University at Buffalo
The State University of New York

Personal Narrative Telling of AAC Users with ALS

Fei Luo, M.A., M.Ed[+]., Lisa Bardach, M.S., CCC-SLP[*], Jennifer Cornish, Ph.D.[+], & D. Jeffery Higginbotham, Ph.D.[+]

[*]University at Buffalo, SUNY [+]Communicating Solutions

AAC-RERC
SPREAD THE WORD

INTRODUCTION

Augmentative and Alternative Communication (AAC) technology is typically introduced to individuals with Amyotrophic Lateral Sclerosis (ALS) when their speech rate has slowed and intelligibility is inconsistent in difficult listening situations such as talking in a group situation (Yorkston, Miller, & Strand, 2004). Several studies have examined how the AAC technology, especially the hi-tech AAC devices, is used by individuals with ALS (Ball, Beukelman, & Pattee, 2004; Doyle & Phillips, 2001; Fried-Oken, *et al.*, 2006; Mathy, 1996; Mathy, Yorkston, & Gumann, 2000, Lasker & Beukelman, 1999; Richter, Ball, Beukelman, Lasker, & Ullman, 2003). The results suggest that AAC devices are often used by these individuals when telling narratives in face-to-face interaction. However, little research has been conducted on how individuals with ALS construct personal narratives using AAC devices. Unlike other types of narrative, the construction of personal narratives is more collaborative and central to the life of an individual with ALS.

Research by Cornish & Higginbotham (2008) has begun to explore how people construct their interactions – including narratives - using AAC technology across different communication tasks. The use of multiple communication modalities (vocal, gestural, device) and joint or co-construction of messages depends on particular temporal and content coordination demands of the communication task. Because this research has focused on individuals with normal physical and communication skills, it is important to compare these findings to a clinical population like ALS.

In this study we investigate how individuals with ALS and their communication partners use their bodies and devices to construct personal narratives. We will also compare personal narratives to story retell narrative constructions, which are commonly used to assess narrative production of AAC speakers.

METHOD

Participants

•ALS - 7 adults with Stage 5 ALS and a familiar partner (e.g. spouse, good friends, etc.).
•Control group - 5 natural speaking adults and a familiar partner.

Tasks

ALS participant asked to be story teller. One participant in Control group randomly selected to do the same.
•Personal Narrative – formulate a narrative from shared personal experience (e.g., "the most interesting thing that happened on one of your trips together"). Partner shared the experience with the Teller.

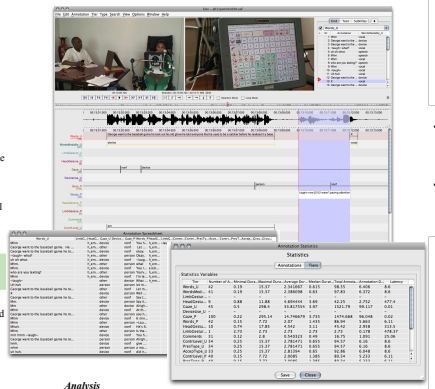
•Retell – Participant asked to retell story based on picture sequence (i.e., Baseball story from Doyle et al.'s Story Retell Procedure (1998)). Partner does not know the story.

METHOD (cont'd)

Annotation and Analysis

Verbal (speech, vocalization, AAC output) and nonverbal (limb & head gesture, and gaze) communication signals transcribed for each participant using EUDICO Linguistic Annotator (ELAN 3.0). Transcripts coded at two levels. Contribution level analysis (Cornish & Higginbotham) used to analyze interaction patterns (i.e. how the participants present and accept presented information). The narrative level analysis (Norrick, 2000) is used to identify the underlying narrative structure.

Elan 3.0 Annotation System with Data Windows



Analysis

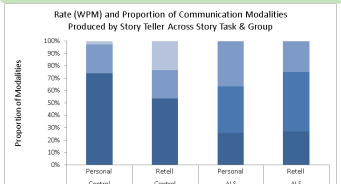
A Group X Narrative Type X Participant Role X Participant mixed linear model was used to analyze the data. Participant was treated as a Random effect. A log transformation was applied to data before analysis. Sparse and/or highly skewed data were analyzed using a Mann-Whitney U test.

Agreement

Inter- and intra-transcriber agreement averaged over 85%.

RESULTS

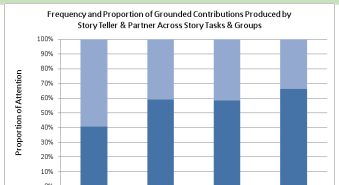
Rate (WPM) and Proportion of Communication Modalities Produced by Story Teller Across Story Task & Group



	Personal Control	Retell Control	Personal ALS	Retell ALS
Limb Gesture	0.30	3.39	0.00	0.00
Head Gesture	2.60	3.35	1.49	0.40
SGD			1.54	0.77
Vocal	8.30	7.79	1.04	0.43

- (Above) Story tellers form the control group were significantly faster utterance producers than were ALS story tellers. Note that ALS story tellers employed the vocal modality (speech, vocalizations) for approximately 20% of their utterances.
- (Below) Differences in attention allocation were found between participant roles and groups. Partners paid less visual attention to task relevant entities (person, device, relevant objects) than AAC users.

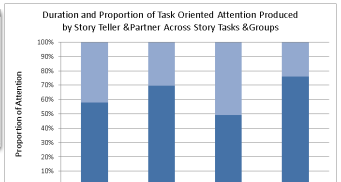
Frequency and Proportion of Grounded Contributions Produced by Story Teller & Partner Across Story Tasks & Groups



	Personal ALS	Retell ALS	Personal Control	Retell Control
Partner	140	23	197	90
Story Teller	96	33	277	176

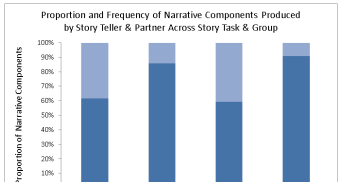
- (Above) ALS group participants produced fewer Grounded Contributions (GCs) than control group participants. Note that this held true for both ALS story teller and their partner, suggesting that dyads coordinated their GCs with that of their partner.
- (Below) Participant production of narrative components differed by group (frequency) as well as task (proportion). Story tellers produced the majority of narrative components in the retell tasks. Participation was much more equitable in the personal narrative task.

Duration and Proportion of Task Oriented Attention Produced by Story Teller &Partner Across Story Tasks &Groups



	Personal ALS	Retell ALS	Personal Control	Retell Control
Partner	412	255	411	142
Story Teller	574	588	399	451

Proportion and Frequency of Narrative Components Produced by Story Teller & Partner Across Story Task & Group



	Personal ALS	Retell ALS	Personal Control	Retell Control
Partner	61	9	128	50
Story Teller	98	55	188	511

DISCUSSION

- Stage 5 ALS participants produce multimodal co-constructed communications when using their AAC systems.
- Similar to findings by Cornish and Higginbotham (2008) using non-impaired AAC communicators, modality, attention displays, grounded contributions and narrative structure are affected by the communication status of the speaker, and the interaction & discourse requirements associated with the communication task.
- These influences also shape the co-constructive efforts of the dyad as evidenced by the proportional changes in GC contributions by story teller and partner.
- Surprisingly, ALS speakers produced approximately 20% of their communication contributions using their residual speech and vocalizations. Observation of the videos reveal that vocalizations were used in circumstances in which the ALS speaker was trying to get their partner's attention, to provide a quick response to their partner's communication, or to repair a misunderstanding.
- Evidence for multimodal, co-constructed narrative communication argues against the use of automated data logging (e.g., LAM) for evaluating communication in social settings.
- This study also provides support for the use of personal narratives for studying interactive communication.

SELECTED 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 & Alternative Communication*, *20*(2), 113-122.

•Cornish, J., & Higginbotham, D.J. (2008). Assessing AAC Interaction I, II, III. Poster Presentations (3), American Speech-Language-Hearing Association, Chicago, November.

•Doyle, M., & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative & Alternative Communication*, *17*(3), 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 & Alternative Communication*, *22*(3), 209-221.

•Yorkston, K. M., Miller, R. M., & Strand, E. A. (2004). Management of speech and swallowing disorders in degenerative disease. Austin. *TX: Pro-Ed.*

•Mathy, P., Yorkston, K. M., & Gutmann, M. (2000). Augmentative communication for individuals with amyotrophic lateral sclerosis. In *Augmentative communication for adults with neurogenic and neuromotor disabilities*.

•Norrick, N. R. (2000). *Conversational narrative: storytelling in everyday talk*. J. Benjamins.

•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. AAC: Augmentative and Alternative Communication, 19(3), 170-186.*

Research for this project was funded in part by the National Institute on Disability and Rehabilitation Research (NIDRR) under Grant #H133E030018