

“Going into a chocolate shop, blindfolded.”: Addressing the speech and language therapy needs of people with Primary Progressive Aphasia

Anna Volkmer, Maria Loizidou, Emilie Brotherhood, Emma Harding, Sebastian Crutch, Jason Warren, Chris Hardy

State of the art:

The research evidence on non-pharmacological interventions for primary progressive aphasia (PPA) is developing. Yet, to date there are only a few case studies exploring the opinions and experiences of people with PPA (PwPPA). This qualitative research study aimed to understand how speech and language therapy (SLT) services can better meet their needs.

Methods:

PwPPA and their family members were recruited to participate in focus groups, via advertisements in the Rare Dementia Support PPA group newsletters. Consenting participants were allocated to one of four focus groups, hosted on an online video conferencing platform. Participants were asked about their communication difficulties, and how SLT could address these needs. All meetings were transcribed, and data examined using Reflexive Thematic Analysis (Braun & Clarke, *Counselling and Psychotherapy Research* 2021; 21 37-47).

Results:

Six PwPPA and 14 CPs representing all three PPA variants and mixed PPA participated in the focus groups. Four main themes were identified during analysis of the focus group discussions: 1. CPs' burden, 2. Adjusting to the diagnosis, 3. Communication abilities and difficulties, and 4. Beyond language. A further ten subthemes were identified.

Conclusion:

This work underlines the importance of a person-centred approach that considers the broader needs of both the person with PPA and the people around them. This will enable service providers to deliver SLT that meets the needs of PwPPA and their families and will also inform future research in this field.

Conflicts of interest

No interests to declare