Perspectives of Persons with Amyotrophic Lateral Sclerosis Who Have Transitioned from Oral to Augmentative Communication

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This research has been reviewed and approved for compliance with the policy of the human subjects Institutional Review Board on 07 January 2013.

Introduction

Amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's Disease or motor neuron disease) is a degenerative condition that gradually robs individuals of voluntary movement, including the ability to communicate via speech or writing. More than 80% of individuals with ALS will develop difficulty speaking or lose communication altogether (Tomik & Guiloff, 2010). Many adopt other means of augmentative communication, including using picture and word boards/books, computers, mobile technology, and interaction strategies. Such supports are often used for the rest of their lives (Ball, Beukelman, & Pattee, 2004). While research on best practices for augmentative communication is ongoing, to date there is little research on the meaning patients give to this transition or the role for speech-language pathologists in supporting emotional adjustment to speech loss.

Objectives

- To explore the perspectives of persons who have amyotrophic lateral sclerosis who require communication supports to help them interact with others.
- To interview persons with ALS about their experiences in losing their speech, factors that impacted emotional adjustment, and advice for speech-language pathologists regarding how they can better support the needs of patients with ALS.

Significance

A better understanding of the experiences of patients, particularly beyond the typical discussion of symptoms, strengths, and weaknesses, can help speech-language pathologists to provide more patient-focused service. Exploring the supports and barriers to emotional adjustment for persons transitioning to communication supports can help both the field of speech therapy and the populations they serve by moving research and practice in a direction that is socially valid: that is, that promoting intervention practices that hold meaning and value for the patient and his or her support network.

Methods

- To date, seven adults (4 males ages 45 – 54; 2 females ages 39 & 77) living in the United States with ALS and complex communication needs have participated in email-based interviews.
- As email data was collected, all identifying information was removed to protect participant privacy. Then it was coded for themes that were common within and between participants' responses. These results are displayed in the table to the right.

Word clouds are a way of representing information graphically by correlating relative text size with word frequency. The more often a word appears, the larger it is compared to the words around it. This cloud, made by running all transcript data through **wordle.net**, offers a snapshot of participants' responses in their own words.

Interpretation & Conclusions

- Supports to coping with speech loss identified in this study included social support, access to information, having hobbies and creative outlets, personal characteristics, and having the opportunity to help or educate others. Participants experienced the transition from natural to aided speech within the broader context of decline in ALS.
- Recommendations to speech therapists were for increased support for recording patients' natural voices and for an open dialog about the meaning patients give to speech loss. Empathy is perceived to be an important quality in speech therapists.

Directions for Future Research

This study is the first in a series exploring the counseling and emotional adjustment needs of persons with acquired speech and language disorders. Expansion to other populations (e.g. multiple sclerosis, Parkinson's Disease) is recommended, as is research on how to provide effective counseling to persons with complex communication needs.

Main Theme	Subtheme	Summary
1. Changes resulting from ALS	1.1 Description of and reactions to changes in physical function and health	Participants described physical symptoms as a "war" that was "unkind" and vicious."
	1.2 Impact of changes in physical function and health	Physical changes impacted areas of participants' lives including hobbies, work, lifestyle, and social roles.
	1.3 Impact of changes on concepts of the future	The physical changes associated with ALS also changed participants' dreams (for self, others), fears (losing speech), and concepts/experience of death and dying.
2. Communication & SLPs	2.1 Description of and reactions to changes in communication	Participants discussed ways that their speech had changed and both negative and positive reactions to the transition. Negative responses dealt with coping with loss of speech. Positive responses related to acquisition and adjustment to the device.
	2.2 Description of and reactions to communication supports and partners	Participants described types of devices, perceived roles of the devices (e.g. restoring lost function/humanity), features that were and were not helpful (e.g. internet access, difficulty setting up the device), and qualities of communication partners and settings that impacted successful communication (e.g. impatient or reluctant partners, difficulty speaking over the phone).
	2.3 Description of and reactions to speech-language pathologists	Participants perceived SLPs as facilitating access to their devices. Qualities that were appreciated were empathy, encouragement, and knowledge. Qualities that were not appreciated were failure to recognize the impact devices have on patients' lives and over-reliance on textbook knowledge in place of empathy.
	2.4 Recommendations for SLPs and AAC	Recommendations for SLPs were to be honest about the likelihood of speech loss and that they be willing to engage in open dialog about emotional responses have to speech loss. Recommendations for AAC pertained to voice banking, namely earlier intervention and more training.
3. Supports	3.1 Therapy and support groups	Some participants took advantage of psychotherapy and peer support groups for persons with ALS.
	3.2 Social support	All participants mentioned the importance of social supports in facilitating their ability to cope with ALS and speech loss.
	3.3 Activities	Participants described activities that helped them to cope, including work, hobbies, and creative outlets (e.g. art, writing, music).
	3.4 Personal characteristics and beliefs	Humor, positivity, determination, and spirituality were described as important supports for some participants.
	3.5 Learning and teaching about life with ALS	Access to information through clinic visits, including the ability to see other persons with ALS in more advanced stages of the disease, were cited as supports. Participants also described their roles in teaching others about ALS.

References:

Ball, L.J., Beukelman, D.R., & Pattee, G.L. (2004). Communication effectiveness of individuals with amyotrophic lateral sclerosis. Journal of Communication Disorders, 37, 197 – 215.

Tomik, B. & Guiloff, R.J. (2010). Dysarthria in amyotrophic lateral sclerosis: A review. *Amyotrophic Lateral Sclerosis, 11*, 4-15.