Author's response to reviews

Title: The experiences of culturally and linguistically diverse family caregivers in utilising dementia services in Australia

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Version: 3 Date: 9 October 2013

Author's response to reviews: see over
October 9, 2013

Dear editor:

The article entitled “The experiences of culturally and linguistically diverse family caregivers in utilising dementia services in Australia”, reports an original study funded by Flinders University in Australia. This manuscript is a revision of a previous submission (MS: 1750674183105944). We really appreciate the review reports from Dr. Chiatti, Prof. Benbow and Prof. Manthorpe. We have made substantial changes to address each point of comments in the report. We have enclosed the ‘Response to Reviewers’ in the cover letter.

This study identified issues pertinent to delivering dementia services from the perspectives of caregivers of people with dementia from culturally and linguistically diverse groups. Those issues are current and affect the utilisation of dementia services in Australia. Those issues are also relevant to countries that possess government funded dementia services and have culturally and linguistically diverse populations. We believe the dissemination of our study by the journal of BMC Health Services Research will make those issues public and inform policy-makers and service providers to improve dementia services.

This work has not been published and is not being considered for publication elsewhere. The first author (Dr. Xiao) designed the research, developed study conception, collected, analysed and interpreted data, and developed the manuscript. The second author (Dr. De Bellis) co-designed this research, developed study conception, collected, analysed and interpreted data, and made significant changes for the manuscript. The third author (Mrs Habel) and the forth author (Ms Kyriazopoulos) helped data collection and critiqued the manuscript.

We really appreciate your support during the review and look forward to hearing from you.

Your sincerely,

Lily Dongxia Xiao
RN PhD FACN

Response to reviewers’ report

Associate Editor's comments

Note: Our responses to the reviewers are in “italic”.
1. Name of ethics committee:

Please update your ethics statement to include the name of the ethics committee that approved your study.

We have updated ethics statement in the text under the heading of “Ethical considerations” as listed in the following:

The Social & Behavioural Research Ethics Committee of Flinders University approved the study (project No. 5008).

2. Explicit consent statement:

Please state in the Methods section whether written informed consent for participation in the study was obtained from participants or, where participants are children, a parent or guardian.

We have stated in the text under the heading of “Ethical considerations” as listed in the following:

Caregivers in the study were adults over 18 years older and had capacity to give informed consent. The anonymity and confidentiality were discussed with participants and written informed consents were obtained from those caregivers prior to the focus groups or interviews.

3. Please follow the RATs guidelines: (http://www.biomedcentral.com/authors/rats)

The changes we have made in the “Ethical considerations” section reflect the RATs guidelines

4. Copyediting:

After reading through your manuscript, we feel that the quality of written English needs to be improved before the manuscript can be considered further.

We advise you to seek the assistance of a fluent English speaking colleague, or to have a professional editing service correct your language. Please ensure that particular attention is paid to the abstract.

Our team members who are native English speakers have edited the written English.

Comments from Professor Susan Benbow

1. Title

This is not a cross cultural perspective on the carers’ experiences. It is an account of the experiences of culturally and linguistically diverse family caregivers in utilising dementia services in Australia.

We have accepted Professor Benbow’s suggestion for the title. The new tile is stated as:
The experiences of culturally and linguistically diverse family caregivers in utilising dementia services in Australia

2. Aim
The aim of the study is described in the abstract as being to explore the experiences of caregivers in dementia service utilisation (page 2) and this is also implied by the third sentence of the Results section, but under the heading Aims (page 8) it is described as to explore the experiences of caregivers in order to understand how they manage dementia services and whether they were satisfied with services. These are slightly different and it would be helpful to clarify the aim or aims.

We have made changes for the aim of the study stated under the heading Aims (page 8) by removing the words of “in order to understand how they manage dementia services and whether they were satisfied with the services”. The changes ensure the consistency of aim stated in the abstract and in the results section.

3. Page 6 refers to Berry (2003) and it is not clear which reference this is in the numbered reference list.

We have checked the references and added reference No 16 to the text. Thank you for identifying the error.

4. Page 9 refers to a paper by Braun and Clarke – I don’t think this is in the numbered list.

We have checked the references and added the reference from Braun and Clarke (No 28) to the text and the reference list. Thank you for identifying the error.

Discretionary revisions

1. Methods
The method is well described, but I wasn’t clear whether coding was carried out manually or using a software package. Page 10 refers to the selection criteria without specifying what they were: does this refer to the two criteria set out on page 8 under the heading participants, namely 1 year of experience in caring and daily contact with a PWD? If that is the case it might be helpful on page 8 to describe these as selection criteria.

We have explained that “These highlighted descriptions were then coded manually” to address Professor Benbow’s comments.

We have added the selection criteria under the heading of “Participants” (see page 8) as professor Benbow suggested. We have also added an explanation in bracket (see the “Participants” section) after the words of “selection criteria” under the heading of “Ethical considerations” (page 10). The statement of “selection criteria” is stated in the following:

“The selection criteria in the study included: (1) family caregivers who had at least one year of experience in caring for a person with dementia; (2) who had daily contact with the care recipient; and (3) resided in the same or a separate household in close proximity” (see page 8).
2. Results
The four themes are clearly set out and illustrated with quotations from the interviews/ focus groups. I would like to see the authors put more emphasis on what we can learn about negotiating services that is pertinent to these particular CaLD carers. Negotiating services for the PWD is probably a big issue for all family carers – what is it about being from a CaLD group that makes this a major issue? Are differing expectations relevant here? (The quotation from Chinese carer 11 suggests this is a factor.)

We rechecked our data and agree with Professor Benbow that different expectations for dementia services make the negotiation of services unique for the CALD groups. We have added a statement under the heading of “Negotiating services for the person with dementia” to support this finding as described in the following:

“However, they had expectations that services would be flexible to meet their schedules and were also culturally appropriate. Such expectations made the negotiation of services unique for the CALD caregivers. The skills described by caregivers in negotiating services included planning, communication and searching of services”. (p. 11)

3. Similarly 3 of the 4 listed characteristics of satisfactory services on page 17 are probably common to many carers, unless the authors have identified ways in which coming from a CaLD community impacts on them. The same might be said of the carers’ negative experiences in utilising services. The quotation from Chinese carer 8 suggests that cultural and linguistic factors might be operating here too.

We agree with Professor Benbow’s suggestion that cultural and linguistic factors impact on CaLD caregivers’ satisfaction and dissatisfaction with dementia services. We have made changes in the first paragraph under the heading of “Characteristics of satisfactory services” and listed changes in the following:

“The caregivers’ satisfaction with services was shaped by their expectations for culturally and linguistically congruent caregiver support. Under these expectations, the characteristics of satisfactory services described by caregivers were: (1) supporting caregivers to develop ability to cope with daily care challenges, (2) providing timely interventions in cases of care crises, and (3) relieving the psychological-emotional burden of caregivers by providing caregiver support groups.” (page 17)

We have also made changes in the theme four under the heading of “Negative experiences in utilising services” and listed changes in the following:

“Negative experiences described by CaLD caregivers were associated with cultural and linguistic factors. For example, An Italian caregiver attributed medication errors her mother experienced during respite care in a nursing home to inadequate intercultural communication that staff might have shown when caring for her mother who barely spoke English.” (page 21)

“This study also identified that the negative experiences of the caregivers could come from the use of ethno-specific dementia services.” (page 22)
“The underdevelopment of ethno-specific services in new migrant groups, understaffing and lack of resources in these service providers might have contributed to the situations caregivers described. Supporting mechanisms, resource development and regulations could be strengthened when considering the establishment of ethno-specific dementia services appropriate to the needs of clients.” (page 23)

4. Discussion and conclusions
On page 25 the authors refer to the potential conflicts of interest between the consumer and the service provider. This is a very important point and it would be helpful to elaborate on it. Similarly the paragraph on page 26 about cultures that value group achievements above individual ones and the implications this might have in terms of educating and preparing families to care for someone with dementia is also very important and could be elaborated further.

We have added discussions to the section related to the potential conflicts of interest as suggested by Professor Benbow. We have amended the discussion in the following:

“In this study when the conflicts of interest arose, the service providers were in a dominant position to decide on the solutions. The CaLD caregivers who had limited English and resources to cope with dementia caregiving were in a vulnerable position to negotiate services. Therefore, the use of a bilingual service advisor may better support this group of caregivers to negotiate services to meet the care recipients and the caregivers’ needs.” (pages 25-26).

We have also added discussions to the section related to collectivist culture. We have changed the discussion in the following:

“Collectivist cultures have shown some advantages in relieving dementia care burden via shared care based on kinship [34, 35]. However, such advantages cannot be overestimated if the migrant family does not have kinship resources in the adopted country. In addition, collectivist cultures are associated with unique family dynamics due to shared responsibility of care in the family and some of these dynamics, such as filial piety can place an additional burden on family caregivers [13, 19].” (page 27)

5. The conclusions state (page 27) that the carers’ “judgement”/ evaluation of dementia services was influenced by their experiences prior to migration. This might be the case but have the authors found any evidence to support this in their study or is this a hypothesis (and if so that should be made clear and it would be more appropriately included in the discussion rather than the conclusions).

We have removed the words of “prior to migration” as we do not have enough space to discuss this issue in this article. Thank you for your suggestion.

6. I think the paragraph regarding the limitations of the study which is currently in the conclusions on page 28 would fit better in the discussion. Specific points that would benefit from clarification:
We have moved the limitations of the study in the section of discussion. Thank you for your suggestion.

7. Page 6. Could the authors explain what is meant by “ethno-focussed” services. This term may be used in Australia but is not necessarily known to people in other countries.

We have change “ethno-focused” to “ethno-specific” throughout the article to keep consistenye with the definition by the Australian Government. We listed the definition in the following:

“Ethno-specific aged care services is defined as a “Service category based on ethnic, linguistic or religious community providing a service to its own members” [14, p. 19] are highly regarded by CaLD caregivers.” (page 5).

8. page 7: the term “adequate beliefs” is used. I suspect the authors mean adequate knowledge. I don’t think a belief is described as “adequate”.

We have replaced the word beliefs with knowledge. Thank you.

9. page 8 states that the study was carried out “in a capital city of Australia”. I thought Canberra was the capital of Australia but having looked this up on Google I have learnt that there are 8 state and territory capital cities. To avoid confusing non-Australians perhaps this could be rephrased.

We have replaced “a capital city of Australia” with “a metropolitan city in Australia”. Thank you.

10. page 9 the top paragraph states that if carers were unable to attend focus groups “individual-based interviews were considered to be appropriate”. Was it the case that carers had a choice of whether to attend a focus group or to be seen individually (which is what I thought had been done) but that if people couldn’t attend the focus group they were allocated they were then offered an individual interview? It would be helpful to make this clear (if I have understood it correctly).

We have reworded the statement to make the procedure clearer as amended in the following:

“However, individual-based interviews were also used if caregivers chose this type of participation or if they were unable to attend a scheduled focus group.” (page 8).

11. Page 10 talks about the process of coding – should the word “intergrade” be integrate?

We have replaced the word “intergrade” with “integrate”. Thank you.

12. Page 10 states that rigor was enhanced by reporting findings back to the participating organisations. I think that if reporting back is to enhance rigor the organisations concerned would need to have chance to respond to the report and give feedback on it. Did this happen?
We have removed the reporting findings back to the participating organisations from the section of rigor as we only sought informal feedback from the organisations after the presentation, rather than formal feedback in writing.

13. what are “ideal” levels of acculturation and who decides what is ideal? (I suspect this would be better rephrased.)

We have replaced “ideal levels of acculturation” with “had achieved assimilation into the Australian culture”. Thank you.

Comments from Professor Jill Manthorpe

Major Compulsory revisions

However my main question to the research team is whether their linkage of this data about caregivers’ experiences really relates to the consumer directed care (CDC), ‘hook’ on which the paper is hung. In my views this seems a somewhat artificial hook and CDC is not explained sufficiently or critically analysed. There is no reference to the emerging literature from Australia on CDC or internationally (especially in the UK and US, and in the Netherlands where it is being truncated).

The full implications of CDC are not explored and the data that are reported do not sufficiently address them. Interestingly, the title makes no mention of CDC and my view is that the research stands alone in its valuable analysis of groups of caregivers. One further indication of the ‘lack of fit’ of this paper with CDC is the authors’ continual reference to this as a ‘reform package’. This sounds rather too much like jargon; it might be better presented as a ‘system change’ with none of the judgements inherent in the word ‘reform’. Importantly some of the reporting of findings/results drifts off to discussion (e.g. end page 12, end of findings section on page 23) about CDC without clear linkages and the discussion needs to be brought together.

This point applies to the abstract which is clear, although the date of the interviews should be included. However the conclusion suggests that CaLD groups need to be prepared for CDC rather than CDC needing to be more attuned to CaLD and other diversities. The authors might like to reconsider this. Similarly, if the focus on CDC is to be maintained there needs to be stronger background about the implications of CDC for minority ethnic groups. These have been considered in the UK and USA. They paint a mixed picture, to my reading, of the benefits of choice but also the risk of undermining provision such as ethno- focused day care centres that offer minority group services or outreach. CDC has many nuances. Overall my recommendation would be to revise this paper to focus on the valuable data it contains and to enhance the discussion around the data rather than speculation.

We have accepted Professor Manthorpe’ suggestions and made substantial changes for the article in order to focus on CaLD caregivers’ experiences in utilising dementia services, rather than the consumer-directed care. We appreciated Professor Manthorpe’s expert opinions that helped us improve the article.

Minor Essential
There are some minor presentation points to be addressed. Personally I don’t like the term PWD; ‘centred respite’ is also unclear to international readers. The limitations of the paper are well expressed in that the settings produced potential bias. However, a further limitation is the lack of inclusion of non CaLD groups, meaning that some caregivers’ expressions of frustration and abandonment might have been shared by non-CaLD groups.

*We have replaced the PWD with person with dementia or people with dementia throughout the article. Thank you.*

*We agree with Professor Manthorpe’s suggestion and have added the limitation to the article as stated in the following. Thank you.*

“Second, the study did not include caregivers from the mainstream culture in the study. Therefore, the study is unable to distinguish whether the issues identified in this study are specific to CaLD caregivers or common to all caregivers of people with dementia.”(page 28)

**Discretionary Revisions**

I would further recommend that the authors mention their thanks to the participants in the interviews/focus groups in the Acknowledgements as well as the study funders.

*We have added our thanks to the participants in the interviews/focus groups in the Acknowledgements as well as the study funding bodies. Thank you very much!"