

Reviewer's report

Title: Decision aids for community service choices by carers of people with dementia: a mixed method evaluation

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Reviewer: Ian Rothera

Reviewer's report:

This paper presents the findings of a mixed methods study to develop and evaluate a Decision Aid (DA) for principal informal carers of community dwelling people with dementia resident in Tasmania, Australia using a qualitative and RCT research design. The usefulness, content and style of the DA was informed through a combination of information and advice derived from a number of sources. The DA was evaluated using a case-control RCT method, and showed some improvements in the intervention group compared to the control group on carer burden, decisional conflict and knowledge around decision-making.

The strengths of this study are the multiple sources of evidence and information used to guide the development of the DA, including interviews and focus groups with informal carers and health care professionals and an expert panel of community service providers. Careful consideration of the views of informants was reflected in the design of the DA. Quantitative evaluation of the DA was also rigorous, comparing an intervention with control group on a number of domains using four outcome measures that assessed carer stress, decisional conflict, knowledge of the 'dementia trajectory' and decision participation preferences. Difficulties in providing an evidence base around dementia outcomes and the availability of services were also considered in the context of developing the DA.

However, there are a number of issues and limitations that the authors will need to further address in the paper (major compulsory revisions):

1. There are several points, that with further clarification, would improve the reader's understanding of the context within which the DA was developed. These are as follows:

- Brief detail/description of the 'weigh scales that help individuals' clarify their values' (p.4) and how they are used to aid decision-making.
- Brief description of the 'process recommended in Ottawa guidelines' (p.4) which was used to inform the research design.
- More information about the Expert Advisory Panel of community service providers (p.4&5). Details on who these experts were i.e. which professions/academic institutions they represented, range of expertise etc.
- How was the convenience sample of interviewees (experienced carers) sourced? (p.5). Who conducted the interviews?

- Why three focus groups? Did this reflect the composition of each group i.e. were there specific (homogenous) participants in each group? How many participants in each group, and how were the numbers decided? How were the participants recruited? Who facilitated the focus groups and how? Were the community health service providers from which the participants were drawn publicly or privately funded or voluntary services? (p.5).
- Only notes were extracted from the audiotaped interviews and focus groups (p.5). Were these fully transcribed and by whom? Who decided which notes were extracted, was this consensus based?
- The iterative process by which feedback was incorporated into the DA needs to be described i.e. what were the steps, who was involved in the process, how was agreement reached, how was the DA modified at each step? (p.5).
- Need to say what GBDA is in full (p.6).
- Specify why the control group was mailed a copy of the DA at the end of the trial (p.6). Was this for information only? Presumably it had no bearing on outcomes or the comparison between the intervention and control groups?
- Why were the follow-up assessments conducted at two weeks and three months, was there a specific reason for this? (p.7).
- It would be useful if the background characteristics described on p.7 could also include some information on the severity of the dementia of the care recipients, as this is likely to have a bearing on carer burden, decision-making etc. This could also be compared across the control and intervention groups.
- It would be useful to know why one of the intervention participants failed to use the DA (p.8).

2. The validity of the findings is limited by the very small total sample size of thirty one participants. Why was the sample restricted to this size? Was this due to the self-selection process, difficulties in recruitment or a restricted population of carers from which the participants were recruited? The size of the study sample does not provide sufficient power to detect a significant difference across the groups on any of the measures even if any differences between the two were due to an actual effect of the intervention and not random variation or chance. This could explain why no significant results were reported by the authors on any of the outcome measures. Despite the fact that some improvements across the intervention/control groups were noted (carer burden/stress, decisional-conflict, knowledge), these cannot be attributed to the DA since the null hypothesis cannot be rejected (i.e. that there are no differences between them). All we can assume from the statistical analysis is that any differences are due to chance and not an effect. The authors do note in the Discussion on p.14, however, that the study would need to be replicated with larger numbers to validate the findings.

3. It would be useful if the authors could provide more information about the DA itself. Specifically, some details on the content and items on the DA and how they were used by the study participants to guide decisions about future care/support options for PWD would be beneficial. Perhaps some discussion around whether

there were specific items that were more important than others in guiding the decision-making process and whether there were qualitative differences/commonalities between the intervention and control groups on those domains identified as underpinning decision-making. Also, the age of the two cohorts needs further analysis/discussion. Participants ranged from 44-90 in the intervention group and 42-85 in the control group. Older people with dementia are likely to have increased physical impairment and needs than younger people and this will have a bearing on the decisions that are made by carers about support needed.

4. The study used qualitative methods to inform the development of the DA. It is a pity that the study participants in the intervention group were not canvassed for their thoughts and opinions on the content and usefulness of the DA, using follow-up interviews/focus groups. This would have enabled the authors to triangulate different sources of evidence in order to evaluate/strengthen the validity of the quantitative findings. It would be useful if this could be considered in the Discussion, particularly in the context of a follow-up replication study.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, and I have assessed the statistics in my report.

Declaration of competing interests:

I declare that I have no competing interests.