



Process Evaluation Of An Intervention To Improve Wellbeing Associated With Rare Familial Dementias

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Introduction

Familial Frontotemporal Dementia (fFTD) and **Familial Alzheimer's Disease (FAD)** are rare autosomal dominantly inherited dementias that place relatives at a **50% risk** of developing the condition. Individuals affected by familial dementia's often experience anxiety, uncertainty about the future, and the challenges of supporting affected family members.

Despite these challenges, there is a lack of psychological interventions tailored to people affected by familial dementias. The IWARF randomised controlled trial (RCT) is a co-produced web-based intervention informed by Acceptance and Commitment Therapy (ACT) principles to support psychological wellbeing in this population.

This study describes a mixed-methods process evaluation of the IWARF intervention.

Aims:

- Explore participants' and facilitators' experiences of the IWARF intervention.
- Understand perceived outcomes and mechanisms of change associated with participation.
- Evaluate intervention engagement, usability and acceptability to inform future implementation and development.

Methods

Design
Mixed-methods process evaluation embedded within the IWARF randomised controlled trial.

Participants
13 participants who are affected by familial dementia | 4 facilitators

Participant Interview Timepoints
9 weeks (n=6) | 26 weeks (n=3) | Both (n=4)

Intervention
9-week ACT-informed digital intervention | 10 modules | 3 facilitator check-ins

Data Collection
Semi-structured interviews | System Usability Scale (SUS) | Usage analytics

Analysis
Framework Analysis | Descriptive statistics

Quantitative Results

Usability (SUS)
IWARF Intervention Sample = 82.95/100
Process Evaluation Sample = 83.54/100

Usability ratings were high across both samples.

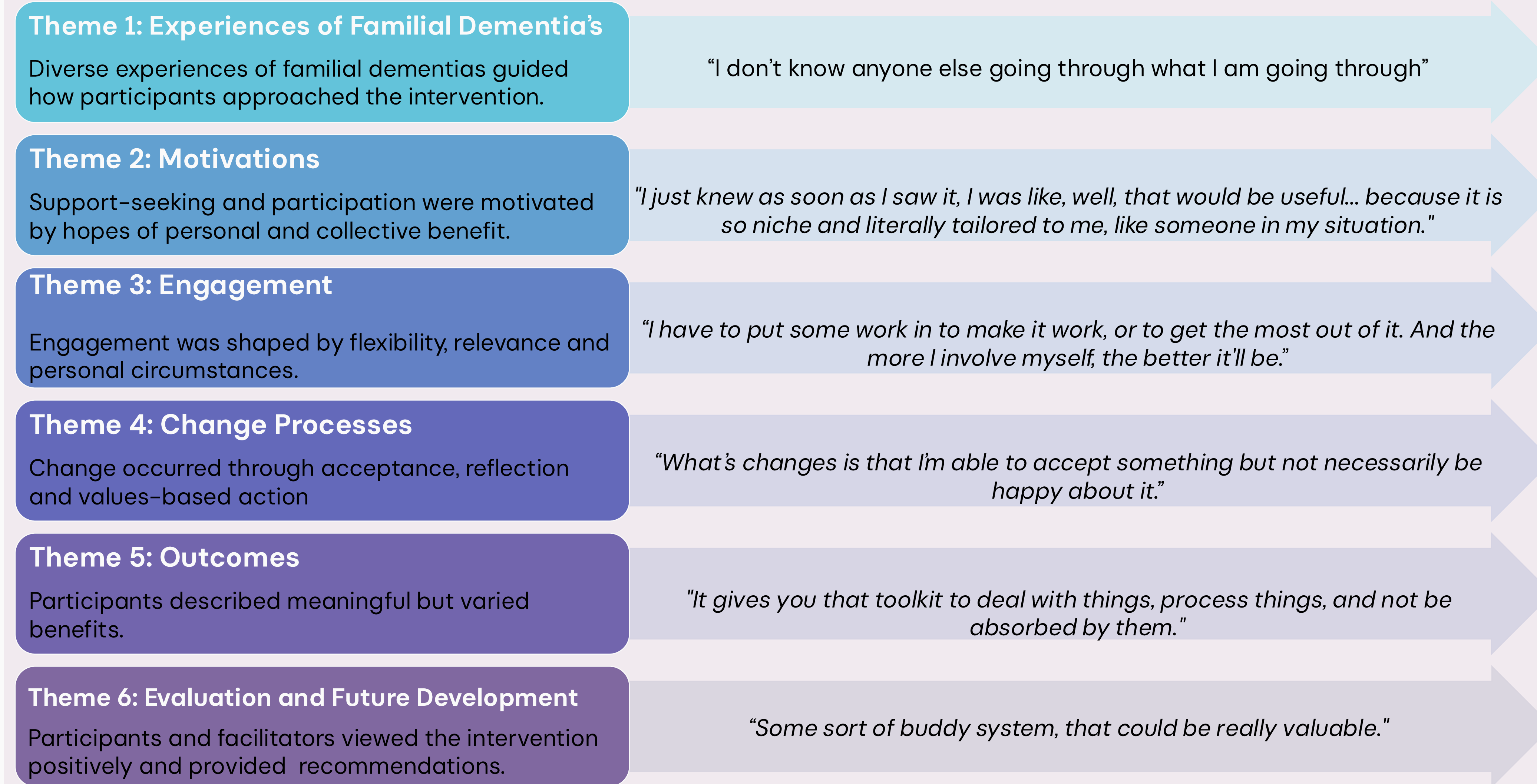
Engagement (minutes)
IWARF Intervention Sample = 145
Process Evaluation Sample = 228

Process evaluation participants demonstrated higher average engagement than the wider group.

Quantitative findings supported qualitative accounts of intervention acceptability and engagement.

Qualitative Results

Framework analysis generated eight themes. The figure below displays a visual summary of the key themes, highlighting contextual factors, engagement processes, mechanisms of change and perceived outcomes following participation in IWARF.



Conclusion

- IWARF was perceived as a highly usable and acceptable intervention that addresses an important unmet need for specialist psychological support for individuals affected by familial dementias. .
- Participants reported improvements in coping, emotional regulation, self-understanding, values-based living and their relationship with diagnosis and genetic risk.
- Participants highlighted the value of facilitator support, opportunities for reflection and repeated skill practice throughout the intervention.
- Future implementation should retain flexible mixed-delivery while strengthening familial dementia-specific content, support for family communication and tailoring across different stages of the familial dementia journey.