



Support Group for Families of People with Primary Progressive Aphasia (PPA)



Speech & Language Sciences

North East Trust for Aphasia

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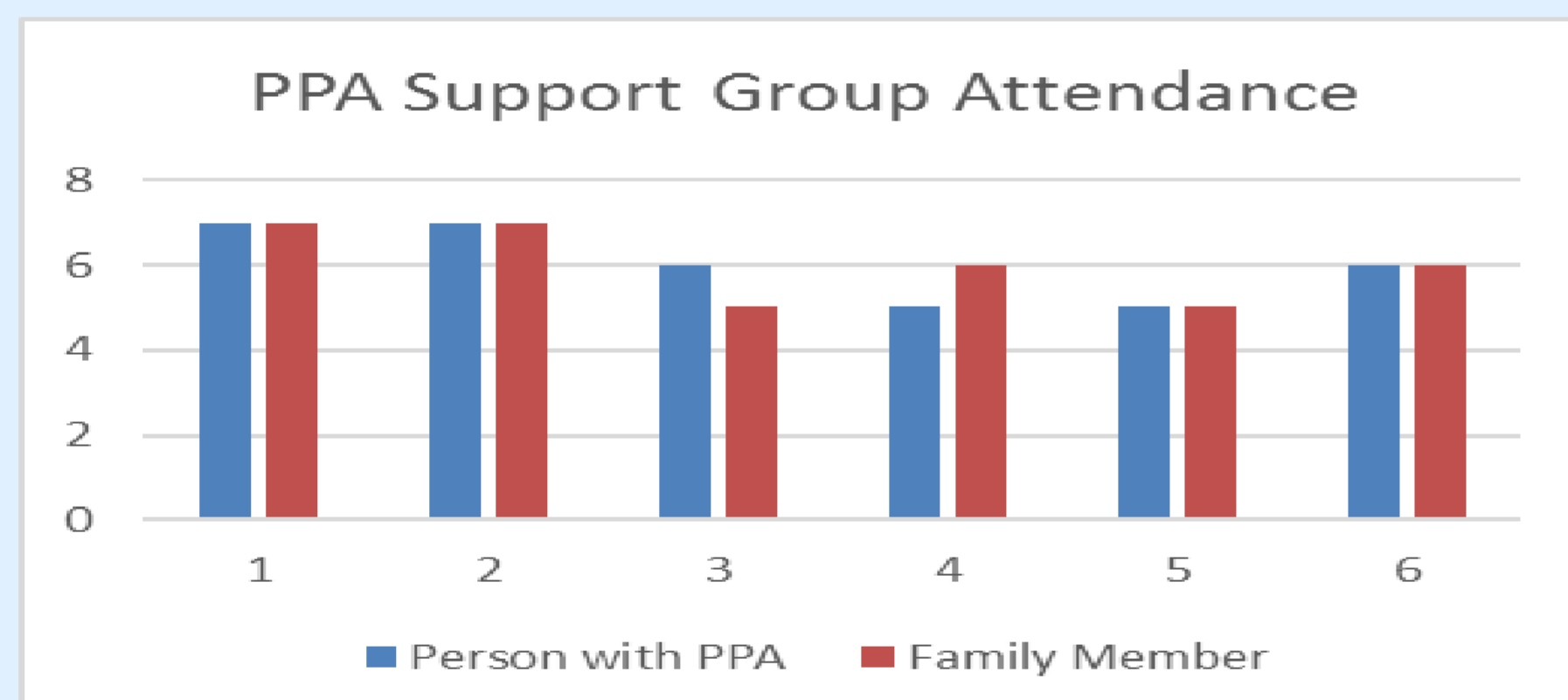
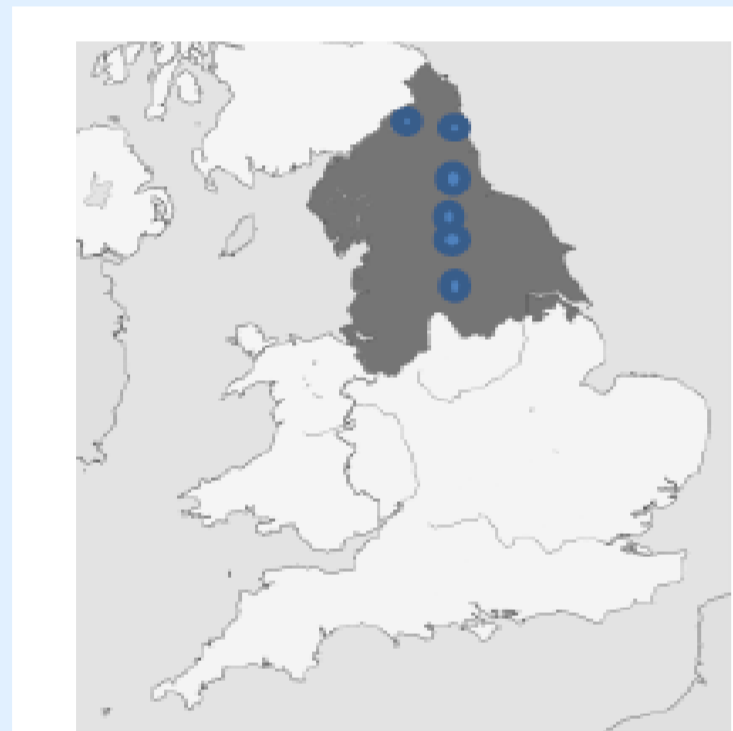
Background & Aims

Primary progressive aphasia (PPA) is a rare dementia, with clients showing progressive decline in language abilities. People with PPA lack access to consistent Speech and Language Therapy support. The North East Trust for Aphasia (NETA) was receiving enquiries from families with a diagnosis of PPA.

The project aimed to set up informal facilitated sessions every two months for a period of a year, with the aim of considering the needs of the people with PPA and their family members, promoting peer support and exploring how communication can be supported.

Group Members

10 people with PPA and their family members from a wide geographical area registered. All attended at least 1 session. 6 families attended most, or all, sessions. Around twelve people attended each meeting.



Content of Sessions

Content was driven by all participants. Sessions allowed members to talk and share information. A peer-led WhatsApp group was set up early in the project. People were keen to hear about opportunities to participate in research. There were presentations from the Regional Communication Aids Service and the Dementia Carer Support Service. General advice on practical communication management was offered opportunistically throughout the project.

Evaluation

Qualitative evaluation was by group discussion of a series of questions posed in advance by the facilitator, then individual written reflection. Group members valued:

Meeting others Access to experts

Exchanging information

They wanted:

The service to continue

More help with communication support

Profile of People with PPA

3 people with primary non-fluent aphasia.

2 non-verbal with minimal alternative communication
1 not attempting speech

4 people with logopenic aphasia

Marked word finding difficulties and problems with topic maintenance

3 people with semantic dementia

1 with relatively good verbal skills
2 with semantic degeneration affecting comprehension and expression

Conclusions & Impact

The project provided a new support service for family members of people with PPA and demonstrated a clear unmet need in the northern region. Peer support was the major outcome. In addition, a wide range of information about access to carer support and entitlement was discussed and distributed. Family members felt they would benefit from strategies to support conversation, but this could not be provided in a group setting due to the variability between individuals.



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