



ALS, AAC Technology, And Caregivers: Attitudes, Skills, and Role Strain

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Abstract

Relationships between role strain, attitudes toward AAC technology, and computer and SGD skills are reported for 34 caregivers of persons with ALS. Overall, caregivers reported positive attitudes toward AAC technology. No significant relationships existed between attitudes toward technology or computer difficulty and role strain. Caregivers' computer skills did not influence role strain. But, communication device skills difficulty was significantly related to role strain.

Research question:

Is there a relationship between caregivers' perceived role strain and caregiver attitudes and skills related to AAC technology?

Data Collection Tools

Communication Device Skills Checklist	17 items; details types and degree of skills caregivers possess to assist PALS with AAC technology use.
Computer Use Skills Checklist	22 items; details type of assistance caregivers provide to PALS to use computers. Queries degree of skills caregivers possess for basic computer use.
Communication Device(s) Attitude Scale	15 items; measures degree of agreement with statements regarding benefits and disadvantages of PALS using AAC technology.

Scales Comprising the CACS: *Caregiver Assessment of Communication Support*

Rewards of Caregiving	10 items; measures aspects of caregiving that are rewarding, and degree to which they are rewarding
Preparation for Caregiving	11 items; measures degree of preparation for caregiving role
Your Reactions to Helping	10 items; measures degree to which caregiving has negatively affected caregiver (e.g., lack of time for oneself)
You and Your Family Member (mutuality)	16 items; measures reciprocity of feelings and points of view
Caregiving Activities Performed	43 items; measures amount of strain from direct care

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 ≥ 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 scales and checklists, and the CACS, alone or with RA.
- Data were analyzed using nonparametric statistical procedures (Spearman's rho).

Caregiver attitudes toward AAC technology and caregiving strain correlations (*p<.01)

Domains of role strain	r	p
Rewards of caregiving	-.196	.291
Preparation for caregiving	.069	.709
Reaction to caregiving	.042	.826
Mutuality	-.182	.318
Difficulty of caregiving activities	-.367	.050

Results: Attitudes

- Mean attitude score (on scale from 1-5 where 1 is negative and 5 is positive) toward AAC technology
- This suggests that this sample of 34 caregivers, overall, had very positive attitudes toward AAC technology.

Results: Attitudes

- There were no relationships between caregivers' role strain and their attitudes toward AAC technology.
- Role strain neither increased nor decreased in relation to caregivers' attitudes about AAC technology.

Computer use skills difficulty and care giving strain correlations (**p<.01)

Domains of role strain	r	p
Rewards of caregiving	.027	.906
Preparation for caregiving	.034	.883
Reaction to caregiving	-.104	.654
Mutuality	-.118	.609
Difficulty of caregiving activities	.273	.245

Results: Computer skills

- Our sample of caregivers were very comfortable with their computer skills (mean=1.25; SD=.366 on scale 1-5 for difficulty).
- They felt that their skills were adequate for computer use.

Results: Computer skills

- There were NO relationships between role strain and general computer use skills.
- Role strain neither increased nor decreased in relation to computer skills, as reported by caregivers.

Communication device skills difficulty and care giving strain correlations (**p<.01)

Domains of role strain	r	p
Rewards of caregiving	-.579	.002**
Preparation for caregiving	-.111	.591
Reaction to caregiving	-.289	.153
Mutuality	-.563	.003**
Difficulty of caregiving activities	.539	.004**

Results: communication device skills

- AAC device skills were related to three domains of role strain for family caregivers:
 - Rewards: Caregivers reported less difficulty with communication device skills when caregiving is more rewarding.
 - Mutuality: Caregivers reported less difficulty with communication device skills when they experience more mutuality with their partners with ALS, they.
 - Other caregiving tasks: Caregivers reported less difficulty with communication device skills when they experience less difficulty with all of their caregiving tasks.

CONCLUSIONS

- Computers are widely used in our culture, and are used comfortably by our PALS' caregivers.
- The computer skills that we measured do not affect the level of role strain experienced by a family caregiver.
- A person with ALS can use integrated (computer-based) AAC technology, and their family caregiver is unlikely to experience a change in role strain because of the computer.

CONCLUSIONS

- AAC technology is viewed as positive by family caregivers of PALS.
- When caregivers have greater skills managing AAC technology they experience greater rewards associated with caregiving, an increased perception of closeness with their partner, and a reduced perception of the total difficulty of their caregiving tasks.

ACKNOWLEDGMENT

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

