



Process evaluation of Randomized Controlled Trial for primary progressive aphasia (PPA) caregivers

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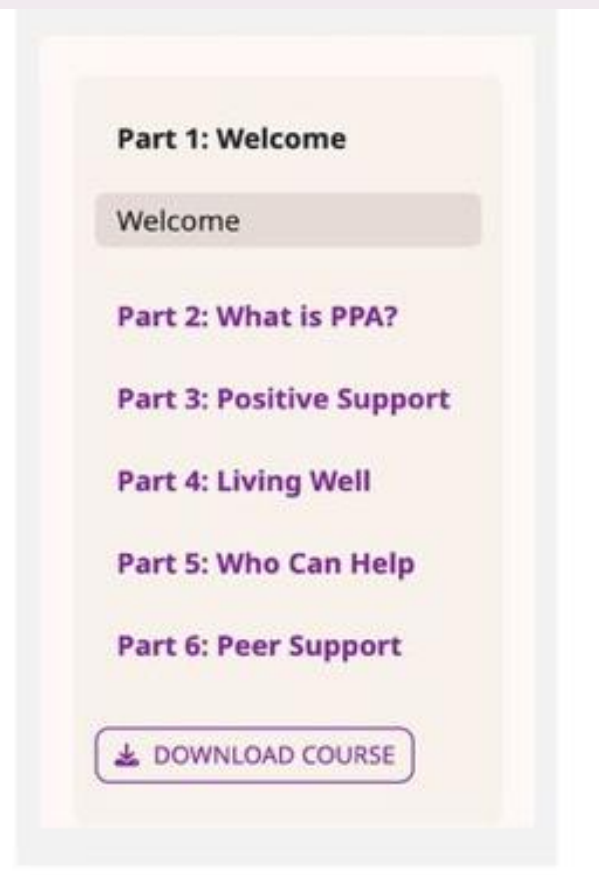
Introduction

- **Primary progressive Aphasia (PPA)** is a dementia syndrome characterised by progressive speech and language difficulties, presenting phenotype-specific challenges for caregivers.
- Caregivers often struggle to find high-quality information and educational resources about PPA.
- Attending in person PPA support or educational groups remains limited by caregivers’ geographical location and caregiving demands.
- Few online educational programmes for caregivers of people with non-memory-led dementias (including PPA) exist, none of which have been evaluated by an RCT or parallel process evaluation.

The “Better living with non-memory-led dementia” (BELIDE) program (Suárez-González et al., 2025).

BELIDE was developed to address this gap, and is an educational intervention comprising of digital resources and videoconference/email facilitator check-ins for caregivers of people living with PPA (PLwPPA).

BELIDE provides phenotype-specific information alongside wellbeing support, management strategies, signposting and practical tasks across 6 modules.



Research questions

- How is BELIDE perceived by PPA RCT participants and what factors and mechanisms influence engagement, user satisfaction and change?
- What are the perceived barriers, benefits and facilitators for future implementation?

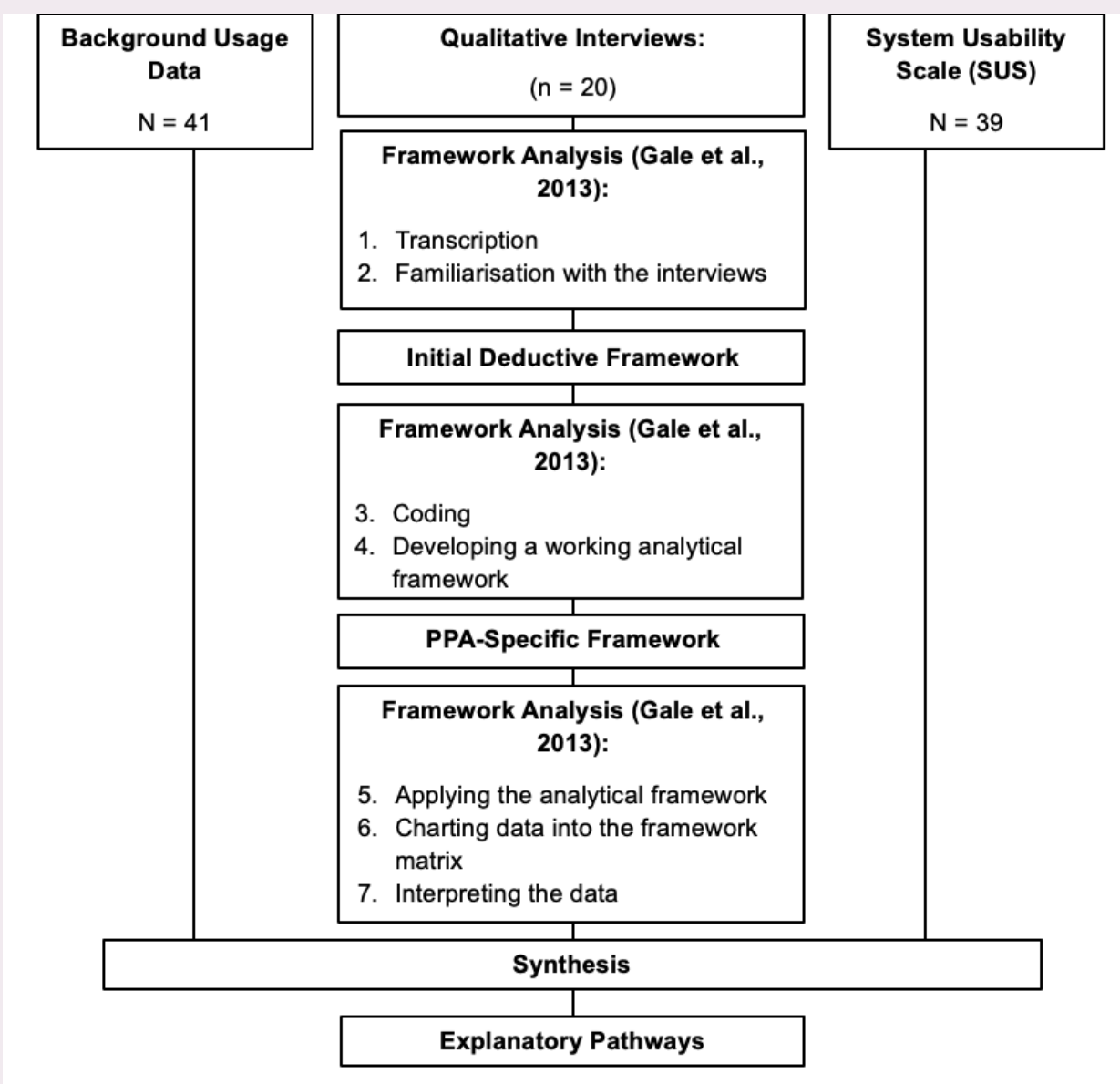
Methods

Participants: 20 PPA RCT participants (qual), 41 PPA RCT participants (quant; 83% spousal, 14 months since diagnosis).

Design: Convergent parallel mixed-methods design.

- 20 interviews were conducted at 8 or 24-weeks post intervention and analysed using framework analysis.
- Background usage analytics and system usability data (system usability scale) were gathered for all PPA RCT participants, analysed through descriptive statistics.

Figure 1: Mixed methods design



Results

Theme 1: Mechanisms of change & gains

- **Making sense of PPA:** Correcting & consolidating PPA understandings which increases self-confidence.
- **Normalisation & reassurance:** Sense of not being alone generated by lived experience stories.
- **Cognitive reframing:** Reinterpreting behaviours as symptoms and adjusting expectations of PLwPPA.
- **Self-care:** Prompted to focus on their own wellbeing.
- **Improving communication:** Gaining strategies improved communication.
- **Benefitting the system:** Sharing knowledge.
- **Limits of change:** Impacts are cumulative with wider support.

Theme 2: What shaped engagement

SUS 82.8 out of 100 (usable)	Usage 54 mins / 4 days	Downloaded content 85%
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- **Timing:** Self-paced delivery fit around daily routines; planned to return to resource after disease progression.
- **BELIDE’s flexible & accessible design:** Appreciation for different formats, most downloaded as this was ‘easier’.
- **Having facilitation:** Offered motivation & support.
- **Minor technical issues:** Some difficulties with logging on.
- **Motivations and expectations:** Motivation to gain knowledge drives engagement.

Theme 3: Future implementation

Delivery pathway: Perceived to have greatest value at diagnosis when information gaps are highest.

Content: Useful but could add more variant specific (e.g. semantic PPA) or future progression (mid-stage) content.

Improving the tech: A need to make sharing easier.

Conclusions

Caregivers reported improvements in self-confidence, coping and capacity to support their person living with PPA after using BELIDE.

Implementation of BELIDE should maintain its blended approach and consider integration within clinical pathways for signposting at diagnosis.

Future research may consider creating a mid-stage or PPA variant specific resource.

Quotes

“Information is power”

“I think I understood things better...like the disease causes the change, not the person.”

“Doing the course made me feel that there was the possibility of managing things“