Adapting to Aphasia

Final Summary Report by Alex Gillespie, Joan Murphy & Morag Place
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Thanks

Thank you to the Economic and Social Research Council (ESRC) for funding the research. A big thank you to all the research participants for taking part and for attending the feedback day. Thank you to the Speech and Language Therapists and Resource Centre Managers who helped us to find participants. Special thanks to George, Helen, Sharon and Gary who allowed us to record them using the mats to include in the training DVD. Finally thank you to the members of the advisory group who helped to develop the research materials.

Project summary

Why did we do the research?

Aphasia affects around 250,000 people in the UK. Aphasia is a communication disability, often caused by stroke. Speaking, understanding, reading and writing can be affected. It has a big impact on everyday life and on relationships. Aphasia causes both people in a relationship to take on new roles and the relationship changes. We wanted to know how these changes made people feel about their identity. We also wanted to find out what communication strategies people used to adapt to aphasia and how they felt about their communication.

Who was involved?

People with aphasia living in Forth Valley
Close communication partners – these were mostly their husband or wife but sometimes their daughter, parent or partner.

What age were they?

Average age was 59 but there were people aged from 35 to 81.

How long had people had aphasia?

The average time was 30 months (2 ½ years) but there were people from 2 months to 8 years post onset.

What caused the aphasia?

18 people had a stroke and two had a traumatic event.

Did people have any additional disabilities?

Fifteen people also had hemiplegia (one-sided paralysis) or dyspraxia.

Where did the research take place?

Morag Place visited people in their own homes.

Findings: Inviting someone for a meal task

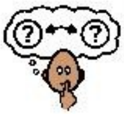
We asked people to imagine they were planning to invite someone for a meal. They had to answer questions. We wanted to see how both people worked together. We observed which strategies each person used to help understanding and speaking.

We knew that people with aphasia and their partners used lots of different ways to communicate. We didn't know which were helpful and how these strategies made people feel.

We watched the videos and noted how the couples organised themselves and what communication strategies they used. We then arranged a feedback day to tell people what we had observed. We asked them to tell us how this made them feel.

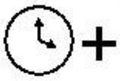
What did we observe?

Below are some of the most common strategies used. Sometimes they helped, sometimes they seemed to distract or confuse.



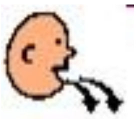
Presenting choices

Using gestures



Giving lots of time

Drawing



Repeating and rephrasing

Guessing

Writing

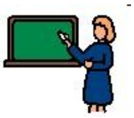
Using symbols

Findings: Inviting someone for a meal task

We noticed that control over the communication was not equal. Who was in charge?

- Most partners took control of the task (asked questions, did the writing etc)
- Most people with aphasia were supported to make the final decisions

Half of partners took on a ‘teacher role’



- they corrected spelling, steered and focused the task, encouraged practice of reading aloud and pronunciation of words

What did people tell us?

Sometimes strategies are unhelpful:
People with aphasia told us that there was no single strategy which was helpful in all situations. Sometimes a strategy helped but sometimes it was distracting. Their partners told us they were working very hard to provide strategies without being confident they were helpful.

Control over the communication is unequal:
People with aphasia felt they lacked control over the communication. Needing communication strategies made some people with aphasia feel disabled and in need of help. Communication partners said they controlled a lot of the communication but felt they had to take on this role. A lot of people felt uncomfortable with the situation.

Outcome: Inviting someone for a meal task

Outcome

We thought about how we could try to address these problems with a practical solution. If people with aphasia could control the way in which their partners communicated with them, it could lead to (1) communication partners using more effective strategies, and (2) people with aphasia feeling more powerful within the interaction.

We asked four people with aphasia and their partners to help us try out an idea. All the people with aphasia had difficulty with understanding what people say. We developed a set of symbols representing nine of the strategies we had observed. We wondered if people with aphasia could choose which strategy would help them understand better and request it from their partner.

We made a symbol card which allowed them to ask their partner to: (1) pause, (2) repeat, (3) rephrase, (4) gesture, (5) write, (6) draw, (7) give the key word, (8) break the sentence into parts, and (9) speak more slowly.
Two speech therapists discussed the idea with the group, tried out some training exercises and made changes to the symbol set.

We will apply for funding to continue with this project to see if our idea could work. This idea is a new direction for communication aids. Most aids are hi-tech. They let people express needs, wants and use small-talk. Many people with aphasia find them difficult to use and unhelpful. There are no aids which are dedicated to giving people with aphasia control over the support they receive and to help their understanding. This would be an exciting development.

Findings: Comparing Perspectives

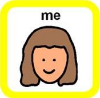
In the second half of the study we asked people with aphasia and their partners to think about two topics:

- Communication
- Identity

We adapted a psychological technique called the Interpersonal Perception Method to use with Talking Mats. People with aphasia and their partners rated each item along a scale.

They had to think about:

- Themselves



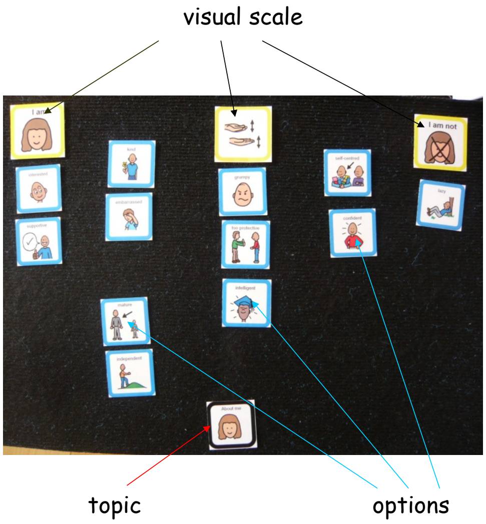
- Their partner

- What their partner thinks about them

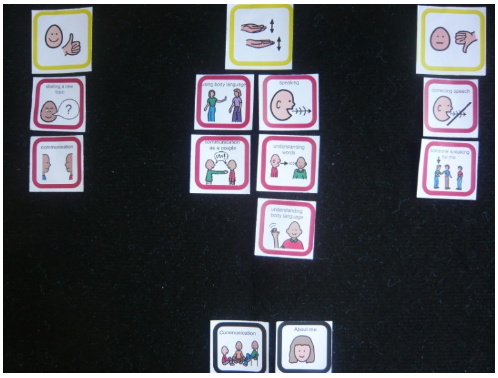
This meant each person did six mats. We were interested to know:

- Do people with aphasia and their partners agree?
- Do people with aphasia and their partners understand each other?

This is an Identity mat.
There were 12 items - kind, grumpy, interested, intelligent, supportive, embarrassed, confident, self-centred, mature, lazy, independent, and overprotective.



Findings: Comparing Perspectives



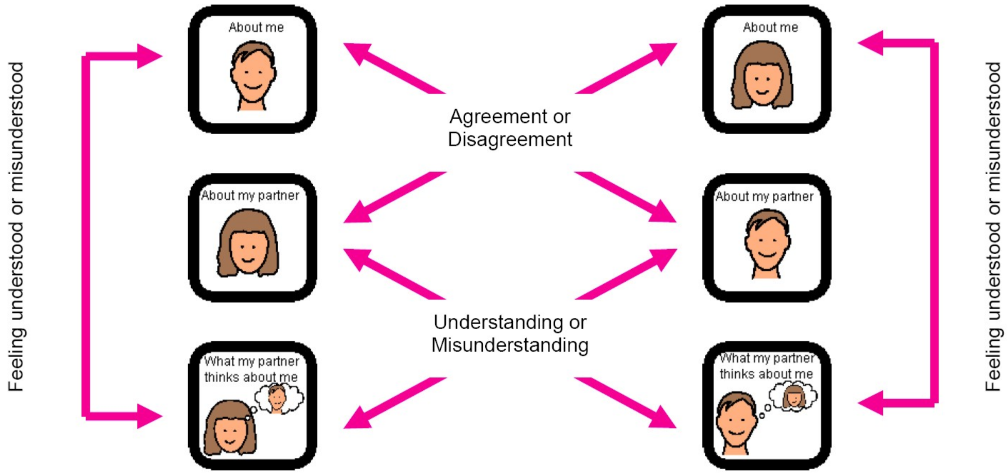
This is a communication mat. There were 9 items - speaking, understanding words, using body language, understanding body language, starting a new topic, someone speaking for me, someone correcting me, overall communication and communication as a couple.

We looked at:

- the ratings people made on the mats about their communication and identity.
- what people said while they completed the mats

This diagram explains how we compared the views of people with aphasia and their partners:

People with Aphasia **Communication partners**

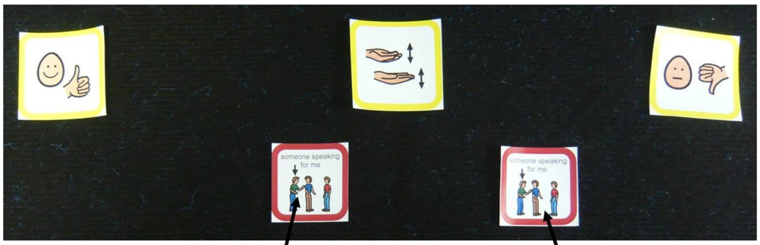


We could identify disagreement by comparing participants' ratings of themselves with how their partner rated them. Misunderstanding was identified by comparing participants' estimations of how their partner would rate them with how their partner actually rated them.

Findings: Comparing Perspectives

How did people with aphasia respond?

The only statistically significant disagreement on the communication mats was about ‘speaking for’.



How partners thought people with aphasia would feel

How people with aphasia actually felt

People with aphasia tended to rate themselves as less happy about being spoken for than their caregivers rated them. For the identity items, they also tended to rate themselves as less intelligent and more independent than their partners rated them.

What did people with aphasia say?

[Placing the ‘being spoken for’ card] No I don’t like that. James [husband] sometimes does it and, eh, and em, it’s not something I’m going to say, he’ll catch the first two digits, words, and finish what I was going to say and it’s nothing what I’m going to say at all! No I don’t like that no. (Hannah, mild aphasia)

Partners want to protect their partner with aphasia (their safety and their feelings) but they also want to help them be independent. People with aphasia need to receive help but they don’t want to appear dependent.

These two dilemmas might explain why partners ‘speak for’ their partner with aphasia. Partners might be trying to protect the person with aphasia’s feelings. Unfortunately, ‘speaking for’ also highlights their need for help. This might explain why people with aphasia have a more negative view of being spoken for than their partners.

Findings: Comparing Perspectives

How did partners respond?

For the identity items, most of the disagreement is about the communication partner. One of the most statistically significant disagreements was about ‘confidence’.

← How confident partners felt

← How confident people with aphasia thought their partners were

Partners tended to rate themselves as less confident, less intelligent, less independent, more embarrassed and less overprotective than their partners rated them.

What did partners say?

You have your panics and your absolute [pause] crises of confidence, I have them, practically on a daily basis at the minute (Claire, partner has severe aphasia)

We found that partners felt less confident than people with aphasia thought they were. Partners may not want to reveal their concerns. In a relationship affected by aphasia, both people need support because both are dealing with the change in circumstances and both have to take on new roles within the household. The person who has had a stroke will have to adjust to living with aphasia. Partners sometimes have to become carers. Both people might need support if they are worried about these changes.

Outcome: Comparing Perspectives & Conclusions

Outcome

During the project many people wanted to see each others mats. They thought it would be useful to know how each other felt.

We developed a new resource called ‘To see ourselves as others see us: a resource for comparing perspectives and enhancing understanding within relationships’.

It includes a DVD and booklet explaining how to use the mats to compare perspectives, a mat, symbols and a book about Talking Mats.

We are very pleased that this new resource has just won a UK ‘Advancing Healthcare Award’.

Conclusions

Our research highlights the need to support both people in a relationship affected by aphasia. It has led to an exciting new development in the field of communication aids. It has also led to the development of a new award-winning Talking Mats resource to help people who have difficulty communicating and their communication partners to hear each others views and to increase understanding within their relationships.