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A Mixed-methods Process Evaluation Of A Randomised Controlled Trial For Posterior Cortical Atrophy Caregivers

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INTRODUCTION

Posterior Cortical Atrophy (PCA) is a rare, young-onset dementia characterised by primary progressive visuospatial decline.

Caregivers face high burden, uncertainty, and limited access to PCA-specific support.

Existing evidence-based, phenotype-specific educational resources for caregivers of non-memory-led dementias remain limited worldwide.

The BELIDE RCT is the first trial to deliver online, phenotype-specific psychoeducational programmes for PCA, Primary Progressive Aphasia, and Frontotemporal Dementia.

A mixed-methods process evaluation was conducted alongside the RCT to understand:

1. How PCA caregivers experienced the BELIDE intervention?
2. What mechanisms of change emerged?
3. How contextual factors shaped engagement and implementation?

METHODS

RCT: 6 modules & 26 submodules, 2x facilitator check-ins, at-home tasks, 8 weeks of self-paced access.

Background usage metrics (n = 29) and System Usability Scale (SUS) scores (n = 30) were analysed.

PCA caregivers from the RCT sample invited to complete remote, semi-structured interviews at 8 (n = 6) or 26 weeks (n = 10) post-intervention.

Qualitative data were analysed using Framework Analysis, combining deductive categories based on the study aims with inductive coding.

Quantitative and qualitative findings were synthesised to identify patterns and conflicting findings.

RESULTS

RCT sample (n = 33): 88% White British, 91% spousal carers & cohabiting, av. 2 years since diagnosis

Interview sample (n = 16): 88% White British, 88% spousal carers & cohabiting, av. 2 years since diagnosis

Theme 1: Implementation and engagement

Average SUS (/100) of 80.8 = 'usable'.

Average of 103 minutes of use over 4 sessions.

'Visual Difficulties' submodule most used (av. 11 minutes; 7.9x more than average submodule use).

Facilitators: Clear language, PCA-specific focus, visual symptom information, diagrams, facilitator contact, and lived-experience excerpts.

Barriers: Minor technology issues, emotional readiness, timing of access, and the "caregiver" label.

Flexible timing and modality of access, and early post-diagnosis access, reported as key for engagement.

Theme 2: Mechanisms of change

Better understanding *led to* confidence and reduced frustration.

Strategies & tasks *led to* activation, self-efficacy and help seeking.

Informative & lived experience content *led to* acceptance, normalisation, validation, and reduced isolation.

Theme 3: Contextual factors

Caregivers described fragmented services, misdiagnosis, and lack of professional and public PCA knowledge.

Caregiver identity impacts caregiving experience and engagement with course.

"... the examples showed where the writing on the page was going up and down and things, it made me see how he's seeing things."

"I don't see myself in such a terrible- in an awful position that maybe I did before [...] seeing that there's things that you can do to really manage this."

"If that was given to me, you know, within the first three to six months of diagnosis, it would be absolute gold dust"

THEMATIC MAP

DEDUCTIVE CATEGORIES, INDUCTIVE CODES, AND SYNTHESIS OF MIXED-METHODS DATA



CONCLUSIONS

The BELIDE PCA intervention was experienced as accessible, well-pitched, and usable.

Participants reported improved understanding of visuospatial symptoms, improved self-efficacy and confidence, and enhanced emotional acceptance.

Flexible, self-paced, and early-post diagnosis access are essential for maximal impact.

Findings support BELIDE's potential for wider implementation to address unmet needs in PCA caregiver support.

Future implementation should consider integrating course into diagnosis pathways, scaffolding use with facilitator contact, and evaluating of usability and relevance for Global Majority caregivers.

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