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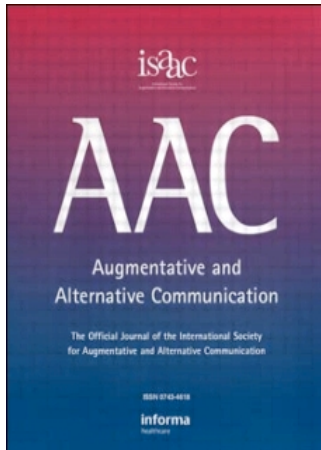
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Acceptance of Augmentative and Alternative Communication Technology by Persons with Amyotrophic Lateral Sclerosis

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A review of the use of augmentative and alternative communication (AAC) technology by 50 persons with amyotrophic lateral sclerosis was completed over the course of 4 years. Ninety-six percent of the participants in this study accepted AAC technology, either immediately (90%) or after some delay (6%), and only 4% ($n = 2$) rejected AAC technology. None of the participants discontinued use of their AAC technology. Reasons for acceptance decisions were discussed in interviews with study participants and the results are presented.

Keywords: Augmentative and Alternative Communication (AAC); Amyotrophic Lateral Sclerosis (ALS); Adult motor speech disorders; Dysarthria

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neuromuscular disease in which motor neurons are destroyed, resulting in weakness, atrophy, and paralysis. Complex speech impairments are common sequelae of ALS, with 80% of persons with ALS experiencing such significant impairment that they require augmentative and alternative communication (AAC) strategies to support their daily communication needs (Sitver & Kraat, 1982). Successful AAC use by people with ALS has been documented by a number of authors. A review of the literature, however, suggests that one quarter or more of these individuals with complex communication disorders did not accept AAC interventions (Mathy, Yorkston, & Gutmann, 2000). For example, Gutmann and Gryfe (1996) found that 27% of a group of individuals with ALS elected not to pursue AAC intervention following evaluation in an assistive technology clinic in Toronto. In addition, a 2 year study in the United States (Albert, Bene, Murphy, & Rowland, 1999) found that among two groups of persons with ALS, speech therapy services were not optimally

accessed. Thirty nine percent of persons in Group 1 (individuals who died during the 2 year study period) and 61.2% of the persons in Group 2 (individuals who were still living at the conclusion of the study) had not accessed speech therapy services at all.

For those people with ALS who do accept and use AAC technology, little is known about specific patterns of acceptance (e.g., high technology versus low technology, early stage versus late stage disease progression, positive attitudes versus negative attitudes toward technology). Doyle and Phillips (2001) reported that the majority of persons with ALS benefit from AAC technology at some point during their disease. Mathy (1996) studied the AAC usage patterns of 36 people with ALS. These individuals used both high- and low-technology AAC strategies, with differences in usage patterns based on the communication task. Preliminary results from a survey reported by Mathy et al. (2000) indicated PALS used high technology for communicating detailed needs and wants, written communication, and stories. This same study indicated that low technology was used for communicating in conversation and to quickly indicate immediate needs and wants.

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Gutmann (1999) identified gender differences, wherein women preferred low technology strategies more often than men (20% for women and 6% for men); and men preferred high technology writing systems three times as often as women.

McNaughton, Light, and Groszyk (2001) described employment experiences of five persons with ALS who used AAC as reported in an online focus group. They identified barriers and supports to employment and found that persons with ALS indicated that they were able to continue employment through the use of AAC systems. The results of this qualitative study also indicated a strong desire among persons with ALS to continue employment in order to obtain intellectual and social stimulation. These outcomes are indicative of successful, primarily high-technology, AAC use.

Mathy, Yorkston, and Gutmann (2000) reviewed AAC use by persons with ALS from numerous sources. They referred to data by Gutmann and Gryfe (1996), who evaluated trends in the use of AAC systems for 126 people with ALS who were seen at an assistive technology clinic in Toronto, Canada. Among those participants, findings indicated that 27% elected not to pursue AAC intervention. Gutmann and Gryfe (1996) developed a critical path strategy for AAC service provision to persons with ALS that identified early intervention, frequent intervention, and early introduction to AAC as components that were essential to increasing AAC acceptance. Gutmann (1999), analyzing the same data, reported that, "women preferred voice output systems twice as often as men (49% for women, 26% for men)" (p. 211). The report further indicated that, "almost an equivalent number of men (27.8%) and women (26%) did not wish any AAC intervention..." (p. 211). Little is known about specific aspects of the Toronto program, therefore comparison of service provision techniques is not possible based on the current literature.

The reasons why some people with ALS and complex communication disorders reject AAC technology are not well understood. There are few published studies in which these issues have been investigated. Doyle and Phillips (2001) suggested several factors that may influence the acceptance of AAC by persons with ALS. These included (a) rate of disease progression, (b) time from initial symptoms to diagnosis, (c) expectations and attitudes of communication partners, (d) experience with and attitude toward technology, and (e) access to early intervention.

Acceptance of assistive technology may be considered along a continuum (Scherer, 1993). At the initial recommendation, people with ALS

may accept technology promptly, with reluctance, or they may reject it altogether. Even after initial acceptance, they may discontinue use of AAC technology at any point because their needs have changed, because their capability has changed, or simply because they no longer prefer to use the device.

The purposes of this study were to document (a) recent acceptance of high-technology AAC by persons with ALS to determine if a pattern of AAC acceptance exists, consistent with the previously reported information; and (b) the reasons provided by persons with ALS for accepting or discontinuing use of current AAC technology. Although low- and no-technology AAC strategies continue to be used by persons with ALS, these strategies have remained relatively unchanged, while high-technology AAC continues to transform and become more accessible among the mainstream population. Previous studies have included examination of AAC technology at an earlier, emergent stage, when fewer devices were available and the interfaces were somewhat more complicated for individuals who were inexperienced in their use. For these reasons, we chose to examine acceptance of high-technology AAC.

METHOD

Participants

We examined high-technology AAC use information from a group of persons with ALS who were diagnosed by the third author, a board-certified neurologist (the American Board of Psychiatry and Neurology awards certification to physicians in the US and Canada only upon fulfillment of extensive educational, practice, and examination requirements). These individuals were monitored for speech and swallowing skills during their quarterly visits to a regional clinic sponsored by the Muscular Dystrophy Association, at two sites in different Midwestern US cities—Omaha and Lincoln, Nebraska. Data were obtained through direct assessment and intervention over a period of 4 years.

The 50 participants in the present study included 28 males and 22 females (reflective of the ALS incidence data). Seventeen of the participants were diagnosed as primarily bulbar, 22 were diagnosed as primarily spinal, and 11 were diagnosed as primarily mixed ALS. Ages of the participants ranged from 36 to 78 years (mean = 60.16 years). All participants spoke American English as a primary language, and all participants reported no neurological impairments other than ALS.

Cognitive deficits were observed for two of the participants, who showed evidence of a rapidly progressive form of frontotemporal dementia. The remainder of the participants ($n = 48$) exhibited normal cognitive functioning, based on a score of 28 or higher on the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) completed during the quarterly Muscular Dystrophy Association clinics. This score was selected because it was the median obtained by persons with at least a high school education for the participants' age groups.

Participants in this study were seen for AAC assessments when their speech was evidencing change; therefore, persons seeking support only for written communication were not included in this research.

The Hollingshead Four Factor Index of Social Status (HFFISS) (Hollingshead, 1975) (Appendix A) was completed for all participants. A higher score obtained from this index indicates a higher ranking in social position (min = 8, max = 66). Participants' occupations included a variety of professional and non-professional activities. Educational levels ranged from partial high school through to advanced post-secondary degrees. Table 1 provides details of the demographic information relative to the HFFISS for all participants.

Procedures

AAC assessments were completed when the participants reached a 90% or lower intelligibility of speech or a 100 words-per-minute or lower speaking rate on the Sentence Intelligibility Test (SIT) (Yorkston, Beukelman, & Tice, 1996), which was administered at each quarterly Muscular Dystrophy Association clinic. As a result of strong support for speech and AAC services by the attending physician (third author) and a need to identify subtle bulbar changes for diagnostic purposes in the Muscular Dystrophy Association clinics, participants who did not exhibit overt signs of bulbar (speech and swallowing) symptoms were referred to the speech-language clinician for quarterly assessments. The same clinician who provided speech and dysphagia services to the quarterly Muscular Dystrophy Association clinics completed the AAC evaluations; therefore, the clinician had established rapport with the majority of the study's participants prior to their having the AAC evaluation recommendation, although for a small number ($n = 4$) the AAC evaluation served as their initial clinical visit. Because of the regularity of clinical visits, low technology AAC interventions and issues are discussed typically within that setting.

TABLE 1 Demographic and social status of participants

Participant	Education	HFFISS	Class
1	CO	44	Technical
2	HS	22	Semi-skilled
3	GS	12	Unskilled
4	CO	22	Semi-skilled
5	CO	48	Technical
6	HS	32	Skilled
7	CO	48	Technical
8	TE	35	Skilled
9	CO	48	Technical
10	HS	43	Technical
11	GR	56	Major business
12	CO	48	Technical
13	GR	45	Technical
14	HS	37	Skilled
15	HS	22	Semi-skilled
16	CO	43	Technical
17	TE	38	Skilled
18	CO	38	Skilled
19	CO	35	Skilled
20	HS	32	Skilled
21	HS	53	Technical
22	HS	56	Major business
23	TE	37	Skilled
24	HS	48	Technical
25	GR	47	Technical
26	HS	24	Semi-skilled
27	CO	42	Technical
28	CO	53	Technical
29	HS	53	Technical
30	HS	22	Semi-skilled
31	CO	56	Major business
32	CO	25	Semi-skilled
33	HS	22	Semi-skilled
34	GR	32	Skilled
35	HS	26	Semi-skilled
36	HS	26	Semi-skilled
37	HS	58	Major business
38	HS	37	Skilled
39	HS	27	Semi-skilled
40	CO	43	Technical
41	TE	47	Technical
42	HS	64	Major business
43	CO	35	Skilled
44	HS	22	Semi-skilled
45	HS	22	Semi-skilled
46	GS	56	Major business
47	HS	22	Semi-skilled
48	HS	14	Unskilled
49	CO	25	Semi-skilled
50	HS	29	Semi-skilled

Note: GS = grade school, HS = high school, CO = college, TE = technical school, GR = graduate school. Vocation is indicated by UE = unemployed, BC = blue collar, WC = white collar. HFFISS (Hollingshead, 1975) scores reflect social status (min = 8, max = 66).

The evaluator (first author) had approximately 20 years of clinical experience, including years of experience working directly with PALS and 6 years of experience working directly with high-technology AAC. Because an AAC evaluation for high-technology devices involves extended periods of time, these assessments were scheduled as

separate appointments outside of participants' regular Muscular Dystrophy Association clinical visits. AAC evaluations consisted of presentations of a selection of high technology AAC devices, ranging by type (e.g., dedicated, multifunctional); manufacturer (e.g., EnkiduTM, DynavoxTM, Words + TM); size (e.g., palm size devices, miniature laptop computer based devices, laptop computer based devices, software for desktop computers); and method of access (e.g., direct only, multiple access methods). During the evaluations, the participants had the opportunity to directly use each device that they and the evaluator identified as potentially useful as an option for their communication. As part of the evaluations, participants were provided the opportunity to have a brief (approximately one week) trial use of the favored devices.

Upon completion of the AAC evaluations, AAC interventions were recommended for each participant. These recommendations were based on the presence of progressive motor speech disorder evidenced by (a) slowed rate of speech (100 wpm or lower) and/or (b) dysarthria of speech (90% or lower intelligibility), as well as (c) communication needs. Participants were presented with a variety of high technology AAC devices during the evaluation process, including both dedicated and multipurpose devices currently available. AAC acceptance, use, rejection, and discontinuance were monitored for each participant until the time of his or her death ($M = 43.8$ months, range 4–181 months, $SD = 37.54$ months).

Acceptance of AAC

Categories of AAC acceptance were established for the purposes of data analysis. Immediate acceptance, delayed acceptance, rejection, and discontinuance of AAC were characterized, using the following definitions.

Immediate Acceptance

This first category was assigned to those participants who had completed an AAC assessment; and decided at that time to obtain AAC technology, receive training, and begin use of the selected AAC technology as quickly as possible.

Delayed Acceptance

This category was assigned to those participants who had initially rejected the AAC assessment or the purchase of AAC technology following the assessment, but who at a later time had approved

the purchase of AAC technology and had then used it to communicate.

Rejection

This category was assigned to those participants who had rejected an AAC assessment or the purchase of AAC technology each time the opportunity was provided, until the time of his or her death.

Discontinuance

This category was assigned to participants who initially accepted AAC technology or accepted AAC technology with a delay, used it for a period of time, and then discontinued its use for any reason. Participants who ceased regular use of their AAC technology prior to the last 2 months of their lives were considered to have discontinued use of their AAC technology. Those who regularly used their AAC technology until within 2 months of their death were considered not to have discontinued use of their AAC technology. Modifications in the AAC technology to accommodate changes in capability (access, mounting) were not considered discontinuance, but rather a feature of ongoing AAC intervention services.

Rationale for Acceptance Decisions

Participants and their family members were informally interviewed regarding their decisions to accept, reject, or discontinue use of their AAC technology. The interviews were conducted by the first author, who served as the primary AAC interventionist for all of the participants. Interviews were completed face-to-face in the clinic or participants' homes and were between 5 min and 10 min in length. Participants and family members were asked to provide a rationale for the decision to accept AAC technology. These discussions were audio recorded, the interview dialogue was transcribed, and then the data were reduced and interpreted (Creswell, 1994). A list of all topics was compiled from these data, similar topics were clustered together, and finally, themes for AAC technology acceptance decisions were explored.

RESULTS

Participants were evaluated for the use of dedicated and multifunctional high-technology AAC devices, and were then monitored with regard to their acceptance decisions regarding the use of AAC technology. In general, a high level of

acceptance was observed, with 90% demonstrating immediate acceptance and another 6% demonstrating delayed acceptance. Only 4% of the participants in this study completely rejected AAC technology.

The Hollingshead index indicated that participants included were identified among all five levels of social class, with (a) 4% representation from the unskilled, laborers, menial service workers group, (b) 30% from the machine operators, semi-skilled workers group, (c) 22% from the skilled craftsman, clerical, and sales workers group, (d) 32% from the Medium Business, Minor Professional, Technical group, and (e) 12% from the Major Business, Professional group. Across these groups of participants, the mean social score obtained was 37.42 ($SD = 13.04$), with a range of 12 to 64 across the five groups. The acceptance data for all participants, based on social class, is presented in Table 2.

Immediate Acceptance

The immediate acceptance data for all participants is presented in Table 2. Ninety percent of the participants ($n = 45$) immediately accepted AAC technology. A similar percentage of males (89%) and females (91%) accepted AAC technology immediately. *T*-test analysis (two-tailed) of the acceptance results by gender indicated no significant differences, $t(2) = 1.19$, $p = 0.36$, between males and females. Also, a similar percentage of persons with primary spinal ALS (88%), primary bulbar ALS (91%), and primary mixed ALS (91%) accepted AAC technology immediately, as indicated in Table 2. Ages of participants who accepted AAC technology were not different compared to other categories, as indicated in Table 2, with the majority of participants in each age group demonstrating immediate acceptance. *T*-tests (two-tailed) were calculated and were found to be non-significant for each age group, consecutively, $t(2) = 1.51$, $p = 0.270$; $t(2) = 1.00$, $p = 0.423$; $t(2) = 1.14$, $p = 0.373$; $t(2) = 1.11$, $p = 0.383$; $t(2) = 1.31$, $p = 0.321$.

Analysis of interviews with participants and their family members revealed three primary themes regarding the rationale for immediate acceptance: communication, participation, and employment (Table 3). First, the communication theme included desire to communicate with family, friends, caregivers, and medical professionals; as well as to *write/tell one's story*. Second, the participation theme included desire for community involvement and *something to do with my time*. Seven individuals expressed the third,

employment, theme as reflective of a desire to continue employment or to volunteer in an area of former employment. One participant had volunteered extensively as an administrator for a religious organization. Another was a professional writer, and her immediate acceptance of AAC technology supported her professional activities in addition to her verbal communication. All of the participants used the AAC technology as their primary means of communication. Two participants used multifunctional devices to enable them to continue employment, by speaking with colleagues and participating in meetings.

Delayed Acceptance

The delayed acceptance data for all participants are also presented in Table 2. Six percent of the participants ($n = 3$) accepted AAC technology with a delayed decision. Two males and 1 female delayed their acceptance of AAC technology. Two persons with bulbar type ALS and one person with spinal type ALS delayed their acceptance of AAC technology. Delayed acceptance was noted in the 30 to 39 year and 70 to 79 year age groups, with the delay time ranging from 6 months to 2 years. All of the participants who delayed acceptance were anarthric for at least 6 months prior to obtaining their equipment and had minimal upper and lower extremity movement when they obtained their AAC technology, and therefore used it as their primary means of communication. Among the participants who delayed acceptance, one selected a dedicated device because of funding availability. Medicare, the federally-funded retirement insurance in the USA, will support funding for dedicated devices only. For this reason, this individual was limited to dedicated devices, although she preferred the multifunctional device features. The remaining two individuals selected multifunctional devices.

Analysis of the interviews with participants and their family members revealed three primary themes regarding the rationale for delayed acceptance (Table 3) Family member resistance reflected two issues: family members believed that they (a) could understand communication sufficiently to meet a person's needs, and (b) were providing adequate care without assistive technology. Two family members who initially resisted acceptance expressed concern that the quality of their ability to provide care was being questioned; however in both cases, they eventually accepted AAC technology as the participant's speech continued to deteriorate. These family members realized that they were unable to provide good care without communicating effec-

TABLE 2 AAC acceptance by onset type, age, gender, and social status

Persons with ALS	Immediate acceptance	No. device type	Delayed acceptance	No. device type	Rejection
Bulbar onset	15 (88)	9M, 6D	2 (12)	1M, 1D	0
Spinal onset	20 (91)	7M, 13D	1 (4.5)	1D	1 (4.5)
Mixed onset	10 (91)	4M, 6D	0		1 (9)
Total	45 (90)	20M, 25D	3 (6)	2M, 1D	2 (4)
30–39 years	3 (75)	3M	1 (25)	1M	0
40–49 years	7 (100)	4M, 3D	0		0
50–59 years	11 (92)	5M, 6D	0		1 (8)
60–69 years	14 (93)	3M, 11D	0		1 (7)
70–79 years	10 (83)	4M, 6D	2 (17)	2D	0
Total	45 (90)	19M, 26D	3 (6)	1M, 2D	2 (4)
Male	25 (89)	14M, 11D	2 (7)	2D	1 (4)
Female	20 (90)	8M, 12D	1 (5)	1M	1 (5)
Total	45 (90)	22M, 23D	3 (6)	1M, 2D	2 (4)
HS 8–19 (a)	2 (100)	1M, 1D	0		0
HS 20–29 (b)	14 (93)	5M, 9D	0		1 (7)
HS 30–39 (c)	10 (90)	4M, 6D	0		1(10)
HS 40–54 (d)	14 (87)	9M, 5D	2 (13)	1M, 1D	0
HS 55–60 (e)	5 (83)	1M, 4D	1 (17)	1D	0
Total	45	20M, 25D	3	1M, 2D	2

Note: Number (percent) of persons with ALS accepting AAC technology ($n = 50$) based on ALS type, age at onset of ALS, gender, and social status. For the acceptance categories (immediate and delayed), a description of the type of device is indicated by: *M* = multifunctional AAC device, *D* = dedicated AAC device. Hollingshead Four Factor Index of Social Status is indicated *HS*, with parenthetical information indicating groups described in text.

tively. One participant and his family reported a theme involving physician resistance. According to this report, the physician viewed speech deterioration as an inevitable part of the disease progression and counseled the family to accept it rather than turn to technology. Three individuals expressed a participant resistance theme: they either denied that they were disabled, or that their speech was difficult to understand, or that they would ever need AAC technology. These individuals also delayed acceptance of low technology AAC strategies. In time, each of these individuals accepted AAC technology, often with the strong encouragement of their family.

Rejection

Cognitive limitations were identified as the primary reason for rejection by both of the participants who rejected AAC technology until the time of their deaths. Both individuals, one male and one female, exhibited symptoms of prefrontal-type dementia sometimes associated with ALS that results in resistance to change, inflexibility of thought, and rigid personality traits (Lomen-Hoerth, et al., 2003; Strong, Lomen-Hoerth, Caselli, Bigio, & Yang, 2003). These individuals rejected all attempts at AAC intervention, including low/no-technology strategies. The AAC technology rejections were associated with spinal and mixed onset ALS; none were observed in participants with bulbar onset. In addition, as indicated in Table 2,

rejection appeared to be associated with the 50–59 year and 60–69 year age groups.

Discontinuance

None of the participants discontinued use of their AAC technology. Within the last month or two of life, many PALS no longer used their high technology AAC systems and resorted to dependent communication strategies. By the definition employed in this investigation, these end-of-life changes were not considered discontinuance.

AAC Technology Accepted

Among the participants who accepted high-technology AAC, 31 selected the Freedom 2000™ Toughbook (or Freedom 2001E™ dedicated device) (Words +, Inc.), 7 selected the Handheld Portable Impact (or dedicated version) (Enkidu™ Research), 5 selected the DynaMyte™ 3100 (Dynavox™ Systems), three selected the Palmtop Portable Impact (or dedicated version) (Enkidu™ Research), and two selected the Dynavox™ 3100 (Dynavox Systems). Table 2 provides the breakdown of devices with respect to whether they functioned solely as dedicated communication devices or multifunctional devices. Although a number of devices were presented during the AAC evaluation in addition to those listed, participants' selections were reflective of the technology that was available during the years between 1998 and

TABLE 3 Acceptance and rejection themes

Immediate acceptance themes (<i>n</i> = 45)	
Communication	<i>n</i> = 37 Need to communicate with family at home and at a distance Need to communicate with friends Need to communicate medical needs Desire to "write/tell their story"
Employment	<i>n</i> = 7 Desire to continue employment Need to communicate in specific ways at work (meetings, teleconferences)
Community participation	<i>n</i> = 20 Desire to continue involvement in community activities Desire to "have something to do"
Delayed acceptance themes (<i>n</i> = 3)	
Family resistance	<i>n</i> = 2 <i>I can understand everything I need to I can take care of my spouse's needs just fine!</i>
Physician resistance	<i>n</i> = 2 <i>You don't need to bother with that, you are going to die soon, anyway. You need to go home and put your affairs in order.</i>
Persons with ALS resistance	<i>n</i> = 3 <i>I am NOT disabled! My speech isn't affected yet and probably won't be. I simply don't need or want that.</i>
Rejection themes (<i>n</i> = 2)	
Cognitive impairment	Cognitive limitations were viewed as the primary reason for rejection (Persons with ALS exhibited prefrontal-type dementia sometimes associated with ALS that results in resistance to new things, inflexibility of thought, and changes in personality).

2003, sources of funding for AAC, communication needs that were met by the systems, and participants' personal preferences.

DISCUSSION

Ninety-six percent of the participants in this study accepted AAC technology either immediately (90%) or after some delay (6%). Only 4% (*n* = 2) rejected AAC technology, and none of the participants ceased use of their AAC technology according to the definition of discontinuance used in this study.

The results of this study indicate a higher level of acceptance for AAC technology among persons

with ALS than has previously been reported (i.e., 96% of the participants demonstrated either delayed or immediate acceptance). It is important to acknowledge that the data reported by Gutmann and Gryfe (as summarized in Mathy, Yorkston, & Gutmann, 2000), were initially reported in 1996, and that they reflected AAC interventions prior to that time. AAC technology has changed significantly since these studies were conducted, such that AAC is now more accepted within society. In addition, the clinic from which the current data were obtained follows the recommendations made by Gutmann and Gryfe (1996) for critical pathways, and it is possible that the increased acceptance may reflect changed clinical methods and intervention procedures.

In addition to the changes in AAC technology, it is important to note that the national program for funding medical care of persons with disability and retirees in the USA began funding selected AAC devices (dedicated speech generating devices) in 2000, which has had an impact on the number of persons with ALS who can now have affordable access to AAC technology.

When provided with early intervention, frequent monitoring of speech, and early introduction to AAC, 90% of participants in the current study readily and immediately accepted AAC technology. For others (6%), acceptance occurred gradually. It is important that speech-language pathology service delivery models support the type of decision-making that facilitates acceptance of functional communication strategies. Current evidence indicates that (a) providing appropriate information regarding the speech-language characteristics of ALS, (b) maintaining ongoing contact to monitor speech changes and determine timing of interventions, and (c) sustaining awareness of AAC service/intervention opportunities are all aspects of clinical decision-making to consider among best clinical practices. These components are essential to ensure that AAC-related technology decisions for people with ALS are based on communication preferences rather than critical need. These data suggest that the practices adopted in a clinic may have an impact on the AAC acceptance outcome; however they do not directly address this issue. Future research is needed to address the impact of the type of clinic, frequency of visits, timely introduction of AAC, and other variables on acceptance.

Lasker and Bedrosian (2001) outlined an AAC Acceptance Model designed to identify factors related to acceptance of AAC. In this model, three components are identified: milieu, person, and technology. The milieu component addresses factors related to communication partners, envir-

onment of the communication, and funding options. The person component addresses factors directly related to the individual who will use AAC, including disease characteristics, attitude, personality, age, skills, needs, and intervention history. The third component, technology, addresses factors associated with an individual device, such as durability, ease of use, size/weight, voice output quality, and cost.

Findings from the interview portion of the present study revealed that the participants with ALS accepted AAC technology for a variety of reasons. Primary reasons included the desire for communication, community participation, and employment—components of which are items from each aspect of the AAC Acceptance Model (Lasker & Bedrosian, 2001). Participants had a desire to communicate with a variety of partners in various environments (milieu), in the face of a rapidly degenerative disease (person) affecting their physical abilities, while leaving their cognitive abilities intact; and by using any means possible (technology). It appears that greater involvement with participants and their families will facilitate acquisition of AAC aspects related to the milieu component. Familiarity with frequent communication partners, occupational/community communication needs, and the availability of funding sources is also important. As Lasker and Bedrosian (2001) described, to optimize AAC acceptance, it is essential that clinicians have knowledge of the individual and the disease processes involved with ALS. One common concern is related to the speed of changes experienced by persons with ALS. Acceptance of AAC over the course of the disease will require AAC devices that can be adapted to changing needs. The third component, technology, requires that clinicians be fully aware of the range of AAC options available and that are appropriate for persons with ALS. Clinicians must be able to explain AAC technology in ways that relate to and are clearly understood by persons with ALS and must also be able to provide access to a range of devices for hands-on implementation and/or trial use.

AAC technology resistance may derive from a number of different sources. In the present study, many of the reasons reported for delays in AAC technology acceptance involved resistance on the part of family, physicians, or the participants themselves (milieu). Although fear of AAC technology, or technology in general, was expressed during several AAC evaluations, none of the participants identified this as a component in decision-making upon completion of the assessment process. Perhaps many of the concerns regarding ability to use AAC technology were

addressed during the assessment. All participants were in the USA, and during the time the current data were obtained, federal government (Medicare) funding for AAC technology for persons with ALS became available, which meant that persons ALS with limited resources were able to obtain personal AAC devices. Hence, this funding may have reduced perceived concerns that AAC technology is cost prohibitive. For speech-language pathologists and all members of the AAC intervention team, there is a need to identify the decision-makers (persons with ALS, family, physicians, friends) and to be aware of their stance regarding AAC technology, most notably any concerns and issues they have. Knowing the reasons for delaying a decision to obtain AAC technology may assist a speech-language pathologist to provide appropriate information that will facilitate the decision-making process.

The primary reasons for rejection of AAC technology were associated with cognitive impairments, which have begun to receive focused research attention in ALS (Lomen-Hoerth, et al., 2002; Swash, 2002). Although it is apparent from other AAC research that cognitive impairment does not typically exclude persons from using AAC technology (DeRuyter & Kennedy, 1991; Doyle, Kennedy, Jausalaitis, & Phillips, 2000; Fried-Oken & Doyle, 1992), the type of cognitive impairment associated with ALS and compatibility with AAC requires additional study. This research should focus on providing a means of functional communication for persons with ALS who develop cognitive impairments associated with prefrontal (frontotemporal) cortex damage (executive function impairments, resistance to change, oppositionality, inflexibility, and decreased word finding and other linguistic impairments).

On the basis of the results of the present study, it is apparent that research is needed in which varied clinical practices and models of intervention are compared. Furthermore, the present study included one individual of an underrepresented minority; which may indicate the need for additional research into AAC technology acceptance patterns by members of underrepresented minorities who have ALS.

Results obtained from the present study may have been influenced in part by personal and other characteristics associated with the clinician (first author), including clinical experience, academic credentials, and type of intervention program selected. Results may also have been influenced by a variety of personal qualities on the part of both the clinician and those who received the interventions ((e.g., ease of interaction, ability to describe variety of equipment and

functional uses, participant comfort level and adaptability to new things). It is the goal of all persons who provide clinical interventions (regardless of personal characteristics) that individuals who are recipients of their services will benefit from them; therefore, future clinical research may require additional scrutiny of these elements to justify clinical outcomes.

SUMMARY AND CONCLUSIONS

In summary, the overall results of this study indicate that 96% of PALS accepted high technology AAC, with 4% rejecting use of the technology. Further clinical research is needed to address the specified weaknesses of the study previously stated. In particular, research is needed to identify the information required to develop a collaborative decision-making relationship among the key persons (persons with ALS, family, physicians, friends) involved in AAC technology selection (Ball, Beukelman, Richter, & Pattee, 2002). A key element in this collaboration should include examination of all aspects of the AAC Acceptance Model (Lasker & Bedrosian, 2001), in order to determine the most efficacious implementation strategies. Information of this nature will allow clinicians to become more knowledgeable and thereby to facilitate AAC technology decision-making.

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APPENDIX A Hollingshead Four Factor Index of Social Status

Scale	Status	Score
Occupation	higher executive proprietor of a large concern major professional	9
	business manager proprietor of a medium-sized business lesser professional administrators	8
	administrative personnel proprietor of a small independent business minor professional	7
	owner of a small business technician semi-professional	6
	clerical and sales worker small farm owner smaller business owner	5
	skilled manual employee craftsman tenant farmer smallest business owner	4
	machine operator semi-skilled worker	3
	unskilled worker	2
	farm laborer menial service worker	1
	Education	graduate professional training
standard college or university graduate		6
partial college training		5
high school graduate		4
partial high school training		3
junior high school (7th to 9th grade)		2
less than 7 years of schooling		1
Social score	Social class	
	8 – 19	unskilled laborers, menial service workers
	20 – 29	machine operators, semi-skilled workers
	30 – 39	skilled craftsman, clerical, and sales workers
	40 – 54	medium business and minor professional technical
55 – 66	major business and professional	

Scoring Instructions:

Spouse 1: (occupation scale score * 5) + (education scale score * 3) = _____

Spouse 2: (occupation scale score * 5) + (education scale score * 3) = _____

1 spouse working, use that score

2 spouses working = use average of both scores

Higher score, higher ranking in social position (min = 8, max = 66)