



Care-giving and AAC Systems in ALS: Quantitative and Qualitative Analyses

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Stress in carers of people with ALS

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based on data from a 3 year project funded by Scottish ALS
Association & the Community Fund by Joan Murphy,
Research SLT

Aim

- To examine aspects of stress in informal carers of people with ALS
- Objectives
- Which aspects of caring do carers find stressful?
 - Do any aspects of caring make the stressful aspects easier to handle?

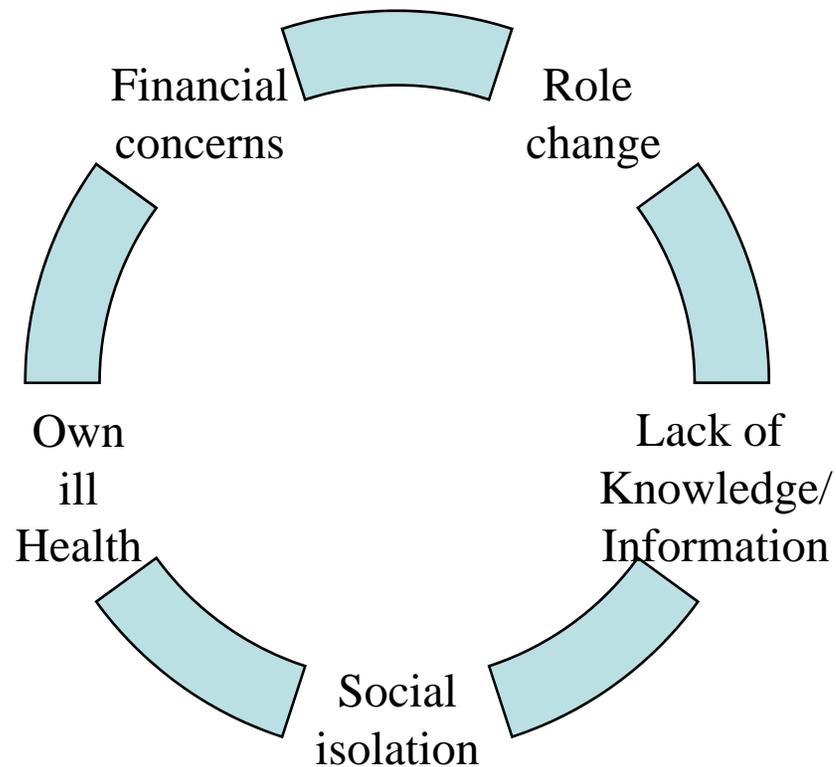
ALS/MND

A progressive and degenerative disease of the motor neurones  severe physical disability affecting limbs, speech, swallowing and breathing

Some cognitive impairment for a minority of people

- Typical age of onset: 45-65
- Prevalence in Scotland: 2.2 per 100 000
- Survival typically 2-5 years from onset of first symptom

Sources of caregiver stress



These factors can result in chronic stress with:

- A less effective immune system

Kiecolt-Glaser et al 1995

- Anxiety and depression

Ramirez et al, 1998

Coping with caregiver stress

Coping: ‘The ways in which we interact with stressful aspects in an attempt to return to some sort of normal functioning’ Ogden, 2004

Emotion focused coping strategies

Managing our negative emotions by the way we *think*:

- Denial: “He might get better”
- Positive reframing: “The illness has made us closer”

And/or by the way we *act*:

- Distraction: Drinking, smoking, shopping, watching TV

Problem focused coping strategies

Managing our negative emotions by the way we *act*:

- Joining a support group
- Applying for financial/practical/domestic help
- Reading up on the information available

Coping with caregiver stress continued

Emotion-focused (EF) and problem-focused (PF) strategies are not mutually exclusive- most people use a combination.

PF strategies are generally associated with **better adjustment** in studies with carers. eg Schulz et al, 1995, Rodrigue & Hoffman, 1995

However, in situations which we cannot control such as incurable disease **EF strategies** can be very helpful, especially

Positive Reframing

“Seeing my wife so ill is extremely painful but it has made me see how important we are to each other and how precious life is. I know I won’t take life or others close to me for granted again”

Husband of wife with advanced cancer

Cognitive Adaptation Theory : *the importance of positive 'illusions'* Taylor et al, 1983, 1984

1. Searching for Meaning

Why did it happen?

95% of women with breast cancer thought they knew why
Taylor et al, 1984

2. Searching for Mastery

How can I control it?

Positive attitude, seeking information etc

3. Self-enhancement

How can I rebuild/protect my self-esteem?

Downward comparisons with others perceived to be 'worse off' eg
lumpectomy



mastectomy



generalised cancer

Why caring for a person with ALS can be particularly stressful



Negative ALS literature

‘death sentence’ to describe ALS diagnosis

Goldstein et al, 1999

‘A relentless disease that ultimately manifests as a profound loss of motor disabilities and death’ to describe the progressive nature of the disease

Strong et al 1996

‘the sufferer’s deep despair being concealed by social smiles and reassurances’ to describe attempts at coping

White, 2003

Stress-related growth

Yet extreme stress can also lead to positive changes in:

- **Relationships**
 - **Coping skills**
 - **Life philosophies**
 - **Values & goals**
- Young & McNicoll 1998- ALS patients who **found meaning** in their experience and **closer relationships** with their families
 - McDonald 1994- a third of their 144 participants believed **something good** came out of their illness
 - Hecht et al 2003 surprised to find 37% of the ALS carers showed relatively **low scores** of caregiver burden

Current study

- Qualitative, retrospective and observational- Video, audio recordings, field notes
- Data from original study into the communication strategies of people with ALS and their carers

Murphy 2004a

Participants: 14 carers of
13 people with ALS

- 4 husbands caring for their wives
- 6 wives caring for their husbands
- 2 sisters caring for their sister
- 1 grand-daughter caring for her grand-mother
- 1 friend

Findings

Carers found these aspects to be stressful:

- Lack of ALS knowledge
- Symptoms: dysarthria, emotional lability, falling
- Patient coping strategies: denial, black humour
- Lack of social support: social isolation
- Lack of material resources: waiting for equipment, alterations
- Change in role
- Communication (including AAC)

Carer stressors relating to ALS

- **Lack of knowledge**

Nearly all carers asked about cause and symptoms of ALS. Some tension between couples when one wanted to know more and the other did not.

- **Symptoms**

Emotional liability especially frustrating

“There’s some nights I’m just beat and I can’t get my head round it at all and then he starts laughing and that makes it worse”

Carer stressors: relating to person with ALS

- Denial of the reality of their disease
Financial strain of holidays booked far in advance etc
- Black humour
Grim Reaper T-shirts
- Social isolation due to partners reluctance to venture out and others' embarrassment
- Long wait for necessary equipment

Carer stressors relating to change in roles

'I suppose I was always in control, or I thought I was. Maybe that's a male thing, I don't know. I always thought I was in control with things, my driving, my ability to do things and I do get very anxious when either I can't do something or it doesn't work out for me and that even has a knock on effect when my wife tries to do something for me and although she's trying her best to do it, she's actually doing it not wrongly, but not as easy as I would have done it.'

Carer stressors relating to Communication

Researcher: *You're still managing to understand?*

Carer: *I think I've lost it now.*

Researcher: *You're struggling a bit?*

Carer: *I do..sometimes she just looks at you as if 'you don't know what I'm saying just **listen**' sort of thing..*

Man with ALS : *"I get despondent.. I think Christ almighty, if you (my wife) can't understand me, what chance has anyone else got?"*

High tech AAC

Reasons for non-use which could lead to stress

- Desire to speak
- Long wait for device
- Slowness
- Obtrusiveness
- Breakdown
- Poor voice
- Lack of training
- Lack of knowledge of professionals
- Manuals
- Vocabulary
- Impersonal
- Problems with hand control

Carers comments about high tech AAC

- *It's no very good because by the time you've punched in an answer to somebody the communication's gone half a mile down the road*
- *I don't think it's altogether right for you. You haven't got the patience anyway*
- *She (the speech and language therapist) sat down with it and sort of took him through it and gave him a book of instructions she had done herself. Just left to puddle along ourselves.*
- *If you're in a strange place and you want to ask to go somewhere, will people all wait in a queue till you spell it out?*
- *Maybe that's a good thing in a way that he doesn't use it because it has maybe made me a wee bit better at trying to listen and to try to pick up what he's saying.*

Murphy 2004(b)

Low tech AAC

Positive comments

- Easier to get
- More personal
- Less obtrusive
- Easier to use
- More interactive

Negative comments

- Lack of training
- Lack of knowledge of professionals

Carers comments about low tech AAC

- *I prefer contact this close (alphabet chart) rather than trying to type something with the Lightwriter ...to lose that personal contact I think is detrimental really*
- *A lot of our communication is non-verbal ... it could be important not to let these non-verbal communications stop ... to become oblivious to it*
- *I much prefer to go through here {POINTING TO ALPHABET BOARD} and it's quicker – It's definitely quicker (than high tech)*

Aspects of caring that made the stress easier to handle

- Shared humour
 - ‘Swinging from a tree’
- Social closeness
 - *We just know each other’s ways, I mean some times we even think the same and then you’ll be saying something and then I’ll say, oh, I was just about to say that”*
- Positive reframing
 - *We know three people who, since I’ve been told {my diagnosis}, have died and they didn’t know they were going to die*
 - *It’s a very frustrating illness this – full of ups and downs but I’m determined that my fighting spirit will come back*

Purposes of human language

- Propositional speaking
 - Transmission of impersonal facts
 - Information encoded on phoneme, word, phrase etc...
- Intimate talking
 - Construction & enjoyment of relationships
 - Casual conversation
 - Affective displays of voice, face and body...
 - Revealing personal thoughts
 - Eliciting social reactions

Locke J(1998) where did all the gossips go? ASHA Summer

Summary

All carers of people with ALS in this study found it a stressful experience especially when they had a

- lack of knowledge
- lack of social support

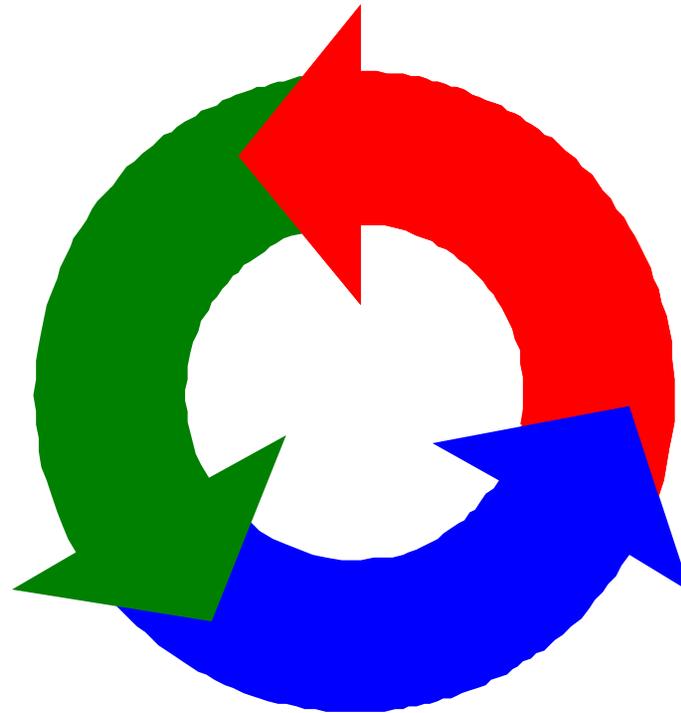
And/or when the person with ALS also had

- communication difficulties
- difficulty using AAC
- emotional lability
- used denial and black humour to cope

Yet many of them also identified positive aspects of caring especially a closer relationship.

Why support carers more?

Less likely to
become a patient
themselves



More likely to give
person with ALS
better care

Less likely to need as much
professional support in the long-term

Discussion

- Do AAC systems add to carer stress?

References

- Kiecolt-Glaser, J.K., Marucha, P.T., Malarkey, W.B., Mercado, A.M., and Glaser, R. (1995) Slowing wound healing by psychosocial stress. *Lancet*, 4:1194-6
- Ramirez, A., Addington-Hall, J. and Richards, M. (1998) ABC of palliative care: the carers. Clinical Review. *BMJ*, 316:208-211
- Schulz, R., O'Brien, A.T., Bookwala, J. and Fleissner, K. (1995) Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes., *Gerontologist*, 35:771-791
- Rodrigue, J.R. and Hoffman, R.G. (1994) Caregivers of adults with cancer: Multidimensional correlates of psychological distress. *Journal of Clinical Psychological and Medical Settings*;1:231-244
- Taylor, S.E., Lichtman, R.R. and Wood, J.V. (1984) Attributions, beliefs about control and adjustment to breast cancer, *Journal of Personality and Social Psychology*, 46:489-502

Goldstein, L. and Leigh, P. (1999) Motor Neurone Disease: A review of its emotional and cognitive consequences for patients and its impact on carers. *British Journal of Health Psychology*, 4:193-208

Strong, M, Lomen-Hoerth, C and Yang, W (2003) Cognitive Impairment in the Motor Neuron Disorders. In P Shaw and M Strong (eds) *Motor Neuron Disorders*, London: Martin Dunitz

White, M. (2003) Nothing more to offer? *Speech and Language Therapy in Practice*, Summer:14-16

Young, J.M. and McNicoll, P. (1998) Against All Odds: Positive Life Experiences of people with advanced ALS. *Health and Social Work*, 23(1): 27-59

McDonald, E.R., Wiedenfield, S.A., hillel, A., Carpenter, C.L. and Walter, R.A. (1994) Survival in ALS: the role of psychological factors, *Archives of Neurology*, 51:17023

Murphy J (2004a) Communication strategies of people with ALS and their partners. *ALS and other motor neuron disorders* 5 (2) p.121 - 126

Murphy J (2004b in press) I prefer contact this close: perceptions of AAC by people with MND and their communication partners. *AAC Journal*

Locke, J.L. (1998). *Where did all the gossip go?: Casual conversation in the Information Age. ASHA, 40, 26-31*

Informal caregivers assess role strain during support of PALS who use AAC

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Caregiver Role Strain

- “The felt difficulty in performing the caregiving role.”
- Includes the psychological constructs of:
 - How prepared is the caregiver to assume the role and understand the process;
 - How much do the caregiver and the care provider agree on their roles.

Research Question #1:

Is there a relationship between caregiver role strain and the perceived quality of the relationship between caregiver and PALS (*“mutuality”*)?

Research Question #2:

Is there a relationship between caregiver role strain and how well prepared they feel for the caregiving role (*“preparedness”*)?

Research Question #3:

Is there a relationship between caregiver role strain and AAC technology attitudes or skills of the caregivers?

METHOD

- 34 caregivers of 27 PALS (persons with ALS) were recruited from ALS Centers in the Pacific Northwest.
 - Oregon
 - Washington
 - Northern California

Subjects: Caregivers (N=34)

20 spouses

5 adult children

5 friends

1 sibling

3 other

Age

➤ Mean: 53.7 years

➤ Range: 23-88
years

Gender

➤ 27 females

➤ 7 males

Subjects: Persons with ALS (N = 27)

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

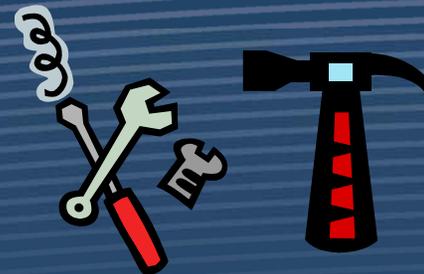
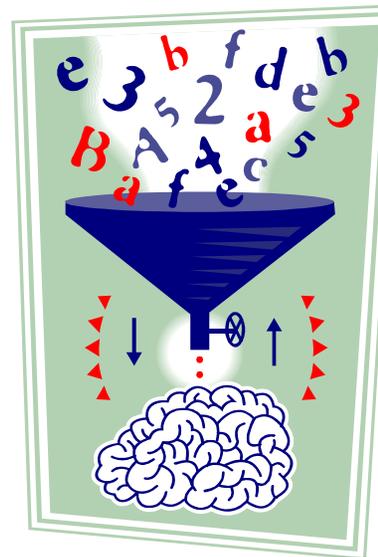
6 females

All used communication
technology for ≥ 1
month

No untreated psychiatric
or significant
neurological disease
other than ALS

- Research Associates met with caregivers and PALS at their homes, over 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.

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Tools Used to Collect Data

AAC Device and Computer Skills, Attitudes, and Use Checklists and Scales

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.
AAC Technology Purposes Scale	Inventories perceived frequency of use and importance of 17 communication purposes;
AAC Technology Complexity Scale	Documents the complexity or components of AAC technology used.

Scales Comprising the CACS: Caregiver Assessment of Communication Support

Caregiving Activities Performed	43 items; measures amount of strain from direct care
Areas of Caregiving Concern	14 items; measures degree of worry about specific concerns
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 Roles Other Than Caregiving	12 items; measures degree to which caregiving is perceived to interfere with other roles (e.g., parent, friend)

CACS scales continued

Your Reactions to Helping	10 items; measures degree to which caregiving has negatively affected caregiver (e.g., lack of time for oneself, lack of personal privacy)
You and Your Family Member	16 items; measures reciprocity of feelings and points of view
Help from Others	9 items; measures degree of help from family, friends and neighbors, paid helpers

AAC Technology Reported:

- Dedicated text to speech devices (e.g., Lightwriter) N=7;
- Computer with specialized software and accessories (e.g., EZ Keys with switch) N=16;
- Symbol or word based dynamic display dedicated devices (e.g. DynaMyte) N=7;
- Computers without adapted software for communication N=3;
- Voice recognition with standard computer software N=1.

Results

#1: Is there a relationship between caregiver role strain and the perceived quality of the relationship between caregiver and PALS (“*mutuality*”)?

Significant correlation

- **Mutuality and rewards of care-giving ($r=.58$, $p<.01$).**
 - *As caregivers felt more connected with their family member with ALS through AAC technology, they experienced greater rewards associated with care-giving.*
 - *Research with other caregivers of stroke survivors also shows that strain from care-giving activities is reduced when preparedness is increased.*

Results

#2: Is there a relationship between caregiver role strain and how well prepared they feel for the caregiving role (*“preparedness”*)?

Significant correlation:

- **Preparedness and rewards of care-giving ($r=.48, p<.01$).**
 - *As caregivers felt more prepared for caregiving tasks, including technology management, they experienced greater rewards associated with caregiving.*
 - ***Research with other caregiver populations shows that the strain of caregiving is reduced when caregivers feel more rewarded.***

Results

#3: Is there a relationship between caregiver role strain and AAC technology attitudes or skills of the caregivers?

No significant correlations ($p < .05$)

Reported between caregivers' reported computer difficulty and any aspects of caregiver role strain.

- *The caregivers' ability to use a computer (or the PALS' computer) is not related to the level of role strain reported by caregivers.*

Significant correlation:

The reported difficulty in managing a dedicated communication device is significantly related to role strain.

- *When caregivers say it is difficult to manage AAC technology, they experience higher levels of care-giving burden.*

Significant correlation:

- Between the difficulty caregivers had managing all of their tasks, and the difficulty in managing AAC devices.
- It was not the number of tasks that added to role strain, but the difficulty of the management.
- *A caregiver could be performing 100 easy tasks and would not report increased strain. But if they were performing difficult tasks (such as managing AAC technology), then role strain was increased.*

No significant relationship ($p < .05$)

- Found between **attitudes toward AAC** technology and caregivers' perceptions of
 - Caregiver preparedness for care-giving activities;
 - Degree mutuality in the caregiver-PALS relationship;
 - Rewards of care-giving.

Implication: Mutuality

- Clinicians should be sensitive to the need for communication that fosters mutuality (a type of social closeness) between caregivers and PALS.
- The rewards of care-giving are felt more when augmentative communication promotes a close relationship.

Implications: Preparedness

- Caregivers need adequate training in maintaining and managing AAC technology.
- Care-giving is more rewarding when they are better prepared for AAC technology management.
- Care-giving appears to be less rewarding when caregivers feel less prepared for AAC technology management.

Implications: AAC skills

- Managing difficult AAC technology adds a burden to family members or informal caregivers of PALS.
- Clinicians should be aware of the caregivers comfort level with complex AAC devices when considering device purchase for PALS.

Implications: Skills

- Concerns about complexity of AAC devices does not carry over to general computer skills for caregivers.
- General computer skills (as measured by our scale) don't appear to add burden to caregivers.
- When someone needs internet access, a communication device, and environmental control systems, clinicians should consider computer applications.

Implications: Attitudes

- While attitudes did not correlate with caregiver burden in our study, we are concerned about the content validity of our research tool.
- Clinically, attitudes toward AAC have been found to affect partners' perceptions.

References

- ALS CNTF Treatment Study (ACTS) Phase I-II Study Group. (1996). The amyotrophic lateral sclerosis functional rating scale: Assessment of activities of daily living in patients with amyotrophic lateral sclerosis. Archives of Neurology, 53, 141-147.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. A. (1990). Mutuality and preparedness as predictors of caregiver role strain. Research in Nursing and Health, 13, 375-384.
- Archbold, P. G., Stewart, B. J., & Hornbrook, M. C. (2001). Family Care Inventory. Portland, OR: School of Nursing, Oregon Health & Science University.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. A. (1992). The clinical assessment of mutuality and preparedness in family caregivers to frail older people. In S. G. Funk, E. M. Tornquist, M. T. Champagne, & R. A. Wiese (Eds.), Key aspects of elder care: Managing falls, incontinence, and cognitive impairment. New York: Springer Publishing Co., pp. 328-339.
- Fried-Oken, M., Fox, L, Rau, MT, Tullman, J. (2002). Caregiver Assessment of Communication Support. Portland, OR: OHSU.
- Smith, C.E. (1999). Caregiving effectiveness in families managing complex technology at home: replication of a model. Nursing Research, 48(3), 120-128.