

4. In Garrett and Lasker's classification system, Generative Communicators are those people with aphasia who

- a. consistently require cueing to utilize external strategies for communication.
- b. can access messages that have been stored in advance but cannot formulate novel information.
- c. independently utilize multiple communication strategies to communicate novel information.
- d. utilize primarily stored messages to communicate.

End-of-Life Issues for People Who Use AAC

Melanie Fried-Oken

Oregon Health and Sciences University
Portland, OR

Lisa Bardach

Communicating Solutions, LLC
Ann Arbor, MI

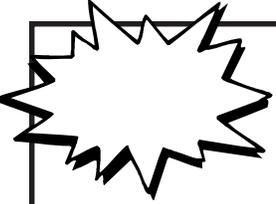
End-of-life issues for families and adults who use AAC were discussed by the following professionals at the 2005 Division 12 Leadership Conference: Lisa Bardach, Melanie Fried-Oken, Candace Ganz, Katya Hill, Mary Ann Lowe, Janis Nicol, Jill Tullman, and Lore Young. Collaboratively, we conducted qualitative research using an evidence-based practice paradigm with personal quotes from a variety of users. We identified key issues related to end-of-life for people who use AAC and established a research agenda that was submitted at the Division 12 leadership conference to all participants.

Schlosser and Raghavendra (2004) define evidence-based practice for AAC as "the integration of best and current research evidence with clinical/educational expertise and relevant stakeholder perspectives, in order to facilitate decisions about assessment and intervention that are deemed effective and efficient for a given direct stakeholder" (p. 3). Within their decision-making framework, we gathered research evidence to inform practice. Specifically, we asked questions, selected evidence sources, executed the search strategy, and examined and synthesized the evidence. Our evidence came from two sources: personal and external data. The personal data were values expressed by individuals who rely on AAC and their significant others. Clients and significant others were asked to comment on the impact AAC had on their lives. The external evidence included research hypotheses and formulation of meaningful, value-based questions that lead to profes-

sional expertise in service delivery (Hill & Romich, 2004).

The ALS Peer Workgroup of the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Program devised an operational definition for end-of-life. The workgroup advised that triggers for initiating discussion about end-of-life care for patients with ALS included any of the following: the patient or family asks, or "opens the door," for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal); there is severe psychological and/or social or spiritual distress or suffering; there is pain requiring high dosages of analgesic medications; the patient has dysphagia requiring a feeding tube; dyspnea or symptoms of hypoventilation are present, with a forced vital capacity of 50% or less; and/or there is a loss of function in two body regions (ALS Workgroup on Improving End-of-Life, in press).

Expert clinicians have addressed the use of AAC during end-of-life care. Stuart (2004) discusses AAC and palliative pediatric care. Hill and Jans (2004) list topics of conversations presented by seven persons with ALS (pALS) who used AAC technology at end-of-life. They include details on daily care, health related issues addressed to providers, instructions to significant others after death, funeral arrangements, and reminiscing (courtship). Fox, Hindal, Fried-Oken, Rau, Tullman, Baker, Wile, and Lou (2005) conducted a study that asked unpaid caregivers to list important communication purposes used by persons with severe loss of function



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secondary to ALS (often individuals near end-of-life). Caregivers report that, when overall ALS severity is greatest, pALS use AAC technology to communicate four "basic need" purposes frequently: calling for help, getting needs met, clarifying needs with caregivers, and giving instructions or directions.

When speech severity is greatest, caregivers report significantly greater importance and frequency for AAC technology to communicate for the social closeness purposes of comforting others, chatting, and having casual conversations. Costello (2004) interviewed patients and their families about the value of AAC at end-of-life. At the 2004 ASHA Convention, he presented a miniseminar with quotes and videos from the families and parents. They highlight the crucial importance that communication plays at end-of-life for families.

For language representation, Kagan has designed a picture vocabulary for persons with aphasia that supports conversation with chaplains and counselors (Kagan & Winckel, 1996). It is part of an interactive series of publications of pictographs for supporting conversation for persons with aphasia and is based on the techniques of Supported Conversation for Adults with Aphasia (SCAT), developed by the Aphasia Institute (Kagan, 1998). Symbols in this volume are presented to discuss problems; feelings, spirituality, health and illness; relationships and issues; people; and settings and time. It includes many end-of-life concepts and messages.

It is clear that a research agenda on end-of-life issues related to AAC is timely and appropriate. With this goal in mind, we submit the following framework, based on analysis of internal and external data sources. The framework organizes five thematic networks, which are depicted in Figure 1. It was derived through a qualitative data

analysis process. Initially, quotes were collected through interviews with AAC users and their families, books and essays written by AAC users and their families, and e-mail queries.

The quotes were brought to the DAAC leadership conference, and the group of AAC professionals listed above went to work. We first sorted the quotes into concept groups. Labels were applied when group members noted recurrent and salient ideas in the concept groups. Finally, concept groups were collapsed to form five recurring and interacting themes. The five themes are aggregates of the concept groups that are sufficiently specific yet inclusive enough to incorporate a set of connected ideas. The five themes are range of AAC options, techno-connectedness, importance of partners, quality of life, and quality of death.

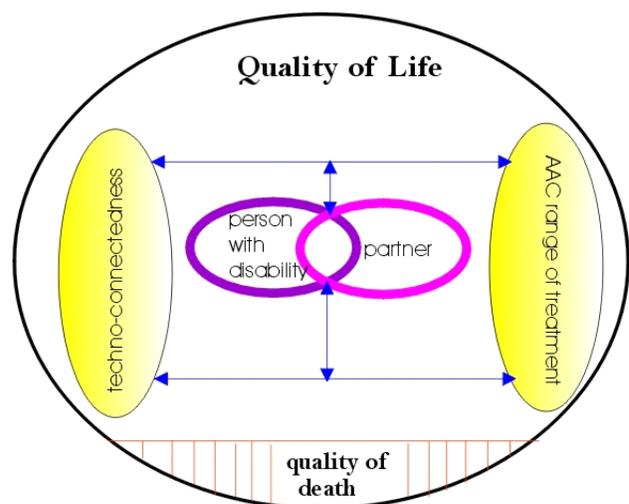
Range of AAC options is defined by the following principle issues: acceptance of technology, vocabulary, basic needs and fun, use of prestored messages, rejection of voice quality, variety of options, confidence, low tech and no tech use, alphabet chart, operational access to devices, and AAC for energy conservation and communication throughout continuum of care. These issues are specific to AAC devices and strategies, with the overriding principle that everything changes, and for each issue, there was a range of viewpoints. For example, Informant A, the wife of a pALS, talked about how AAC has affected the lives of herself and her spouse (L. Bardach, personal correspondence, December 16, 2004):

A lot of the time I am able to guess what he needs by what he is looking at. But there are just some things you would never guess in a million years. One day he let me know that he had a problem. I guessed and guessed. Then he wrote in the computer that he had a wedgie. The computer is a wonderful aid and it has made the last 2 years of his life much more bearable. I can't imagine how you could get through all this without the computer. One of the nicest things he says to me through the computer is "I love you."

Informant B, discussing her mother with ALS, stated (M. Fried-Oken, personal correspondence, October 12, 2004):

She didn't take the machine to her museum meetings. She used a pad, pencil, and friends. I think some were uncomfortable with her speech (sound) and disease (not knowing what ALS is). Unfortunately, socializing and eating go hand in hand. This disease can isolate people from social or business settings.

Figure 1. Framework for End-of-life Issues



"Techno-connectedness" refers to use of technology to retain social contacts, reduce isolation, and normalize communication. Recurrent ideas found from the personal data include online connected—playing the field, Internet access, telephone access, ECU use, access, maintaining ADL function with computers, retaining normalcy by using the computer, AAC to reduce isolation, connectedness, independence, age of client covaries with computer use.

Informant C, a pALS talked about his SGD (L. Bardach, personal correspondence, December 12, 2004):

Allowing me to stay connected to the on-line community, via the Internet and email (now), as well as the promise of continued capability for augmented one-on-one communication (later), makes my AAC device an indispensable tool.

Informant D has ALS and uses an integrated communication system. He noted (M. Fried-Oken, personal correspondence, November 23, 2004) :

The use of a computer to access email and the Internet can be of extreme value to the ALS patient. Because ALS is a relatively rare disease, there is a wealth of valuable information and support that is rarely available in such volume or detail elsewhere. This includes the latest information about current treatment options and research advances, both of which are evolving rapidly, in addition to a variety of online support groups. For many ALS patients, especially those not located near a major metropolitan area, the Internet offers the only real means of interacting with ALS experts and other patients. For patients who have limited

speech ability and/or use of their arms and hands, the internet may offer the only real option for social interaction through email, chat rooms and bulletin boards and for independently directed and controlled access to news, education and entertainment.

The ability to use a computer opens up endless possibilities not only for basic communication but also for creativity, learning, employment, environmental control, entertainment. It can be of critical importance in enabling the ALS patient to be a proactive partner in their own medical treatment and in allowing the patient some continued independence and control as the disease progresses. It can therefore have a profound impact on the patients' quality of life and patients have testified to it making all the difference in being able to tolerate their situations. Unfortunately, despite these distinct advantages, computer based augmentative and alternative communication is high tech and therefore inherently more complex.

Informant E, wife of a pALS, talked about how AAC has affected the lives of herself and her spouse (L. Bardach, personal correspondence, December 16, 2004):

He has had his EZ Keys for over 2 years. It is such a blessing. He not only uses it to communicate but also spends hours every day on the internet, where he can read the newspapers, go to religious sites, see the TV lineup, read information CDs, play music CDs, and hear devotions.

The theme of partners was derived from the following recurrent

issues: wife important, different people to interact with using other things than AAC, significant others present, knowledgeable support, social closeness; multimodal communication with partners. other people's attitudes toward AAC.

Informant F (King, 2000), an adult with developmental disabilities who uses a Pathfinder, found himself in the intensive care unit and commented:

It was really helpful to have my attendants (friends and people who know how to communicate with me) come to the hospital to assist with understanding what I wanted to tell the doctors and nurses. It was like we all had ESP with one another. The guessing game came in handy when I had spelled a word wrong and didn't know how to spell a word.

Informant G recalled her husband's use of AAC before he died with ALS (M. Fried-Oken, personal correspondence, August 29, 2004):

I think the greatest little tool for us was the alphabet chart. We had them all over the house and we taught everyone who came to visit how to use it. It was our life line throughout our journey. It allowed Ron to express his thoughts and it helped those who wanted so desperately to know what he was thinking to interact with him."

Quality of life is described by the World Health Organization (WHO, 1998, p. 17) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." There were many instances of references to quality of life from the personal data. Salient issues included normalcy, power of

communication, will to live, sense of community, emotions, fear, loss, safety, reassurance, fun, options with AAC, confidence, I love you, loss of status with AAC, personal preferences, dignity, emotional well being, intimacy, role changes in family, and social closeness.

Informant H, an engineer with ALS and total quadriplegia, stated (M. Fried-Oken, personal correspondence, September 22, 2004):

Communication via the use of AAC, be it an alphabet chart or a computer based program, is critical to the caregiver's ability to provide quality care. As important, it also is critical to maintaining inter-personal relations between the caregiver and patient. The quality of the caregiver/patient relationship is a significant factor in whether care giving is considered an act of love, a chore or a burden. The inefficiency of communicating using AAC can be frustrating for the caregiver. I try to type up what I want to say in advance and also use email.

I believe having AAC devices for direct communication are not only a medical necessity but also have a dramatic impact on quality of life and therefore the will to live. However, speech generating devices are only part of the solution. For patients that can't setup and use these devices independently, an easily and quickly available alternative solution like an alphabet or communication chart is also essential. Furthermore, the ability to use a computer for tasks such as email and Internet access can be of extreme educational, entertainment and social value to the ALS patient. Likewise, environmental control can have a signifi-

cant impact on the quality of life and emotional well being of the ALS patient.

The quality of death was another unifying theme that emerged. Its recurrent components included: connectedness; intimacy; communication until the day I die; the big loss without communication; and dignity to be able to express end-of-life decisions. Also the four messages used in the hospice mantra—I forgive you, you forgive me, I love you, it's okay to let go—were repeated often.

When talking about communication on the last days, Informant I, the mother of a 7-year-old girl with an anaplastic astrocytoma of the thalamus (J. Costello, personal correspondence, June 29, 2004) stated: "In the end, she just wanted us to know she loved us. She wanted to make sure we didn't forget."

Informant J, a 29-old-woman with a terminal disease, talked about signing a "do not resuscitate" (DNR) for herself and designing a communication tool to allow her to discuss advanced directives (M. Fried-Oken, personal communication, October 14, 2004): "I issued a DNR not because I want to give up, but because there is a limit to what I want done with me. I know what it is like to be living on a vent. I want to have the option to say that I don't want to do it any more."

Based on these themes and personal data, meaningful, value-based questions that are important to the client were formulated. A research agenda aimed at seeking answers based on personal evidence was proposed. The questions concerning clients at the end-of life stage of illness are:

1. What are the most effective AAC interventions to optimize communication?
2. What are the most important strategies to optimize technology-connectedness?

3. What are the quality of life measures related to communication?
4. What are the quality of death measures related to communication?
5. What are the AAC interventions to improve quality of life?
6. What are the AAC interventions to improve quality of death?
7. What are the quality of life measures related to communication?
8. What are the quality of death measures related to communication?

We submit the beginning of a research agenda to address these issues. Research efforts from these personal data might include:

1. Define, operationalize, and quantify the impact of ability of communicate on quality of life
2. Determine the best model for service delivery to clients with ALS at end-of-life
3. Conduct within-subjects research to measure improvement, define success, and determine what tools can be used to measure current ability to communicate
4. Look at questions from the perspective of different cohorts

The best way to conclude a qualitative analysis manuscript is with a personal quote. It represents the core values of the research approach, and the crucial role of the stakeholders to the field of AAC.

Informant K, the mother of a 12-year-old boy with juvenile Huntington's disease, summed up the value of AAC at the end-of-life when she discussed the loss of communication (J. Costello, personal correspondence, July 5, 2004):

Communication has been the biggest loss for all of us because that is the way we give each other reassurance, love,

and safety. You can take away many things, but if you take away his communication, then you are taking away my son.

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Continuing Education Questions

1. Triggers for initiating discussion about end-of-life care for patients with ALS include

- following the diagnosis by the physician.
- the patient functions well within society.
- the patient enjoys eating all foods.
- the patient or family opens the door to discuss end-of-life interventions.

2. "An individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns" refers to

- cultural competency.
- quality of life.
- quality of death.
- communicative competence.

3. The use of technology to retain social contacts, reduce isolation and normalize communication in the face of end-of-life issues is referred to as

- social networks.
- participatory action.
- techno-connectedness.
- environmental control.

4. Issues that families discuss around quality of death include

- being able to write their needs and wants.
- shopping for new clothes.
- travelling.
- the big loss of communication, intimacy, and dignity.