Available online at www.sciencedirect.com
SCIENCE DIRECT®
Journal of Communication Disorders 37 (2004) 197–215
Journal of Communication Disorders

Communication effectiveness of individuals with amyotrophic lateral sclerosis

Laura J. Ball[a,*], David R. Beukelman[a,b,c], Gary L. Pattee[a]

[a]Munroe-Meyer Institute, 985450 Nebraska Medical Center, Omaha, NE 68198-5450, USA
[b]University of Nebraska-Lincoln, Omaha, NE, USA
[c]Institute for Rehabilitation Science & Engineering, Omaha, NE, USA

Received 6 November 2002; received in revised form 16 September 2003; accepted 23 September 2003

Abstract

The purpose of this study was to examine the relationships among speech intelligibility and communication effectiveness as rated by speakers and their listeners. Participants completed procedures to measure (a) speech intelligibility, (b) self-perceptions of communication effectiveness, and (c) listener (spouse or family member) perceptions of communication effectiveness for speakers with amyotrophic lateral sclerosis (ALS). The results of this study revealed that perceptions of communication effectiveness for speakers with ALS were quite similar for the speakers and their frequent listeners across 10 different social situations. ALS speakers and their listeners reported a range of communication effectiveness depending upon the adversity of specific social situations.
Learning outcomes: (1) As a result of this activity, the participant will be able to identify social contexts that are identified by persons with ALS as difficult for effective communication. (2) As a result of this activity, the participant will be able to describe ALS symptomatology using the International Classification of Functioning, Disability, and Health. (3) As a result of this activity, the participant will be able to administer the *CETI-M* as a measure of communication effectiveness for persons with ALS. (4) As a result of this activity, the participant will gain information that will assist them in counseling persons with ALS and their families.

Keywords: Amyotrophic lateral sclerosis; Dysarthria; Communication effectiveness; Intelligibility

1. Communication effectiveness of individuals with amyotrophic lateral sclerosis

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive motor neuron disease for which there is no known cause or cure. ALS impacts nearly every aspect of one's body and

* Corresponding author. Tel.: +1-402-559-6460; fax: +1-402-559-5737.
E-mail address: lball@unmc.edu (L.J. Ball).

0021-9924/$ – see front matter © 2003 Elsevier Inc. All rights reserved.
doi:10.1016/j.jcomdis.2003.09.002

one's life. For example, communication is effected at several levels. Motor weakness and spasticity impact speech movements (Caruso & Burton, 1987; Strand, Buder, Yorkston, & Ramig, 1994). Changes in the motor system result in reductions in speech intelligibility and rate, and a gradual reduction in ability to participate in communication situations.

Traditionally, the field of motor speech disorders has emphasized performance measures designed to assess the functioning of the articulatory, velopharyngeal, laryngeal, and respiratory subsystems during speech. Overall performance measures of speech intelligibility and rate have also been documented. These strategies were apparent in the work of Darley, Aronson, and Brown (1969a, 1969b, 1975). Of the 38 dimensions of assessment in their system, none assessed communication performance in societal contexts. Kent et al. (1990, 1992) demonstrated a similar pattern with extensive measurement of articulatory performance and speech intelligibility. Yorkston and colleagues (Yorkston & Beukelman, 1981; Yorkston, Beukelman, & Tice, 1996; Yorkston, Beukelman, & Traynor, 1984) developed intelligibility and speaking rate measures, but did not assess communication effectiveness in societal contexts. The widely used ALS scale developed by Hillel et al. (1989) includes speech intelligibility as a primary focus, and none for social participation.

In the absence of assessment data about the societal participation of dysarthric speakers, there has been a tendency to make clinical assumptions about communication effectiveness based on their speech intelligibility. However, the data underlying these assumptions have been limited. In 1989, Beukelman and Yorkston compared speech intelligibility and message comprehension in dysarthric speakers. They concluded that when sentence intelligibility scores were greater than 81%, listeners were able to comprehend the content of messages quite effectively. When sentence intelligibility, however, was below 81%, comprehension accuracy decreased markedly.

To date, there have been little published data on the effect of dysarthria in terms of successful communication in different social settings (Yorkston, Strand, & Kennedy, 1996). In 1992, Beukelman and Mirenda introduced the Participation Model as a decision-making framework for providing intervention services to augmented communicators. In their model, the need for and the success of AAC interventions were assessed based on the patterns of participation in social, educational, recreational, and vocational settings.

In order to provide a framework to systematically understand the consequences of health conditions, such as ALS, the authors use the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) Part 1: Functioning and Disability. Part 1 of the ICF model focuses on domains that describe body functions and structures, activities, and participation in the context of health. Part 2 of the ICF model focuses on contextual domains, including both environmental and personal factors.

The *Body Structures and Functions* domains occur at the level of the body and may include anatomical parts or physiological functions. These domains are typically assessed in medical settings (e.g., neurons, nervous system, muscle tone, mental function, sensory ability, voice, speech, cardiovascular, or respiratory function). The *Activities and Participation* domains impact life areas and reflect the overall capability of a person to execute a task or an action (e.g., eat, walk, articulate intelligibly, or communicate) and how that

person participates in social contexts or situations; their involvement in a life situation. These domains are typically assessed in either a standard environment, such as a clinic setting, or the person's current environment, such as home or community. Part 2 of the ICF also includes contextual factors (environmental and personal) that examine external influences on functioning (e.g., the physical, social, and attitudinal world, as well as personal attitudes).

2. Body functions and structures related to ALS

ALS is caused by the degeneration of motor neurons (upper and lower) of the brain and spinal cord, affecting a large proportion of muscles in the body. Eventually, motor neuron degeneration results in bulbar dysfunction (affecting speech and swallowing) in addition to spinal dysfunction (affecting arm and leg movements). ''The symptoms of ALS are generally classified by site of involvement (i.e., upper motor neuron (UMN), lower motor neuron (LMN)) and by regions of involvement (i.e., brain stem, cervical, thoracic, or lumbosacral spinal cord levels)'' (Mathy, Yorkston, & Gutmann, 2000, p. 185). UMN dysfunction results in muscle weakness, increased muscle tone, spasticity without muscle wasting, hyperactive reflexes, plantar extensor response, and clonus.

The El Escorial (Brooks, 1994) and Airlie House (Traynor et al., 2000) criterion outline specific characteristics present for definitive diagnosis of ALS. To confirm diagnosis, LMN signs in two limbs, UMN signs in at least one region, and progression of symptoms must be present. LMN dysfunction results in muscle weakness, decreased muscle tone with muscle wasting, hypoactive reflexes, plantar flexor response, and fasciculations.

Speakers with ALS often experience significant impairment in respiratory function as musculature for breath support increasingly weakens and becomes paralyzed. As a result of decreased respiratory support for persons with ALS (PALS), speech characteristics include difficulty achieving appropriate vocal loudness for conversational utterances (Yorkston, Strand, Miller, Hillel, & Smith, 1993). In addition, they may experience difficulty producing lengthy utterances without taking numerous breaths and exhibit voice disturbances related to decreased laryngeal airflow.

Speech disorders related to the progressive dysarthria associated with ALS occur as the bulbar symptoms increase. Because of the involvement of both upper and lower motor neurons, a mixed form of dysarthria is most commonly observed (Aronson, 1980). As a result, PALS will exhibit speech signs of both spasticity and flaccidity. Changes in tongue function include (1) reduced range and velocity of movement (Hirose, Kiritani, Ushijima, & Sawashima, 1978); (2) reductions in tongue strength (DePaul, Waclawick, Abbs, & Brooks, 1998); (3) smaller vowel space areas (Turner, Tjaden, & Weismer, 1995); and (4) flattening of vowel formant (particularly F_2) trajectories (Kent et al., 1990, 1992; Weismer, Martin, Kent, & Kent, 1992). Velopharyngeal incompetence with resulting hypernasality and nasal emission is commonly associated with ALS (Yorkston, Beukelman, Strand, & Bell, 1999). Additionally, Aronson, Ramig, Winholtz, and Silber (1992) identified phonatory instability in speakers with ALS from acoustic analyses, which resulted in imprecise consonants, hypernasal resonance, and harsh vocal quality in the resulting speech.

3. Contextual factors related to ALS

Environmental Factors may include any external influences on functioning and disability related to ALS. In some cases, the environment may facilitate and in other cases, increase the disabling impact of ALS. Because of the progressive nature of ALS, persons with the disease are faced with the likely need for use of assistive technology for numerous life functions, including wheelchairs for mobility, adaptive equipment for eating, lifts for transitioning, adapted vehicles for transportation, ramps and home modifications to accept the equipment, and often opting for life extending procedures (e.g., respirator or mechanical ventilation). An additional aspect of this involves facilitators, often family members, who may or may not be readily accepting of each new environmental adaptation necessary.

Personal Factors include internal influences on functioning and disability related to ALS. The impact of receiving a diagnosis of an incurable disease on the person and their core group of caregivers, and the way in which they react, may have a significant impact on their choices for interventions. In addition, PALS commonly are diagnosed with depression following the ALS diagnosis. If the symptoms continue and remain untreated, this may impact their choices.

4. Activity and participation related to ALS

At the *Activity* level of communication disorder associated with ALS, speech production becomes unintelligible even to the most familiar listener in interactions rich in contextual information. The typical exercises/strategies implemented by speech-language pathologists for persons with other neurogenic disorders are contraindicated in PALS due to the nature of the disease process. In fact, research (Watts & Vanryckeghem, 2001) has documented that resistance exercises, oral motility and strengthening activities, isometric exercises, and loudness activities focusing on intensive vocal fold adduction exercises (Ramig, Countryman, & Thompson, 1995) may actually result in decreased voice quality and rapid rate of decline in intelligibility in PALS. As speech-language pathologists are aware, degenerative conditions require special consideration when selecting a clinical intervention.

Interventions that may be appropriate include palatal lifts to facilitate velopharyngeal closure, rate reduction strategies, and vocal rest. Because of the inapplicability of many traditional therapeutic interventions and the rapidly degenerative nature of ALS, augmentative and alternative communication (AAC) strategies become paramount. Generally, determining when to intervene with AAC strategies and/or devices has been based upon an individual's intelligibility (Hillel et al., 1989) and, more recently, on changes in speaking rate (Ball, Beukelman, & Pattee, 2001; Yorkston et al., 1993).

The participation level of a disorder focuses on the ability of an individual to participate successfully in social settings. *Activity and Participation*, particularly *Participation*, is the focus of the current research project. Recently, measures of communication effectiveness have been used to document the participation of persons with neurologically based communication disorders. The Communication Effectiveness Index (CETI) (Lomas et al., 1989) was developed to document communicative interactions of persons with

aphasia. In this study, persons with aphasia and their spouses generated CETI items as a result of interactions from daily communication situations. These items were then placed into a 7-point rating scale for assessment of situational communication effectiveness based on self- and/or listener judgments. The CETI was found to demonstrate internal consistency, as well as test–retest and inter-rater reliability. In addition, it was found to be valid as a measure of functional communication and was responsive to changes in performance over time (Lomas et al., 1989).

Lomas et al. (1989) indicate that for persons with aphasia, the "major value of this instrument is as a measure of change in communication effectiveness, thus enabling clinicians to evaluate individual patients' progress in therapy and ... to evaluate recovery of communication ability ..." (Lomas et al., 1989, p. 122). Speech-language pathologists serving PALS are concerned with frequent, ongoing evaluation of the individual's communication decline associated with ALS. Because of this, it was determined that an adaptation of the CETI scale for PALS would be an appropriate instrument for use in measuring communication effectiveness in this population.

Assessment of communication effectiveness completed by both the PALS and their significant/frequent communication partners provides personalized evidence on communication performance. In the modification for this project, the CETI design format was unchanged, and thus provides direct involvement of the immediate caregiver or spouse (Lomas et al., 1989). Changes to the CETI involved specific questionnaire items more relevant to PALS (*CETI-M*), as determined by a group of three PALS (see Appendix A). Additionally, because of the heterogeneity of communication characteristics and their progression among PALS, obtaining assessment information from the individuals themselves and their immediate family members may allow greater generalizability of information obtained in this study to other individuals with ALS (Bedrosian, 1995).

The purpose of this project was to study the relationships among speech intelligibility and communication effectiveness as rated by speakers with ALS and their listeners. The goals of the study are to measure and analyze (a) speech intelligibility, (b) self-perceptions of communication effectiveness, and (c) listener (spouse or family member) perceptions of communication effectiveness for speakers with ALS.

Research questions were: (1) How closely do speakers with ALS and their frequent communication partners agree on which situations are most difficult for communication? (2) Which communicative situations are more difficult for PALS? (3) What is the difference between PALS self-ratings and the ratings of them by their communication partners? and (4) What is the relationship between *Activity and Participation* (intelligibility of speech in sentences and communication effectiveness rating)?

5. Method

5.1. Participants

Twenty-five persons ($N = 25$) with ALS participated in this study. These participants were recruited for the investigation because they: (1) were diagnosed with ALS-probable

or ALS-definite (Traynor et al., 2000) by a board-certified neurologist (third author) prior to participation in this study, (2) had a communication partner(s) who agreed to participate in the study, (3) were native speakers of American English, (4) reported no speech-language or hearing impairments other than those resulting from ALS, (5) were able to read the stimulus material, and (6) attended and received services in a regional medical center specialty clinic for PALS, where they completed the procedures under supervision of the first author. The ALS participants ranged from 42 to 76 years of age; 60% ($n = 15$) were male, 40% ($n = 10$) were female. Onset of ALS motor signs was mixed for 16% ($n = 4$), bulbar for 36% ($n = 9$), and spinal for 48% ($n = 12$) of the participants. This is distributed similarly to the population of PALS in general. Their speech intelligibility ranged from 0 to 100% on the *Sentence Intelligibility Test* (SIT) (Yorkston, Beukelman, et al., 1996) at the time of data collection.

Table 1 contains the specific data for each participant, indicating type of ALS onset, intelligibility score, and speaking rate at the time of participation. Time since the diagnosis was varied due to the range of diagnosticians seen by the participants prior to their involvement in the clinic. Onset information tends to be difficult in this population because symptoms are often attributed to other diagnoses. None of the participants had received speech therapy. At this date, only two participants survive, both of whom

Table 1
ALS type and SIT scores for participants with ALS

Participant	Onset type	Intelligibility (%)	Speaking rate (wpm)
1	Spinal	25	30
2	Mixed	78.18	156.44
3	Bulbar	0	0
4	Bulbar	0	0
5	Bulbar	0	0
6	Bulbar	41	75.5
7	Spinal	95	95
8	Spinal	66.36	99.55
9	Mixed	97.27	153.86
10	Mixed	84.5	88.95
11	Spinal	97	220
12	Spinal	96.36	179.05
13	Mixed	100	137
14	Bulbar	98	125
15	Spinal	0	0
16	Spinal	69.09	140.03
17	Bulbar	85	149
18	Bulbar	0	0
19	Spinal	97	142
20	Bulbar	95.45	103.34
21	Spinal	93	125
22	Bulbar	76.4	105.5
23	Spinal	91	86
24	Spinal	95	120
25	Bulbar	90	99.24

exhibited spinal onset of ALS and have experienced an atypical, slowly developing progression.

Twenty-nine ($N = 29$) communication partners participated in this study. These participants were recruited for the investigation because they (1) had daily contact with an ALS participant, (2) were a native speaker of American English, (3) reported no speech-language or hearing impairments, (4) were able to independently read and complete the questionnaire, and (5) accompanied a person with ALS to a regional medical center specialty clinic for neuromuscular disorders, where they completed the procedures under supervision of the first author. The communication partner participants ranged in age from 35 to 69 years. Sixty-three percent were spouses ($n = 18$), 31% were children ($n = 9$), and 6% were caregivers ($n = 2$) who were not immediate family members. All PALS participants had at least one communication partner in the sample, four additional communication partners were included in the group as a result of a person with ALS' child and spouse both agreeing to participate.

5.2. Materials

5.2.1. Communication effectiveness ratings

The modified CETI (*CETI-M*) implemented for the current study was described by Yorkston et al. (1999) and uses a visual analog and Likert scale for 10 contextual situations. The Appendix A contains the adaptation of CETI (*CETI-M*) created for this project and completed by both individuals with ALS and their communication partners.

The CETI was originally designed for persons with aphasia. Yorkston et al. (1999) modified the index to focus entirely on social communication situations by eliminating items that referred to communication acts. The authors and four PALS (who regularly collaborate to plan research about the communication performance of PALS) determined the contextual items included in the index used in this study.

The first author provided directions for completion of the *CETI-M* questionnaire verbally to the participant prior to presentation. In addition, directions were printed at the top of each questionnaire. Individuals with ALS completed self-perceived ratings of communication effectiveness using the *CETI-M* (Appendix A) for 10 contextual situations. Communication partners (spouse or family member) completed their perceived ratings regarding the individual with ALS' communication effectiveness (Appendix A) in the same situations. These ratings provide a measure of the perceived social limitation of the person with ALS when communicating.

5.2.2. Intelligibility of speech

At the time of completion of the *CETI-M*, a clinical measure of sentence intelligibility was obtained. Each individual with ALS read the 11 ''short test'' sentences from the SIT (Yorkston, Beukelman, et al., 1996; Yorkston, Strand, et al., 1996). The SIT sentences ranged from 5 to 15 words in length and were unrelated to each other.

In the standardization procedures for the SIT, reported reliability indicates no significant inter-judge differences for intelligibility ($F = 0.39$ and 2.69; d.f. $= 3, 30$). Inter-judge reliability coefficients for the SIT are reported to range from 0.93 to 0.99 for intelligibility. Inter-sample reliability reported in the SIT standardization procedures examined making

multiple comparisons over time. Results of this analysis indicated inter-sample correlation coefficients ranging from 0.92 to 0.99 for intelligibility measures.

5.2.3. Audio recordings

Each participant with ALS' verbal utterances was audio recorded (digitized) using a digital recording device (Macintosh iBook™ computer, Apple Computer, 2000) and a computer software program (SoundEdit Pro©, Macromedia, 1996) with a head-mounted, anti-noise NC-17 microphone (Andrea Electronics, 1999) positioned 5 cm from the corner of the speaker's mouth. Later, a listener (unfamiliar with the person or sentence/context) transcribed the sentences. Results were summarized as percent of all words spoken that were intelligible and rate of speech production.

5.3. Procedures

During routine visits to the regional ALS clinic, participants and their communication partners were asked if they were willing to participate in a research project that documented the progression of the communication symptoms and their use of AAC communication devices. After informed consent was obtained, the participants completed a series of activities that included the SIT and the *CETI-M*. In a single clinic visit, the speech-language pathologist administered the SIT, followed by the *CETI-M*. The ALS participants read each of the SIT sentences aloud as they were audio recorded. Because the sentences were transcribed at a later time, participants were unaware of their intelligibility results from the SIT at the time that they completed the *CETI-M*. The ALS participant and the communication partners completed the *CETI-M* separately. If necessary, a speech-language pathologist or a research coordinator assisted the participants with ALS to complete the *CETI-M*, typically by marking the response form in accordance with the participants' gestured responses, if the participant was unable to hold and manage a pen or pencil.

An ASHA-certified speech-language pathologist with 4 years of clinical practice and experience administering the SIT clinically to persons with dysarthria transcribed the SIT sentences using standard procedures (Yorkston, Beukelman, et al., 1996; Yorkston, Strand, et al., 1996). This transcriber was a nondisabled young adult who was a native speaker of American English and reported no hearing or language impairments. To ensure unfamiliarity with the stimulus material, this individual was not present during the administration of the SIT (audio recording sessions) and was unfamiliar with the speakers (participants). The audio signals were presented to the transcriber using Andrea anti-noise NC-17 earphones. The duration of the SIT sentences was measured from the audio waveform using the SoundEdit Pro© (Macromedia, 1996) software application. Speaking rate was computed in words per minute (wpm) and sentence intelligibility was computed from the SIT.

5.4. Reliability

Pearson product–moment correlation measures were completed as an assessment of reliability for the *CETI-M*. Results ($r = 0.97$) indicated high internal test reliability. Upon

completion of the initial reliability measures, individual item analysis was completed. This indicated significant correlational value for all items.

The speech-language pathologist transcribed each sample per standard SIT administration and then a second ASHA-certified speech-language pathologist transcribed the SIT sentences for 10% ($n = 3$) of the speakers with ALS. The transcriptions of the second ''reliability'' judge were compared to the first judge who originally transcribed the SIT sentences. Inter-judge reliability measures examined correlation of transcription among judges. Results of the Pearson product–moment correlation (r=0.98) indicated high inter-judge reliability. These measures are consistent with the standardization reliability results of the SIT.

6. Results

6.1. Communication effectiveness ratings by ALS speakers and listeners

An analysis of agreement among speakers with ALS and their communication partners was completed. The first research question, ''How do speakers with ALS and their frequent communication partners agree on which situations are most difficult for communication for the person with ALS?'' was addressed with calculation of a Wilcoxon signed ranks analysis to determine if significant differences existed for the *CETI-M* items between the two participant groups. No significant differences were observed for any of the *CETI-M* items. Table 2 contains the rank order according to mean *CETI-M* scores of the two participant groups (PALS, communication partners) for communication effectiveness according to social situation (*CETI-M* item) and the corresponding Wilcoxon level of significance.

To address the second research question ''Which communicative situations are more difficult for PALS?'' the items were placed in rank order. A review of Table 2 reveals that both groups identified the same situations by level of difficulty, indicating that both speakers with ALS and their frequent listeners agree regarding level of contextual

Table 2
ALS communication effectiveness rankings and Wilcoxon significance for *CETI-M* items

Rank	Situation	*Z*	*P*
ALS speakers and listeners			
1	Familiar persons, in a quiet place	−0.07	0.95
2	Strangers, in a quiet place	−0.09	0.93
3	Familiar person on the phone	−0.02	0.99
4	Speaking with young children	−0.64	0.52
5	Strangers, on the phone	−0.47	0.64
6	Speaking while traveling in car	−0.50	0.62
7	Speaking at a distance	−0.40	0.69
8	In a noisy environment	−0.26	0.79
9	Speaking before a group	−0.26	0.79
10	Lengthy conversation (>1 h)	−0.49	0.62

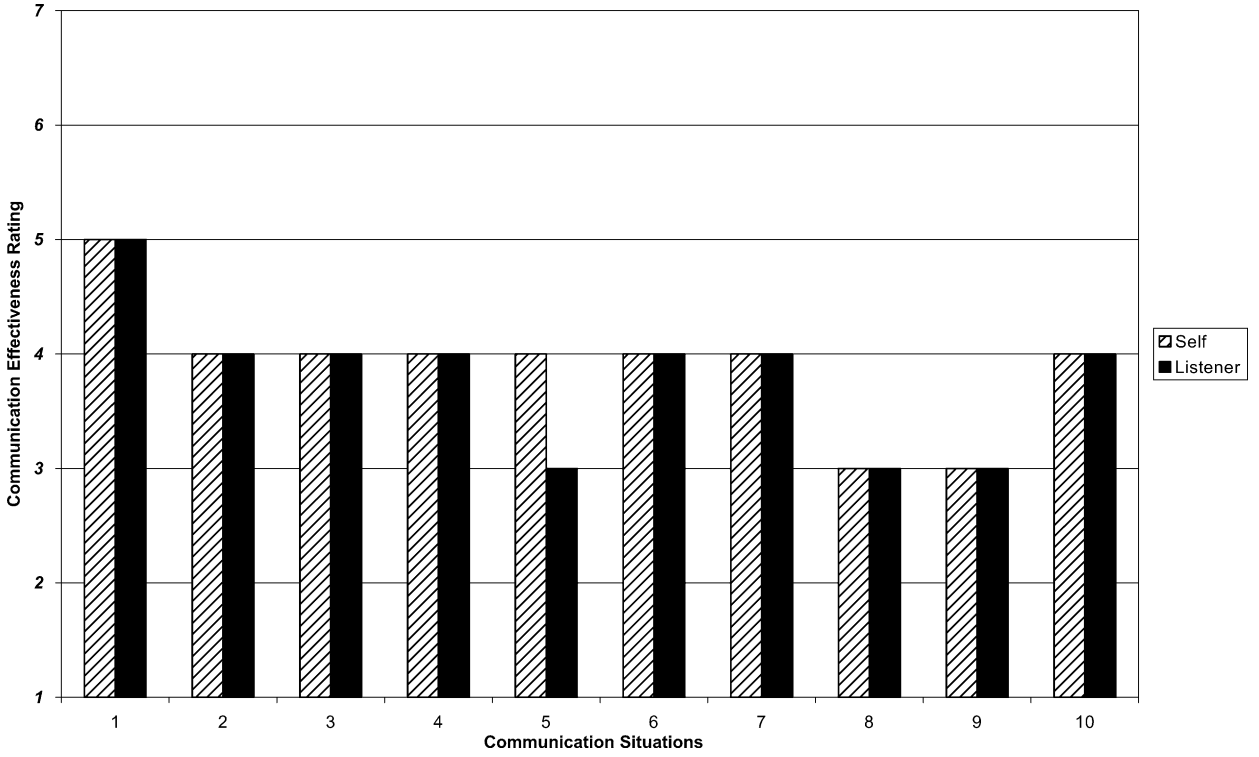

Fig. 1. Mean communication effectiveness ratings by speakers with ALS and their listeners for 10 social situations. Each situation is rated according to how effectively the person with ALS communicates with: 1—a familiar person in quiet; 2—a stranger in quiet; 3—a familiar person on the phone; 4—with children; 5—a stranger on the phone; 6—in a car; 7—at a distance; 8—in noise; 9—in a group; and 10—conversations over an hour in length.

communication difficulty. Both groups rated ''speaking in a quiet environment to a familiar person'' as the most effective communication situation, ''while speaking in a quiet environment with an unfamiliar listener'' was the second most effective situation. ''Speaking in a noisy environment,'' ''speaking before a group of people,'' and ''speaking for prolonged periods of time'' were the three least effective communication environments. These results support the conclusion that ALS speakers and their frequent listeners rank communication effectiveness by social situation quite similarly, and that both groups identify the same order of situational difficulty.

6.2. Comparison of communication effectiveness ratings for ALS speakers and listeners

The third research question, ''What is the difference between PAL's self-ratings and those of their communication partners?'' was addressed next. Fig. 1 contains a plot of the mean communication effectiveness rankings by 25 ALS speakers and their listeners for each of 10 social situations (*CETI-M*). A review of this figure reveals that both groups rated

Table 3
Spearman's rho correlations for *CETI-M* items

	CETI-M items									
	1	2	3	4	5	6	7	8	9	10
PALS ($n = 25$)										
1	–	0.92**	0.85**	0.87**	0.76**	0.74**	0.88**	0.75**	0.83**	0.82**
2	0.92**	–	0.79**	0.87**	0.77**	0.77**	0.85**	0.66**	0.87**	0.88**
3	0.85**	0.79**	–	0.94**	0.73**	0.81**	0.83**	0.62**	0.69**	0.74**
4	0.87**	0.87**	0.94**	–	0.85**	0.81**	0.84**	0.70**	0.85**	0.85**
5	0.76**	0.77**	0.73**	0.85**	–	0.73**	0.70**	0.64**	0.84**	0.72**
6	0.74**	0.77**	0.81**	0.81**	0.73**	–	0.64**	0. 46*	0.62**	0.68**
7	0.88**	0.85**	0.83**	0.84**	0.70**	0.64**	–	0.67**	0.75**	0.76**
8	0.75**	0.66**	0.62**	0.70**	0.64**	0.46*	0.67**	–	0.83**	0.71**
9	0.83**	0.87**	0.69**	0.85**	0.84**	0.62**	0.75**	0.83**	–	0.89**
10	0.82**	0.88**	0.74**	0.85**	0.72**	0.68**	0.76**	0.71**	0.89**	–
Communication partners ($n = 31$)										
1	–	0.92**	0.85**	0.87**	0.76**	0.74**	0.88**	0.75**	0.83**	0.82**
2	0.92**	–	0.79**	0.87**	0.77**	0.77**	0.85**	0.66**	0.87**	0.88**
3	0.85**	0.79**	–	0.94**	0.73**	0.81**	0.83**	0.62**	0.69**	0.74**
4	0.87**	0.87**	0.94**	–	0.85**	0.81**	0.84**	0.70**	0.85**	0.85**
5	0.76**	0.77**	0.73**	0.85**	–	0.73**	0.70**	0.64**	0.84**	0.72**
6	0.74**	0.77**	0.81**	0.81**	0.73**	–	0.64**	0. 46*	0.62**	0.68**
7	0.88**	0.85**	0.83**	0.84**	0.70**	0.64**	–	0.67**	0.75**	0.76**
8	0.75**	0.66**	0.62**	0.70**	0.64**	0.46*	0.67**	–	0.83**	0.71**
9	0.83**	0.87**	0.69**	0.85**	0.84**	0.62**	0.75**	0.83**	–	0.89**
10	0.82**	0.88**	0.74**	0.85**	0.72**	0.68**	0.76**	0.71**	0.89**	–

Note. *CETI-M* items include: 1: familiar person, quiet; 2: stranger, quiet; 3: familiar person, phone; 4: child; 5: stranger, phone; 6: car; 7: at distance; 8: in noise; 9: in group; and 10: long time.

* $P < 0.05$.

** $P < 0.01$.

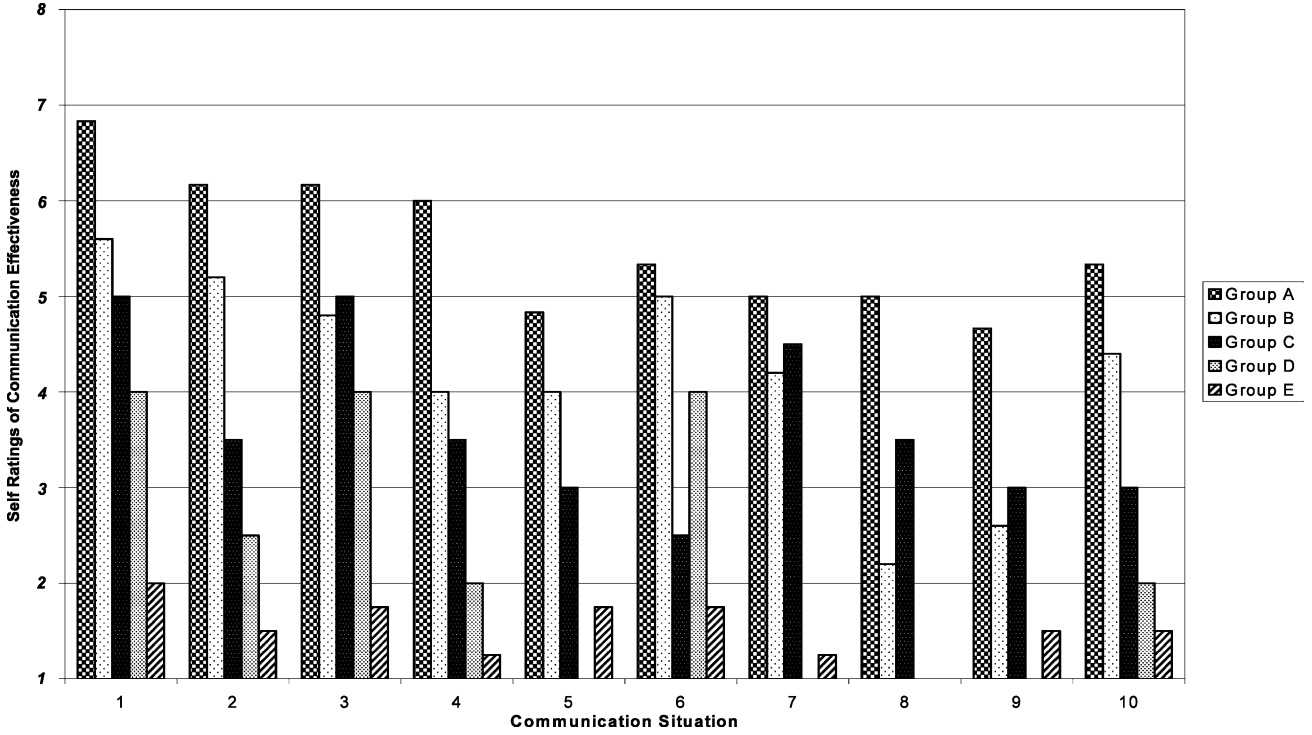

Fig. 2. Ratings of intelligibility groups. Each person with ALS rated their communication effectiveness with each communication situation: 1—a familiar person in quiet; 2—a stranger in quiet; 3—a familiar person on the phone; 4—with children; 5—a stranger on the phone; 6—in a car; 7—at a distance; 8—in noise; 9—in a group; and 10—conversations over an hour in length. Note. Groups are divided along levels of intelligibility, with Group A representing: 96–100%; Group B: 91–95%; Group C: 81–90%; Group D: 71–80%; and Group E: less than 71%.

the *CETI-M* items similarly. A Wilcoxon signed ranks analysis was calculated to determine if there was a significant difference between the ratings by each group of participants (PALS and communication partners) on each *CETI-M* item. No statistical significance was identified.

A correlation of the communicative effectiveness ratings obtained from ALS speakers and for their listeners was $r^2 = 0.87$, $P = 0.00$. These results further support the similarity with which ALS speakers and their frequent listeners perceive their communication effectiveness by social situation. As a result of this similarity, the remaining results are interpreted using the self-ratings from the speakers with ALS only.

6.3. Communication effectiveness and intelligibility: self-ratings

In order to address the third research question, "What is the relationship between *Activity and Participation* (intelligibility of speech and communication effectiveness rating)?" a Spearman's rho correlation was calculated to determine the existence of a possible relationship. Table 3 contains the individual Spearman's correlations for PALS and communication partners.

Results of this analysis (between PALS speech intelligibility scores and self *CETI-M* ratings) indicate a significant positive relationship between intelligibility of speech in sentences (SIT) and self-perceived ratings of communication effectiveness ($r_s = 0.945$, $P = 0.000$). Fig. 2 is a graph of mean communication effectiveness ratings by ALS speakers for five levels of sentence intelligibility (Group A: 96–100%, Group B: 91–95%, Group C: 81–90%, Group D: 71–80%, and Group E: less than 71%) individually. This

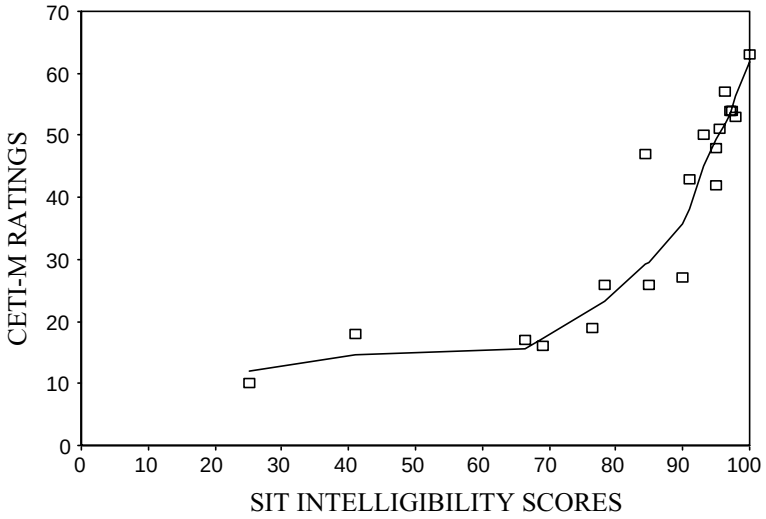

Fig. 3. Intelligibility scores impact on communication effectiveness ratings. Graph of Spearman's rho correlational analysis for self-ratings of communication effectiveness and sentence intelligibility (SIT) scores. Mean ratings above 30 on the scale are observed below an intelligibility score of 85%.

Table 4
Communication effectiveness (*CETI-M*) ratings for intelligibility groups

Group	*N*	Mean rating	S.D.	Mean INTEL
A	6	5.53	1.14	97.35
B	5	4.2	1.5	92.8
C	2	3.65	1.6	84.75
D	2	2.25	1.4	77.29
E	4	1.53	0.78	50.36

Note. *N*: number of participants with ALS in the group; S.D.: standard deviation; INTEL: intelligibility score.

figure is presented to demonstrate the decline in self-ratings of communication effectiveness with various levels of decrease in intelligibility across *CETI-M* situations. In these groups, varying intelligibility levels were represented, with at least one onset type represented in each intelligibility group. Fig. 3 contains a graphic version of the results from the Spearman's rho analysis, demonstrating the high correlation between perceived communication effectiveness and intelligibility of speech.

In addition to presenting the mean ratings for each of the 10 speaking tasks by intelligibility group, data were averaged across these activities. Table 4 depicts the descriptive statistics associated with each intelligibility grouping of participants. In summary, mean self-ratings by PALS indicated that communication effectiveness is perceived as impaired considerably, while intelligibility remains quite high, even as high as 90%. Other decreases in communication effectiveness are noted with only minor declines in intelligibility.

7. Discussion

Previous research has indicated differences in agreement regarding perceived communication ability of dysarthric speakers as rated by the speaker and their communication partners (Hustad & Morehouse, 1998; Hustad & Shapley, 2003). In order to address these issues, this project was completed.

7.1. Similarity of ALS speaker and listener perspective

The results of this study reveal that speakers with ALS and their frequent listeners rate the communication effectiveness of these speakers quite similarly. This conclusion is quite consistent with our observations of PALS within a clinical setting and anecdotal observations with their family members. It is rather unusual for PALS and their communication partners to disagree regarding the impact of the speech disorder on their ability to communicate socially. While they may occasionally disagree about the need to consider AAC communication alternatives, these differences appear to be based on other issues, such as financial impact, imposition of sophisticated technology on caregivers, or the relative importance of communication, as compared to walking, lifting, and other physical skills.

Little research of this nature has been completed with dysarthric speakers with etiologies other than ALS. Sullivan, Brune, and Beukelman (1996) investigated the impact of speech intervention on the performance of persons with Parkinson's disease and had the speakers complete communication effectiveness questionnaires, however, spouses or other frequent listeners did not participate. Additional research is needed to determine if the relative agreement in judging communication effectiveness by dysarthric speakers and their family members is as consistent with other dysarthric speakers as it is this with ALS. The importance of this may be reflected in acceptance of interventions, successful treatment outcomes, and implementation into daily communication. In addition, differences in perceptions may become another goal of interventions, to address disagreements and determine effective communication solutions.

7.2. Communication effectiveness across social situations

It is apparent from a review of the results of this study that perceptions of communication effectiveness differ across social situations. These results are generally consistent with the perceptions of situational ease that Sullivan et al. (1993) collected from speakers following laryngectomy. The patterns of situational data collected in the current study are not surprising, as PALS and family members rated the speakers with ALS to be more effective in quiet environments, somewhat less effective over the telephone and with small children. Still less effective were ratings obtained of PALS when speaking in the car or at a distance, and finally least effective in particular adverse situations—in a noisy environment, speaking before a group, and speaking for a long period of time.

The clinical implications of these findings suggest that an assessment of persons with motor speech disorders, particularly ALS, might include a survey of the social situations in which they are required or prefer to speak. Undoubtedly, their communicative effectiveness cannot be predicted from a speech intelligibility test administered under near optimal speaking and listening conditions. Rather, clinicians should be aware that some social situations become difficult for speakers with ALS with even a slight decrease in speech intelligibility and nearly all situations become difficult when intelligibility in less than 70%. In fact, we urge clinicians to have speakers with ALS and frequent listeners assess their communication effectiveness for standard situations, such as those assessed in this study, as well as situations that are unique to them.

Finally, it is our informal observation that speakers without disability are relatively unaware of the adversity of social situations with the obvious exception of speaking before a group and speaking in noisy crowds. In other words, normal speakers are able to adjust to adversity by using clear speech strategies, such as speaking more loudly, articulating more precisely, and controlling their speaking rate (Pinchey, Dublach, & Braida, 1985, 1986, 1989) without giving much thought to the strategies that they are using. With the onset of a degenerative motor speech disorder, speakers and their most frequent listeners often benefit from information and education about adverse speaking situations and strategies for dealing with communication breakdown (Yorkston, Beukelman, et al., 1996; Yorkston, Strand, et al., 1996). It is hoped that the results of this study will provide information upon which these educational efforts can be based.

Acknowledgements

This publication was produced in part under Grant # H133E980026 from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education. The opinions expressed in this publication are those of the grantee and do not necessarily reflect those of NIDRR or the Department of Education. The project was also supported in part by the Barkley Trust, the Munroe-Meyer Institute for Genetics and Rehabilitation, and the Muscular Dystrophy Association. The authors wish to thank the PALS, their caregivers, and the peers for their participation in our research program.

Appendix A. Communication effectiveness survey (modified CETI)

Person Completing the Survey:

- ❑ *Speaker with ALS*
- ❑ *Family/Friend/Caregiver*

Please evaluate how effectively the speaker communicates in these situations. Read the item describing each of the situations and decide how successful the speaker communicates. If you think that communication is very effective, circle the 7. If communication doesn't occur at all, circle the 1. Circle any number on the scale that best describes communication in that situation.

1. Having a conversation with familiar persons in a quiet environment.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

2. Having a conversation with strangers in a quiet environment.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

3. Having a conversation with a familiar person over the phone.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

4. Having a conversation with young children.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

5. Having a conversation with a stranger over the phone.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

6. Having a conversation while traveling in a car.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

7. Having a conversation with someone at a distance.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

8. Having a conversation with someone in a noisy environment.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

9. Speaking or having a conversation before a group.

1	2	3	4	5	6	7
Not at all effective						*Very effective*

10. Having a long conversation with someone (over an hour).

1	2	3	4	5	6	7
Not at all effective						*Very effective*

Appendix B. Continuing education

1. Speech characteristics associated with ALS may include:
   a. Decreased loudness.
   b. Spasticity and flaccidity.
   c. Velopharyngeal incompetence.
   d. Reduced range and velocity of lingual movement.
   e. All of the above.
2. Components of the International Classification of Functioning, Disability, and Health focus on:
   a. Body functions and structures, activities, and participation in the context of health.
   b. Classification of various disability types.
   c. Consequences of ALS on communication.
   d. The El Escorial and Airlie House criteria.
   e. Upper motor neuron and lower motor neuron wasting.
3. Communication effectiveness was evaluated to document participation. How was this done?
   a. Speech-language pathology assessment.
   b. The CETI-M was completed by the treating speech-language pathologist.
   c. The CETI-M was completed by the family members of the PALS only.
   d. The CETI-M was completed by the PALS and family members.
   e. The CETI-M was completed by the PALS only.
4. Which communication situation(s) is/are difficult for PALS?
   a. Speaking in a noisy environment.
   b. Speaking for prolonged periods of time.
   c. Speaking at a distance.
   d. Speaking in a car.
   e. All of the above.
5. Which communication situation(s) is/are easy for PALS?
   a. Speaking with small children at a daycare.
   b. Speaking in a quiet environment with a familiar person.
   c. Speaking to a group of people at a social event.
   d. Speaking using clear speech strategies.
   e. Speaking in a well-lit environment with an unfamiliar person.

References

Andrea Electronics. (1999). *NC-71 noise canceling Apple compatible headset microphone*. Melville, NY.

Apple Computer, Inc. (2000). *iBook portable computer, Mac OS 9.0.4*. Austin, TX.

Aronson, A. (1980). Definition and scope of communication disorders. In D. Mulder (Ed.), *The diagnosis and treatment of amyotrophic lateral sclerosis* (pp. 217–224). Boston: Houghton Mifflin.

Aronson, A., Ramig, L., Winholtz, W., & Silber, S. (1992). Rapid voice tremor, or "flutter," in amyotrophic lateral sclerosis. *Annals of Otology, Rhinology and Laryngology, 101*, 511–518.

Ball, L., Beukelman, D., & Pattee, G. (2001, November). *ALS communication effectiveness*. Poster session presented at ASHA National Convention, New Orleans.

Bedrosian, J. (1995). Limitations in the use of nondisabled subjects in AAC research. *Augmentative and Alternative Communication, 11*(1), 6–10.

Beukelman, D., & Mirenda, P. (1992). *Augmentative and alternative communication*. Baltimore, MD: Paul H. Brookes Co.

Beukelman, D., & Yorkston, K. (1989). Augmentative and alternative communication application for persons with severe acquired communication disorders: An introduction. *Augmentative and Alternative Communication, 5*(1), 42–48.

Brooks, B. R. (1994). El Escorial World Federation of Neurology criteria for the diagnosis of Amyotrophic Lateral Sclerosis. *Journal of Neurological Sciences, 124*(Suppl.), S96–S107.

Caruso, M., & Burton, E. K. (1987). Temporal acoustic measures of dysarthria associated with amyotrophic lateral sclerosis. *Journal of Speech and Hearing Research, 30*, 80–87.

Darley, F., Aronson, A., & Brown, J. (1969a). Clusters of deviant speech dimensions in the dysarthrias. *Journal of Speech and Hearing Research, 12*, 462–496.

Darley, F., Aronson, A., & Brown, J. (1969b). Differential diagnosis patterns of dysarthria. *Journal of Speech and Hearing Research, 12*, 246–269.

Darley, F., Aronson, A., & Brown, J. (1975). *Motor speech disorders*. Philadelphia: W.B. Saunders.

DePaul, R., Waclawik, A., Abbs, J., & Brooks, R. (1998). Histopathological characteristics in lingual muscle tissue in ALS: Perspectives on the natural history of the disease. In M. Cannito, K. Yorkston, & D. Beukelman (Eds.), *Neuromotor speech disorders: Nature, assessment, and management* (pp. 69–84). Baltimore: Brookes.

Hillel, A., Miller, R., Yorkston, K., McDonald, E., Norris, F., & Konikow, N. (1989). ALS Severity Scale. *Journal of Neuroepidemiology, 8*, 142–150.

Hirose, H., Kiritani, S., Ushijima, T., & Sawashima, M. (1978). Analysis of abnormal articulatory dynamics in two dysarthric patients. *Journal of Speech and Hearing Disorders, 43*(1), 96–105.

Hustad., K., & Morehouse, T. (1998, November). *Exemplary practices for beginning communicators: Implications for AAC*. Paper presented at the American Speech-Language-Hearing Association Annual Convention, San Antonio, TX.

Hustad, K., & Shapley, K. (2003). AAC and natural speech in individuals with developmental disabilities. In J. Light, D. Beukelman, & J. Reichle (Eds.), *Developing communicative competence*. Baltimore, MD: Paul H. Brookes Publishing Company.

Kent, J., Kent, R., Rosenbek, J., Weismer, G., Martin, R., Sufit, R. et al. (1992). Quantitative description of the dysarthria in women with amyotrophic lateral sclerosis. *Journal of Speech and Hearing Research, 35*, 723–733.

Kent, R., Kent, J., Weismer, G., Sufit, R., Rosenbek, J., Martin, R. et al. (1990). Impairment of speech intelligibility in men with amyotrophic lateral sclerosis. *Journal of Speech and Hearing Disorders, 55*(4), 721–728.

Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A., & Zoghaib, C. (1989). The communicative effectiveness index: Development and psychometric evaluation of a functional communication measure for adult aphasia. *Journal of Speech and Hearing Disorders, 54*(1), 113–124.

Macromedia, Inc. (1996). SoundEdit™ 16 Version 2© computer software. San Francisco, CA.

Mathy, P., Yorkston, K., & Gutmann, M. (2000). AAC for individuals with Amyotrophic Lateral Sclerosis. In D. Beukelman, K. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 183–232). Baltimore: Paul H. Brookes.

Pinchey, M., Dublach, N., & Braida, L. (1985). Speaking clearly for the hard of hearing I: Intelligibility differences between clear and conversational speech. *Journal of Speech and Hearing Research, 28*, 96–103.

Pinchey, M., Dublach, N., & Braida, L. (1986). Speaking clearly for the hard of hearing II: Acoustic characteristics of clear and conversational speech. *Journal of Speech and Hearing Research, 29*, 434–446.

Pinchey, M., Dublach, N., & Braida, L. (1989). Speaking clearly for the hard of hearing III: An attempt to determine the contribution of speaking rate to differences in intelligibility between clear and conversational speech. *Journal of Speech and Hearing Research, 32*, 600–603.

Ramig, L., Countryman, S., & Thompson, L. (1995). Comparison of two forms of intensive speech treatment for Parkinson's disease. *Journal of Speech and Hearing Research, 38*(6), 1232–1251.

Strand, E., Buder, E., Yorkston, K., & Ramig, L. (1994). Differential phonatory characteristics of four women with amyotrophic lateral sclerosis. *Journal of Voice, 8*(4), 327.

Sullivan, M., Brune, P., & Beukelman, D. (1996). Maintenance of speech changes following group treatment for hypokinetic dysarthria of Parkinson's disease. In D. Robin, K. Yorkston, & D. Beukelman (Eds.), *Disorders of motor speech: Assessment, treatment, and clinical characterization* (pp. 287–310). Baltimore: Brookes.

Sullivan, M., Beukelman, D., & Mathy-Laikko, P. (1993). Situational communication effectiveness with rehabilitated laryngectomized individuals. *Journal of Medical Speech-Language Pathology, 1*(1), 73–90.

Traynor, B., Codd, M., Corr, B., Forde, C., Frost, E., & Hardiman, O. (2000). Clinical features of Amyotrophic Lateral Sclerosis according to the El Escorial and Airlie House diagnostic criteria. *Archives of Neurology, 57*, 1171–1176.

Turner, G., Tjaden, K., & Weismer, G. (1995). The influence of speaking rate on vowel space and speech intelligibility for individuals with amyotrophic lateral sclerosis. *Journal of Speech and Hearing Research, 38*(5), 1001–1013.

Watts, C., & Vanryckeghem, M. (2001). Laryngeal dysfunction in Amyotrophic Lateral Sclerosis: A review and case report. *BMC Ear Nose Throat Disorders, 1*(1), 1. Epub November 13, 2001

Weismer, G., Martin, R., Kent, R., & Kent, J. (1992). Formant trajectory characteristics of males with amyotrophic lateral sclerosis. *Journal of the Acoustics Society of America, 91*(2), 1058–1098.

World Health Organization (2001). *International Classification of Functioning, Disability, and Health: ICF*. Geneva: World Health Organization.

Yorkston, K., & Beukelman, D. (1981). *Assessment of intelligibility of dysarthric speech*. Tigard, OR: C.C. Publications.

Yorkston, K., Beukelman, D., Strand, E., & Bell, K. (1999). *Management of motor speech disorders in children and adults* (2nd ed.). Austin, TX: Pro-Ed.

Yorkston, K., Beukelman, D., & Tice, R. (1996). *Sentence Intelligibility Test* (Version 1.0) [Speech analysis]. Lincoln, NE: Tice Technology Services.

Yorkston, K., Beukelman, D., & Traynor, C. (1984). *Computerized assessment of the intelligibility of dysarthric speakers*. Austin, TX: Pro-Ed.

Yorkston, K., Strand, E., & Kennedy, M. (1996). Comprehensibility of dysarthric speech: Implications for assessment and treatment planning. *American Journal of Speech-Language Pathology, 5*(1), 55–66.

Yorkston, K., Strand, K., Miller, R., Hillel, A., & Smith, K. (1993). Speech deterioration in Amyotrophic Lateral Sclerosis: Implications for the timing of intervention. *Journal of Medical Speech-Language Pathology, 1*(1), 35–46.