Carers making decisions about place of care: The DECIDE study

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Overview

Why did we do the DECIDE Study?

What is the DECIDE study?

What did we find?

What next?
Background

540,000 family carers of people living with dementia in the UK.

Carers feel there is a lack of support and confusion about the available options.

Some evidence that decision aids might help and recommended in guidelines.
What is the DECIDE Study?

**Primary aim**

‘To develop and test in a RCT the feasibility and acceptability of a decision aid to enable family carers of people with dementia to make decisions about the future place of residence of the person for whom they care’.

**Secondary aims**

‘Does the decision aid have any impact on Decisional Conflict?’
‘What barriers do carers face when making this decision?’
Phase 1: Development Phase

Co–designed intervention with people living with dementia, family carers and healthcare professionals
Phase 2: Testing

- Feasibility Randomised Controlled Trial
- 21 DECIDE / 20 Control
- Baseline, 1 and 10 week follow-up
- 9.2/10 for usefulness
- 4.6/5 for relevance

Participant recruitment

- Participated: 41
- Declined: 7
Decisional Conflict Scale: Baseline vs 10 week follow-up

- **Total decisional conflict**
- **Uncertainty sub-scale**
- **Informed sub-scale**
- **Values sub-scale**
- **Support sub-scale**
- **Effective sub-scale**

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<tr>
<th>Decisional Conflict Scale and Sub-scale Scores</th>
<th>Intervention Baseline</th>
<th>Intervention 10 week</th>
<th>Control Baseline</th>
<th>Control 10 week</th>
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<td><strong>Mean score</strong></td>
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* indicates statistically significant differences.
How DECIDE helped...

Discussion with a third party

“If you’re someone emotional it is good to have someone to support your decision outside of your family to say ‘you’re making the right decision’ and give that support. It’s difficult without that” [Son of person with dementia]

Acknowledging impact of the decision on carers own lives

“It’s like your whole world disintegrates. And the life you know is gone, everything’s been turned upside down on its head and I think for the partner it’s hard. It’s hard because you just think what am I supposed to do, where do I go, who do I talk to?” [Wife of person with dementia]
Ongoing challenges...

**Difficulty with family shared decision**

“Family are very emotional and what you are deciding and doing is tough”
[Son of person with dementia]

“The thing is that everyone is frantic with their lives so they don’t want to deal with it... I call it wilful blindness; they don’t want to see how bad it is”
[Daughter of person with dementia]

**The system or a crisis forced the decision**

“After we called they said we had to move in five days”
[Son of person with dementia]

“It’s the time scale issue that, I know that it takes time to find places that are good and you often have waiting lists”
[Daughter of person with dementia]
Conclusions

DECIDE facilitated...

Discussion of options
Discussion about impact on carers own life
Knowledge about which professional to contact
Healthcare professionals advice

Ongoing barriers...

Involving multiple family members and the person with dementia
Crisis and system will trigger a decision
Problems negotiating services

Carer decision-making
Next steps

• Shared decision-making

• Hospital setting

• Full-scale RCT?
Thank you for listening

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