"ASK US AND WE WILL TELL YOU!"

PERSPECTIVES OF PERSONS WITH ALS ON THE TRANSITION FROM UNAIDED TO AIDED COMMUNICATION.

Vanessa Smith, M.S., CCC-SLP

REFRESHER ON ALS

- Amyotrophic lateral sclerosis, AKA Lou Gehrig's Disease
- A type of motor neuron(e) disease (MND)
- Fatal degenerative neuromotor disease characterized by:
  - Bulbar or spinal/limb onset (spasticity, flaccidity, or combo)
  - Onset at around 50-60 years of age
  - >80% of patients develop dysarthria; 25-30% have dysarthria as presenting Sx
  - 5-10% have frontotemporal dementia; as many as 50% have cognitive impairment

(Chio et al., 2009; Kiernan et al, 2011; Tomik & Guiloff, 2010)

PERSPECTIVES ON ALS

- There is a growing body of literature exploring patient perspectives in ALS.
    - Foley, Timonen, & Hardiman (2012) published a review of forty-seven studies on patient perspectives published between 1988 and 2011.

- Research on how individuals experience life with ALS is growing:
    - Diagnosis (O'Brien et al., 2011)
    - Perceived roles of providers (Beisecker, Cobb, & Zeigler, 1988)
    - Quality of /Meaning in life (Fegg et al., 2010; Grehl et al., 2011; Nelson et al., 2003; Olsson et al., 2010; Roach et al., 2009; Vignola et al., 2008)
    - Reasons for wanting to end their lives (Maessen et al., 2010).

PERSPECTIVES ON ALS

- In terms of communication for persons with ALS, studies have looked at:
  - Maintaining employment (McNaughton, Light, & Groszyk, 2001)
  - Patients' perceptions of the devices (Murphy, 2004b)
  - Acceptance of devices (Ball, Beukelman, & Pattee, 2004a)
  - Perceived purposes for using a device (Fried-Oken et al., 2006)
  - How long devices are used (Ball et al., 2007)
  - Recommendations for best practices in assessment and intervention (e.g. Brownlee & Palovcak, 2007; Ball, Beukelman, & Bardach, 2007; Beukelman et al, 2007; Doyle & Phillips, 2001; Murphy, 2004a)

SOMETHING IS MISSING…

Studies have looked at patient perspectives on the experiences of having the disease or of having the device.

So far there is not much emphasis on the experience of transitioning to needing supports or the SLP’s role in easing that transition.

- A very recently published study by Korner et al. (2012) found that having a device improved QoL for PALS.
  - ST (the intervention) was rated as less meaningful.
  - But no discussion of the therapeutic relationship (the therapist)

QUESTIONS

(1) How do persons with ALS experience the transition from unaided to aided communication?

(2) What factors have influenced that transition?

(2) What advice do persons with ALS have for SLPs to help with that transition?

DESIGN

- Qualitative study
- Semi-structured email interviews
  - One intro / “grand tour” question
  - Five topic questions
    - Prepared?
    - Experience with mental health?
      - Would alter this to ask about supports in general if continuing with this study
    - Coping challenges
    - Dreams/Fears
    - Advice for SLPs?
  - One open-ended summary question
- Thematic analysis

PARTICIPANTS

- Five individuals with ALS and CCN
- Four males, one female
- (And one male who completed consent but dropped out before answering any questions)

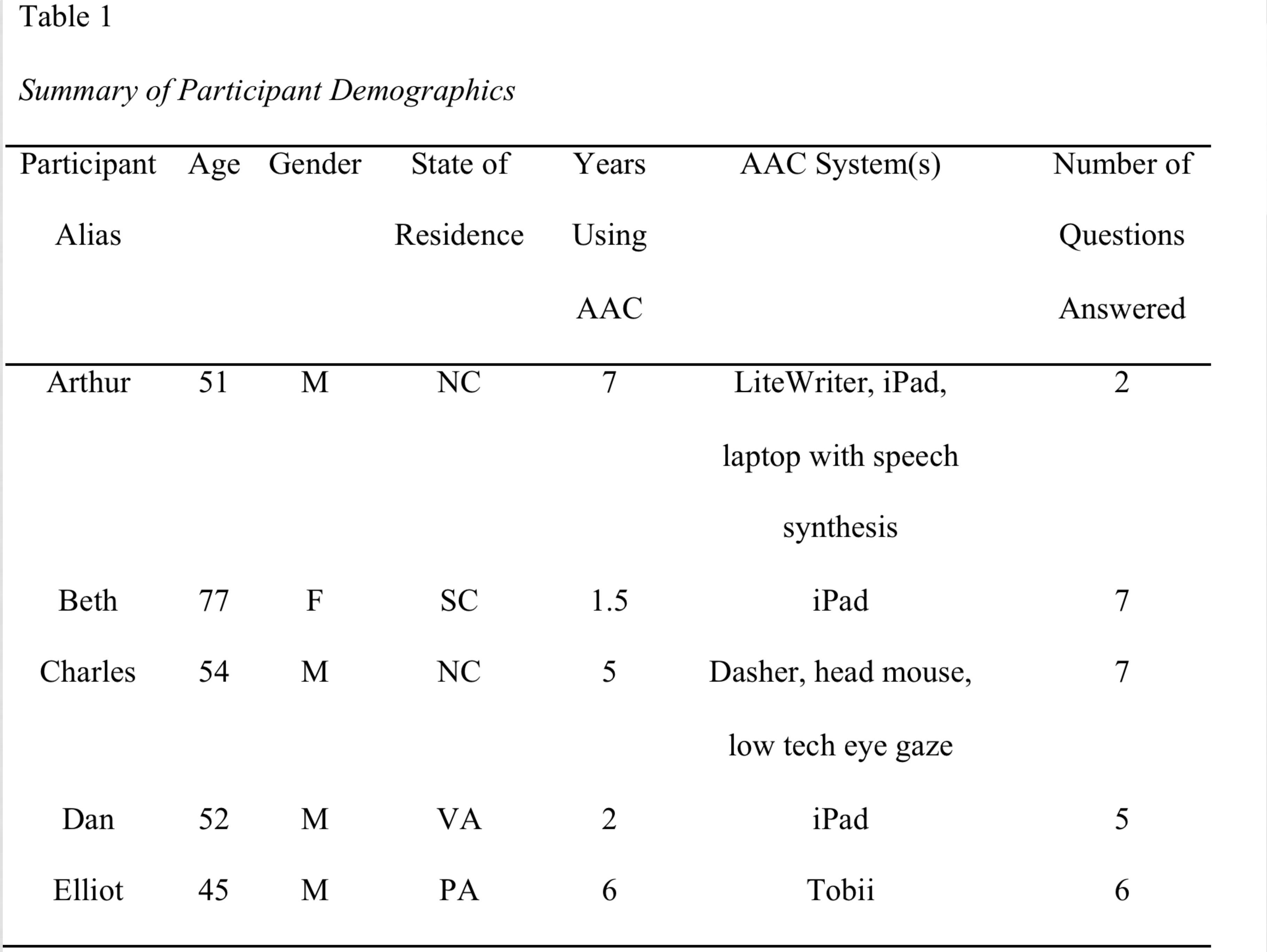

Table 1

Summary of Participant Demographics

Participant Alias	Age	Gender	State of Residence	Years Using AAC	AAC System(s)	Number of Questions Answered
Arthur	51	M	NC	7	LiteWriter, iPad, laptop with speech synthesis	2
Beth	77	F	SC	1.5	iPad	7
Charles	54	M	NC	5	Dasher, head mouse, low tech eye gaze	7
Dan	52	M	VA	2	iPad	5
Elliot	45	M	PA	6	Tobii	6

RESULTS!

- 303 thought units
- 12 subthemes organized into 3 main themes
  - It was previously 26 subthemes across 4 main themes
  - Under original coding scheme, there was "substantial" inter-rater reliability (Cohen's kappa = 0.79); but has not been retested since the change in coding.
    - Suggest waiting until more data is available to re-do reliability and finalize codes

THEME 1: CHANGES RESULTING FROM ALS

- 1.1 Impact on physical function & health
    - Symptoms
    - Reactions

- 1.2 Impact on lifestyle
    - Work
    - Hobbies
    - Social roles / opportunities

- 1.3 Impact on concepts of the future
    - Dreams
    - Fears
    - Death and Dying

THEME 2: COMMUNICATION & SLPS

- 2.1 Changes in communication
  - Voice changing
  - Reactions to changing voice
  - Anticipating future loss

- 2.2 Communication supports & partners
  - Transitioning to devices
  - Positive & Negative reactions
  - Reasons for having a device
  - Communication partners

THEME 2: COMMUNICATION & SLPS

- 2.3 SLPs
  - Positive Qualities
  - Negative Qualities

- 2.4 Recommendations for SLPs & AAC
  - Advice for SLPs: Be honest
  - Advice for SLPs: Listen!
  - Advice for AAC: Voice Banking

THEME 3: SUPPORTS

- 3.1 Psychotherapy & Peer Support Groups
- 3.2 Social Support!
- 3.3 Activities
  - Work, hobbies, creative endeavors
- 3.4 Personal Characteristics
  - Positivity / Determination
  - Humor
  - Spirituality
- 3.5 Teaching / Learning about ALS
  - Exposure
  - Teaching

THEME 3: SUPPORTS

- Time?
  - Not yet included; pending more data

DISCUSSION

- Themes on transition & coping fit into existing literature on ALS
  - Perspectives studies on ALS have found very similar themes, such as physical decline, loss, change in quality of life, faith/ religion, control, dignity, family, social support, altruism, fighting ALS, appreciating life, having hobbies, and appreciating feeling listened to (Foley, O'Mahoney, & Hardiman, 2007; Hecht et al., 2002; Matuz et al, 2010; Olsson et al., 2010)

  - Confirms that "speech loss" is part of the overall picture of ALS; not separate from it. It is part of the decline and all that it entails.

DISCUSSION

- Advice for SLPs: Open, honest, bi-directional relationship that allows for affect
    - <u>Highly</u> consistent with existing literature on communication disorder counseling, which emphasizes empathy, positivity, bilateral information exchange (i.e. both listening and teaching), being trustworthy, and providing support for discussion of emotional responses to the disorder (Crowe, 1997; Flasher & Fogle, 2012; Holland, 2007; Heur, 1997; Luterman, 2008; Riley, 2002; Toner & Shadden, 2002)
    - Possibly adds some social validity to these?

- Advice for AAC: Voice banking
    - Less well represented in the literature.
    - Highlights need for further research, particularly regarding acceptance?

CLINICAL IMPLICATIONS

(1) Be honest but positive & willing to learn.
    (1) Offer "technology and encouragement."
    (2) Allow for time to be a supportive strategy, but don't waste that time.

(2) Support social networks.
    (1) Train as many communication partners as possible, including other providers.
    (2) Re-affirm commitment to always include caregivers in decision-making & problem-solving.

(3) Ascertain what the individual's constellation of coping supports/strategies is; make sure they have access!
    (1) Problem-solve together as needed.
    (2) Re-evaluate from time to time.

CLINICAL IMPLICATIONS

(4) Start voice banking ASAP
  (1) Don’t wait until some cut-off (wpm, SIT) to start Tx.
  (2) Be involved in the process, don’t give up or shrug it off.
  (3) Mentoring?
  (4) Voice donating? (e.g. Yamagishi et al., 2012)

(5) Be informed on what’s available in terms of apps
  (1) Keep up with tech.
  (2) Don’t pick something simply because it’s what’s known or comfortable. Keep searching, be collaborative, be willing to learn.

(6) Focus on self-expression, not just words
  (1) Allow for discussion of death, fears, dreams (meet *their* needs).
  (2) Art, music, creative catharsis

NEW DATA

- Dan; 30 November 2012.

- Question #6: *If you could give advice to a speech therapist who works with people who have ALS, what would you say?*

- "Be patient and keep up with technology. I can only speak from my perspective but we are a stubborn bunch. You should not force an ALS patient to accept a solution they are not ready to embrace. They will eventually accept that solution or find one more accommodating. There are many paths to take and ALS affects each of us differently. Perhaps most importantly always involve spouse / children / caregiver whenever possible as they have a better understanding of the communication challenges."

LIMITATIONS

- VERY small n
- Characteristics of participants
  - Multidisciplinary ALS research/treatment centers in PA, SC
  - Cognitive & metacognitive strengths
  - Two writers
  - Means, motive, & opportunity
- Themes generated by researcher(s)
- Some replies very short
  - Lloyd, Gatherer, & Kalsy (2006)

FUTURE RESEARCH

- Collect more participants
  - Consider other populations
- Interview mental health professionals
  - Supports?
  - Strategies / Techniques?
- Voice banking
  - Interviews: how to facilitate
  - Efficacy: does intervention to promote acceptance work?
- CSD counseling
  - Lit review, clarification of definition, application to PwCCN
  - Strategies for persons with complex comm/cognitive needs
  - Socially valid?
  - Any impact on communication, QoL?

QUESTIONS?