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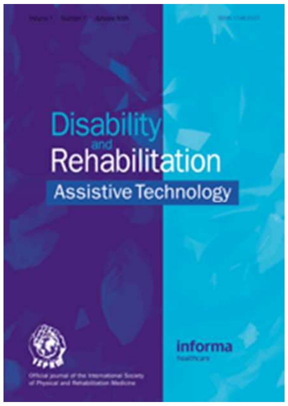

Communication change in ALS: Engaging people living with ALS and their partners in future research

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Communication change in ALS: Engaging people living with ALS and their partners in future research

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Communication change in ALS: Engaging people with ALS dysarthria in future research

Objective: To involve people living with ALS (plwALS) in the scoping and identification of research priorities related to the changes in ALS communication including the use of Augmentative and Alternative Communication (AAC).

Methods: Two focus groups of plwALS at early and late stages of change to speech intelligibility were carried out as a Patient and Participant Involvement (PPI) exercise. The transcriptions of these groups were analysed thematically and compared between groups.

Results: Aspects of anticipation, preparation, adaptation and partnership were identified as key to dealing with communication change as a result of ALS. In particular the involvement of partners was clearly significant, as was the impact on them as well as the plwALS.

PlwALS successfully contributed to focus groups and the process of group discussion about communication itself appeared constructive.

Conclusions: Research and new interventions should focus further on how to support the partners of plwALS. Future research with plwALS should place AAC strategies and technology in the context of wider communication and investigate how best to support the anticipation, preparation and adaptation to communication change. Specific areas of research need relating to this support are suggested.

Keywords: communication; AAC; communication aid; augmentative communication

Introduction

Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND), is an incurable disorder in which survival following symptom onset is around 3 years [1]. Individuals succumb to a rapidly progressive degeneration of motor neurons. The consequences are a progressive weakness of limb muscles, loss of speech and swallowing, and respiratory failure. The annual incidence is 1.5-2.5 per 100,000 [2] with 6000 individuals affected in the UK at any one time.

Speech problems (dysarthria) resulting in problems with intelligibility occur in more than 80% of people living with ALS (plwALS) [3]. Approximately one third of people with ALS experience bulbar MND [4], an aggressive form of the disease affecting speech and swallowing muscles early in the disease process. Speech deterioration is cited by plwALS as one of the most problematic symptoms [5]. The initial period of dysarthria appears to have a strong impact on quality of life [6, 7] and in the longer term the psychological effects of communication change on plwALS and family members can be profound but are often overlooked [8]. Communication is rated by plwALS as a key domain for independence [9]. Additional communication difficulties are associated with changes in cognition [10]. These include impairment of fluency, executive function, language and memory [11].

While many plwALS lose their ability to communicate verbally, this does not mean losing communicative abilities altogether [12]. Many plwALS rely on augmentative and alternative communication (AAC) strategies and technologies [13]. These encompass a wide range of electronic and non-electronic approaches which may be aided or unaided. There is a notably high AAC acceptance rate by plwALS [14] with reports that 46% of plwALS still use AAC technology within one week of end of life [15]. Recent evidence associates early AAC intervention for plwALS with higher longitudinal quality of life for patients and carers [16]. AAC systems appear to improve or at least stabilize quality of life and mood in plwALS suffering from dysarthria [7]. Professional guidelines reflect this preference for early referral for AAC support (National Institute of Clinical Excellence, 2016).

Several studies have examined perceptions of communication and AAC by plwALS and their carers. There is much support for the benefits of AAC [7, 17] although some evidence suggests that it may not necessarily support the full range of communicative functions, including social closeness [18] and communicating with health professionals [19]. Spouses describe unique changes in communication styles as their partners begin to use AAC strategies and technology [8].

Significantly, the communication needs of plwALS change over time. This might typically be described as a spectrum covering people with mild dysarthria, who use their speech and are understandable to most people, to those with little or no intelligible speech who may be totally reliant on AAC to communicate. This transition has to date received little attention [13, 20]. Inevitably communication changes as end of life approaches, with a decrease in all modes of communication including natural speech, gesture, and AAC [21].

There is no doubt that that AAC is viewed as important by plwALS and their significant others. What we have yet to establish are expectations of communication and change over time by plwALS, what is most important to people about their communication changes, how best to support these changes, and what interventions to support communication we should be researching. At present much of the evidence is survey or questionnaire based with a focus on the use of AAC rather than communication between plwALS and others.

The involvement of people with communication impairments in research (i.e. not just as participants) has been promoted and evidenced in areas such as aphasia [22, 23] and dementia [24].This forms part of a wider initiative to actively support Public Patient Involvement (PPI) when developing research questions and priorities [25]. To date engagement with plwALS and associated speech problems in the research process itself has been notable absent.

The work described here was designed and implemented as PPI with the aim of involving plwALS in the scoping and identification of research priorities related to the changes in communication that are symptomatic of ALS. The intended outcome of this work was to establish topics and areas of research need as described by plwALS and their partners in order to inform the design of future research and AAC technology. In addition the work intended to trial the use of focus groups [26] with participants, grouped by the symptomatic stage of their disease progression, who had difficulty with speaking.

Method

Recruitment of participants was carried out via a single UK ALS centre. The study was approved by the management of the UK ALS centre within which it was carried out. PlwALS known to the centre and who had previously indicated that they could be contacted about PPI opportunities were screened by a member of the ALS Centre care team based on their last recorded ALSFRS recorded speech score. Those with a score of 3 ("detectable speech disturbance") or 4 ("Normal speech process") were assigned to Group 1 while those with a score of between 0, 1 or 2 on the scale ('loss of useful speech' to 'intelligible with repeating') were assigned to Group 2.

Potential participants in each of these groups were contacted about the focus groups by way of an invitation letter and consent form. Individuals who responded to this letter were contacted by telephone and invited with their partners or carers to the appropriate focus group meeting. Transportation expenses to the centre were offered to participants. Where participants were not able to physically sign the consent forms, consent was confirmed using the individual's communication method and this was recorded as witnessed by their partner and one of the focus group facilitators.

Data Collection

Topic guides (included as online appendix) were developed for each focus group based on a previous literature review of the topic and on the intended focus of consultation. The guides were developed and then revised through discussions with an expert panel comprising a representative from the Motor Neurone Disease (MND) Association - a UK organisation with the role of supporting plwALS, a service user representative, a local and specialist AAC practitioner, an ALS AAC researcher and an ALS specialist neurologist. The questions for each group aimed to address the same aspects of the topic although some wording changes were required to reflect the cohort in each group. It was decided not to simply present participants with a list of possible research ideas for acceptance or rejection but rather to provide space for discussion on communication in order to allow potential research ideas to emerge. Topic guide questions were not posted in advance as it was felt this might steer the conversation too significantly. Participants were aware of the topic of the focus group prior to the meeting and at the end of the focus group participants were offered the opportunity to send additional responses to the questions if they felt that they had anything to add that they had not been able to say.

Two focus groups were carried out at the ALS care centre in October and November 2015. The focus groups were led by the first and second authors who are both experienced at carrying out focus groups with individuals with speech and communication difficulties. The third author, a consultant neurologist at the centre introduced the sessions to participants, and the session was also attended by the local representative of the MND Association in a pastoral and supportive capacity.

The focus groups were video as well as audio recorded to assist with transcribing any non-verbal communication. The recordings were transcribed using a commercial transcription service and checked and anonymised by the first author.

Analysis

The broad method of analysis was that of a thematic analysis [27] of the transcriptions using a framework analysis approach. NVivo version 10 (QSR International) was used as the data management and coding tool.

The first author initially coded the transcripts into descriptive themes, these themes were then reviewed and developed into a thematic framework. The coding and framework was then reviewed by the second author with minor revisions made. A description of the themes was then distributed for comment to a carer and MND Association representative who suggested no further revisions. Finally, the first and second authors compared themes between the two groups.

Results

Three plwALS attended the first focus group of which two attended with their partners (the third participant's partner was unable to attend). Three plwALS and partner dyads attended the second focus group (for those living with ALS and affected speech) with two additional partners of individuals who had lived with ALS and had since died also attending. All participants with ALS lived with their partners in their own homes. Details of participants are provided in Table 1.

INSERT TABLE 1 HERE.

The data are presented below by presenting the analysis of the two separate groups.

Group 1: PlwALS with unaffected or minimally affected speech

This group comprised five participants: three plwALS and two of their partners.

Anticipation of changes to communication

Participants were aware of and anticipating changes in their communication but not all wanted to acknowledge it

Most were aware through having seen others at a later stage of the disease while some had also actively sought information through the MNDa and social networking. Anticipation of AAC use was described negatively in terms of the time it takes to communicate, the portability of equipment and the effort required to use equipment, including potential fatigue.

Preparedness: Preparation for changes

On the whole, the group was very determined to "*find ways and means of doing things"* and *"fight*" the process of the disease. There was however some sense of fear about upcoming potential changes to speech. The group had experienced this fear and also already experienced frustrations with the changes in their speech (even though they may be classified as having good intelligibility). Not all participants had considered or made preparations for changes in communication but many had focused significant energy and emotion on this.

There was a very strong motivation for some to prepare by voice banking (creating a personalised synthetic voice) and aspects of voice identity were discussed as highly significant to some. This preparation was discussed *"in spite"* of some challenges in the process which participants described as *'hard work'* and also in needing to complete the process before they noticed any significant changes in their speech. As well as the potential technical and process improvements to voice banking this discussion highlighted a need for more nuanced understanding of voice identity and also ongoing support*: I don't think it's any good professionals going away and saying 'well you can do this and you can do this, you go on the computer and you do model talker or you can do video diaries for your children or grandchildren'. You need support with that because there's enough going on in your life and things are difficult enough on a day to day basis without expecting people with MND to sit down and do those things on their own because everyday life is a challenge without, you know, expecting people to just go and do that on their own. It's something somebody needs to do with you, not just say 'go away and do it'."*

Most participants had not considered the concept of preparing spoken or written phrases in advance before but some felt that preparing by teaching the system their individual language and mannerisms of speech could be of benefit to research and develop further. The effort required to record the *'meaningless'* phrases required for voice banking was noted by one participant who felt this effort could be better used to record phrases with personal meaning.

Using video or audio to leave a legacy was also felt particularly pertinent by those with children and another aspect warranting further support and investigation.

How much participants wanted to know, or to not know, about communication changes appeared to be an individual concept. One participant, who had felt the most trepidation about preparing, felt more direction about speech and communication at early stages from a consultant would have made a difference to her actions. For some Twitter and social networking were key sources of information and community but others did not know how to access information in this way and some had been encouraged not to look on the internet:

they all tell you 'don't look on the Internet'. Why not? The Internet is a wonderful tool, you just have to pick and choose what websites you look at

All in the group felt that the experience of discussing communication during the focus group had been positive and in itself could be investigated as a form of support or therapy. Participants described that meeting others with the condition could be an empowering and an effective way of sharing information and strategies. Most participants had met others with ALS before, however meeting someone at a different stage in the condition could be harrowing and depended on the psychological and emotional state and approach of an individual in coping with the diagnosis.

Feelings about, and response to change:

All in the group had detected changes in their speech and for some this was the first indication of a problem that led to diagnosis. These changes could appear small to others listening but were perceived as significant changes to the individuals and it was suggested that this was poorly understood.

(on going to clinic) He knows that his speech has deteriorated, I know that it's deteriorated and I know that he sounds different and J described it as sometimes he feels like he's talking through his nose and he feels all clogged up inside. But yet when he goes to the clinic they quite often say 'how's your swallowing and how's your speech?' and J says 'well my speech is getting worse' and they say 'it sounds normal to me'. "J says 'well my speech is getting worse' and they say 'it sounds normal to me'.

All had had problems communicating with others and had noticed changes in how others perceived them, or communicated with them. Participants described experiencing frustration with changes in their speech, even though they were classified as having 'good' intelligibility. Some participants had seen others with ALS speaking and found this distressing. There was some sense of fear about upcoming potential changes to speech.

Throughout the discussion of change, support of partners also seemed to be key to all in coping with the diagnosis and considering the future. In a number of cases these attitudes to preparation and the future were felt differently between partners.

Group 2: Those living with ALS with affected speech

This group comprised eight participants: three plwALS who used AAC strategies and their partners and two partners of individuals who had died as a result of ALS.

Anticipation of changes to communication

Participants highlighted a fresh appreciation of the importance of communication and the role it plays in independence and quality of life.

You need some way of communicating those emotions, those feelings, and it helps you to cope with the MND.

Participants described that learning to use a communication aid took time and depended on the individual. As well as learning to use the device there were challenges in learning how to best to use it to communicate. No participants described having experienced formal support in learning to use the communication aid, or communicate with it and felt that this process could be better supported and researched.

Once learnt, features such as word prediction and pre-composition of phrases were described by some as beneficial but that could be improved.

The changes to communication that participants experienced were varied and included a number that they had not anticipated. The lack of naturalistic communication had a significant impact on both partners in a couple. Participants had not anticipated the emotional and psychological impact of changes to communication, and had not experienced any support in dealing with this.

it's getting to used to inside not being able to join in that banter in the pub, not being able just to respond to something that's been said … it's so important to me , and I'm sure to you, to know that somebody understands that feeling of loss.

Preparedness

Some participants had tried using communication aids before they needed them whereas others had waited until they had to use them or until there was a 'tipping point' that made them use one. One plwALS described being proactive in seeking out information about communication aids (but not other equipment he may need) "*Because technology is wonderful but it takes a while to learn how to use it yourself.*" Other participants consciously or unconsciously chose not to consider future communication changes. No participants described a structured approach to preparing for changes to communication.: *"No, just pick it up really as you go along. You stumble along"* .

The group felt it was not possible to prescribe a set 'journey' of communication aid use as it depended on many different factors. The key was being able to use the appropriate aid at the right time. The group had varying opinions as to what information about changes in communication should be provided – some felt they would want to know all the information early, others wanted it 'just in time': *"when he first started, a speech therapist came with all these machines, all these computers but, you know, at that point he was speaking not too bad really, you know, quite well."*

This group did not focus greatly on voice banking and had mixed views – for some this would have been a big factor in improving the communication aid and for others this made no difference. Some felt that hearing an individual's voice 'back' was emotionally very hard: *"It just emphasises even more that R's voice has gone".*

Some in the group were aware that devices could learn through word prediction how an individual used them. One example of not being able to transfer learnt word predictions from one AAC system to another highlighted the challenge and further development required related to this aspect of preparation.

Adapting to changes in communication

The use of a synthesised voice itself was discussed as being different from speaking. The concept of identity was challenging and changing with the use of communication aids and perceived as not well understood. *"That's not you speaking, it might be you manipulating the pen but it's not you speaking"* and *"It is so frustrating. You feel within your head what you are saying is clear. We have tried to carry on with life as normal. It took me a long time to accept that it was me."*

There was a preference to use speech for as long as it was at all possible, even when this was very challenging. Experience of loss of speech as the condition progresses is challenging and everyone around the person has to adapt to this. Partners often acted as translators or voices despite the change in relationship this creates.

For some the change in communication had impacted on their social network and with whom they communicated although some described this as a temporary restriction whilst they developed strategies to cope or change attitudes of those around them. Couples adopted different strategies to managing the changes in communication and in implementing strategies to adapt and again, none had been taught or supported in these.

The role of the partner and the impact on them

It was clear throughout the group that partners have a key role in communication. The difficulty with communicating challenges the tool that most people use as part of coping with problems – talking about them with others.

Partners described the emotional impact in not being able to talk to their loved ones in the same way as previously.

I do need to toughen up because yeah, it hurts that you can't be more expansive.

Partners also described having changed communicative roles within the partnership. Communication difficulties changed the content and style of conversations but also gave partners the role of *"anticipation and the interpretation"* of speech and utterances from communication aids : " *it's something that I'm having to get used to is shortening things, like you say just saying 'tea' or whatever. You do abbreviate things now and sometimes I find it a bit difficult. Like coming here you said you've got to ring five people. That would previously have been a 'I'm really sorry but would you mind' and it's blunt isn't it? Of course it is but that's just something else for me to get used to. It's not R being uncaring."*

Partners also had to learn new skills to help mediate communication for the plwALS. These skills seemed to not be recognised explicitly by partners as skills, and were not taught or coached – they were an adaption to the situation. " *I can pick up quite a lot of his conversation and pick things up and put my own words in between it if I can get odd words if we know what we're talking about. It's if he suddenly goes onto a different subject, then I've lost it, 'well we weren't talking about that!'."*

Discussion

The motivation behind this work was to ensure that plwALS were more involved with communication impairment research. The intended outcome of the work reported in this paper was to establish topics and areas of research need as described by plwALS and their partners related to changes in communication arising from ALS. The original anticipated outcome was identified research priorities that would relate to AAC provision. However the actual outcomes focused more on the wider communication journey with four common themes identifying research priorities emerging across the two groups who were at different stages of the symptoms of the disease:

- Anticipation: Looking into the future and predicting changes to communication.
- Preparedness: Preparing (or not) for these changes.
- Adaptation: Response and adaptation to the changes in communication.
- Partnership: The role of the partner and the impact on them.

For both the plwALS and their partners there was a significant psychological impact of the anticipation of communication changes that appeared under supported and researched. The UK National Institute of Clinical Excellence (2016) suggest early referral for AAC support, however from this work it was clear that there was scope to improve the approaches to information provision and support related to communication changes as well as use of AAC. A more nuanced investigation into the best methods of supporting anticipation of communication changes is warranted including the consideration that communication may require more clinical attention earlier in the ALS journey.

The first group of plwALS, who had relatively unaffected speech, were perhaps understandably much more focused on what they saw as aspects of preparedness. In particular voice and message banking were clearly a focus for this group. The different attitude towards this element of preparedness by the second group was marked however. Both groups recognised the amount of individual work required for a successful outcome. It is clear that the concept of identity is of importance to plwALS and that personalised voice synthesis can have a significant impact for some. It is also known that the optimal time in terms of the level of dysarthria of a plwALS using the current voice banking is critical to the quality of the synthesised voice [28]. Our findings may suggest that for some the focus of preparation effort might be more successfully placed elsewhere – for example in psychological support and other more practical preparation of both the individual and their partner.

Regarding adaptation, there is a clear realisation that participants need to adapt to different modes of communication. This entails both learning new skills, with partners learning how best to carry out the new roles they adopt as conversational mediators and translators, and plwALS learning how to integrate AAC methods with existing modalities as a new way of accomplishing communication.

Participants not yet using AAC perceived the future use of AAC negatively – this may highlight that AAC design issues such as speed and naturalness of communication remain pertinent and/or that further investigation is needed around how these initial perceptions may affect future AAC use and success. Participants identified some specific

AAC developments such as the ability to prepare for and adapt device usage more effectively by better learning the written language of the plwALS.

Adaptation was most obviously observed in terms of adaptation to the physical access to AAC technology (e.g. through eye-gaze selection) but should also be understood in emotional, psychological and interactive terms [29, 30]. The value of AAC systems for plwALS has, in the past, been considered self-evident. However, the relative merits of different systems and their wider impact on communication and relationships has only recently begun to be established and warrants further work. The understanding of AAC as part of a wider communicative process , by professionals as well as plwALS, may also require further consideration.

The integral role of partners to the communication process is evident but appears under researched given its prominence in these data. The fact that plwALS and their partners might feel differently about communication invites a more nuanced view of family dynamics which may well impact on the success or otherwise of adaptive communicative strategies as the disease progresses. Changes in levels of communicative spontaneity, for example, may place additional emotional pressures on existing relationships, as may the unexpected finding that some significant others may find hearing their partner's voice (via voice banking) difficult to cope with. What is clear is that being a partner involves changes in communication responsibilities such as becoming a conversational mediator. How this plays out in practice has been evidenced in part [31, 32] but requires further investigation. Whilst it is important to consider the communication needs of the individual themselves it is clear that there is inadequate support for the partner who needs to learn a range of new skills, cope with their changed role and also the psychological impact of their partner's changed ability to communicate – it is clear that this is also an under researched aspect of communication change in ALS.

A secondary aim was to trial the use of focus groups with participants who had difficulty with communication grouped by the symptomatic stage of their disease progression. Others have demonstrated that, whilst potentially challenging, meaningful involvement is possible with individuals with other forms of communication disability [22] and here we have extended this to plwALS. We have shown that focus groups can work for PPI involvement and that clearly plwALS can make an important collective contribution to the research process. What we must do now is look to how best extend this contribution to sustain engagement, possibly through virtual engagement as well as face-to-face.

Feedback from participants and the facilitators highlighted the constructive benefits of discussing communication and its challenges within a small group setting. It is not common for people to discuss communication and speech deterioration with others in this way. There are established self-help groups for people with non-progressive conditions but progressive speech loss invokes negative change, something that might be viewed as uncomfortable or distressing. With appropriate facilitation the experiences reported here suggest that there is a role for small group support and possibly group intervention for plwALS with specific reference to communication.

Conclusions

Speech deterioration and the use AAC form the basis of most communication related research in the field of ALS. The evidence generated over the past 30 years is meaningful but lacks critical engagement with plwALS to inform both the direction and design of the research itself. Whilst the challenges to this engagement are significant there is little doubt that plwALS experiencing changes to their speech can make an important contribution. The PPI findings reported here reveal that aspects of anticipation, preparation, adaptation and the involvement of partners require further investigation.

The results of this work imply that we should extend the existing research focus on AAC systems and their use by plwALS to include the whole process of communication change and support. This includes how the use of AAC, of whatever type, is approached and understood as a process rather than a one-off solution. Feedback reported here suggests that one key question we should be asking is not 'whether AAC is useful?' but rather 'how can communication best be supported?'. This question places AAC provision and intervention within a wider context of communication; not treating any form of AAC as a straightforward replacement for unintelligible speech but rather as one element of a complex support process.

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Table 1. Participant Details

Group 1: PlwALS with unaffected or minimally affected speech				
P1	plwALS	Male	40-50	Speech. Some partner support. Powered wheelchair user – independent control via joystick.
Pt1	Partner	Female	40-50	-
P2	plwALS	Female	60-70	Speech. Ambulant, with assistance in stand/sit transfers.
Pt2	Partner	Male	60-70	-
P3	plwALS	Male	60-70	Speech. Ambulant with walking stick for support.
Group 2: Those living with ALS with affected speech				
P4	plwALS	Male	50-60	Ipad Mini with Clarocom App. Direct Access. Writing. Speech (with partner support). Ambulant.
Pt4	Partner	Female	50-60	-
P5	plwALS	Male	40-50	Smartbox Powerbox with The Grid 3 software & Text based keyboard and phrase package. EyeGaze access. Eye pointing (with partner support) Powered wheelchair user (partner control)
Pt5	Partner	Female	40-50	-
P6	plwALS	Male	60-70	Writing. Speech (with partner support). Ambulant
Pt6	Partner	Female	60-70	-
Pt7	Partner	Male	60-70	-
Pt8	Partner	Male	60-70	-

Implications for Rehabilitation.

- People living with ALS (plwALS), are rarely involved in setting the research agenda in the areas of speech and augmentative and alternative communication.
- Enabling plwALS to contribute to research, even those with no speech, is feasible with appropriate support.
- Feedback indicates that communication change and AAC are experienced in different ways by plwALS
- Research and intervention should focus on how to support the anticipation, preparation and adaptation to communication change for plwALS