

Introduction

The Tavistock Aphasia Centre and North East Trust for Aphasia (NETA) Support Centre are hosted at Newcastle University. The Aphasia Centre provides intensive group and individual therapy building on experience over its 21 year history. The Support Centre offers long term support to people with aphasia with group activities, one day per week. Following a block of therapy (Aphasia Centre) and group activity (Support Centre), participants provide feedback about their experience. It is, however, important to understand the longer-term perspective about the impact these experiences may have on communication and wellbeing.

Methods

Qualitative semi-structured interviews were conducted with ten people with aphasia, who varied considerably in terms of when they had their stroke/brain injury, when they attended the Aphasia Centre (1-18 years ago) and the extent they were involved in Support Centre activities. Interviews were transcribed and then analysed using the framework method (Galel, Heath, Cameron, Rashid & Redwood, 2013).

Main Themes

Communication change

People described perceived changes in communication and their knowledge about aphasia. Changes resulted from overall recovery as well as a consequence of their experience at the Aphasia Centre and/or NETA Support Centre.

"they were getting harder and harder but my speech was improving all the time"



"even um my hairdresser when I went to get my hair cut he said to me your speech has improved"



- All participants perceived their speech (assumed to reflect spoken production in a wider sense) to have improved; reading ability was also frequently mentioned.
- Participants also discussed the importance of learning about aphasia.
- Interestingly, few participants recalled the specific details of the therapy.

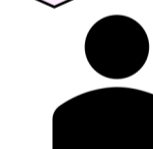
Experience/effects of aphasia/stroke

People described the communication changes, physical effects and wider emotional and psychological effects of stroke and aphasia.

"people tend to talk about feeling depressed (..) and feeling um (..) that they can feel very low (..) and people obviously feel lonely"



"you become frustrated you know you can get a bit a bit cross about it and then sometimes think what's the point really"



"you end up withdrawing and let the conversation go you end up a bit (..) conversations going on around you not through you and says I'm going upstairs and sit upstairs and they don't even know you're gone"



- Participants displayed insight into other people's difficulties and compared them to their own problems.

Social change

People described perceived changes in relationships, support networks and participation in activities. Changes resulted from overall recovery as well as a consequence of their experience of the Aphasia Centre and/or NETA Support Centre.

"we wanted to take that uh aphasia awareness out to the world"



"when I uh volunteer here on a Wednesday I really enjoy it just you know helping people and seeing how they're getting on"



- Most participants developed a support network of friends. For some this appeared to be either equally or more important than improvement in communication.
- Participants felt more able to be involved in volunteering, fundraising and research activities and participate in external activities e.g. travel.

Discussion

People reflected on the overall impact of their aphasia and discussed the importance of social support and the friendships developed whilst attending. They also commented on changes in their communication skills but, as most people did not discuss their specific therapy, it is clear they perceive these changes to be down to the whole 'experience' of the services. Results from this study will feed into the ongoing planning and delivery of aphasia services at Newcastle University. This study is one of few attempts to consider the long-term effects of aphasia provision; exploring this further will help us to understand long term therapy and support needs.

Reference

Galel, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*, 13, 117.