Author's response to reviews

Title: Who pays and who benefits: How different models of shared responsibilities between formal and informal carers influence projections of costs of dementia management in Australia.

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Author's response to reviews: see over
Revisions addressed from BMC:
1. Abstract - Please shorten your abstract to no more than 350 words.
   Completed, text changed (pages 2 and 3).
2. Abstract - Include the aims of your study within the background section of your abstract.
   Completed, text changed (page 2).

Revisions addressed from referee 1, Paul Clarkson
1. The assumption that once in institutional care, in a nursing home for example, costs are fixed can be challenged. These patients would still receive out patient appointments, contact with general practitioners etc., and there are emerging studies into liaison services with nursing homes which suggest that such costs would vary by location, depending on whether a district had developed such a liaison service or not. Such costs would also vary at an individual level. However, perhaps the words ‘relatively’ fixed are important here; the paper mentions this point as an assumption but perhaps it can be said that this is just one limitation of the model proposed. It is a relatively minor point but perhaps the authors can make mention of it?

   The paper makes reference to costs being relatively fixed on the justification that the award wage for formal carers is fixed in Australia, and the carer to patient ratio is relative to the institution/patient. It is accepted that the current study does not account for further possible costs whilst in institutional care (e.g. GP visits). While data currently available is sufficient for estimating some of these costs, the current study was limited by design to the primary cost of formal and informal care. However, such costs could be accommodated by the current model, and might be a possible avenue for future research.

2. It would probably be good just to state some of the interventions that could potentially delay progression or onset by way of description. Without these the reader is left with a systematic analysis but without anything to pin it on; much relies on the reader’s knowledge of the original paper that outlines the simulation model. Just a few lines description (in a box for example) would add to the paper.

   The interventions discussed in the paper are hypothetical, as is the norm in similar papers concerning interventions and prevalence. However, further description was added on page 7 to clarify this point as this was also raised by other referees.

3. Of course, costs of formal care are not always costs to the same agency, e.g. costs of home care may be attributed more to the local municipality or authority rather than the health department. So, in presenting formal care costs (to government?) it must be stated that there may be a differential contribution from health and social services budgets; this may be important for policymakers to consider and may be important to state in the paper. ‘Who pays?’ may be not just ‘formal’ services but health, social services or the voluntary sector (currently a big issue in countries like England). The relative mix and contribution of each is important to acknowledge: there may be different constituents and perspectives for Federal and State governments for example as a different basis for decision making arises in terms of funding for long term care. A response to these cost
projections will also necessitate different considerations depending on ‘who pays; if home support agencies are the primary responsibility of the voluntary sector for example then the response will be a call for greater funding from the State government. These considerations have implications when the model presented is interpreted by readers in different countries who will be more aware of the relative mix of formal resources in their country. So, it is a question of taking supply factors into account in the interpretation. I’m not suggesting the authors should re-calculate their whole model but some acknowledgement of the fine grained detail that would need exploring would be useful in the discussion.

The ability to associate costs of care to certain sectors (such as to volunteers, the private sector, public sector, state and federal governments) is limited by the differing reporting requirements of these bodies. This disallows an individual analysis of the cost contributions of these sectors, hence the primary concern of this study was in global formal and informal costs. This is acknowledged in the discussion (page 17). As reporting requirements become more consistent, such an analysis will be viable.

Revisions addressed from referee 2, Laurie Brown

Major Compulsory Revisions
1. The paper assumes the reader has significant prior knowledge of the Australian aged care system and especially dementia care. Given the research is based on changes in ‘location’ and type of care (informal/formal care), these terms need to be described in more detail - this can be achieved by providing an overview of dementia care within Australia in the background.

   Suggestion accepted, introductory information supplied at start of background section (pages 3 and 4).

2. The dementia prevalence model needs to be described in sufficient detail within the paper so a reader understands the modelling approach and methods used and not simply referenced.

   Changes accepted. The Dementia Prevalence Model has been briefly described in the method section (page 7). Further detail into the model is complex and beyond the scope of this paper. The reader should access the original paper for a greater understanding into the mechanics of the model.

3. Data sources used should also be made explicit and again not just referenced.

   Data sources have now been made explicit in the method section (page 8), though this was not deemed necessary in the background section of the paper.

4. In methods, the interventions are described as ‘feasible’. More justification of the two interventions need to be provided – both are very illustrative but they are hypothetical interventions (or the authors should describe what real-life strategies they are based on).

   Example provided on page 7 as per referee 1’s request. We do not believe that further justification is required as the norm in this area of research concerning interventions is those of either 2 or 5 years (as acknowledged). The authors of this study have chosen to use a theoretical, conservative approach of 2 years consistent with the field of study.

5. Tables 1-3 really provide results and in my opinion do not belong in the
methods section and should be re-located to the results section.

Tables 1-3 concern data collected as a precursor to the computation of the results. They are appropriately allocated to the method section.

6. Some of the results aren’t immediately intuitive e.g. delaying progression by 2 years leads to increased prevalence. I assume this is because of reduced mortality (fewer people progress to moderate dementia, hence to severe dementia and then to death). The authors should provide more explanation as to why they observed the results they did.

Changes to the text have made this point more explicit (page 13).

7. Can confidence intervals be calculated from the modelling methods used and attached to at least some of the results? Is a 10% relative shift a statistically meaningful change?

This study does not aim to provide definitive statistical results, and hence such results are not reported. The study aims to provide boundaries for hypothetical yet plausible scenarios of dementia prevalence in the future. As data becomes available, such an analysis might be considered.

Minor Essential Revisions

1. The paper needs ‘internationalising’ – how does dementia prevalence now and in the future and dementia care compare with what is happening in other countries?

There is good reason to believe that similar trends of prevalence would be apparent in other Western based countries, where there are similar rates in the increase of dementia and care types. The best indicator of similarity in these countries would be to apply the dementia prevalence model to the specific data sets of these areas. This point has been raised in the discussion (pages 15, 17).

2. What data are re-calculated (are datasets recalculated or are parameters in the model changed?)

The datasets in the model were recalculated from the mentioned studies as discussed in the method section pages 8 and 9. This involved triangulating data by severity type, care location and care type.

3. I agree with the authors that the absolute values produced by the model are a “best guess” and what is more ‘accurate’ and of interest are the relative shifts.

Despite this, the authors seem very emphatic in the way they have reported their absolute values and may want to use language that better indicates that these are estimates only.

Changes to the text (page 13) have been made to make this more explicit.

Discretionary Revisions

1. Figure 1 is visual but a table providing these results would be space-saving.

Figure 1 was created to allow direct comparison to the paper Changing the Trajectory of Alzheimer’s Disease: A National Imperative (reference 5). This paper uses similar analysis to the current study and utilises figures in the same design as Figure 1.

2. Many of the actual results are repeated in the discussion – this is repetitive
and not really necessary (if new numbers are introduced then shift these back to the results section).

This is a valid point. However the authors have decided to leave the mentioned results in the discussion section in order to emphasise their importance. The mentioned data are integral to the subsequent analysis in the discussion.

Revisions from referee 3, Samantha Hollingworth:

2. Are the methods appropriate and well described? Mostly (see queries below)
   
   This has been addressed below.

6. Are limitations of the work clearly stated? No – more needs to be included in the study on limitations, and possibly some areas for future research.
   
   Changes to the text have been conducted to include limitations of the model and areas of future research.

7. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished? I think this needs to be more clearly stated (see comment 2 above).
   
   While there were multiple sources referenced used to justify and establish the model, this has been more clearly stated (page 5) as suggested.

Minor Essential Revisions

1. Pp2-3 Abstract seems long. Is there a word limit for the abstract?
   
   This has been changed as per editor’s instructions.

2. Need a general aim in the abstract
   
   This has been changed as per editor’s instructions.

3. P4 define ADL at first appearance
   
   Change completed (page 5).

4. P4 typos ? in “No one has attempted to estimate the future cost of dementia care in Australia by taking into account the influence of person with dementialocation, type of care, and dementia severity over time.”
   
   Checked, spelling mistake not apparent in our version.

5. P7 Be more specific that the low ($27) and high ($33) costs are for informal and formal care. What are these costs? What were they derived from? Salaries (direct)?, indirect?, or both?
   
   Low and high costs have been edited to indicate these as informal and formal costs (page 8). Salaries were derived from data supplied from DANDAD [9], which equated low and high costs as global cost/global hours. The text has been edited (page 9) to include the reference for this data, although the method the authors used to create these values was not deemed necessary for inclusion in the main text.
6. P15 typo “career”
   Change completed (page 18)

7. Fig 2 – use black and white ‘colours’ for different bars (e.g. white, grey, black).
   Explain arrow and lines on 2040 bars in figure legend or as subscript.
   We tested the readability of this figure with other authors and agreed that the current
   ‘colours’ are understandable. We agree that further explanation concerning arrow and lines on 2040
   bars need further description and this has been added to subscript (page 23).

Major compulsory revisions - more general comments which need to be addressed.

This paper relies on the model developed previously by the authors (ref 1). Some
of the following questions may have been dealt with in that paper but the issues
still need to be addressed in this one:

8. What current interventions are there to delay onset/delay progression? Are
   there any on the horizon? Cognition enhancing drugs are unlikely to provide
   these.
   
   This has been discussed previously in reference to comments from referee 1 and 2.

9. Interventions to slow disease progression and delay disease onset will save
   5% and 14%, respectively but what are the costs of those possible interventions?
   Have they been included?
   
   No, as the interventions discussed are hypothetical such costs could not be included. This
   point has been raised in the limitations of the study.

10. Why two years for these scenarios? Based on what?
    This has also been discussed in regard to comments of referee 2. Two years is a conservative
    hypothetical estimate which is the norm in this field of research.

11. Did you do sensitivity analyses based on costs, prevalence? None discussed.
    No, a sensitivity analysis was not conducted. As was discussed in referee 2, point 7., this study
    did not aim to provide definitive statistical results. The study aimed to provide boundaries for
    hypothetical yet plausible scenarios of dementia prevalence in the future. Further clarification to the
    outcomes of computer modeling research has been added to page 6.

12. What is the perspective of the modelling? Health system? Government? e.g.
    costs of care $27 for low and $33 for high? Who pays these costs (see above)?
    
    Our primary discussion in this paper is global formal and informal costs. The justification for
    this was discussed in point 3 of referee 1. Future studies might apply another level of analysis, for
    example, between government agencies, family care, and volunteer based care.

13. No clear discussion of limitations of the research/modelling.
Further limitations to the research modelling has been included, which also takes into point 9 of this referee.

14. On p14 you refer to costs of screening using biomarker technology to possibly delay onset. These are likely expensive. Have these costs been included? Who would you screen?

This is a limitation of the study as addressed in points 9 and 13, and addressed in the discussion.

15. How do your estimates compare with other studies (e.g. Access Economics)?

Comparing studies such as these is not always appropriate as each study aims to achieve a ‘best guess’ in their estimates and assumptions of dementia and its prevalence. For example, our study differs considerably in both assumptions and costs to a similar study by the Alzheimer’s Association [5]. It is very difficult for any study to account for all costs, and hence the variation reported in the literature. As acknowledged in previous points, the aim of this study was not to provide definitive results, but to provide boundaries in to which costs associated with dementia occur. A more open discussion of the cost of dementia would facilitate a greater understanding of the cost of dementia.