

AAC Technology Management by Informal Caregivers

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Abstract

Persons with amyotrophic lateral sclerosis (ALS) who cannot speak or write due to the progressive nature of the disease use augmentative and alternative communication (AAC) technology for speech. Often, they must rely on informal caregivers to help set up, maintain, adapt, and upgrade AAC equipment as their neurodegenerative disease progresses. It is crucial that caregivers see the benefits rather than burdens of these tools for social interaction, for daily communication, and to maintain or improve quality of life. It is unclear at this time how AAC technology is, indeed, viewed by informal caregivers.

This project's long-term objectives are: to examine the relationship between AAC technology use by persons with ALS (PALS) and their caregiver's perception of role strain; and to examine the relationship between the caregiver's attitude and skill base with AAC technology and perceived level of role strain. Specific aims are: (1) to develop and evaluate the psychometric properties of a questionnaire to measure subjective role strain of caregivers who manage the AAC technology for PALS; (2) to develop a checklist to identify 3 domains of AAC technology use: type, purpose and frequency of use; (3) to investigate the relationship between caregiver role strain and AAC technology use; (4) to develop and evaluate the psychometric qualities of a questionnaire to measure caregiver

attitudes and skills related to AAC; and (5) to investigate the relationship between caregiver role strain and caregiver attitudes and skills related to AAC technology.

Fifty informal caregivers who manage AAC technology for PALS will complete 2 surveys and 1 checklist. Portions of the Family Care Inventory (Archbold, Stewart, & Hornbrook, 2001) will be adapted to assess role strain. The AAC Technology Use Checklist will provide data regarding frequency, type and purpose of AAC technology use. The AAC Technology Attitude & Skill Scale will be compiled from previous AAC measures (Glennen & DeCoste, 1997; Culp & Carlisle, 1988; May & Waters, 1997). Experts will assess content validity; Cronbach's alpha will examine internal consistency of adapted scales. Results will be reported descriptively, and with ANCOVAs, using ALS severity as the covariate. Results will provide preliminary data for an NIH R01 proposal to investigate the efficacy of various intervention plans to reduce role strain and increase skill base and positive attitudes for informal caregivers who manage AAC technology.