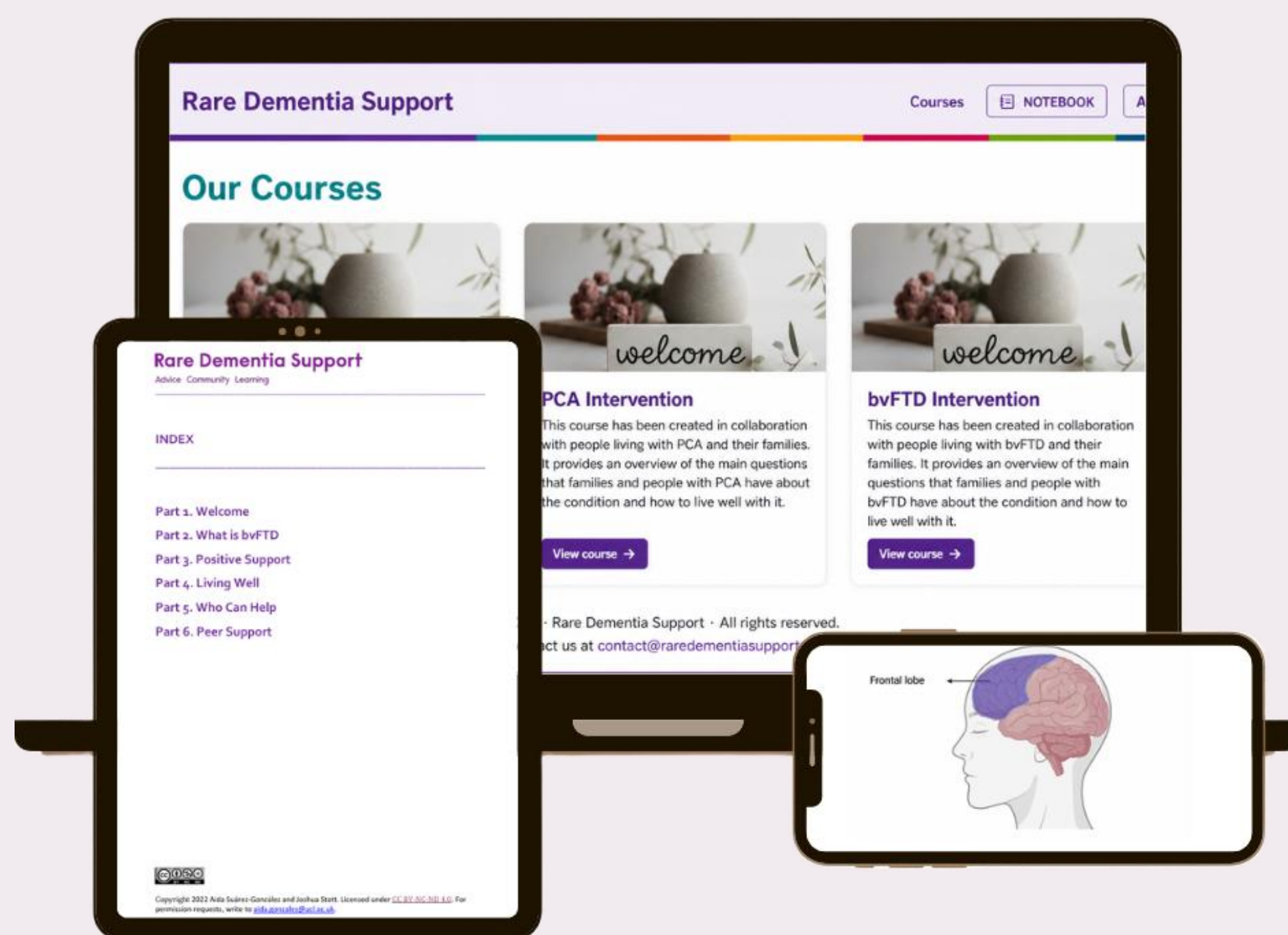


Background

- Behavioural variant frontotemporal dementia (bvFTD) is characterised by changes in behaviour, personality, empathy, judgement and executive functioning.
- These symptoms can be difficult for families to understand as neurological in origin and may create distinctive emotional and relational challenges for carers.
- Most dementia carer interventions are designed around memory-led dementias and may not address bvFTD-specific needs.

BELIDE Program (Suárez-González et al., 2025)

The better living with non-memory-led dementia (BELIDE) programme is a co-produced, blended digital-human intervention for carers of people with non-memory-led dementias, including bvFTD.



It provides bvFTD-specific education, wellbeing support, symptom-management strategies, signposting and peer-support resources across six online modules, with facilitator contact and practical tasks.

Research Questions

To explore how carers of people with bvFTD experienced and engaged with BELIDE, including perceived benefits, mechanisms of change, barriers and unmet needs.

Methods

Participants: 27 carers of people with bvFTD were invited; 14 participated, contributing to 16 interviews. Two of those participants completed interviews at both 8 and 26 weeks.

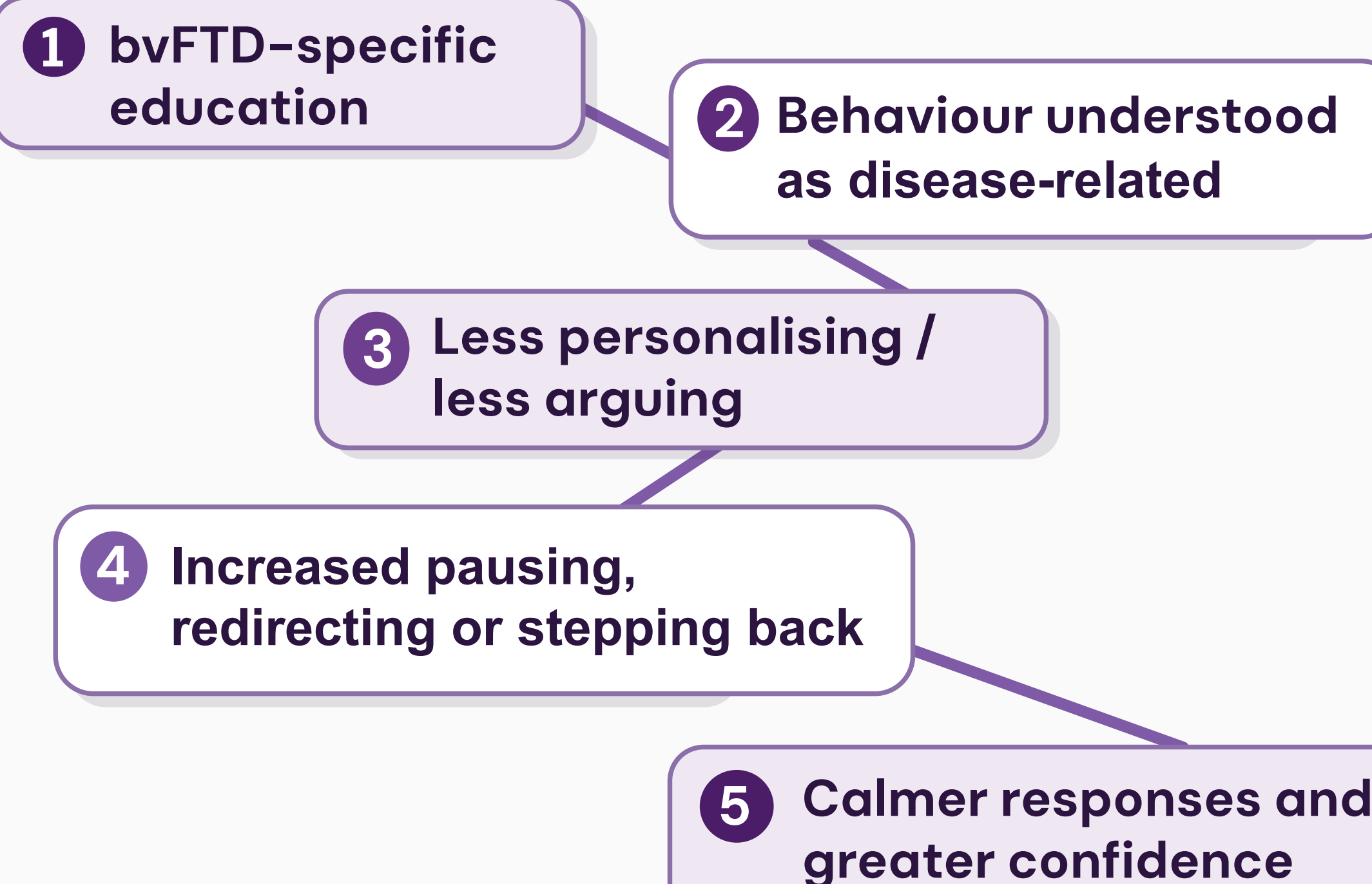
Design: Qualitative process evaluation embedded within the BELIDE randomised controlled trial.

Data collection: Remote semi-structured interviews conducted at approximately 8 and/or 26 weeks post-intervention.

Analysis: Framework Analysis, combining deductive categories from the BELIDE logic model and Medical Research Council process evaluation domains with inductive coding of carers' accounts.

Mechanism Pathway

How BELIDE appeared to help



Results

1. Accessible and flexible, with a re-access gap

Carers generally found BELIDE easy to access and navigate. Engagement varied, from reading fully to dipping in or saving useful sections. Some participants wanted to revisit BELIDE later but were unsure how to re-access it.

2. Reframing behaviour as illness-related

bvFTD-specific information helped some carers understand behaviour as disease-related rather than intentional or personal, supporting pausing, redirecting, stepping back and avoiding arguments.

3. Reassurance and validation

BELIDE's value was not always new knowledge. For several carers, it confirmed that their experiences made sense and that they were "doing the right thing."

4. Support needs varied by context

Usefulness varied by knowledge, timing, bvFTD presentation and emotional readiness; some carers wanted more individualised or emotional support.

Quotes:

"It's the disease, not the person"
"I felt reassured that I'd done things right"
"It saves you not having to explain it"

Conclusion & Implications

- BELIDE offered accessible, bvFTD-specific support, with strongest value in reframing behaviour and validating carers' experiences.
- Refinement should focus on re-access, timing, tailoring and links to emotional support.