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Duration of AAC Technology Use by Persons with ALS

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The purposes of this research report are (1) to document the duration of augmentative and alternative communication (AAC) technology use by 45 persons with amyotrophic lateral sclerosis (ALS), 7 of whom were still living (with mechanical ventilation) and continue to use the technology; (2) to identify factors that might influence duration of AAC technology use; and (3) to report the AAC technology donation trends of families after persons with ALS are no longer living. The duration of AAC use varied considerably across participants; however, the mean duration was 28.4 months for all participants, 25 months for persons with primary bulbar ALS, and 34.2 months for those with spinal ALS. Review of the data reveals that invasive ventilation and timeliness of referral for AAC assessment have a greater impact on duration of AAC use than ALS type. Of those with ALS who were no longer living, 60% of their families had donated AAC devices to an AAC loan program or to another person with ALS, 32% retained the device, and 8% returned loaner devices to the equipment lending program that had originally provided the device.

Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular disease whose cause remains unknown and for which no cure has been identified. Severe motor speech impairment is common for persons with ALS. Ball, Beukelman, and Pattee (2003) reported that approximately 95% of persons with ALS are severely dysarthric or unable to

speak at some point prior to their death. Because of this high percentage of severe speech impairment, the assumption is that persons with ALS will benefit from using augmentative and alternative communication (AAC) technology to converse.

There have been few reports about AAC acceptance and use by persons with ALS. In a Gutmann

and Gryfe (1996) account reported in Mathy, Yorkston, and Gutmann (2000), approximately 72% of men and 74% of women accepted and used AAC technology. However, in a recent report by Ball, Beukelman, and Pattee (2004a), 90% of persons with ALS accepted and used AAC technology immediately, while another 6% accepted and used AAC technology following some delay. No differences were reported between male and female participants' acceptance. Those who delayed AAC technology acceptance did so for a variety of reasons, including personal resistance to change, physician unwillingness to refer, and family reluctance to relinquish the role of "most effective communication partner." Of the 4% who completely rejected AAC, the participants demonstrated either (a) severe co-occurring frontal temporal dementia or (b) experienced multiple serious health conditions, such as cancer or heart disease, in addition to ALS.

Based on the extant published research, AAC technology acceptance and use has apparently increased during the past few years. One reason for this recent increase in acceptance is likely due to new funding availability for this technology. Beukelman, Yorkston, and Garrett (2007) indicated that the availability of funding for AAC technology and services has improved considerably in the United States during the last decade, with Medicaid funding consistently available in most states. In 2000, Medicare began funding AAC technology (considered durable medical equipment); by assigning the moniker of Speech Generating Devices (SGDs) specifically to the devices that produce speech output. The impact of this nationwide change in policy is that SGDs have been subsequently approved for coverage by numerous other funding institutions, including private insurance companies (Beukelman, Yorkston, & Garrett, 2007) and the Veteran's Administration (L. Golinker, personal communication, January 29, 2007), among others.

Several research groups have reported attitudes toward AAC technology and AAC technology use patterns by persons with ALS, their caregivers, and family members. Mathy et al. (2000) documented the communication activities supported by various communication methods for persons with spinal and bulbar ALS. Fried-Oken et al. (in press) reported very positive attitudes of ALS caregivers toward AAC technology. In this study, caregivers with greater AAC technology skills reported greater rewards associated with caregiving. They reported increased perception of closeness to

the person with ALS and less difficulty providing care. Richter, Ball, Beukelman, Lasker, and Ullman (2003) compared the attitudes of people with ALS, caregivers, and unfamiliar listeners toward AAC strategies. They reported a high level of agreement among those with ALS and their caregivers, with clear preference for using AAC strategies as compared to attempting to decipher unintelligible natural speech. A high level of agreement among the listener groups and unfamiliar listeners was also identified.

A review of the literature reveals little systematically collected information about the duration of AAC technology use by persons with ALS. Mathy et al. (2000) reported on the AAC use patterns of 33 persons between 1988 and 1996, whom Mathy (1996) initially described in a presentation. For all of these persons with ALS, duration of AAC use averaged 1.2 years. Those with bulbar ALS averaged 0.8 years and those with spinal ALS averaged 1.8 years. The physical, nutritional, respiratory, and communication status of the participants at the time of data collection is unclear.

One might hypothesize that duration of AAC technology use for persons with ALS depends on many factors, including life expectancy, nutritional status, and timeliness of AAC delivery. Life expectancy varies depending upon the type of ALS, as demonstrated by the 5-year survival rate for persons with spinal ALS being essentially three times longer than those with bulbar ALS. Life expectancy is longer for persons who opt for mechanical ventilation. Noninvasive ventilation (such as BiPAP®; Respironics, 1989) has been associated with improved quality of life, and perhaps increased survival. Invasive ventilation via tracheostomy can extend life considerably; however, it does not alter the progression of other neurological symptoms (Yorkston, Miller, & Strand, 2004). Clinically, the general consensus is that a decision to use invasive ventilation extends the duration of AAC use overall, and as a result it extends the duration of time during which AAC technology is accessed with increasingly limited residual movement capability.

A second hypothesized influence of length of AAC technology use is improved nutritional status. Although 20–30% of persons with ALS have bulbar onset, eventually nearly all experience bulbar symptoms, which in addition to dysarthria, result in dysphagia (Mitsumoto, Chad, & Pioro, 1998). Dysphagia places them at risk for dehydration and malnourishment, with one study finding that 16.4% of persons with ALS were malnourished

(Dupont, Preux, Truong et al., 1999). Because malnourishment is a prognostic factor for survival, persons with ALS who were malnourished had a 7.7 fold increased risk of death (Dupont et al., 1999). Although enteral/intestinal delivery of nutrition (e.g., percutaneous endoscopic gastrostomy feeding tube, or PEG) improves the quality of life for persons with ALS, it may or may not significantly increase life expectancy, particularly if inserted late in the disease (Chio et al., 1999; Chio et al., 2002; Desport et al., 2000; Mazzini et al., 1995; Mitsumoto et al., 2003). The current American Academy of Neurology ALS Practice Parameters (Miller et al., 1999) specify that PEG is indicated when persons with ALS have symptoms of dysphagia with accelerated weight loss due to insufficient caloric intake, dehydration, or ending meals prematurely because of dysphagia or choking on food (Mazzini et al., 1995). The timing of PEG is also considered in the context of pulmonary status, with recommendations for PEG placement before forced vital capacity falls to 50% of predicted values (Mathus-Vliegen, Louwerse, Merkus, Tytgat, & Vianney de Jong, 1994). Neurologists are increasingly recommending PEG placement early in the disease process, prior to significant weight loss and/or respiratory decline. As a consequence, persons with ALS spend less time eating, have more energy and adequate hydration, and therefore can spend more time in social situations of their choice. Often participation in these social situations increases the need and opportunity for AAC use.

The third hypothesis of factors influencing duration of AAC use is that it is likely dependent on the timeliness of the AAC assessment and acquisition of technology. Ball, Beukelman, and Pattee (1999, 2001, 2002) described a strategy to predict the timing of AAC assessment and acquisition based on observed decline in speaking rate. They recommend that when speaking rate calculated from sentence reading tasks reaches 125 words per minute, with 190 words per minute considered typical for adult speakers (Yorkston, Beukelman, & Tice, 1996), an AAC evaluation should be initiated. However, anecdotal reports (L. Bardach, personal communication, November 13, 2007) reveal that many persons with ALS do not receive an AAC evaluation until much later in the course of their condition, often when speech is no longer intelligible. Certainly, timing of AAC technology assessment and acquisition impacts duration of AAC use by a person with ALS, with late referral resulting in an abbreviated period of use.

Fourth, it is hypothesized that duration of AAC technology use is likely related to access options

and social support. Ball et al. (2004a) found that persons with ALS continue to use their AAC systems at minimum until within 1 month of their death. With access options that provide persons with ALS the ability to continue to use their AAC technology, even with extremely limited movements, it is expected that persons with ALS will use the technology for lengthier periods of time. When social support is provided by AAC technology facilitators, who assist in ongoing AAC technology set up and positioning, persons with ALS will likely increase duration of AAC technology use (Ball, Schardt, Kim, & Beukelman, 2005; Beukelman, Fager, Ball, & Dietz (2006).

The purposes of this research report were to:

1. document the duration of AAC technology use by 45 persons with ALS, six of whom were still living via mechanical ventilation and continued to use AAC technology,
2. identify factors that might influence duration of use, and
3. report the AAC technology donation trends of families following the person with ALS' death.

METHODS

This research was approved by and conducted within the guidelines of the University of Nebraska Medical Center Institutional Review Board. All participants signed informed consent prior to enrollment in a longitudinal study examining speech characteristics and AAC use. Data for this research was acquired retrospectively from assessment scores obtained during clinical interactions that are maintained in a database and prospectively from interviews of surviving family members and caregivers.

Participants

Forty-five (N = 45) persons with ALS who accepted and used AAC technology served as participants in this investigation. Criteria for inclusion in the study were that participants:

1. were diagnosed with ALS-definite as defined by the El Escorial (1999) criteria by Dr. Gary L. Pattee, a board-certified neurologist;
2. were evaluated for AAC technology and presented with a variety of at least five potential devices for use;

3. were recommended AAC technology upon completion of the AAC evaluation on or before April 2006; and
4. accepted AAC technology for their communication.

The study involved persons with two ALS diagnostic types; 53% ($n = 24$; 17 male, 7 female) bulbar ALS, and 47% ($n = 21$; 11 male, 10 female) spinal ALS. At the time of this report, 87% ($n = 39$) of the participants were deceased. Of the six participants who continued to survive, all were supported with PEG and mechanical ventilation (5 with tracheostomy and ventilator, 1 with full-time BiPAP® ventilation).

Speech and AAC technology use information was entered into a database for people with ALS seen during clinical visits at two midwestern ALS clinics sponsored by the Muscular Dystrophy Association. Participants were subsequently assessed for AAC technology by one of five different community speech-language pathologists, all considered to be AAC clinical specialists experienced in providing AAC to persons who have ALS. All participants accepted AAC technology, either immediately or after some delay (Ball et al., 2004a), to support their functional communication. Eighty-seven percent of participants ($n = 39$) were regularly evaluated in a regional ALS specialty clinic and were scheduled for regular clinical visits (i.e., every 3 months). The other 13% ($n = 6$) were referred for AAC evaluations from regional physicians and were not involved in a regular ALS specialty clinic.

Participants' ages at the time of diagnosis ranged from 29 to 80 years, with a mean age of 56.6 years. Socioeconomic status scores of the participants ranged from 19 to 66 ($M = 42.1$) based on The Hollingshead Four Factor Index of Social Status (FFI) (Hollingshead, 1975). The FFI uses education, occupation, gender, and marital status to determine a composite social status. Each family's composite score was computed by multiplying the Occupation scale value by a weight of 5 and the Education scale value by 3 and summing the products. Hollingshead Education scores ranged from 1 (less than seventh grade) to 7 (graduate professional training), and Hollingshead Occupation codes ranged from 1 (farm laborers/mental service workers) to 9 (higher executives, proprietors of large businesses, and major professionals). Hollingshead Four Factor Index raw scores ranged from 19 to 66, with higher scores reflecting higher socioeconomic status (SES). In homes

with two employed adults, the scores were averaged to obtain one score per family. A higher score obtained on this index denotes a higher ranking in social position (min = 8, max = 66); participants included a range of social position and reflected a sampling of each level of SES identified by this index, with the majority of scores surrounding the mean. All participants spoke American English as a primary language, were literate to a minimum commensurate with seventh grade, and all participants reported no neurological impairments other than ALS.

Procedures

The first author reviewed and obtained information for the present study from the Nebraska ALS database, which contains data obtained from clinical visits of persons with ALS (Ball et al., 2002). Information obtained from the database included age, gender, SES, ALS type, AAC technology presented, AAC technology accepted, date of AAC evaluation, date of AAC technology receipt, total months of AAC technology use, date of death, and some equipment disposal information. Information regarding date of death, when not available from the Nebraska ALS database, was obtained from ALS clinic staff ($n = 4$) or treating speech-language pathologists ($n = 1$). Information regarding AAC technology use patterns near the end of life and the remaining information regarding donation of equipment was obtained through interviews (some via telephone and others face to face) with surviving spouses ($n = 25$) and caregivers (primarily adult children who served as AAC facilitators, nursing staff, and close friends) ($n = 20$). Interviews with the surviving spouses or caregivers were completed by the first author or the community speech-language pathologist who had been the primary contact regarding AAC technology. Because of the emotional nature of the interview due to proximity from the participant's death, a formal question format was not used; however, interviewers were instructed to obtain the answers to the following closed- and open-ended questions:

1. Did the person communicate at the end of life?
2. Please describe how the person communicated at the end of life.
3. What has happened to the AAC technology the person used? and
4. How was the decision made regarding what to do with the AAC technology when the person was no longer using it?

Interviews were broadly transcribed online as the interview progressed and then these data were added to the database information for each participant. The total of this information allowed for the computation of duration of use data. Timelines were also established for delayed referrals, ventilator use, and PEG nutritional supplementation from the Nebraska ALS database.

RESULTS

Duration of AAC Technology Use

AAC technology selected for use by the participants varied according to specific needs and options desired and were also dependent on the devices commercially available at the time of their evaluation. At the time of AAC evaluation, participants' mean speaking rate in sentences was 62.1 words per minute (range 1–129 wpm) and mean intelligibility was 51.3% (range 0–98%). These scores in-

dicate an overall significant need for AAC, with a large number ($n = 31$, or 69%) falling below the criterion level specified by Ball et al. (2002) for timely referral.

Specific devices used by this group of participants included nine different devices produced by seven different manufacturers. The selection of these devices was influenced by (a) specific communication needs and preferences, (b) specific access needs and preferences, and (c) systems that were commercially available when the evaluations were completed or when recommendations were made. A second potential influence related to specific types of use. A small number ($n = 9$, or 20%) continued to work until their physical disability precluded it, and they used their AAC technology at work until that time.

The duration of AAC technology use varied considerably across participants, as Figure 1 illustrates. Overall mean duration of use for all participants was 28.4 months, with 13.3% of the participants on long-term mechanical ventilation

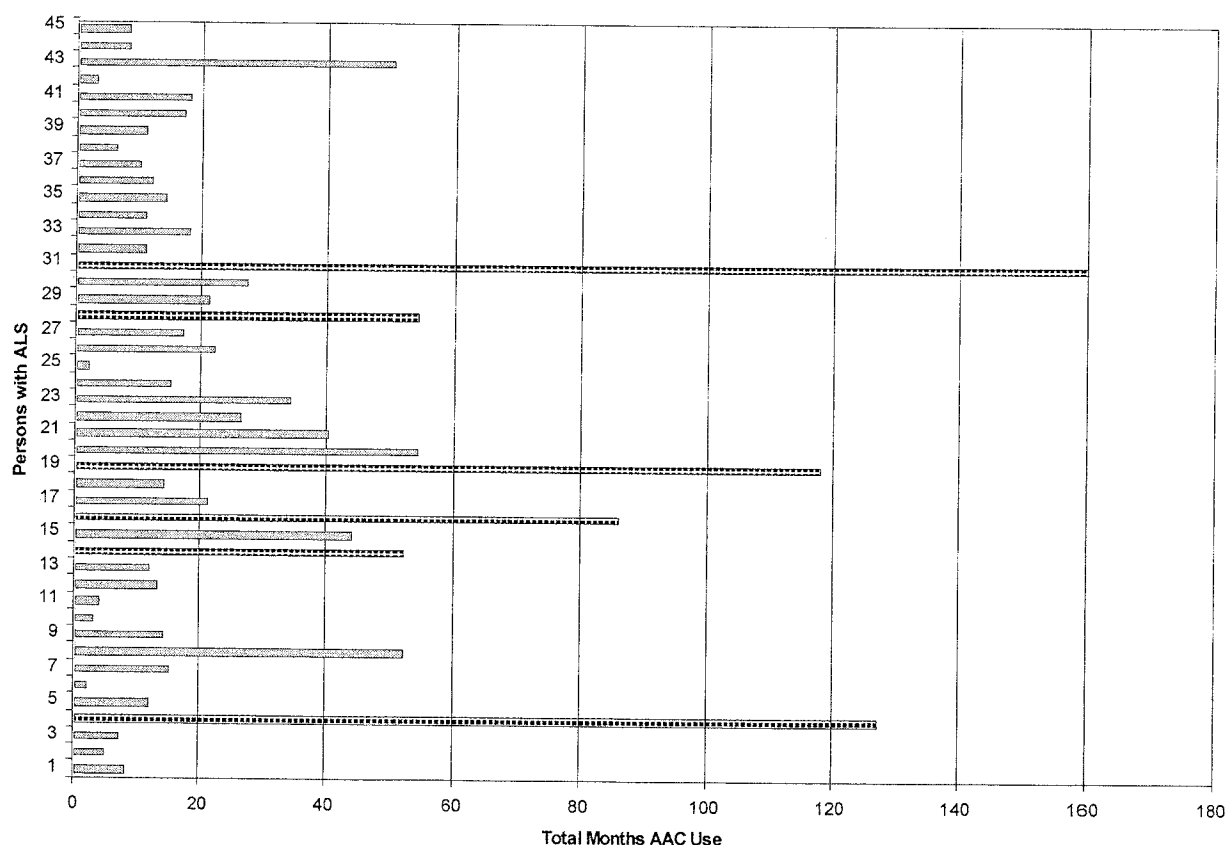


Figure 1. Total number of months of AAC technology use by persons with ALS. *Note:* Bars with a pattern indicate participants who elected to use mechanical ventilation and are continuing to use the AAC technology. Solid bars indicate participants who are now deceased.

continuing to use their equipment at the time data was collected. Of the total 45 participants, 87% ($n = 39$) used (or continued to use up until this publication) a single AAC device, while 13% ($n = 6$) used more than one device. All of the participants who used more than one device also chose invasive ventilation to extend the duration of their lives. Of the participants who used more than one device, all six used only one additional device. Two changed devices because they were provided a temporary-use device for a period of time from an AAC equipment lending program. These persons already presented with severe dysarthria at the evaluation and required a functional communication system immediately. They were consequently loaned a device, which was replaced by the device they selected during the assessment upon its arrival. An additional three persons with ALS used their initial system until it was outdated and no longer functional or impractical to repair and replaced with newer technology of the same type. One participant changed technology when he could no longer access his initial device, and the device did not accommodate alternative means of access (e.g., Braille-n-Speak). Funding was available for all but one participant, with the majority accessing Medicare (Medicare = 27, Medicaid = 6, Private Insurance = 5, Lending Program = 4, Private Pay = 2, VA = 1).

Table 1 illustrates the mean duration of use for all participants and for groups according to type of ALS, age, gender, and SES. The mean duration of use for persons with bulbar ALS was 25.2 months, with a range from 3 to 118 months. The three participants with the longest use (i.e., 60, 84, & 118 months) all chose to be supported with invasive ventilation and tracheostomy. The four individuals with bulbar ALS who used their AAC technology less than a year were all considered to be late

referrals (i.e., they did not meet the speaking rate guidelines for timely referral) for AAC intervention. Because of the short duration of use, these researchers examined the data for specific information that might indicate a relevant cause for such a brief period of use in each case. In the first example, the person who used AAC technology for only 3 months was referred when she could not use her natural speech to meet any communication needs. The person who used AAC technology for 4 months was referred for AAC assessment with a speaking rate of 101 words per minute and a significantly impaired intelligibility score of 70%. The person who used AAC technology for 5 months was referred when her speaking rate was 51.5 words per minutes and her speech intelligibility was only 37.5 percent. Finally, the person who used AAC technology for 8 months was also referred when he was no longer speaking.

The mean duration of use for persons with spinal ALS was 32.1 months, with a range from 2 to 160 months. In this group, the person who used AAC technology for 2 months was referred very late and was experiencing considerable respiratory issues, so she was provided with a device from a regional equipment loan program. She clearly did not meet the guidelines (Ball et al., 2002; Ball, Beukelman, & Bardach, in press) for referral based on speaking rate and intelligibility. Two others used their AAC devices for less than a year; in both cases their speaking rate was below the 125 words per minute guideline at the time of referral. The two persons with spinal ALS who used AAC technology for the longest durations, 60 and 160 months, both chose invasive ventilation and were both still living when this data was analyzed. The longest duration of AAC technology use for a person with spinal ALS who did not choose mechanical ventilation was 50 months.

TABLE 1. AAC technology use by persons with bulbar and spinal ALS.

ALS Type	Age Mean Years	Gender		SES* Mean (Range)	Months Used Mean (SD)	Funding		Mechanical Ventilation		Device Status		
		M	F			NO	YES	NO	YES	D	K	U
Spinal	52	10	7	43.1 (24,66)	34.2 (44)	2	15	14	3	9	5	3
Bulbar	58.7	18	10	41.5 (19,66)	24.9 (27.1)	4	24	25	3	21	4	3
Total	56.6	28	17	42.1 (19,66)	28.4 (34.3)	6	39	39	6	30	9	3

*Socioeconomic status as measured with the Hollingshead Four-Factor Index (1975).

Current device status is noted with D = Donated, K = Kept by family, U = Currently using.

Use of AAC Technology at End of Life

According to AAC facilitator, caregiver, and/or family member reports, all of the participants used their AAC technology for functional communication until within 1 month of their deaths (reported for the 39 participants who were deceased at the time of this report). Of these 39 participants, 46% ($n = 21$) used AAC technology during the last week of their lives. Ninety-four percent ($n = 34$) reported reliance on low-tech strategies as well as use of high-tech AAC devices. All reported an increased use of low-tech strategies such as eye-linking, eye-gaze, message signals (mostly facial or eye movements), and partner-dependent scanning during the final weeks and months of life.

Donation of AAC Technology

Six of the total 45 participants continued to use their AAC devices at the time the data was analyzed for this article, but for the remaining 39 participants' families, 60.4% donated the AAC technology to an AAC equipment loan program or to another person with ALS. For the eight percent who had used AAC technology from a lending program, all had returned the device to that program. An additional 31.6% retained the AAC technology, although many indicated that they were thinking about donating the devices, but were having difficulty doing so because they fondly remembered when the person had used it. "I took the communication device with me (to a gathering of family and friends after his death) and played a couple of his jokes. My heart just kind of pounded because that was really Tom" (Rutz, 2005). Families that retained the devices typically were those for whom the death of the person with ALS was quite recent, usually within 1 year, or when the devices contained an extensive number of stored messages.

DISCUSSION

This study described factors that impact the duration of use for AAC technology, examined patterns of use for AAC technology toward the end of life, and explored the disposal of AAC technology following the death of a group of persons with ALS.

Factors that Impact Duration of Use

A consideration of the factors that impact duration of AAC technology use is important for appropri-

ate intervention, as well as for forming decisions on which to base policy. Functional communication is an essential component to improved quality of life for persons with severe physical limitations, such as those experienced by persons with ALS. The mean duration of AAC technology use of 28.4 months supports the assumption that AAC technology plays a sustained role in supporting persons with ALS, their caregivers, family members, and social networks in functional communication. However, the details reveal considerable variability in AAC technology use.

Although published reports do not yet reflect the trend, there is anecdotal information from clinical programs in the United States that increasing numbers of persons with ALS are opting for invasive mechanical ventilation. This trend has implications for AAC intervention, in that these individuals will need to access their AAC systems with progressively less residual motor control as their lives are prolonged. Although the factors that influence this trend have not been investigated, one might assume that improvements in technological support in the areas of nutrition, ventilation, and communication should be considered.

One apparent weakness of this study involves the inclusion of persons who have accepted invasive ventilation and continue to survive. Although these researchers considered use of the date when the person with ALS initiated full-time use of invasive ventilation as an endpoint (i.e., indicating that these participants were no longer able to sustain life with unsupported ventilation), the decision was ultimately made to include the ongoing use data in this report. Because the percentage of persons with ALS who elect to use mechanical ventilation in the general population is consistent with the number of persons in this study who chose this option, it was deemed appropriate to include them in these data, even though their reported duration of use is not yet finalized. As a result, these data show that the decision to choose invasive ventilation appears to have a substantial impact on the duration of AAC technology use.

Participants with the longest duration of AAC technology, regardless of ALS type, were those who chose mechanical ventilation. Of the 45 participants, six chose to use mechanical ventilation, and all six continued to use AAC technology at the time data collection for this study was finalized. In reality, the data reported in this article underestimate the duration of AAC use for these persons; those with invasive ventilation continue to live at

the time the data were collected and the duration data continue to increase.

The decision to choose invasive ventilation is complex, and the impact of invasive ventilation on AAC use duration raises several intervention issues. Not only does it impact AAC technology selection, but it also impacts living arrangements, care requirements, and quality of life. When possible, it is preferable that this decision is made, or at least identified as an option, as early in the course of the disease progression as possible. In this manner, decisions about technology, living arrangements, and family support may be made with consideration for mechanical ventilation. It may become particularly problematic when invasive ventilation is procured without extensive thought or planning. For example, a person with ALS receiving an emergency tracheostomy in response to a sudden respiratory failure, or while being treated "temporarily" for a condition, while holding on to a false hope for cure or misdiagnosis, may only much later realize the full impact of this life-extending decision. In such situations, life can be extended without planning for and arranging the necessary provisions to support and maintain AAC technology.

Although ventilatory support lengthens life for persons with ALS, it also is accompanied by ongoing decreases in motor function. Therefore, the AAC technology chosen for these persons must be of the type that supports a range of different access options. If this strategy is not undertaken, there will be the need for the person to obtain different technology as motor control deterioration is observed. Of the 45 participants in this study, two required a change in AAC technology to provide functional communication following sustained ventilatory support because they could no longer complete the movements necessary to access their initial device. In neither case was the decision to pursue invasive ventilation made at the time of initial device selection. One participant who had originally planned to opt for invasive ventilation has acquired a system that is operated using eye gaze, with the idea of providing ongoing access while confronting continued decline in muscle activity.

The decision to use eye gaze AAC technology will likely become more prevalent as this technology has improved in recent years and continues to become more affordable, accessible, and reliable. With this in mind, it is important to consider that some research has identified a subset of persons with ALS who have visual tracking difficulties that might potentially restrict their ability to

use a system accessed with eye gaze (Katz et al., 2006; Saito & Yamamoto, 1989). Katz et al. (2006) found a relationship between ocular apraxia, severe cognitive impairment, and bulbar ALS among a subset of persons with ALS. These authors suggest using ocular motility testing to screen for cognitive deficits. These skills will also be imperative to predict the ability to use any AAC system in which access is based on eye gaze. As with all AAC devices, the basis of a decision whether to acquire a particular system must be formed by evaluating the person with ALS' direct interaction with and demonstrated ability to use the system for functional communication.

Because historically the type of ALS has an impact on the overall life expectancy of a person with ALS, one might hypothesize that the type of ALS might have considerable impact on the duration of use of AAC technology. However, the data reported in this study do not support that conclusion. While the time from initial symptoms (or definitive diagnosis) until one needs AAC technology is shorter for persons with bulbar as compared to spinal ALS (Ball et al., 2004a), the duration of use is only slightly longer for those with spinal ALS. A recent study (Czaplinski, Yen, Simpson, & Appel, 2006) reveals a trend toward slower disease progression and prolonged survival among a contemporary group of persons with ALS (1999–2004) versus an historical group (1984–1999). These researchers revealed that the median survival time from symptom onset was 4.32 years in the contemporary group compared to 3.22 years in the historical group. This increase in survival time and slowed rate of progression appeared to be independent of other factors including age, gender, diagnostic delay, site of symptom onset, baseline respiratory functioning, and use of available therapies (Riluzole, NIV, PEG). Their observations suggest the possibility that disease progression has changed over time and become less aggressive or that the results may be due to other aspects of improved multidisciplinary care. Nonetheless, while the group of participants in the current study would all fall into the "contemporary" category, it appears that the decision of whether or not to seek ventilatory support has a much more powerful impact on duration of AAC use than the type of ALS.

The use of PEG and noninvasive ventilation (BiPAP®) has increased and is now considered part of the basic standard of care for persons with ALS. This is reflected in the participant's data for this study, in which 38 (84.4%) of the 45 participants

had both PEG and BiPAP® in use from early in the disease or as soon as respiratory difficulty or weight loss were noted. These were the last 38 participants enrolled in the study. The same participants who used PEG also used BiPAP®.

Finally, the timeliness of the referral of persons with ALS for AAC technology assessment has an important impact on duration of use. A review of the data reported in this article reveals that in nearly every case, those who used their AAC technology for less than 10 months, were referred "late." That is, considerable time had passed after the speaking rate guidelines (125 words per minute) indicated a referral for AAC intervention was necessary. Often, these persons were referred when their speaking rate was well below the guidelines or when they were no longer able to use their natural speech to meet even their most basic communication needs. In a recent report, Ball, Beukelman, and Pattee (2005) documented that speaking rate can be monitored as accurately over a conventional analog telephone as with face-to-face in a clinical setting. They recommend the use of telephone-monitoring strategies when distance, weather, or lack of transportation makes regular clinical evaluations impractical. This strategy may be easily implemented to facilitate timely referrals. Timely referral for AAC intervention remains a critical decision-making issue for persons with ALS, their families, and their physicians.

End of Life Use of AAC Technology

All of the ALS participants used their AAC technology until within 1 month of their deaths. Many used the technology during the last days of their lives. During the last months of life, most people with ALS required changes in medical and personal care. For some, additional care personnel came into their homes, while others were transferred to hospice settings. In each case, AAC technology and low tech interaction instructions were provided to the new caregivers. Usually, this instruction was provided by the person's AAC facilitator and occasionally by the AAC interventionist.

Toward the end of life, increased use of low-tech strategies such as eye linking, eye gaze, message signals (mostly facial or eye movements), and partner-dependent scanning, were used and routinely reported by family members and caregivers. AAC interventionists often were consulted to develop the strategies and to provide instruction to the AAC facilitator, who then instructed other communication partners.

Donation of AAC Technology

At the time that data were collected, approximately 30% of the families retained the AAC devices that had been used by persons with ALS prior to their deaths. Eight percent had returned the equipment to the loan bank because it was owned by the bank and not by the individual, and 31% retained the technology. Anecdotally, the clinical staff reported on donation patterns in groups. One group donated the equipment to the loan bank or to another individual with ALS very shortly following the death of the original owner (sometimes the following day), while another group reported great difficulty "giving up" the equipment and usually did not donate the technology until at least one year following the death of the person who relied on AAC technology. During informal conversations, the family members of these persons frequently reported that they found it very difficult to donate the equipment, because the stored messages and the "voice" were among the most intense recent memories that they had of the individual. Several commented that, on special occasions, they would "remember" their loved-one by playing messages aloud and recalling times when these messages had been used to connect with family and friends.

It should be noted that these donation patterns occurred in a context in which the AAC-related or medical staff did not actively encourage technology donation or share information about how other families had donated AAC or other assistive technology. When family members inquired about donation options, they were told of the local choices available to them. Had the medical or clinical staffs encouraged those who used AAC or their families regarding donation, the donation patterns would likely be different than those reported in this article. Often, people with ALS will ask about how to dispose of equipment when they no longer require its use. Some families obviously want to keep their family member's communication device, while others attempt to sell the equipment. When asked, an explanation of the role of donations is often helpful, because unless faced with lack of funding themselves, few are aware of problems associated with acquiring this costly equipment. Because Medicare does not fund durable medical equipment for persons in nursing facilities, and hospices do not fund AAC technology, there is a group of people with ALS who may find themselves excluded from some funding options. If their personal funds are not sufficient to purchase this technology, donated

devices can serve a vital role in maintaining their communication. Additionally, for persons who are referred very late for an evaluation, after their speech no longer supports their communicative needs, donated devices may provide a bridge of communication until the equipment recommended at the evaluation arrives.

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