



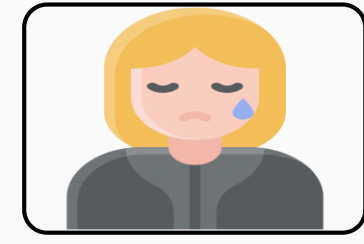
Grief And Loss In People Living With Dementia: Developing And Field-Testing The “Navigating Loss In Dementia” Online Group Intervention

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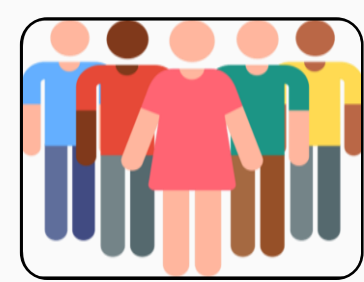
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Background



Grief is a response to any **loss** that is significant to an individual.



Some **people living with dementia** might feel that they are experiencing grief and loss. This experience is **unique** to each person.



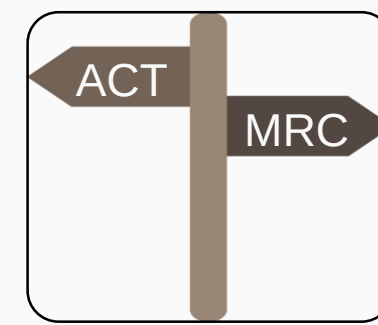
There is not a lot of research about **support** for people living with dementia who might be **experiencing grief**.

There is even less research about the experience of grief in people living with **rarer forms of dementia**.

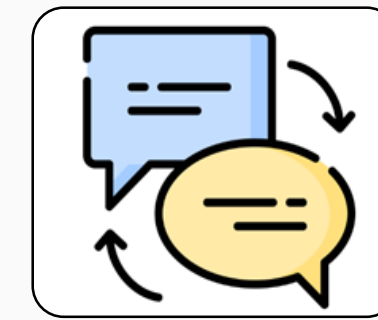


This study aimed to **develop** and **field-test** an **online group intervention** focused on navigating grief and loss for people living in the **early stages of dementia**.

Method



We followed the **Medical Research Council [MRC] guidance for developing complex interventions** (Skivington et al., 2021), using **grief theory** and **Acceptance and Commitment Therapy [ACT]** informed approaches to develop the programme.



The intervention was designed using previous research findings, including a **literature review** (Waddington et al., 2024) and **research conversations** with 14 people living with **rarer forms of dementia** (Waddington et al., 2025).



The ‘**Navigating Loss in Dementia**’ programme was **co-designed** with people living with rare dementias, as well as academics, clinicians and dementia support professionals.

Results

Participants

- **Four** people living with **early stage young-onset dementia**
- Diagnoses:
 - Young-Onset Alzheimer’s Disease
 - Dementia with Lewy Bodies
 - Posterior Cortical Atrophy
 - Primary Progressive Aphasia

Programme Format

- **Context:**
 - online via Zoom
- **Number of sessions:**
 - eight
- **Session length:**
 - an hour and a half
- **Frequency:**
 - weekly
- **Two** facilitators
- **Four–six** people living with dementia

Session Topics

1. **Introduction**
2. **Thoughts and feelings (part one)**
3. **Thoughts and feelings (part two)**
4. **Identities**
5. **Relationships**
6. **Thinking about the future**
7. **Moving forward**
8. **Conclusion**

Feedback:

- The programme was **accessible, enjoyable** and **engaging**.
- **Peer support, mindfulness, balancing losses and gains**, and the opportunity to **collaborate on research** were particularly valued.
- Participants recommended offering the programme more widely, emphasising the importance of **appropriate timing** and **targeted recruitment**.

“...The bit of magic is the togetherness of the group meetings...that made it more powerful than it would have been as individuals.”

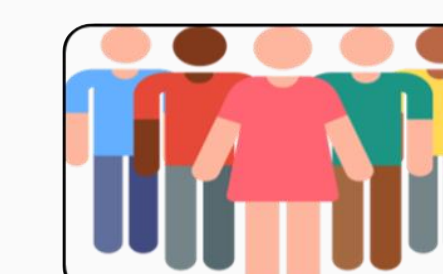
“(The ‘Navigating Loss in Dementia’ programme) is the only thing that has ever dealt with this issue. So therefore, it stands alone. And it is high quality, and it’s brilliant.”

““You actually feeling what you’ve lost...can make you change your mind and start gaining things...”

Conclusion



The “**Navigating Loss in Dementia**” programme offers a potentially **feasible** and **acceptable** way to support people living with rare forms of dementia to understand and respond to their experiences of grief and loss.

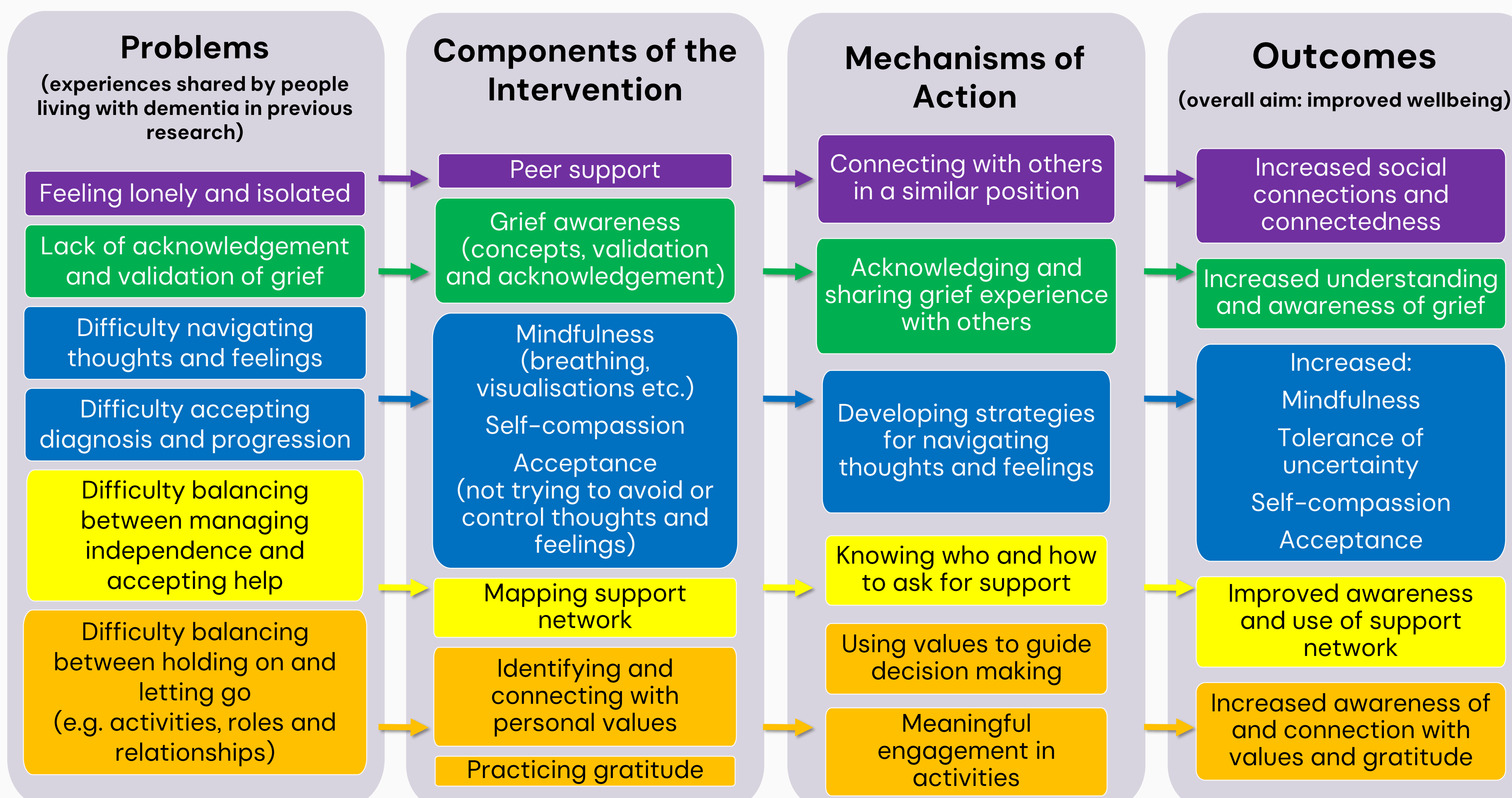


Further field-testing with more diverse groups is needed to **incorporate feedback** and **refine programme suitability**. We would also like to extend delivery to people living with **more common forms of dementia**.



We hope to use these findings to improve **knowledge, awareness and support** for the experience of grief and loss in people living with **different forms of dementia**.

Logic Model



References

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