



# ALS Severity and Caregivers' Reports of Communication with AAC Technology

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# Abstract

**We surveyed 34 caregivers of 27 people with ALS (PALS) to examine relationships between ALS severity and AAC technology use.**

- AAC technology use for basic needs increased when overall ALS severity increased.**
- AAC technology use for most basic need communication purposes and selected social closeness purposes increased when speech severity worsened.**
- AAC for story telling decreased as PALS lost the ability to walk.**

# Research question

Is there a relationship between the **frequency** and **importance** of AAC technology use by dyads of caregivers and PALS and four different domains of ALS severity:

- Overall severity
- Speech severity
- Handwriting severity
- Walking severity

# Data Collection Tools

<p><b>Communication Device Use Checklist</b> (Fried-Oken, Fox, Rau, &amp; Tullman, 2003).</p>	<p>17 items; measures importance and frequency of using AAC technology to achieve communicative purposes within Light's (1988) 4 social domains.</p>
<p><b>ALS Functional Rating Scale - Revised</b> (ALSFRS-R) (ACTS Phase I-II Study Group, 1996).</p>	<p>11 categories of function, such as speech, salivation, handwriting, cutting food, dressing, and hygiene, that are graded on a 5-point scale from 0 (no function) to 4 (normal). An additive score is reported.</p>

# Caregiver Demographics

**Subjects: Caregivers  
(N=34)**

**20 spouses  
5 adult children  
5 friends  
1 sibling  
3 other**

**Age**

**Mean: 53.7 years  
Range: 23-88 year**

**Gender**

**27 females  
7 males**

# PALS Demographics

- **Months post diagnosis**
  - Mean: 52 months
  - Range: 9 – 156 months
- **ALS severity score**
  - Mean: 10.44
  - Range: 0 – 32
- **Age**
  - Mean: 60.3
  - Range: 37-88 years
- **Gender**
  - 21 males
  - 6 females
- All used communication technology for  $\geq 1$  month
- No untreated psychiatric or significant neurological disease other than ALS

# Method

- **PALS and informal caregivers were identified through ALS clinics and AAC practices in the Northwest USA.**
- **Research associates met with caregivers and PALS at their homes, by email or telephone to complete the demographics form and ALS Severity Rating Scale.**
- **Caregivers completed the AAC checklist.**
- **Data were analyzed using nonparametric statistical procedures (Spearman's rho).**

# Results: Total Severity

- **When overall ALS severity is greatest, caregivers report PALS use AAC technology to communicate more frequently ( $p \leq .05$ ) for four basic need purposes:**
  - ***calling for help,***
  - ***getting needs met,***
  - ***clarifying needs with caregivers,***
  - ***giving instructions or directions.***

# Results: Speech Severity

When speech severity is greatest, caregivers reported significantly greater **importance** and **frequency** for AAC technology to communicate for the social closeness purposes of:

- *comforting others,*
- *chatting,*
- *having casual conversations*

# Results: Speech Severity

When speech severity is greatest, caregivers reported significantly greater **importance** and **frequency** for AAC to communicate for the basic need purposes of:

- *calling for help,*
- *getting needs met,*
- *clarifying needs with caregivers,*
- *giving instructions or directions.*

## Results: Walking Severity

- When walking is more impaired, caregivers reported more **frequent** use of technology to *call for help* ( $p \leq .05$ )
- Caregivers say using AAC technology to *tell stories* is less **important** and used less **frequently** when walking is more difficult ( $p \leq .05$ ).

# Results: Handwriting Severity

- **No significant relationships exist between handwriting impairment and use of AAC technology.**

# Discussion

- 1. Speech severity, in this sample, is correlated with more communication purposes than walking, handwriting, or overall severity. Yet, only Basic Need and Social Closeness purposes change with speech severity.**

- 2. The trend in handwriting shows weak negative correlations. It appears that once PALS are using AAC technology, handwriting changes don't influence how technology is used.**
  
- 3. With this sample of technology users, we may not be capturing changes to communication function with early upper extremity weakness.**

4. **More than 50% of caregivers report that AAC technology is unnecessary for *calling for help* (Fried-Oken, et al. 2003). But this study's correlations show AAC technology is most important and most frequently used by PALS to *call for help* when speech is most impaired and when overall ALS symptoms are greatest.**

**5. When PALS lose walking independence, they rely less on AAC technology for story telling. Perhaps their number of partners decline and life experiences are less varied, so the need for stories declines.**

**6. Speech severity represents a separate domain. It is not correlated with either handwriting or walking.**

***Note: The sample does not represent a full range of severity levels. It is skewed toward profound impairment in each of the severity domains measured.***

## References

- ACTS Phase I-II Study Group (1996). The amyotrophic lateral sclerosis functional rating scale. *Archives of Neurology*, 53, 141-147.**
- Fried-Oken, M., Fox, L.E., Rau, M.T., & Tullman, J. (2003). American Speech-Language Hearing Association annual convention, Chicago, IL**
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication systems: State of the art and future directions. *AAC Augmentative and Alternative Communication*, 4, 66-82.**

### **Acknowledgment:**

**This project is funded by a subcontract from the University of Washington/RehabNet~West through NIH/NICHD/NCMRR #R24HD39629**

