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Short report

A feasibility randomised controlled trial of the DECIDE intervention: dementia carers making informed decisions

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Summary

Family carers report high levels of decisional conflict when deciding whether their relative with dementia can continue to be cared for in their own home. We tested, in a feasibility randomised controlled trial, the first decision aid (the DECIDE manual) aiming to reduce such conflict. Twenty family carers received the DECIDE intervention, and 21 received usual treatment. The intervention group had reduced decisional conflict compared with controls (mean difference −11.96, 95% confidence interval −20.10 to −3.83, P=0.005). All carers receiving the intervention completed and valued it, despite some still reporting difficulties with family conflict and problems negotiating services.

Declaration of interest

None.

Copyright and usage

People with dementia usually want to live in their own homes for as long as possible.[1] Deciding whether or not a person with dementia should remain at home or move to a care home is a major cause of carer stress. Safety, health and well-being of the person with dementia and others and desire for autonomy are often key issues. Decisions are often made contrary to the person with dementia's current or previous known wishes and evoke feelings of failure or guilt.[2] Decisional conflict describes uncertainty about which course of action to take when the choice among competing actions involves risk, loss, regret or challenges to personal life values.[3] Carers in many healthcare decision-making scenarios report decisional conflict, which is distressing and can lead to decisions being avoided.[4,5] Decision aids have improved knowledge, reduced decisional conflict and encouraged individuals to become more involved in making a range of health decisions.[6]

We developed and tested the first decision aid (the DECIDE manual) designed to reduce decisional conflict in dementia family carers deciding about place of care, in line with the Medical Research Council (MRC) developing complex interventions guidance, 2008,[7] through systematic review and qualitative interviews with people with dementia, their carers and healthcare professionals,[8,9] and in this study, we tested its acceptability and feasibility.

Method

This study was approved by the North East – Newcastle & North Tyneside 2 National Research Ethics Service Committee (January 2015; REC Reference: 15/NE/0015). We recruited adult, current, unpaid, main family carers for people with moderate or severe dementia (Mini-Mental State Examination (MMSE) <20) not currently living in residential care and carers of people with any severity of dementia where the carer was actively considering care home placement, from four London NHS memory clinics between May 2015 and January 2016. Carers were required to have English language skills sufficient to participate in interviews. Carers were only included if they had capacity to give informed consent. After giving written informed consent, carers were individually randomised by computer to intervention or treatment as usual.

The DECIDE manual (available from the authors on request) is a guided decision aid that participants read and complete with the support of a 'decision coach' (K.L. in this study). This was completed immediately after baseline assessments, taking approximately 45 min. Participants keep the completed version. None of the memory clinics used specific, structured resources for discussing place of care decisions with carers of people with dementia; therefore, control participants were given the Alzheimer's Society factsheet 'Selecting a care home' and advised to speak with their clinicians if they would like to discuss any issues raised further.

We collected sociodemographic details at baseline. All participants completed face-to-face assessments at baseline and 10 weeks later in a location convenient to them (own home or university buildings). Our main outcomes were acceptability and usefulness of the manual (rated on Likert scales) and the Decisional Conflict Scale (DCS).[10] Carers also completed the Hospital Anxiety and Depression Scale (HADS).[11] We performed an intention-to-treat analysis using last observation carried forward in place of missing data to test our hypotheses that the DECIDE manual would be acceptable and useful and that family carers who received the DECIDE manual intervention would report lower total decisional conflict scores. Those randomised to the intervention group also participated in an audio-recorded, semi-structured qualitative interview about their experiences of using the DECIDE manual at the 10-week follow-up visit. K.L. informally identified main themes from the interview responses.

Results

Overall, 41 of 48 (85%) carers referred to the study completed baseline measures and were randomised. One control group carer was uncontactable after completing the baseline assessment; the other 40 (98%) participants completed the study (Fig. 1).

Demographics of all participants are shown in Table 1, with our sample consisting predominantly of White British carers. All carers allocated to the intervention group rated the DECIDE manual as 4 (n=8) or 5 (n=12) on the 5-point Likert scale of relevance (mean 4.60, s.d.=0.503) indicating that they found it very relevant. On the 10-point Likert scale of manual usefulness, 1 carer rated the manual as 7, 6 carers rated it as 8, 1 rated it as 9 and 12 rated it as 10 (mean=9.20, s.d.=1.06), indicating that they found the manual useful or very useful. There was no significant difference in the

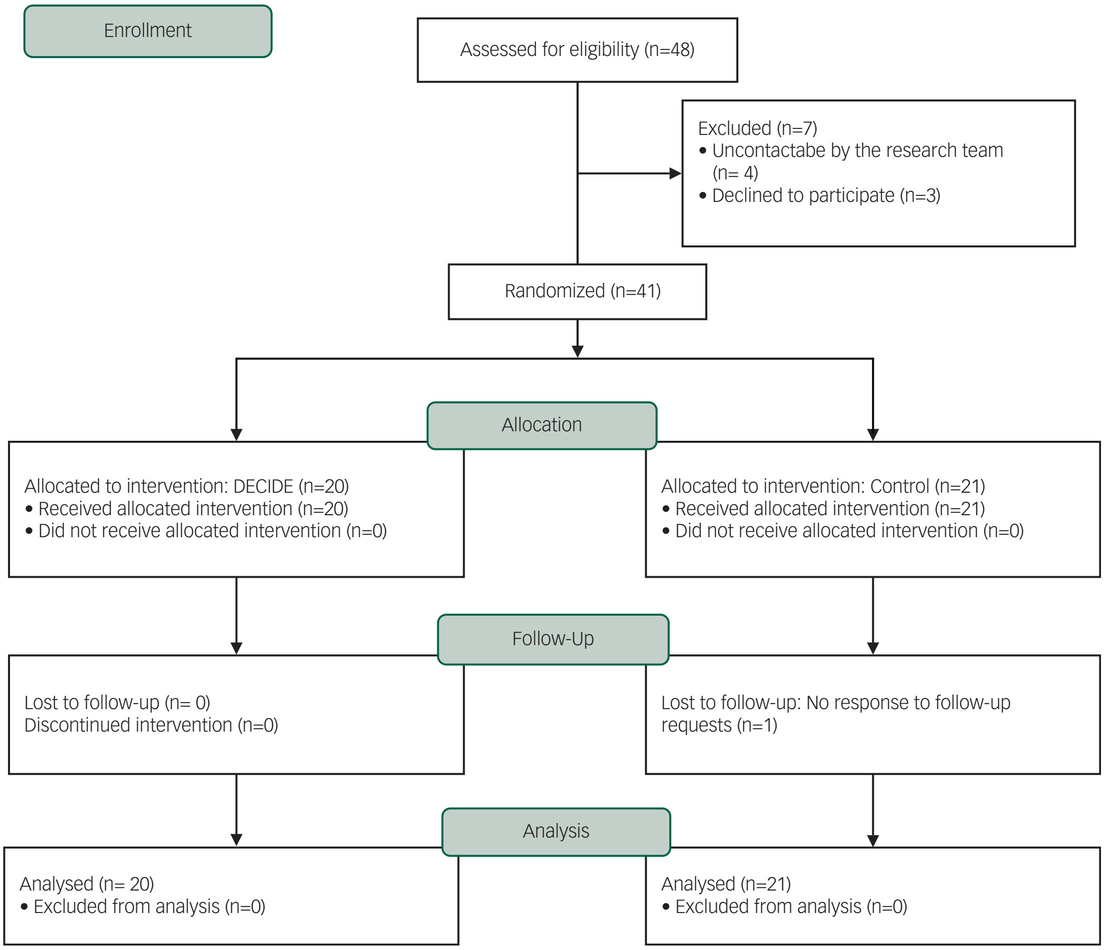

Fig. 1 Flow diagram of participant recruitment.

mean DCS score between intervention and control groups at baseline (mean difference −0.89, 95% confidence interval (CI) −9.61 to 7.83, $t(39)=0.21$, $P=0.838$). At 10-week follow-up, the intervention group had a significantly lower mean DCS score compared with control participants (24.72 compared with 36.68; mean difference −11.96, 95% CI −20.10 to −3.83, $t(39)=-2.97$, $P=0.005$); this remained significant after controlling for baseline scores (ANCOVA $F(1,38)=12.38$, $P=0.001$). At follow-up, there was no significance between group difference in anxiety (mean difference −0.024, 95% CI −2.94 to 2.89, $P=0.987$) or depression scores (mean difference 0.421, 95% CI −2.23 to 3.10, $P=0.750$). In qualitative interviews, carers reported that the DECIDE manual did not remove all barriers to decision-making. Disagreements between the person with dementia and other family members trying to share decision-making were often unresolved, despite carers who took part in the trial being clearer about their own decision. There was still some confusion and lack of clarity for a number of carers regarding which healthcare professional or service they should contact about this decision.

Table 1 Participant characteristics

		Intervention arm (*n*=20) *n* (%)	Control arm (*n*=21) *n* (%)
Gender	Male	5 (25)	10 (48)
	Female	15 (75)	11 (52)
Age (years)	40–54	5 (25)	7 (33.3)
	55–64	7 (35)	7 (33.3)
	65–74	5 (25)	4 (19)
	75–84	3 (15)	3 (14.3)
Relationship to person with dementia	Spouse or partner	10 (50)	7 (33)
	Child	10 (50)	14 (67)
Carer and person with dementia currently live together?	Yes	11 (55)	10 (48)
	No	9 (45)	11 (52)
Ethnicity	White British	16 (80)	13 (62)
	Other White	3 (15)	3 (14)
	Asian	1 (5)	2 (9)
	African-English	0 (0)	1 (5)
	Black Caribbean	0 (0)	1 (5)
	Other: Hispanic mixed	0 (0)	1 (5)

Discussion

Carers of people with dementia who were making decisions about where their relative should live in the future were willing to take part in the study; those that received the DECIDE intervention found it useful and relevant and reported less decisional conflict 10 weeks after receiving it, compared with the control group. Total DCS scores of 25 or lower have been associated with making and implementing decisions and scores that exceed 37.5 with delays making or acting on decisions;[12] so, our results suggest that the DECIDE intervention may have increased the likelihood that decisions about how care home placement would be made and implemented.

These findings should be treated with caution as the small sample size limits their generalisability. Outcome assessments were not blind although they were self-complete and standardised. K.L. administered all the interventions so we could not assess any 'therapist effect'.[13–15]

This positive preliminary evidence that the DECIDE manual may reduce decisional conflict suggests that professionals should be proactively engaging carers in discussions about future place of care and provides a tool to assist these discussions. We trialed the DECIDE manual in memory services, but it may be useful in old age hospital wards too, as many people with dementia who move to a care home do so directly from hospital. Dementia significantly increases the length of hospital admissions, often because of issues with the discharge process,[16] and it would be interesting to establish if the DECIDE manual reduced time in hospital in people with dementia; a pragmatic, larger and blinded trial is now required to evaluate real-world effectiveness and cost-effectiveness.

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