left hand side, move down. When Alec blinks, stop at that row. Then go to the side. When Alec blinks, stop at that letter.' We needed real simple rules.

The placement of an alphabet board should be considered, as well. Vic suggested that the poor location of the alphabet board in the user's field of vision was a problem.

> One of the problems, before I forget, was that people wouldn't know how to hold the board high enough for me. I'm laying on my back and they're standing up. I'd have to have it held up here (points above head) so I can see it. They'd hold it down here (points to chest level). So I'm trying to look at the thing like this (tucks chin down into chest). It's at waist level for them. They need to hold it at their head level so I can see what's going on. Or if I was pointing at it, sometimes they wouldn't hold it up, or too high, or not high enough so I couldn't get a row. So people wouldn't be aware of holding at a proper height for me and not for them . . . If they were holding the board at a good level, it was real easy for me. But if they weren't, it wasn't that easy for me to use.

The patients indicated that, in general, the simpler the technique, the better. Approaches that required significant learning effort by the user and listener were not recommended. Electronic devices appear to be the last option for most patients. This recommendation is consonant with the Dowden, Honsinger, and Beukelman (1986) comment that neither the patient nor the nursing staff can be asked to learn a new communication technique because of time limitations and intervention priorities, and that AAC interventions that facilitate communication immediately will be the most successful. In fact, most of the patients in the Dowden, Beukelman, and Lossing (1986) study relied on the simple approaches of modified natural speech and electrolarynges.

Common Reactions to Severe Communication Disabilities

Common reactions to the sudden onset expressive communication disabilities were discussed by all five patients. Table 4 summarizes the individual reactions.

The overriding reactions that were expressed by the 5 patients included frustration, fear, panic, feeling a loss of control, helplessness and impatience, and apathy.

TABLE 4: **Common Reactions Described by the Five Patients to Severe Expressive Communication Disabilities**

	Mike	*Alec*	*Deb*	*Rose*	*Vic*
Fear	x	x	x	x	x
Frustration	X		x	x	x
Loss of Control	X			X	
Helplessness	X		x	x	
Impatience		X			X
Panic	X				
No Desire to Communicate			X		

Four of the five patients reported frustration with the speechless condition. Rose E. said:

> I would get frustrated when I was having an awful time coughing up secretions and needing to be suctioned, or if I was too warm and needed to get some blankets off in a hurry. It seemed like forever before I could make someone understand that I needed the communication board and spell out the words.

Alec did not experience frustration. He said:

> As long as I was getting my food through the tube, and air through the machine, and able to go to the bathroom, that pretty much covered my basic needs. If I didn't communicate, it wasn't too traumatic. All my basic needs were getting met so I wasn't frustrated.

Fear was discussed by three patients. Rose spoke for the whole group when she expressed the fear of no control over the body.

> I sometimes would lose the switch at the side of my head as I moved because I was constantly thrashing around. Not just trying to get comfortable. I think it was because of fear. I just wanted to know that I was still able to move a portion of myself and call for help if I needed it.

Mike discussed his fear when he lost his only way to communicate:

> Of course, sweating from this Guillain-Barre from time to time my little headband and eyebrow wrinkle switch would fall off. And then I would have no way to call the nurse and there would be panic . . . Wanting the nurse was more of a security blanket. You'd like to know that there's really a human being close to you because you're scared and you need some way to tell her that.

Deb stated that since her electronic communication device was hung from the ceiling above her head, she was always fearful that the device would fall on her. She opted not to use the device and relinquish the power of communication. She also discussed a lack of desire to communicate because she was too sick to learn nonspeech options.

Recommendations for Future Interventions and Suggestions for Other Nonspeaking Patients

The final goal of this study was to elicit recommendations and suggestions for new or improved interventions

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from these experienced AAC users. A number of astute recommendations were offered and are discussed below.

Firstly, patients suggested that we teach a hierarchy of strategies to facilitate the fastest and most effective communication. They all emphasized that communication failure is likely to occur because of the "abnormal nature of the alternatives." Patients stressed that it is important to choose a system that is as close to natural communication as possible for both the user and partners. Each system should be within reach and require as few movements as possible to acquire, activate, and stop.

> There wasn't much room to have all these things sitting right around on your bed. So you had to get the person, point, they had to figure out which communication device you wanted to use. And once they had figured that out, they had to bring it over and plug it in, or whatever. It was just much quicker and more natural to use your eyes. All you can do is look, cause you're paralyzed. It was always there, easily accessible, reasonably easy to understand.

Most patients were frightened in the hospital setting and had little time to learn new techniques. They clearly indicated that complex alternatives should be the very last option in the hierarchy. VB suggested keeping conversation simple and concrete, and talk about the present instead of past or future events. Start with a 20 questions format for emergent medical needs. Have the medical needs categories listed in front of the patient or on the wall so that it is available to staff and family. Rely on a communication board that is stored in a consistent visible location for personal and conversational control needs. In addition, when multiple approaches are offered, it is advantageous to identify the contexts when each approach is most useful. A topic specific word board or body chart might be used when a patient is working with a physician to indicate pain, while an alphabet board would be used to generate novel messages with spouses.

Secondly, every patient stressed that clinicians must consider the personality of the patient and the family constellation. These normally speaking patients come to this new communication task with expectations. The additional variables of acute illness, fear, lack of control, and helplessness must be considered. Any approach that is recommended must be accepted by the patient and partners if it is to become a successful intervention. Smith-Lewis and Ford (1987) also stress this when they state that the user must be considered in all points of the decision making process.

Thirdly, most patients indicated that intervention is only successful if staff and family training is implemented. Communication partners respond differently to AAC techniques depending on the complexity of the technique, the amount of time they spend with the patient, and their comfort level. Every effort must be made to identify communication partners and to train them in AAC techniques and strategies. Light (1989), in her discussion of communication competence as an interpersonal construct, supports this point when she writes, "It is critical that AAC intervention extends not only to the client, but also to facilitators, the significant others in the client's life." (p. 138).

If every nonspeaking patient had a caregiver or an identified advocate who was trained in the AAC techniques and could, in turn, foster communication with the patient, more effective and efficient information transfer would result. This point is stressed by Mike and Alec as they related their experiences with family members.

> I think my wife and sons had a preconceived notion of what you're trying to say. After the first two letters, they decide what the word is. So they stop paying attention to what you're trying to tell them. That gets a little frustrating. I was trying to ask a question about REAL ESTATE and we got the first R-E out, my ex-wife and I. My boy's name is REID. That starts with R-E. And she already decided that I was talking about REID and asked, 'How's Reid's work going?' I shook my head and I finally gave up. I was frustrated.

Alec discussed his family's discomfort and lack of understanding with communication alternatives.

> They'd just get frustrated. My mom would try to figure out what I was saying and she'd get sorta nervous. That would pretty much be the end of our attempt because I'd realize she wasn't picking up on my message so I'd stop. Normally, that was the end of our visit. She'd get so frustrated she'd say, 'Well, I guess maybe I should go." Then she'd leave and never knew that all I was telling her was thank you for coming.

Finally, the theme that recurred in every interview was the need for constant inservice training of nursing staff and ICU personnel. Rose described a problem with staff training that led to a life-threatening situation. Of all the failures related, Rose's was the most crucial and really points out the need for comprehensive staff training and understanding of the AAC techniques. Training needs to take place on all nursing shifts as is evident from the following story.

> One night I was being given medication and had a food tube down my nose. I started regurgitating. It had come up out of my stomach. I was trying to make the nurse understand that I was regurgitating and for her to stop pumping anything more into my stomach. And it really got so bad that I ended up with a code 99. 'No," I just kept shaking my head, 'No, don't do that.' She didn't know how to use the alphabet board. That really made me think that, God, the Good Lord has just got to make these people understand that they have to be oriented to the alphabet board.

AAC specialists must determine the level of expertise of the nursing staff and ensure that each nurse is trained adequately in basic AAC techniques. The more complex approaches and device operations should be introduced when they are used by patients. Alec gave clear suggestions for staff training.

> I think all of the nurses in the ICU should have a clear understanding of how to use a communication aid. Then, not only could I have communicated with them easier, but my mom or whoever could've said, 'Can you show me how to use this?' Then they all would have known

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> exactly the same way to explain it. I think the staff should be trained separately from initial contact with the patient. I think they should already know how. At least the basic tools. It might be too much of a problem to teach the whole staff all about all the things, but I think the whole staff should know about the basic tools. And they should have a separate kind of training so that whenever a patient comes in, any staff member can go up and say, 'Here. Now let's use this here. A speech therapist will be down later. But right now, this is a basic method. And you can count on any nurse here knowing exactly how to use this and you can communicate with any of us.' We should have had at least that. Staff needs to be trained.

SUMMARY

The natural oral communicator who becomes a temporary nonspeaker from neurologic disease, mechanical or surgical intervention, or the introduction of lifesaving equipment, can critique AAC intervention in a new and vital way. They can relate how satisfactory augmented communication is, and what obstacles can be overcome to effect successful expression. The suggestions provided here by cognitively intact adults who relied on AAC approaches during Guillain-Barre syndrome or botulism episodes are quite pragmatic and simple. At times, however, professionals overlook the obvious principles. Many of the suggestions already should be incorporated into standard practice. However, family members and professionals may or may not remember to implement them under the stressful conditions that generally surround a very ill patient in a busy ICU.

These comments are also applicable for other nonspeaking populations. With any clinical group where time constraints and the stress of acute illness interfere with communication interaction, we must seriously consider the suggestions offered by these veteran nonspeakers. Regardless of age, etiology, or length of speechlessness, we must strive to improve service delivery. We must continually evaluate our effectiveness to train patients, their families, and staff members to maximize communication potential for individuals with severe expressive communication disabilities.

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