

Critical Review: For patients with Amyotrophic Lateral Sclerosis (ALS), what are the outcomes associated with augmentative and alternative communication (AAC) devices?

Caitlin Brown

M.Cl.Sc (SLP) Candidate

University of Western Ontario: School of Communication Sciences and Disorders

This critical review examines the outcomes associated with AAC users who have ALS. The following outcomes are of interest: a) perceptions of listeners, b) patterns of use and c) acceptance or rejection. Study designs include: repeated measures, survey, retrospective cohort, and qualitative research. Overall, the evidence suggests the need to further investigate outcomes of AAC use in patients with ALS. Included in this critical review are recommendations for future research as well as implications for clinical practice in the field of speech-language pathology.

Introduction

ALS is a degenerative neuromuscular disease, which results in weakness, atrophy, paralysis of functions and eventually death (Ball, Beukelman, and Pattee, 2004). The prevalence of ALS is estimated to be 6-8 per 100,000 people in the United States (Miller & Borasio, 2001). There are three types of ALS: bulbar, spinal, and mixed. In general, patients with bulbar ALS will have speech and swallowing functions affected first, while patients with spinal ALS will maintain their speech and swallowing functions until later in the progression of the disease (Doyle and Phillips, 2001). Regardless of the type of ALS, most patients will eventually rely on AAC systems to communicate. When speech-language pathologists know the outcomes associated with AAC systems in patients with ALS, they will be better able to aid in the decision-making process of an AAC system.

Objectives

The primary objective of this paper is to critically evaluate existing literature regarding three major outcomes of patients with ALS who use AAC systems: perceptions of listeners, patterns of use and acceptance/rejection of device. The secondary objective is to propose evidence-based practice recommendations to speech-language pathologists who are providing AAC assessment and intervention to patients with ALS.

Methods

Search Strategy

Computerized databases, including PubMed, CINAHL, Proquest, SCOPUS, and Google scholar, were searched using the following search strategy:

((Amyotrophic lateral sclerosis) OR (ALS))
AND ((augmentative and alternative communication)
OR (AAC)).

The search was limited to articles written in English.

Selection Criteria

Studies selected for inclusion in this critical review were required to investigate any of the three outcomes (perceptions of listeners, patterns of use or acceptance/rejection) that were associated with patients with ALS using AAC systems. Study subjects included patients with ALS and/or their communication partners. Selection criteria did not include level of technology (i.e. electronic or non-electronic) in the AAC system, any demographic variables or specific stages or types of ALS. Studies were conducted from a variety of institutions in the United States of America including Nebraska, New York, and Oregon. Literature reviews, position papers, or studies that did not include any one of the outcomes of interest were excluded from this review.

Data Collection

Results of the literature revealed four articles that matched the aforementioned selection criteria: counterbalanced repeated measures design, survey, qualitative and retrospective cohort design studies. Levels of evidence were based on the Oxford Centre for Evidence-based Medicine Levels of Evidence (OCEBM, 2009). Results are organized based on each outcome.

Results and Discussion

Outcome a) Listener Perceptions

Purpose. Richter, Ball, Beukelman, Lasker and Ullman (2003) completed two repeated measures studies (in one research paper) that were congruent with outcome a) listener perceptions. The first study compared the attitudes of patients with ALS, their caregivers, and unfamiliar listeners toward one speaker with ALS who used three types of communication modes (natural speech, communication notebook and synthesized speech). The communication notebook was utilized by a laser pointer attached to his eyeglasses in order to point to passages that had been previously typed. The

synthesized speech consisted of an EZ keys Reader with an Ellipse switch accessed using a SlimArmstrong switch, which was mounted to the wheelchair. The second study evaluated the attitudes of patients with ALS, their caregivers, and unfamiliar listeners toward one speaker with ALS who used three types of message formulation techniques (word-by-word, sentence-by-sentence, and complete narrative). The speaker would activate his switch to the desired formulation technique and the output came from the DECTalk Perfect Paul synthesized voice. In both studies, participants watched videos of the man speaking and assessed their attitudes toward the speaker on a 7-point Likert scale on a variety of elements needed for communication including competence, effectiveness, comfort, understandability, and willingness to participate in storytelling conversation. After the final video, participants were asked to rate the communication mode and message formulation technique that they preferred best. Both studies were counterbalanced to avoid any story or learning effect. For example in study one all listeners heard three separate stories told with a different type of communication mode.

To test group differences between listener and the independent variable (communication mode in study one and message formulation technique in study two), appropriate ANOVAs were performed. A bonferroni adjustment (because of the multiple test comparisons) and a Geisser-Greenhouse adjustment (due to lack of homogeneity) were calculated from the preference data. Appropriate post hoc t-tests were performed for the communication aspects and each of the three participation groups (patients with ALS, their caregivers and unfamiliar listeners).

Results. The results of Ball et al. (2003) indicate a high level of agreement between all listener groups. Study one demonstrated a statistical difference favoring the communication notebook and synthesized speech over unintelligible natural speech. Study two revealed a statistical difference favoring sentence-by-sentence and complete narrative message formulation techniques over a word-by-word technique.

Critique. This study has several strengths including the use of counterbalancing (in both studies) and the method of obtaining natural speech from the speaker with ALS (in study one). Natural speech as a communication mode was recorded on the same day in order to keep intelligibility consistent. In addition to appropriate methods, the results of the study are based on appropriate use of statistical measures. One weakness in the study includes a lack of discussion

regarding recruitment of participants. There is usually an inherent bias of those who agree to participate for studies and therefore it is important to know how these participants were recruited. Another weakness is the evaluation of only one speaker with ALS. Future studies should focus on multiple speakers with ALS.

Overall, based on the appropriate use of study design (considered 2b level of evidence), including use of counterbalancing, recording natural speech on the same day, and appropriate use of statistical analysis, findings are suggestive that communication modes and message formulation techniques alter attitudes of listeners who are speaking to people with ALS. Further research is needed to determine the underlying reasons for these perceptions.

Outcome b) Patterns of Use

Purpose. Fried-Oken, Fox, Rau, Tullman, Baker, Hindal, Wile and Lou (2006) evaluated patterns of importance and patterns of use in high technology AAC devices for patients with ALS based on caregiver reports. Twenty-four caregivers of twenty-six persons with ALS were used in this survey research. This study defined the term caregiver as any unpaid assistance provided by family, close friends, or neighbors. The caregiver had to be assisting a person with a confirmed diagnosis of ALS by a certified neurologist and that person had to have owned their AAC device for at least one month and used the device within six months before the beginning of the study. Caregivers were asked to rate the frequency of use, importance, and mode of communication for 17 communication purposes that were based on Light's (1988 as cited in Fried-Oken et al., 2006) four categories of social interaction. Classification of communication purposes was broken down into three sections: basic needs (calling for help), new information (discussing important issues and health care) and social closeness (participating in a casual conversation and telling stories). In order to rank the purposes of communication, the authors used the Communication Device Use Checklist (Fried-Oken, M., Fox, L, Rau, M. T., Tullman, J., & Lou, J. S. 2003 as cited in Fried-Oken et al., 2006). To verify construct validity, a prototype of the checklist was distributed to five AAC experts and their recommendations were taken into consideration for the final version of the checklist. Internal consistency of multiple items on the checklist that were investigating the same construct was calculated using Cronbach's alpha (Cronbach, 1951 as cited in Fried-Oken et al., 2006): basic needs (.92), new information (.82) and social closeness (.87). These results indicate an acceptable

level of internal consistency. Administration of the checklist was conducted face-to-face in the participants' home or on the telephone. Demographic information including gender, ALS severity, relationship to patient with ALS and time known or resided with patient with ALS was also documented.

Results. Results from the checklist indicate that caregivers ranked 'getting needs met' and 'clarifying needs' as reasons for high level of frequency use of AAC devices. It is important to note however, that 25% of caregivers reported no use of AAC devices for these categories. 'Giving instructions or directions to others' and 'staying connected with family and friends' were ranked next for highest levels of use. A Spearman's r was calculated and determined a positive correlation between frequency and importance for each of the 17 communication purposes. Results of the study indicate that caregivers reported 'getting needs met' and 'giving instructions or directions to others' were the most important reason for using an AAC device. More than 60% of caregivers reported that some type of AAC device was used for face-to-face communication across all purposes of communication. The use of other communication techniques (including using the telephone, writing and email) significantly varied.

Critique. Strengths of this study include the construct analysis on the Communication Device Use Checklist (Fried-Oken et al., 2003). Internal consistency measured by Cronbach's alpha was appropriate. As well, recruitment of participants from a variety of locations including ALS support groups, ALS clinics, AAC vendors and AAC clinical practices led to more diversified sampling. Statistical analysis within this study was appropriate. However, the study has significantly stronger weaknesses than strengths. One limitation is the lack of information provided regarding the administration of the Communication Device Use Checklist (Fried-Oken et al., 2003). Data obtained from the checklist may be affected by the administration and should be stated clearly. However, based on the limited information and reviewing the checklist in the appendix, it is unclear whether responses over the telephone would be valid. Another weakness of this study is the lack of information regarding study design (this study is considered level 4 experimental evidence) or regard of checklist limitations. No study is perfect and therefore the limitations need to be expressed in order to validate the results.

Based on limited amount of detail about study design, including the administration of the checklist, and

checklist limitations, results of this study can be considered equivocal.

Outcome c) Acceptance or Rejection

Purpose. Zeitlin, Abrams, and Shah (1995) reviewed their experiences providing AAC services to people with ALS to predict acceptance or rejection responses of AAC systems. This retrospective cohort study included 24 medical records of patients with ALS who received AAC evaluations at Helen Hayes Hospital (New York). Each patient received a full evaluation, which included an examination of speech mechanisms, language and cognitive ability, posture, mobility status, sensory functions and the patients' ability to use a variety of techniques to operate a communication system. The age, sex, educational attainment and reason for obtaining an AAC system was recorded. The level of physical disability was expressed on a six-point scale developed by Currier, Jackson, and Meydrech (1982 as cited in Zeitlin et al., 1995). The level of oral communication impairment was expressed on a 10-point scale developed by Hillel, Miller, and Yorkston (1989 as cited in Zeitlin et al., 1995). Patients were then classified as users or non-users of AAC. "A non-user was defined as a patient who was evaluated and for whom an AAC device was prescribed, but who did not use the device for communication" (Zeitlin et al., 1995, p. 218). Conversely, a user was defined as a patient who was prescribed an electronic or non-electronic AAC device and used it for the purposes of communication (either for personal or vocational uses). Communication use was further investigated by a follow-up telephone interview; however intensity of the AAC device was not investigated.

Results. The user group obtained a mean score of 4.1 on the Hillel et al. (1989 as cited in Zeitlin et al., 1995) scale of oral communication (where scores of 7 or below indicate speech abnormalities and scores of 2 or below indicate no oral communication). For the non-user group, the oral communication mean score was 6.2 ($p > .01$). Both groups obtained a mean score of 3.1 ($p > .06$) on the Currier et al. (1982 as cited in Zeitlin et al., 1995) scale of disability. This corresponds to a disability evaluation of "moderate, unable to work, or needing help to walk" (Zeitlin et al., 1995, p. 218). Based on a student t-test, there was no statistically significant difference between the two groups with either the oral communication scores or the disability scores. However, combined oral communication and total disability score were analyzed using a two way ANOVA and revealed a significant difference between disability scores on the Currier et al. (1982 as cited in Zeitlin et al., 1995) scale and oral communication scores on the Hillel et

al. (1989 as cited in Zeitlin et al., 1995) scale. Based on these results the authors concluded that impaired oral communication skills or disability scores alone cannot predict acceptance or rejection of an AAC system. Total disability (which includes oral communication and physical disability) is better able to predict use of AAC devices by patients with ALS. Within the non-user group reasons for rejection of AAC devices included: poor cognitive ability, lack of financial resources and rejection of technology as a means of communication.

Critique. This study is evaluated as a level 2b level of evidence for study designs, and the overall study design is suitable based on the research question. The statistical analysis performed on this data is appropriate. If the authors did not perform the ANOVA, they would not have found the combination of oral communication and physical disability as significantly different between the two groups. Limitations of this study include the validity of the scales used to categorize users and non-users of AAC devices. As described earlier, the Currier et al. (1982 as cited in Zeitlin et al., 1995) scale and Hillel et al. (1989 as cited in Zeitlin et al., 1995) scale was used to determine overall physical disability and oral communication, respectively. However, there is no mention of either scales' construct validity, therefore the reliability of each scale is uncertain. Several confounding variables were not taken into consideration including the relationship between the professional administering the evaluation and the patient. Furthermore, this study was published in 1995 leaving the results possibly outdated.

Unknown reliability of measures, lack of acknowledgement of confounding variables, and the fact that this paper was published over 15 years ago make the results of this study equivocal.

Purpose. Ball, Beukelman, and Pattee (2004) also studied the outcome of acceptance or rejection of AAC devices in patients with ALS. Inclusion criteria included a diagnosis of ALS with no other neurological impairments. Fifty patients with ALS participated in this mixed methods study. Comprehensive AAC assessments were completed when the participants reached a 90% or lower intelligibility of speech or a 100 words-per-minute or lower speaking rate on the Sentence Intelligibility Test (SIT) (Yorkston, Beukelman, & Trice, 1996 as cited in Ball et al., 2004), during their quarterly Muscular Dystrophy Association clinic visit. The same clinician who provided speech and dysphagia services at the quarterly Muscular Dystrophy Association Clinic completed the AAC evaluation.

This clinician had approximately 20 years of clinical experience, which included working with patients with ALS and prescribing AAC devices. During the AAC assessment, the clinician introduced a variety of high technology AAC devices ranging by type, manufacturer, size, and method of access. After a one week trial of a loaner device, the participants and their family members were informally interviewed to discuss their decisions to accept or reject the device. The informal interview occurred at either the clinic or in the participants home. Interviews were audio-recorded, transcribed and revealed several topics and themes.

Results. 90% of patients in the study immediately accepted the high technology AAC device (6% had delayed acceptance). Within the immediate acceptance group, there was no statistical difference between gender, age, or type of ALS (determined by t-test). Results from an informal interview exposed reasons for accepting the AAC device, which included desire for communication with family, friends, caregivers and medical professionals, community participation, and employment. Family members' belief that they could communicate sufficiently with patients with ALS and/or felt they were providing adequate care without assistive technology were the major themes discussed for delayed acceptance. In addition, denial of the progression of the disease was another theme identified in the delayed acceptance group. Reduced cognitive level was the primary reason that participants rejected AAC devices.

Critique. Results are consistent with the AAC Acceptance Model (Lasker & Bedrosian, 2001). This model identified three components for acceptance of AAC devices: milieu (which includes communication partners and the environment), person (which includes the individual and their personal characteristics) and technology (which includes type, ease of use, weight etc.). In this study, the individual with ALS (person) used high-technology AAC devices (technology) to communicate with a variety of communication partners (milieu). Another positive quality of this study includes the exclusion criteria that participants could not have any other neurological impairments other than ALS. This allowed the participants opinions to sustain their reliability and to minimize any confounding variables. Another strength of this study included the strong favorable rapport between the participant and the evaluating clinician (with the exception of four participants where it was their first visit). Furthermore, researchers critically examined their own role as a potential bias which is another strength

of this study. The first author served as the “primary AAC interventionist” (Ball, Beukelman, & Pattee, 2004, p. 116) and therefore personal (i.e. ease of interaction, ability to accurately describe all AAC equipment, etc...) and professional (i.e. clinical experience, academic credentials, etc...) biases may have altered the results of the study. The notion that the authors took time to identify possible personal and professional confounding variables adds to the value of the results. One weakness of this study is the lack of discussion regarding recruitment of participants. Since, as mentioned previously, there is usually an inherent bias of those who agree to participate for studies, it is important to know how these participants were recruited.

Overall, based on the results being consistent with a pre-existing model, valid exclusion criteria, appropriate use of quantitative and qualitative analysis and the minimization of confounding variables, the results of this study are compelling. In addition, this study has the highest level of evidence (level 2a) for study design within this critical review. Further research should include low technology AAC systems and the relationship of personal and professional characteristics of the evaluator.

Summary and Conclusions

AAC systems are commonly used during the progression of ALS and therefore associated outcomes should be researched. Nevertheless, there is little research studying outcomes of AAC use with ALS. Four studies were included in this critical review, which explored the following outcomes: listener perceptions, patterns of use, and acceptance or rejection. However, some of the studies exhibited numerous limitations and therefore their results should be considered with some caution. To date, there is only one study that provides compelling evidence on the reasons why patients accept or reject high-technology AAC devices. Future research should focus on repeating suggestive and compelling research in order to support and confirm results as well as investigating other outcomes associated with patients with ALS who are AAC users. Equivocal studies mentioned in this critical review could be used as a starting point for future research.

Clinical Implications

The reviewed literature revealed several themes:

- a) Listeners prefer a communication notebook or synthesized speech to unintelligible natural speech. When using a communication notebook, listeners prefer a sentence-by-sentence or

complete narrative message formulation technique to a word-by-word technique.

- b) Getting needs met and giving instructions were the biggest reasons for using AAC devices.
- c) There are multiple factors that influence acceptance or rejection; with the primary factor for rejection being reduced cognitive ability.

Clinicians may use this information cautiously to enrich their understanding of potential outcomes related to AAC. When clinicians know the outcomes associated with AAC use, they are better able to adapt the AAC system, thus providing a higher quality of life to patients with ALS.

References

- Ball, L. J., Beukelman, D. R., & Pattee, G. L. (2004). Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 20 (2), 113-122.
- Beukelman, D. R., Fager, S., Ball, L., & Mietz, A. (2007). AAC for adults with acquired neurological conditions: a review. *Augmentative and Alternative Communication*, 23 (3), 230-242.
- Blackstone, S. W., Williams, M. B., & Wilkins, D. P. (2007). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication*, 23 (3), 191-203.
- Bliney, B., Morris, M. E., & Perry, A. (2003). Effectiveness of physiotherapy, occupational therapy, and speech pathology for people with Huntington's disease: a systematic review. *Neurorehabilitation and Neural Repair*, 17 (1), 12-24.
- Brownlee, A., & Palovcak, M. (2007). The role of augmentative communication devices in the medical management of ALS. *Neurorehabilitation and Neural Repair*, 22, 445-450.
- Doyle, M., & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 17, 167-178.
- Fried-Oken, M., Fox, L., Rau, M. T., Tullman, J., Baker, G., Hindal, M., et al. (2006). Purposes of AAC device use for persons with ALS as reported by caregivers. *Augmentative and Alternative Communication*, 22 (3), 209-221.
- Lasker, J. P., & Bedrosian, J. L. (2001). Promoting acceptance of augmentative and alternative communication by adults with acquired

- communication disorders. *Augmentative and Alternative Communication*, 17, 141-153.
- McNaughton, D., Light, J., & Groszyk, L. (2001). "Don't give up": employment experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 17, 179-195.
- Miller, R. G., & Borasio, G. D. (2001). Clinical characteristics and management of ALS. *Seminars in Neurology*, 21 (2), 155-166.
- OCEBM Table of Evidence Working Group. "The Oxford 2011 Table of Evidence". Oxford
- Centre for Evidence-Based Medicine.
<http://www.cebm.net/index.aspx?o=5653>
- Richter, M., Ball, L. J., Beukelman, D. R., Lasker, J., & Ullman, C. (2003). Attitudes toward communication modes and message formulation techniques used for storytelling by people with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 19 (3), 170-186.
- Zeitlin, D. J., Abrams, G. M., & Shah, B. (1995). Use of augmentative/alternative communication in patients with amyotrophic lateral sclerosis. *Neurorehabilitation and Neural Repair*, 9 (4), 217-