Trial participants’ experiences of early enhanced speech and language therapy after stroke compared with employed visitor support: a qualitative study nested within a randomized controlled trial

Alys Young¹, Timothy Gomersall² and Audrey Bowen³ on behalf of the ACT NoW investigators

Abstract

Objectives: To explore trial participants’ experiences of the process and outcomes of early, enhanced speech and language therapy after stroke with support from an employed visitor.

Design: Qualitative study nested within a randomized controlled trial.

Participants: Twenty-two people who, after stroke, had a diagnosis of aphasia (12), dysarthria (5) or both (5) and who participated in the ACT NoW study.

Setting: Eight English NHS usual care settings.

Method: Individual interviews. Thematic content analysis assisted by a bespoke data transformation protocol for incorporating non-verbal and semantically ambiguous data.

Results: Participants highly regarded regular and sustained contact with someone outside of immediate family/friends who engaged them in deliberate activities/communication in the early months after stroke. Participants identified differences in the process of intervention between speech and language therapists and employed visitors. But no major discriminations were made between the impact or value of this contact according to whether provided by a speech and language therapist or employed visitor. Participant-defined criteria for effectiveness of contact included: impact on mood and confidence, self-recognition of progress and the meeting of individual needs.

Conclusions: As in the randomized controlled trial, participants reported no evidence of added benefit of early communication therapy beyond that from attention control. The findings do not imply that regular...
Introduction

Around a third of people with stroke experience persisting problems with aphasia or dysarthria, limiting their ability to communicate through speech, writing or gesture.\(^1\) This restricts everyday activities and social participation, has adverse psychological effects and negatively impacts on families and informal caregivers.\(^2,3\)

The ACT NoW Study (Assessing Communication Therapy in the North West), used a mixed-methods approach (randomized controlled trial and qualitative study) to examine the effectiveness, cost-effectiveness, service use and service users’ views of early, intensively resourced, flexible intervention delivered by speech and language therapists, compared with an equivalent amount of contact but not therapy provided by ‘visitors’ (employees not volunteers).\(^4\) This paper focuses on the qualitative study. It explored, through individual interview, trial participants’ perceptions of the process and outcomes of either the intervention (speech and language therapy) or attention control (visitor contact).

Patients were externally randomized to either speech and language therapy which commenced as soon as clinically indicated at a maximum frequency of three contacts per week for up to 16 weeks, or to a visitor. Visitors were trained to deliver social attention and activities absent of any intuitive form of communication therapy.\(^5\) Both the intervention and the attention control were, therefore, defined in part by human agency.

This study seeks to disentangle the effects of the person (visitor or speech and language therapist) from what they actually did (intervention or attention control) within the trial. This is needed because, while trials are good at providing robust evidence about whether an intervention is effective, they are less good at explaining why a result has occurred.\(^6\) This is a particularly pertinent issue for non-pharmacological trials where the personal and social context in which an intervention occurs inevitably will assert some kind of influence.\(^7,8\)

The qualitative study was designed to enable participants to identify factors which they regarded as important in evaluating the process as well as the outcomes of their experiences. The analysis of these perceptions, while standing alone, was also intended as contributory evidence toward explaining potential variations in effectiveness within and between groups in the trial. This paper is, therefore, published as a companion to the randomized controlled trial. It contributes to the debate about the implications of the main trial results for professional behaviour, patient experience and service delivery.

Methods

Both trial participants and carers were involved in the qualitative study but only results from participant interviews are reported here. The study’s formal research aims were:

- to explore participants’ experiences of speech and language therapy intervention or visitor attention control;
to evaluate from participants’ perspectives the effectiveness of speech and language therapy intervention or visitor attention control, both in terms of process and outcome;

- to compare the perceived impact on participant well-being of speech and language therapy intervention or visitor attention control.

We approached all participants in the ACT NoW study who had completed their post-outcome (six-month) assessment between June 2008 and April 2009. ACT NoW exclusion criteria meant that there were no potential participants with pre-existing learning disabilities or dementia likely to prevent benefits from therapy, subarachnoid haemorrhage, serious medical conditions (e.g. terminal disease), unable to complete eligibility screening even after three attempts or, with communication problems that had already resolved.4

The study obtained Multicentre Research Ethics Committee approval (06/MRE03/42). Informed consent for participation in the qualitative study was obtained from each participant separately from their informed consent to participate in the randomized controlled trial. This was (1) to ensure that any concerns about having to be interviewed did not unduly influence recruitment to the main trial; (2) to distinguish the aims of the qualitative study from other aspects of the trial so that it would be clear what might be expected of those who agreed to be interviewed.

The original intention had been to purposively sample, based on such criteria as severity of impairment, age, gender, ethnicity, socio-economic status. However there were limited numbers of eligible participants at the time of data collection, therefore a whole sample approach was used. Of the 36 potential participants, 22 agreed to take part drawn from 8 out of the 12 sites in which ACT NoW took place. Of those who did not participate, 5 had withdrawn from the trial, 6 did not consent, 2 declined information about the qualitative study and 1 was readmitted to hospital. Sixteen (73%) participants had a baseline communication impairment that was rated in the ‘severe’ category on the Therapy Outcome Measure.9 This proportion is similar to that in the non-participant group (n = 11) (79%) and in the larger sample (n = 170) in the randomized controlled trial (68%).4

Twelve participants had been randomized into the speech and language therapy group, 10 into the visitor group. There were 13 men and 9 women in the sample with a median age of 73 years (range: 53–98 years). Five had a diagnosis of dysarthria, 12 of aphasia and 5 had both aphasia and dysarthria. The self-rated Communication Outcomes After Stroke (COAST) scale10,11 was designed to ascertain perceived level of communication disability and impact on daily life. Eleven of the qualitative sample scored above the median on COAST, 6 had scores up to the median and in 5 of cases there were three or more missing values, indicating a more severe degree of disability.

**Interviews**

Qualitative interviewing of participants with aphasia/dysarthria is entirely possible12–14 but some basic assumptions of qualitative interviewing cannot be taken for granted, such as sustained narrative engagement. Typically people with aphasia or dysarthria can vary considerably in the extent to which they might have impairments in expression and/or understanding. Adaptations by the interviewer and a more structured approach to data elicitation are helpful.11 We maximized the potential involvement of participants with the greatest difficulty communicating by training the interviewer (TG) in the techniques of Supported Conversation for adults with Aphasia (SCA)15,16 and through the design of the interview.

The interview method incorporated prompt cards for expressions, pictorial representations of activities and visual analogue scales to represent degrees of emotion or opinion.6 These communication ramps could be used in different ways depending on the individual’s degree and kind of communication difficulty. They could be ignored, or used simply as an aide-memoire to remain focused on the topic of discussion. They might replace specific words/expressions that the participant was unable to articulate, or pointing to them combined with gesture might be used to convey meaning. What was important was that the form of the interview and the
means of the interview were maximally flexible to encourage participation from people with different communication needs and strengths. The ACT NoW research user group, made up of people with aphasia and/or dysarthria, also supplied the interviewer with training through means of role play and feedback on mock interviews in which they both participated and critically observed.

The interview schedule was divided into three sections: (1) questions that invited a discussion of what had taken place during their contact with the speech and language therapist or visitor (description); (2) questions that encouraged participants to explore what they thought about the contact with speech and language therapist or visitor (appraisal); (3) and questions that invited participants to judge the impact of their experience on themselves or others (evaluation). All interviews were video recorded to capture verbal and non-verbal expression.

Analysis

The data varied in style of expression, degree of elaboration and intelligibility. The vast majority were amenable to conventional forms of transcription. In two of interviews there was either so little spoken language expression and/or non-verbal communication that the intended meaning was uncertain. In a further three there were some instances of ambiguous content. We developed a data transformation protocol to manage data where conventional transcription was not possible. It was guided by three principles: (a) a respect for participants’ efforts to ensure that their opinions were recorded, by whatever media of communication they could use; (b) a concern not to over-interpret data where the meaning was not clear; (c) to develop a process that had the potential to address the three levels of meaning sought in the data collection: description, appraisal and evaluation.

The data transformation involved the re-presentation of data in a prose form amenable to conventional data processing. There were four stages, involving authors TG and AY.

All data were watched and conventional verbatim transcription applied where there was clarity – this included the marking in written form of any gestural communication where meaning was straightforward.

All data were re-watched and where there were gaps in the verbatim text transcription the researcher added notes using the QSR NVivo tool ‘data-bites’. These notes addressed the possible meaning of the data and degree of certainty of interpretation.

Where the researcher was less confident about the interpretations, an experienced speech and language therapist watched the relevant sections of video and independently interpreted the meaning. If there was disagreement, the speech and language therapist and researcher discussed their interpretations until a collaborative meaning was reached. Where agreement was still not possible, the data section was not used.

A new document was created in NVivo consisting of a prose summary made up of content statements derived from the data-bite notes. A link was then created between the re-presentation and the original transcript to insert the prose in the appropriate section of the original interview.

We used a thematic analysis approach because we were primarily concerned with understanding the content of what participants said and drawing out conceptual frameworks based on their perceptions and experiences, rather than analysing how they expressed themselves and the narratives they might form. An open coding approach influenced by the research aims generated 40 initial codes. Consensus was sought on overlapping or redundant codes resulting in an agreed final list of nine. The analysis derived from each thematic category was written out separately, before considering their inter-relations and reaching an overarching interpretation consisting of six topics, reported below.

These topics do not map onto the three research aims in a linear way. They are guided by the participants’ emphases not by the structure of the questions asked. The topics are representative of the most significant issues from participants’ perspectives which emerged from the exploratory interviews. In the direct quotations used, we changed some of the examples participants gave as they revealed specific interests that might make the participant identifiable.
Results

Mood

Participants identified the positive effect on their mood of their speech and language therapy or visitor experiences as a key marker of effectiveness. This positive impact could occur either as a result of contact with someone who was friendly and supportive serving to lift them out of a low mood, or because such contact could distract them from the difficulties of living with the consequences of stroke:

If you’ve had a stroke, which is a dreadful thing to have, it’s on your mind the whole time and I thought well, at least I’m doing that, I’m starting to have these conversations. Which I did . . . it stopped me thinking, it put me in someone else’s spot for an hour, didn’t it? I stopped thinking about number one and started thinking about somebody else . . . It’s very easy to get involved in your own little thing isn’t it? . . . he [the visitor] would tell me different things. Yeah, I think it was good. (Visitor contact)

The professional identity or role of the individual speech and language therapist or visitor was of far less importance than their personal qualities in generating such positive effects. Participants identified five helpful characteristics for positive interactions during contact:

- the ability to put someone at ease;
- the ability to make an individual feel important;
- the visitor/speech and language therapist displaying a positive mood themselves;
- being empathic;
- being a good communicator.

Confidence

Both speech and language therapy and visitor experiences were viewed by participants as helping to enhance personal confidence but differences in the process of care were observed. Those with visitor experience described enhanced confidence in terms of the normalizing effects of regular contact with a stranger. Visits meant they had to engage in social interaction and face their concerns about communicating with someone who did not know them well. They had to practise everyday tasks like getting up to answer the door, making a cup of tea and show they could cope beyond their immediate family. Those with speech and language therapy experience tended to view improvements in confidence as direct consequences of specific tasks and newly acquired strategies, rather than indirect benefits of social encounters.

Very um . . . helpful she’d [the therapist] point out where you were going wrong and, and finding you . . . how to get it right . . . just build your confidence up so where, where you think ‘oh, I can’t do that word,’ just, just try a different way or . . . work out what you could say instead, take out words you couldn’t say y’know so y’know like when they say, oh, I use three words instead of one it’s because you can’t do the one (laughs) so use three, it’s easier. (Speech and language therapy)

Recognising progress

Participants strongly emphasized the importance of being able to recognize their own progress. The extent of improvement was often of less importance than the sense of moving forward.

He’s [the visitor] done a good job, I was talking to everybody and I don’t know, maybe I’m going back, but everybody says, me sister says ‘you can talk a lot better, I can understand you now. (Visitor contact)

It doesn’t seem that much but it is a big thing doing things like that for you and one of the girls on the . . . me, meat thing [in the supermarket], she were good ‘cause I just had to point to what I wanted, but I saw her last week, she said ‘ooh, yes, we know what you can say now can’t you?’ Y’know. (Speech and language therapy)

There was a difference in how speech and language therapy or visitor contact was seen as contributing to the observation of progress. Those with therapy experience described how the therapist
might deliberately point out their areas of weakness or skills they needed to develop/re-learn in a targeted way. Before and after measures of how well they were doing were also built in.

For those with visitor experience, the emphasis was on self-perceived differences. Having to communicate socially with the same person over time was seen as a good basis for self-judgements of improvement. For some people, the fact that the conversation partner was not someone who knew them well was important because they had to make additional efforts to understand and be understood. For some participants who lived alone or had very limited contact with family and friends, an assured social encounter was a prerequisite for testing out whether they were getting better. Without it they might not talk regularly with anyone.

For many participants there was an acknowledgement of spontaneous improvement (e.g. in speech or mobility). Consequently, the extent to which the visitor or speech and language therapist contact was seen to be a contributory factor also varied. Nonetheless, the sense of being able to recognize one’s own progress was of overriding importance.

**Guidance and support**

Participants gave very different descriptions of the kind of guidance and support they had received from speech and language therapists or visitors. Visitors were trained not to engage in deliberate strategies of therapeutic activity. The fact that participants did not perceive them to be doing so is important for evidencing the fidelity of the attention control within the trial design. By contrast, participants strongly perceived the purposefulness and structure of speech and language therapy, referring to ‘building blocks’, ‘strategies’ and ‘deliberate learning’ that was not evident in the data from those with visitor experience. However, unique to descriptions of the visitor experience was the value participants placed on being able to give to the visitor, usually in relation to knowledge and know how. The reciprocity was regarded as therapeutic.

I gave her [the visitor] the name of one or two greenfly sprays that I found useful. Now it could well have been that she knew all that, but she accepted it in the sense that it was new to her, so it made me feel as though I was achieving something imparting information. (Visitor contact)

**Meeting individual needs**

Participants highly valued speech and language therapists or visitors who could make their interaction seem specifically relevant to the individual. The most effective examples of encounters were ones that felt tailored to who the participants were, not just what their clinical problem might be.

I’m . . . football fanatic so most of the things she [the therapist] got me to read and do was over football and that’s where . . . the letter ‘M’ came into it. I found I struggled saying [inaudible] . . . [Manchester] United, she did football teams to make it interesting for me. She’d pick my interests out and put it into a way of teaching me that I enjoyed. I think that’s why I enjoyed the speech therapy so much. (Speech and language therapy)

On the rare occasion when a participant expressed dissatisfaction with the contact they had received, failure to recognize individual need or to contextualize the response to the individual’s circumstances, were usually components of the problem.

**Amount and intensity**

Participants valued a high amount of contact, whether with speech and language therapists or visitors. High amount of contact was defined by frequency, number and length of visits and/or amount of time spent with them. Furthermore, the amount of support was perceived to be closely connected with the benefit. More contact felt like more benefit in quite a straightforward equation for the majority of participants. Some participants also discussed the importance of frequency of contact being tempered with sensitivity to meeting the particular needs which participants were experiencing at any given time. Part of this sensitivity was about flexibility
and awareness of how easy it might be to feel overloaded which could undermine the benefits of a large amount of contact. This was true both among those who had speech and language therapy and those who had a visitor. No concerns were expressed that the large amount of contact had come too early in their recovery process.

**Discussion**

The qualitative study nested within the randomized controlled trial was designed: (1) to generate data in its own right on participants’ experiences; (2) to be integrated with the results of the main trial in order to understand better some of the mechanisms underlying the main trial’s results; (3) to contribute to implications for policy and practice that might be drawn from the main trial’s results.

The principal result of the main trial was: ‘that people with aphasia or dysarthria who receive an early, well-resourced but individually tailored best practice Speech and Language Therapy communication intervention demonstrate similar levels of functional communication ability at six months to those who receive visiting from a non-therapist employed to provide an attention control consisting largely of informal conversation but no specific communication training’.

The qualitative study also found that no major differences in impact or effectiveness were perceived depending on whether participants had a speech and language therapist or a visitor. However, in addition it identified that there were factors common to both experimental conditions which participants perceived as important based on their experience of one or the other. Namely, that the person with whom they had contact, whether a visitor or speech and language therapist, was valued for being an empathic, good communicator who could put them at their ease, engage with them in an individualized manner which made them feel important, lifted their mood and contributed to their self-perceived sense of progress and confidence.

It was not that participants were blind to the identity or role of the person with whom they had contact within the trial. Nor that the differences in the activities of visitor or speech and language therapist could not be discerned. It was that both sets of people, speech and language therapists and visitors, were valued for similar qualities and effects arising from shared positive factors common to both experimental conditions. Neither the findings from the main randomized controlled trial nor the qualitative study imply that regular contact with any non-professional can have beneficial effects for someone with aphasia or dysarthria in the early weeks following a stroke. The qualitative study points to specific conditions that would have to be met for that contact to have a positive effect.

The qualitative study was able to identify differences in the experiences of participants about the processes of speech and language therapy and visitor contact. Speech and language therapy was regarded as purposeful and its effects explicitly measurable. Contact with a visitor was regarded as something from which indirect benefits were discernible and measures of progress largely self-reflective. This is important in reinforcing the fidelity of the attention control within the overall randomized controlled trial design as well as demonstrating that the skills, techniques and expertise of speech and language therapists are evident to the lay participant. Participants did not perceive the speech and language therapists and visitors to be doing more or less the same thing.

The findings from the qualitative study demonstrate that early, regular and sustained contact with an individual outside of the participants’ immediate family/friends was strongly perceived to be of benefit. The amount and intensity of contact, whether from a speech and language therapist or a visitor, was strongly liked and equated by participants with greater perceived effectiveness provided that due attention is paid to the possibility of an individual feeling overloaded.

It is worth remembering that the randomized controlled trial in which this qualitative study was nested recruited people in the acute stage of stroke and offered up to four months of intervention. Therefore, early, well-resourced intervention (average 20 contacts) had high user acceptability as long as it was flexible to individual needs. This finding is an important contribution to how the implications of
the randomized controlled trial results are interpreted for future policy and practice in stroke rehabilitation. Seen from this study’s participants’ perspective, ‘early and lots of it’ is a stronger message than any residual concerns about whether that contact should be provided by a speech and language therapist or visitor.

**Strengths and weaknesses of the study**

The main weakness of this study is the small numbers available to participate which precluded a purposive approach to sampling. The strongly positive data about early and sustained contact might be biased by nature of the sample. It is unknown whether those who chose not to participate had more negative views and therefore were less inclined to make the further commitment to be interviewed. Also, participants were only interviewed once which meant that it was not possible to trace how initial reflections on their experience might change with time as recovery and/or enduring disability becomes apparent. Although care was taken to ensure that the qualitative analysis was undertaken independent of and prior to the analysis of the randomized controlled trial, influences between the two parts of the study will inevitably have occurred within a common ACT NoW team. The study is also limited by the fact that only service users were interviewed. There is no parallel qualitative data from the speech and language therapists or visitors involved.

The main strength of this study is that the qualitative component of ACT NoW focused on the main trial experience, rather than being an element of pre-trial design. It is therefore possible to integrate its findings with those of the randomized controlled trial. It is also a strength that the qualitative study succeeded in engaging a wide diversity of participants, including those with the most severe communication impairments and collecting data at a very early stage in stroke patients’ experience. A diagnosis of aphasia is a common exclusion criterion from many rehabilitation trials and other research designs. Our results show that this exclusion is unjustifiable. It marginalizes people with communication problems and produces evidence that is unrepresentative of the clinical populations we seek to serve.

**Clinical messages**

For someone with aphasia or dysarthria in the early weeks following a stroke, well-resourced intervention has high user acceptability if:

- it positively impacts on mood and confidence
- promotes self-recognition of progress
- endorses the individual
- is delivered by an empathic, positive, good communicator.

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**Conflict of interest**

The authors declare that there is no conflict of interest.

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