

Purposes of AAC Device Use for Persons with ALS as Reported by Caregivers

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Thirty-four informal caregivers who support 26 persons with ALS reported on AAC technology use. Each caregiver completed the Communication Device Use Checklist, a survey tool developed for this study based on Light's (1988) classification of the purposes of social interaction (*Augmentative and Alternative Communication*, 4, 66–82). The checklist includes 17 purposes of communication and asks participants to judge importance, mode, and frequency of use for each purpose. Results show that the three communication purposes used most frequently and valued as important by caregivers involve regulating the behavior of others for basic needs and wants (getting needs met; giving instructions or directions to others; and clarifying needs). Consistent reports of use and frequency for the purposes of staying connected (social closeness) and discussing important issues (information transfer) indicate that AAC technology can assist the dyad in maintaining previous relationships. The face-to-face spontaneous conversation mode is used most frequently, despite the slow rate of production, the lack of permanence, and the demands on conversational partners during message generation. Clinical and research implications are discussed.

Keywords: Augmentative and alternative communication; Amyotrophic lateral sclerosis; Communication purposes; Caregivers

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) affects approximately 20,000 people in the United States in any given year (Borasio & Miller, 2001). The progression of motor loss that characterizes the disease results in life changes for people with ALS and their families. A diagnosis of ALS portends changes in the ability to walk, speak, eat, and eventually, the ability to breathe and to sustain life (Armon & Moses, 1998). Persons with ALS (PALS) and their families must adapt in order to cope with these changes, and to remain as functional and independent as possible over time.

A mean age of onset of 58 years suggests that ALS is often diagnosed while men and women are in the most productive years of their lives (Borasio & Miller, 2001). For these individuals, symptoms of the disease may first become

apparent while they are managing family, career, and financial responsibilities. For others, symptoms may emerge after retirement, when they are experiencing life with fewer external obligations and a greater emphasis on maintaining social connections with others. For each family living with ALS, patterns of interaction are likely to differ depending on a person's age at diagnosis as well as the life cycle stage of their family (Fox & Sohlberg, 2000). Other factors that may affect interaction patterns include, but are not limited to, levels of fatigue for both persons with ALS and caregiver, cognitive change experienced by persons with ALS, disease type at onset, disease stage, and rate of progression (Ball, Beukelman & Pattee, 2004; Chio et al., 2004; Lou, Reeves, Benice, & Sexton, 2003).

AAC interventionists frequently recommend communication systems that include speech-generating devices so that, despite the loss of speech,

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persons with ALS may continue to fulfill the roles (e.g., parent, worker, spouse) considered important in their lives (Doyle & Phillips, 2001). To fulfill these roles, individuals need to communicate in all of the essential areas of social interaction described by Light (1988): to meet their basic needs, to share new information, to establish and maintain social closeness with others, and to follow the rules of social etiquette. Many types of AAC technology are capable of storing and retrieving messages to fulfill communication needs in all of these areas (Bardach & Newman, 2003). Case studies and empirical research, however, have suggested that AAC technology is employed selectively to fulfill different purposes (Murphy, 2004; Doyle & Phillips, 2001; McNaughton, Light, & Groszyk, 2001; Mathy, Yorkston, & Gutmann, 2000). For example, Mathy and colleagues (2000) have reported that quick needs are often communicated using unaided or low technology methods, while in-depth information and stories are more likely conveyed using high technology AAC systems. McNaughton et al. (2001) reported that AAC technology is used for continued employment in order to maintain intellectual and social stimulation.

Researchers who have examined the use of low and high technology by persons with ALS discussed other challenges associated with AAC use. Beukelman and Lasker (1988) suggested that people with ALS use unaided or low technology AAC more frequently with familiar communication partners and high technology AAC more frequently with unfamiliar partners. Others have suggested that unfamiliar partners prefer the use of low technology AAC tools when persons with ALS tell stories (Richter, Ball, Beukelman, Lasker, & Ullman, 2003). Ball et al. (2004) examined acceptance of AAC technology by persons with ALS, and noted that 96% of 50 participants accepted AAC technology, either immediately (90%) or after some delay (6%) and only two individuals rejected AAC technology. Mathy et al. (2000) reported the results of a survey of 36 persons with ALS, which showed that a person's initial ALS symptoms impact the use of AAC techniques. Their respondents with initial spinal symptoms were more likely to use more high technology AAC than were people who initially presented with bulbar symptoms. They proposed that the use of handwriting to meet early needs by persons with bulbar ALS may predispose those people to more frequent use of low technology AAC approaches. In contrast, the use of computers for writing in the early stages of spinal ALS may predispose those particular

individuals to use integrated AAC systems to meet more of their communication needs.

Use of AAC technology depends upon a communication system that is adaptable to motor function changes that occur as the disease progresses, and that allows for production and storage of messages to address each of the areas of social interaction described by Light (1988). It is also likely that AAC technology use depends upon an awareness of partners' concerns, skills, and preferences (Murphy, 2004).

The present study considered the opinions of family caregivers who are relatives, friends, and other unpaid individuals caring for adults with ALS. The term *family caregiver* is commonly used interchangeably with the term *informal caregiver* to refer to the many types of unpaid assistance provided by family, close friends, and/or neighbors. This is in contrast to care provided by formal structures: government agencies; private organizations; institutions; and paid, professional, in-home care providers (Schulz, O'Brien, Bookwala, & Fleissner, 1995). Persons with ALS are typically cared for by informal caregivers. There are, in fact, differences in the type of care provided by informal and paid caregivers (Krivackas, Shockley, & Mitsumoto, 1997). Previous research examining AAC technology use (Ball et al., 2004; Murphy, 2004; McNaughton et al., 2001) has used data gathered from persons with ALS directly, rather than their informal caregivers or partners or professional care providers.

The current study aimed to discover patterns of importance and patterns of use of AAC technology for 17 communication purposes that expand upon Light's (1988) four categories of social interaction. In addition, the study aimed to explore relationships between reported importance, mode of communication, and frequency of use for each purpose, as reported by informal caregivers who support individuals with ALS who use AAC. The present study was part of a larger effort that gathered information about a sample of ALS caregivers.

METHOD

Design

Survey methodology and convenience sampling were employed to obtain subjective responses regarding the caregiving experience of informal caregivers of persons with ALS who use AAC technology. Information related to the mode, frequency of use, and importance ratings of AAC technology was obtained with the Communication Device Use Checklist (Fried-Oken, Fox, Rau, & Tullman, 2003). The appendix presents

this checklist as well as its accompanying legend, and is described in detail below. In addition, demographic data on caregivers and persons with ALS, as well as ALS severity ratings, were obtained from each caregiver/PALS within the ALS dyad. The present study is part of a larger pilot effort to detail the relationship of AAC technology to a variety of caregiving activities and issues.

Survey Tools

Data were obtained using the Communication Device Use Checklist (Fried-Oken et al., 2003). One scale in the checklist includes 17 purposes of communication, grouped according to Light's (1988) classification of social interaction. For example, calling for help and getting needs met quickly were considered reflective of expressing needs and wants. Discussing important issues and conversing about health care were considered examples of providing new information. Having a casual conversation and telling stories were classified as examples of developing social closeness. Being polite was classified as an example of fulfilling social etiquette. (See Appendix for the complete checklist.) To determine content validity, an initial checklist was distributed to five additional AAC experts nationally. Their suggestions were incorporated into the final version of the scale. Internal consistency of multiple-item social interaction categories was determined using Cronbach's alpha (Cronbach, 1951): basic needs (.92); new information (.82); social closeness (.87). No Chronbach's alpha was calculated for etiquette as the category contained only one item. These results indicate an acceptable level of internal consistency. Caregiver participants were asked to rate the frequency of use (on a five-point scale from *never/don't know* to *hourly*), importance (on a four-point scale from *unnecessary* to *mandatory*), and mode of communication (face-to-face, written, e-mail, or telephone) for each of the 17 communication purposes. Participants could specify other communication purposes for AAC technology use that were not included in the scale by responding to an open-ended question ("other") at the end of the scale.

Severity of ALS was assessed using the ALS Functional Rating Scale (ALS-FRS) (ALS CNTF Treatment (ACTS) Phase I–II Study Group, 1996). This research instrument subjectively rates 11 different domains of functions, such as speech, swallowing, handwriting, and walking, on a five-point scale from 0 (*most severe*) to 40 (*normal functioning*). It is standardized as an aggregated score with all of the subscales. For this report, the aggregate severity score was used

rather than individual sub scores, because the research emphasis is on the social aspect of communication rather than individual sub-systems. Additional reports of severity of speech, handwriting, and walking in relation to communication purposes are available elsewhere (Fox et al., 2005).

Participants and Setting

Thirty-four informal caregivers of 26 persons with ALS were recruited from local ALS support groups, ALS clinics, AAC vendors, and AAC clinical practices. The study inclusion criteria were (a) that caregiver participants could not be paid caregivers (b) that persons with ALS had to have owned their AAC device for at least one month and must have used the device within 6 months prior to the interview and (c) that persons with ALS had a confirmed diagnosis of ALS by a certified neurologist.

Caregivers ranged in age from 23 to 88 years, with a mean age of 54 years. Participants were 20 spouses, four adult children, four friends, one sibling, and five others (i.e., partner of an ex-wife, sister-in-law, spousal equivalent). Twenty-seven caregivers were female and seven were male. In some instances, a person with ALS had more than one informal caregiver. The 26 persons with ALS ranged in age from 37 to 88 years, with a mean age of 60.3 years; 22 persons with ALS were male and four were female. ALS severity in the present sample, with a possible spread from 0 (indicating *severe disability*) to 40 (*normal*), ranged from 0 to 32, with a mean of 11.22 ($SD = 10$). Tables 1 and 2 summarize the demographic information for caregivers and persons with ALS, respectively.

Caregivers reported the following AAC technology use: six persons with ALS used dedicated text-to-speech devices such as the LightWriter SL87™; 13 persons with ALS used computer-based systems with specialized software, such as EZ Keys™; four persons with ALS used symbol or word based dynamic display dedicated devices, such as the DynaVox 3100™; two relied on computers without adapted software for communication; and one used voice recognition on a standard desktop computer as an access mode. (Lightwriter SL87 is made by Toby Churchill, Ltd., and vended by ZYGO Industries, Inc., Portland, OR. EZ Keys is made by Words +, Lancaster, CA. DynaVox 3100 is made by DynaVox Systems, Pittsburgh, PA.)

Interviews to obtain demographic information and to administer the Communication Device Use Checklist were conducted face-to-face whenever possible in participants' homes. In 11 instances, interviews were conducted by

TABLE 1 Demographic data for 34 caregivers, in ascending order by age.

Age	Gender	Education	Occupation	Relationship to person with ALS	Time known or resided with person with ALS (months)
23	M	13	Personal assistant	Son	276
25	M	16	Student; research assistant	Son	300
32	F	20	Researcher	Friend	40
33	F	16	Physical therapist	Daughter	396
36	F	12	Certified nursing assistant	Spouse	120
37	F	16	Computer programmer	Spouse	156
39	F	14	Caregiver	Girlfriend	28
41	F	14	Student; medical assistant	Sister-in-law	28
44	M	17	Accountant	Son	528
44	M	17	Accountant	Son	528
45	F	14	Grocery clerk	Spouse	336
50	F	12	Caregiver	Spouse	240
50	F	14	Police officer	Friend	240
55	M	15	Retail manager	Brother	28
56	F	18	Family therapist	Spouse	420
57	F	16	N/A	Spouse	396
57	F	18	Administrator	Spouse	288
57	F	14	Bank teller	Spouse	240
57	F	14	Medical clerk	Spouse	432
57	F	16	Legal secretary	Spouse	42
57	F	18	Teacher	Friend	240
58	F	16	Retired teacher	Spouse	288
59	F	17	Internet consultant	Spouse	66
59	F	14	Executive director	Spouse	456
60	F	16	Teacher	Spouse	480
61	F	20	Retired professor	Spousal equivalent	48
63	F	16	N/A	Spouse	300
65	F	12	N/A	Spouse	564
65	F	16	Teacher	Daughter	780
66	F	16	Retired	Friend	360
66	F	12	Homemaker	Spouse	576
69	M	12	Magician	Spouse	216
69	M	16	Retired	Spouse	708
70	F	16	N/A	Spouse	492
88	M	16	Retired	Friend	120

telephone. Length of time for the face-to-face interviews was approximately 30–45 minutes. All interviews were conducted by a rehabilitation professional who was a member of the research team. All attempts were made to make caregivers comfortable during these data collection sessions.

Responses from caregivers were analyzed to address the following research questions: How frequently do persons with ALS use AAC technology for each communication purpose? What is the perceived importance of each communication purpose? What is the relationship between the frequency of use and perceived importance for each communication purpose? What modes are used to convey messages for each communication purpose? The data also were reviewed with respect to Light's (1988) four categories of social interaction. For example, issues such as whether there were any differences between the frequencies of use across categories or whether there were any differences between the

importance ratings across categories were considered.

Data Analysis

Data were analyzed with descriptive statistics and correlational procedures (SPSS, version 11.5.0).

RESULTS AND DISCUSSION

Frequency of Reported Use of Communication Purposes

Figure 1 shows the percent of total respondents who rated frequency of use with AAC technology in each of the following scoring categories: (0) don't know/never, (1) occasionally, (2) weekly, (3) daily or (4) hourly. Table 3 lists the median score for each communication purpose and the number of respondents who gave each frequency of use score. The data reported here are ordinal level

TABLE 2 Demographic data for 26 persons with ALS in ascending order by ALS severity level.

Age (years)	Gender	ALS severity	Number of months post diagnosis	Number of months using AAC technology
52	M	0	81	60
60	M	0	72	48
51	M	1	31	12
37	M	3	56	31
48	M	3	156	121
65	M	3	61	5
59	M	4	14	2
65	M	4	144	24
48	M	5	98	36
67	M	5	33	12
60	M	6	38	10
67	F	6	39	2
61	F	7	21	3
47	M	8	46	27
60	F	8	24	8
69	M	14	36	4
67	M	14	84	24
88	F	15	16	12
62	M	16	38	24
75	M	18	96	60
59	M	18	17	216*
67	M	22	15	1
59	M	29	9	8
65	M	29	28	456*
49	M	30	60	4
54	M	32	11	1

*Persons with ALS report that they used computers for 18 and 38 years, respectively.

data, therefore measures of central tendency should be interpreted with care. While we report median scores to help the reader see certain broad trends, we encourage the reader to review the data in Table 3 to better appreciate the diversity of responses provided by the participants.

According to Figure 1 and Table 3, respondents reported that AAC technology was used for all of the 17 communicative purposes included in the checklist. The highest levels of use, as indicated by a median of 3.0, were for two communication purposes within the expressing basic needs category: getting needs met and clarifying needs with caregivers. More than 35% of caregivers reported hourly use for getting needs met, and 23.5 and 26.5%, respectively, reported daily use for getting needs met and clarifying needs. It is of interest to note that more than 25% of the caregivers in this sample reported no use of AAC technology for those two purposes, suggesting that AAC technology varies across dyads for a variety of reasons (personal preference, health and communication status).

The next highest levels of use, as indicated by a median of 2.0, were for giving instructions or directions to others and staying connected with family and friends. A large percentage of caregivers (32.4%) reported hourly technology use for giving instructions, and another 32% reported

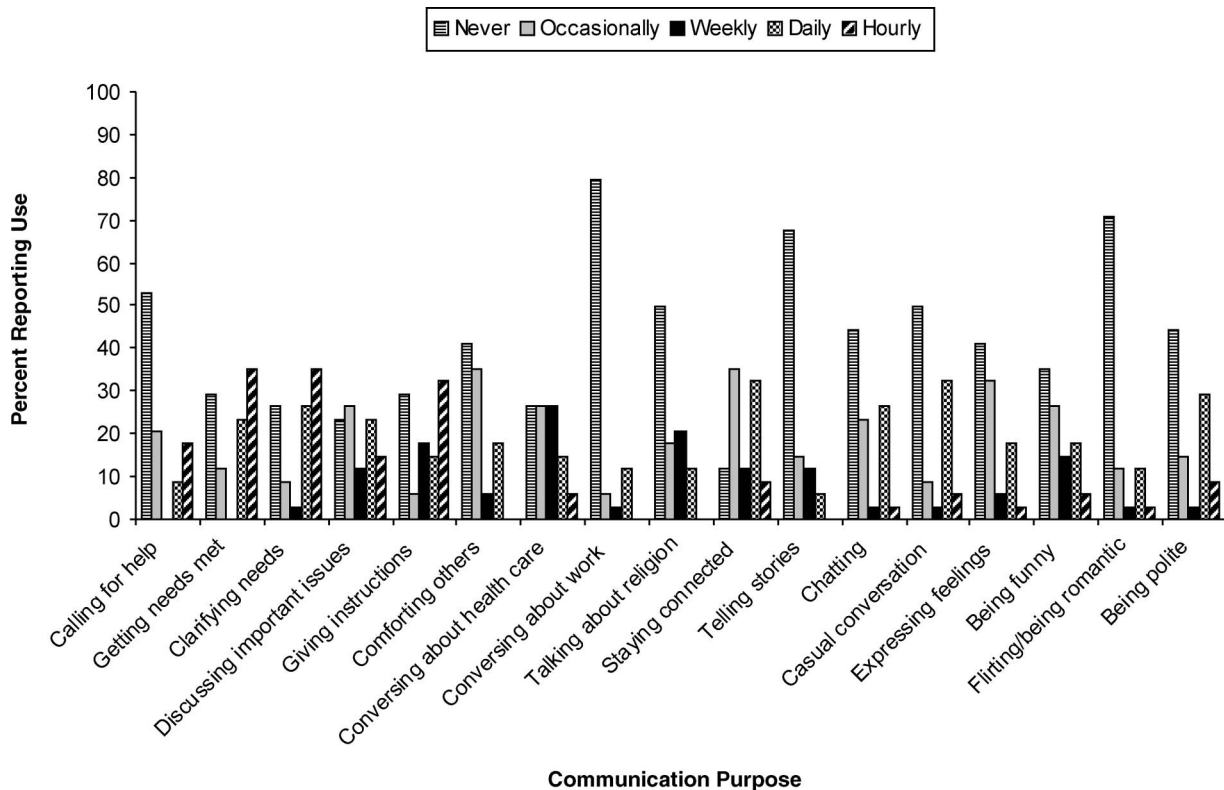


Figure 1. Percentage of caregivers reporting frequency of use of AAC technology for 17 purposes of communication.

TABLE 3 Median frequency of use scores and number of caregivers in each score category.

Purpose	Median score	Number of caregivers (<i>N</i> = 34) in each category				
		No use	Occasional use	Weekly use	Daily use	Hourly
Calling for help	.0	18	7	0	3	6
Getting needs met	3.0	10	4	0	8	12
Clarifying needs with caregivers	3.0	9	3	1	9	12
Giving instructions	2.0	10	2	6	5	11
Discussing important issues or concerns	1.5	8	9	4	8	5
Comforting others	1.0	14	12	2	6	0
Conversing about health care	1.0	10	8	9	5	2
Conversing about work	.0	27	2	1	4	0
Talking about religion	1.0	16	7	7	4	0
Staying connected	2.0	4	12	4	11	3
Telling stories	.0	23	5	4	2	0
Chatting	1.0	15	8	1	9	1
Having casual conversation	.50	17	3	1	11	2
Expressing feelings	1.0	14	11	2	6	1
Being funny	1.0	12	9	5	6	2
Flirting or being romantic	0.0	24	4	1	4	1
Being polite	1.0	15	5	1	10	3

daily or weekly use of the technology. In summary, two-thirds of caregivers were provided with some form of instruction by persons with ALS who used AAC technology. Anecdotally, one of the authors observed a person with ALS who participated in this study using his integrated AAC system to tell his wife how to prepare his favorite hamburger casserole when friends were coming to dinner. This interaction occurred after the person with ALS was no longer taking any nutrition by mouth, confirming that, in this case, directing his wife's behavior was intended by the person with ALS to convey new information, not to address his basic wants and needs.

A similar number of respondents (32%) reported that persons with ALS used AAC technology daily to stay connected with others, while nearly 12% reported weekly use and 35.3% reported occasional use. It is noteworthy that caregivers reported such high levels of use for a purpose that falls clearly within the social closeness classification. In fact, when compared with all other communication purposes included in the survey, the smallest number of respondents (four) reported AAC technology was never used to stay connected. Thus, although a higher number of respondents reported frequent use of technology to achieve some of their basic needs (clarifying and getting needs met) or to convey new information (giving instructions), it is important to note that AAC technology was described as being used by almost all of the participants in this sample to stay connected with family and friends.

An additional purpose that we classified in the new information category, discussing important issues, had a median score of 1.50. Although the

most frequently reported score in this category was 1, denoting occasional use, close to 15% of respondents said that technology was used hourly for discussions, 23.5% made daily technology use for this purpose, and nearly 12% reported weekly use for discussions. With only eight caregivers reporting that they never used AAC technology for this purpose, it had the second lowest level of non-use for the purposes included in the checklist, again suggesting widespread use among the participants.

A majority of caregivers reported that technology was not used for the remaining 11 communication purposes. It is important to note, however, that at least some caregivers of persons with ALS reported at least daily use of AAC for every one of the communication purposes, again highlighting the importance of considering the data on an individual basis. AAC technology was used both for comforting others and for expressing feelings on a daily basis by 17.6% of the individuals in the dyads, and 14.7% of the respondents reported technology use for daily conversations about health matters. The use of humor in conversation was reported by 15% of caregivers, who described daily technology use for being funny. Daily use of technology for chatting and being polite also was reported by relatively high numbers of caregivers (26.5 and 29.4%, respectively).

The lowest median scores were calculated for having casual conversation (*Mdn* = 0.5), calling for help (0.0), conversing about work (0.0), telling stories (0.0), and being romantic (0.0). Non-use rates ranged from 50% for having casual conversation and 52.9% for calling for help to 70.6% for flirting and being romantic and 79.4% for

conversing about work. Rates of reported non-use for these purposes were higher than for any of the other communicative purposes measured by the checklist. In our sample, most persons with ALS were not employed, thus conversation for this social role was no longer important. Likewise, flirting and being romantic is not appropriate when a person with ALS is being cared for by a sibling, child or friend. Fourteen caregivers were not spouses.

The reported median score of 0 for using AAC technology to call for help illustrates the importance of examining results on an individual basis. A majority of respondents (18 of 34) reported that AAC is never used for this purpose, contributing to the median score of 0. Caregivers either anticipated many persons with ALS' needs; or speech, unaided, or no-tech AAC methods were used by the majority of the participants in the dyads. At the same time, nine individuals were reported to use AAC technology to call for help on at least a daily basis, highlighting the importance of this technology to these individuals. Doyle and Phillips (2001) also found that high tech AAC was not used when interaction was primarily with well-taught or familiar communication partners and for basic need purposes. In their case studies, persons with ALS used technology more when they were in the middle stages of the disease, and relied less on AAC technology as severity of motor impairment increased. A similar pattern of distribution is seen for having a casual conversation. While half of the participants reported no use of technology for this purpose, 13 reported hourly or daily use of AAC devices.

Levels of low use were more consistent for telling stories. A majority of participants (67.6%) reported that AAC technology was never used to tell stories. None of the caregivers reported hourly technology use for telling stories, less than 6% of respondents reported daily use, and only 11.8% reported that persons with ALS use technology weekly for this purpose.

Importance of Each Communication Purpose

Figure 2 shows the percent of caregivers who rated importance of AAC technology for the 17 social purposes as (1) unnecessary, (2) optional, (3) desirable, and (4) mandatory. Table 4 provides the median scores for each purpose and the number of respondents who gave each importance of use score. A comparison of Figures 1 and 2 suggests that patterns of importance and frequency of use were similar for this sample of caregivers. Results of a bivariate correlational analysis (Spearman's r) showed a significant

positive correlation between frequency and importance for each of the communication purposes ($r_s(17)=0.87$, $p < 0.05$), confirming that the dyads' use of technology and perceptions of importance were, indeed, related.

Again, median scores should be interpreted with care, but can provide insight into trends across participants. Interpretation of the data reveals that the most important purposes for AAC technology use were in getting needs met and giving instructions or directions to others ($Mdn = 4.0$). More than 50% of respondents said technology was mandatory and 14.7% said that technology was desirable for both purposes. Individual variation is clear, as slightly less than 30% said that technology was unnecessary and one individual said it was optional for getting needs met and giving instructions. Clarifying needs, with a median score of 3.5, was either mandatory or desirable for more than 70% of the respondents. Perhaps the majority of respondents who assigned high ratings to these communication functions considered caregiving a joint activity between the person with ALS and his or her caregiver. It is plausible that the one-third of respondents who rated these functions unnecessary or optional were fulfilling these roles without feedback, direction, or partnership from the persons with ALS they supported. Still another possibility is that these persons with ALS were not as dependent on the caregivers for general assistance, and may have been at the early or middle stages of ALS, as suggested by Doyle and Phillips (2001), or were communicating these requests through speech and gestures rather than through technology.

Other purposes with relatively high median importance ratings (3.0) included staying connected, discussing important issues or concerns, comforting others, conversing about health care, chatting, expressing feelings, being funny, and being polite.

More than 80% of the respondents rated technology use for staying connected as either mandatory or desirable. This finding supports the importance individuals with ALS and their partners place on activities such as interacting with friends and colleagues that enhance quality of life (Clarke, Hickey, O'Boyle, & Hardiman, 2001; McNaughton et al., 2001). Greater than 70% of respondents said that discussing important issues and conversing about health care were mandatory or desirable. More than 60% of respondents said that using AAC technology was mandatory or desirable for being funny, confirming that most caregivers liked persons with ALS to use AAC technology for humor, and that communication with technology added levity

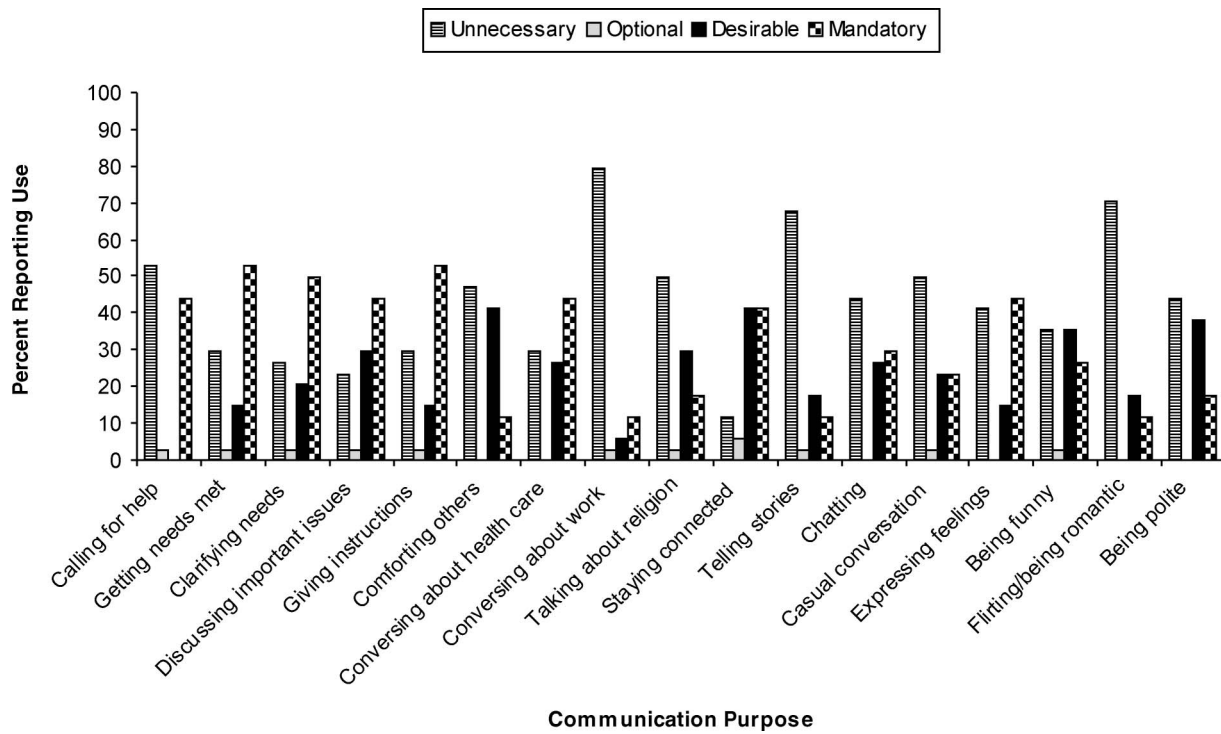


Figure 2. Percentage of caregivers reporting importance of AAC technology for 17 purposes of communication.

TABLE 4 Median importance scores and number of caregivers in each score category.

Purpose	Number of caregivers (<i>N</i> = 34) in each category				
	Median	Unnecessary (1)	Optional (2)	Desirable (3)	Mandatory (4)
Calling for help	1.0	18	1	0	15
Getting needs met	4.0	10	1	5	18
Clarifying needs with caregivers	3.5	9	1	7	17
Giving instructions	4.0	10	1	5	18
Discussing important issues or concerns	3.0	8	1	10	15
Comforting others	3.0	16	0	14	4
Conversing about health care	3.0	10	0	9	15
Conversing about work	1.0	27	1	2	4
Talking about religion	1.5	17	1	10	6
Staying connected	3.0	4	2	14	14
Telling stories	1.0	23	1	6	4
Chatting	3.0	15	0	9	10
Having casual conversation	1.5	17	1	8	8
Expressing feelings	3.0	14	0	5	15
Being funny	3.0	12	1	12	9
Flirting or being romantic	1.0	24	0	6	4
Being polite	3.0	15	0	13	6

to the stresses of disease progression, dependency and caregiving.

While 44.1% of participants said technology for calling for help was mandatory, at the same time, a high percentage of caregivers rated importance of calling for help with AAC technology as unnecessary (52.9%). Perhaps these persons with ALS had developed a consistent method for requesting help that did not involve AAC technology (e.g., vocalization, head-nod).

Those who used technology valued it highly; others who used forms of communication such as eye gaze, vocalization, head nod, or blinking rated importance low for AAC technology. The use of AAC technology might have been too slow or complicated for this purpose among those dyads; especially those who still had some speech or vocalization skills. Fox et al. (2005) found a significant positive correlation between speech severity and importance and frequency of AAC

for calling for help, suggesting that AAC technology is least important for persons with ALS whose speech is least impaired and it is most important to persons with ALS who have lost speech entirely.

Other purposes with low importance ratings included talking about religion and having casual conversation ($Med = 1.50$). Again, it is important to examine the pattern of individual scores. While many individuals gave these purposes low ratings, close to half (47%) described talking about religion and having casual conversation as desirable or mandatory. The range of scores may reflect individual variations that existed prior to the onset of ALS (e.g., individuals differ in the importance of religion in their lives). Another possibility is that individuals may differ in their interest in using AAC for casual conversation, reserving its use for “critical” messages. Many individuals gave low importance ratings to conversing about work, telling stories, and flirting or being romantic ($Mdn = 1.0$). Again, while some individuals rated these as mandatory or desirable, the overall low importance ratings for these purposes may have reflected life changes experienced by persons with ALS. As employment comes to an end, or as romance is expressed nonverbally between spouses, persons with ALS might not need the technology to achieve these purposes. They might rely on other modes of expression, low tech or no-tech options, for the very personal messages between spouses.

Four Categories of Social Interaction

Reviewing the 17 purposes with respect to four social interaction categories deserves attention, as well (Light, 1988). The two purposes with the highest median frequency of use scores involved regulating the behavior of others for basic needs and wants. They were clarifying needs with caregivers and getting needs met. Clearly, communicating basic needs is a critical issue as persons with ALS become dependent on caregivers and lose the physical or verbal control of their environment. It is interesting to note, however, that communication for developing social closeness and the exchange of information were also highly rated. AAC technology was perceived by informal caregivers to assist the user and his or her close friends and family to retain their relationships, express their personalities, and reinforce their expectations on communication. We learn that, in the face of changing physical and speech skills, AAC technology can be used to help communicators and their partners to maintain their premorbid roles and relationships.

Median importance scores were more diverse than frequency of use scores. The highest median importance scores included three purposes in the expressing basic needs category: getting needs met, clarifying needs, and giving instructions. Mid-range scores addressed purposes in the information transfer, social closeness, and etiquette categories. Low importance scores included one basic need (calling for help), two information transfer purposes (conversing about work and religion), and three social closeness purposes (telling stories, having casual conversation, and being romantic). Although the highest rated purposes in importance to caregivers were in the basic need category, there was no clear pattern of perceived importance for AAC technology when the social categories of communication are examined. Again, the level of speech severity, the different definitions of the caregiving roles, a presumed joint responsibility to the caregiving role by some dyads, and the level of dependency on the informal caregivers by some persons with ALS, all may have resulted in the variation in the perceived importance of social interaction categories.

Mode of Communication

In the upcoming sections we report on modes of communication used with AAC technology. Our scale asked participants to report the frequency, importance, and mode of AAC technology use for each purpose. We can report only the percentage of face-to-face communication *with* AAC technology; it is important to state that we did not collect data on other communication modes used during face-to-face interactions.

As shown in Figure 3, the majority of respondents (more than 60%) reported that persons with ALS used AAC technology for face-to-face communication across all purposes. The use of other techniques varied. Of those who used AAC technology to talk about work, 14.3% used written messages and 28.6% used e-mail. E-mail also was used by 33.3% to stay connected, 27.3% to tell stories, 20% to converse about health care, by 15% to comfort others, and 17.6% to talk about religion. Writing was used by 19.2% of those who used AAC technology to discuss important issues and by 17.6% for talking about religion, but it was used by less than 15% of the respondents for all other purposes. Telephone use was reported only by one respondent, who used it for clarifying needs with the caregiver.

Face-to-face communication was reported as most critical in the caregiving setting. It is interesting to note that face-to-face communication is less permanent than either writing or email,

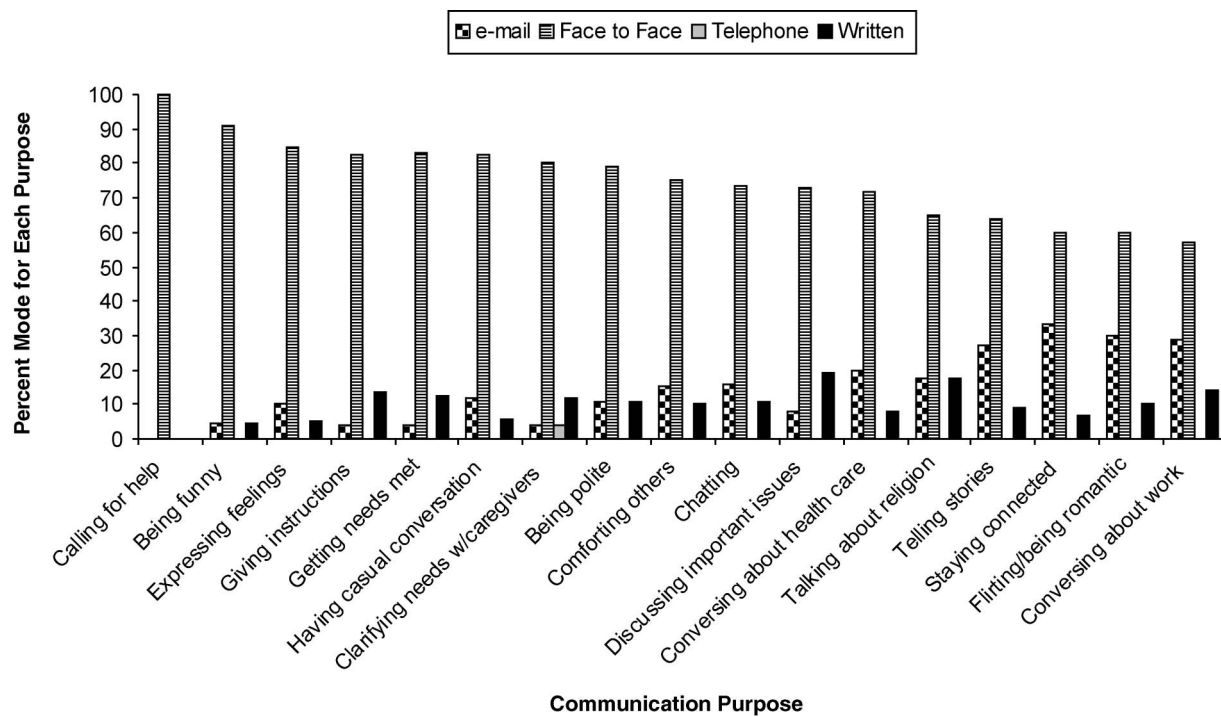


Figure 3. Percentage of caregivers reporting modes used for 17 purposes of communication.

and requires direct attention by the dyad during this time dependent exchange. Message generation with the modes of email and writing are not dependent on time, do not require the presence of the communication partner, and are permanent. AAC professionals often investigate techniques to speed up the rate of communication for spontaneous conversation. AAC users with acquired disabilities who formerly relied on speech often report their frustration with the slow augmented conversational rates. Still, when we asked participants in this sample about how AAC technology was used, face-to-face was the most frequently used mode of communication.

Perhaps the requirements of the caregiving relationship dictate use of face-to-face communication, and the interaction is so valued, that the time constraints become less burdensome. We cannot ignore the use of the other modes of communication for specific purposes, however. Since persons with ALS have expectations about the power and urgency of verbal interaction for every communication purpose, all possible modes of communication should be available, even if they are infrequently used.

Research Implications

This study investigated the perceived frequency, importance, and modes of AAC technology use for achieving a variety of communication interactions as reported by caregivers of persons with

ALS. Data provide empirical evidence from the caregiver perspective that has been lacking in the AAC field. Previous reports of AAC technology use have been obtained with persons with ALS as informants, or have used data that were collected post hoc. This study used a rigorously designed survey tool to collect responses from informal caregivers.

The Communication Device Use Checklist developed for this study could be used to measure outcomes for persons with ALS who use AAC technology, and to provide evidence of the pragmatic uses of AAC technology by persons with ALS. This instrument resembles the INCH: Interactive Checklist for Augmentative Communication (Bolton & Dashiell, 1984). Both surveys are tools to document AAC use, and can be completed at different times and in various environments. While the INCH quantifies modes of communication from behavior to equipment use, the Communication Device Use Checklist quantifies purposes of interaction with AAC.

Advocates for AAC technology use by persons with neurodegenerative disease may assume that more is better. That is to say, if more communication purposes are expressed with AAC technology, then interactions may be considered richer, more substantial, and more successful. In fact, we do not know whether persons with ALS who rely on AAC technology and their families feel successful with their communication, or whether the number of communication purposes

expressed can even be used as a measure of success. It would be intriguing to design a research study to examine users' and caregivers' perceptions of interaction success based on the number, diversity, or range of communication purposes expressed with AAC technology. Additionally, psychosocial measures could be examined in relation to communication purposes. It is possible that quality of life for persons with ALS and caregivers may differ according to the frequency of communication to achieve different purposes. For example, quality of life for persons with ALS may be related to the frequency of communication for social closeness, but caregivers' quality of life may be related to frequency of communication to meet basic needs. Furthermore, the research could be extended to comparisons between the number, diversity or range of communication purposes expressed by non-disabled populations without AAC technology, and the communication purposes expressed by AAC users with multi-modal communication, with and without AAC technology.

This tool could be used longitudinally as well, to determine if there are changes in the frequency and importance of different communication purposes at different stages in disease progression. As ALS progresses, do persons with the disease rate the frequency and importance of device use purposes differently? Fox and colleagues (2005) have examined communication purposes in relation to severity of ALS. In a between subjects analysis, they found that there is a relationship between ALS severity and some of the communication purposes identified as most important and most frequently used. For example, as the ability to speak declines, importance and frequency of communication to achieve basic needs increases.

Clinical Implications

A number of clinical implications emerge from these data. First, respondents in this study reported that AAC technology was used primarily for face-to-face interaction; however, writing and email were used by a moderate number of persons with ALS for selected purposes. In particular, email was often used to achieve social closeness and to convey new information. It will be important to assess each person's current, past, and openness to future use of email to determine whether there are opportunities for using that mode to maintain and strengthen social bonds as persons with ALS lose mobility.

The data also suggest that interventionists will do well to identify the specific communication purposes that are important to each person with

ALS and his or caregiver during the AAC assessment process. Some persons with ALS and their caregivers will want to use AAC technology frequently to meet basic needs, but these data, as well as research findings of Murphy (2004) and Mathy and colleagues (2000), suggest that others may prefer to use speech, unaided, or simple aided methods to communicate about a range of social purposes. In addition, the findings of this study suggest that if AAC technology is available, most persons with ALS will use it to stay connected with family and friends and to discuss important issues. Interventionists will facilitate use of technology for these and other high-priority purposes by identifying potential partners, environments where communication is likely to occur, and by carefully assessing the kinds of messages people with ALS need to achieve each of their high priority communication purposes. The Communication Device Use Checklist can be applied to facilitate this process in the clinical evaluation. In addition to aiding the process of identifying important areas of communication need and guiding message selection, assessing the importance of communication purposes may assist in device selection for dyads that want to use AAC technology.

The checklist may also be useful for identifying discrepancies between partners' interaction expectations. Iris Fishman, as part of her work with the ALS Association's Speak Up! Project, described one example of the clinical use of the checklist. A 65 year-old man named Milt had presented with moderate dysarthria secondary to ALS. He had recently acquired the Lightwriter SL87TM for spontaneous expression. His wife, Claire, complained about the device during an AAC treatment session. Claire reported that Milt never used his device and that she didn't want to nag him about it anymore. When Claire and Milt were asked to complete the Communication Device Use Checklist separately, it became clear that they had different expectations for device use. Claire wanted Milt to use the device to discuss new information. Milt only was willing to use the device to get his immediate needs met. The objective information available from the completed checklist helped Milt and Claire to understand differences in their priorities and provided an opportunity for them to change their interaction expectations related to the device (I. Fishman, personal communication, November 16, 2003).

Use of the checklist could guide follow-up treatment, as well, if the tool is administered longitudinally. While the current research did not address persons with ALS or caregiver training with the AAC technology before or during use,

it is possible that purposes of communication shift as the user and caregiver become more familiar with the equipment and its potential usefulness. Administration of the checklist pre- and post-intervention would help to determine the effect of training on AAC use.

The Communication Device Use Checklist may have implications beyond the ALS population. For example, it is applicable to caregivers and adults with dysarthria who use AAC, regardless of diagnosis; and may be useful for persons with static conditions such as cerebral palsy or brain stem strokes, as well as persons with improving neurodegenerative disease conditions (traumatic brain injury or Guillain-Barre Syndrome). Indeed, this checklist can be used with any person with severe dysarthria or anarthria over time to document changes related to the frequency and importance of different communication purposes that occur.

In addition, support personnel working in group homes, supported employment, or independent living settings with adults with developmental disabilities who use AAC technology may be helped to better understand their interactions with the AAC user through the use of the checklist. Nurses and certified nursing assistants who support persons in skilled nursing facilities might be motivated to change their interaction styles if they understood the various purposes of communication and could use the checklist to assess their communicative interactions with care recipients. Mismatches can indicate where to direct treatment, so that there is a common expectation. For example, the job coach who is working with a young woman who relies on a speech generating device because of a traumatic brain injury might discover that co-workers are only expecting communication related to basic needs and wants while the device user is requesting communication to develop social closeness. The home health nurse who visits an elderly individual with aphasia who relies on a communication book for interacting with his daughter might show the family that basic needs and wants are not the only purposes of communication that are important in social situations. The checklist permits some quantification of the concepts of frequency and importance of different communication purposes, and can be easily understood by caregivers and many care recipients to increase satisfaction with communication and, ultimately, quality of life.

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APPENDIX

Communication device use checklist: Purposes.

Communication purpose	Frequency	Importance	Mode
Expressing needs and wants			
Calling for help			
Getting needs met			
Clarifying needs with caregivers			
Giving instructions or directions to others			
Exchanging information			
Discussing important issues or concerns			
Conversing about health care			
Conversing about work			
Talking about religious or philosophical issues			
Developing social closeness			
Expressing feelings			
Staying connected with family and friends			
Telling stories			
Chatting			
Having casual conversation			
Comforting others			
Being funny			
Flirting or being romantic			
Fulfilling social etiquette			
Being polite			
Other (please specify)			

Key: Frequency: 1 = occasionally, 2 = weekly, 3 = daily, 4 = hourly.
 Importance: 1 = unnecessary, 2 = optional, 3 = desirable, 4 = mandatory.
 Mode: F = face-to-face, W = written, T = telephone, E = e-mail.