Author’s response to reviews

Title: Advancing Care for Family Caregivers of Persons with Dementia through Caregiver and Community Partnerships

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Reviewer reports:

Reviewer #1: Despite this article's context being American it is understandable and extremely interesting at a time when so many people are diagnosed with dementias of all kinds and their families find themselves in the caregiver role as you describe it. In England we call ourselves Carers.

"Thank you for this comment – I do think that the term ‘carer’ sometimes helps to differentiate better between health care professional who is also called a caregiver and family caregiver – we sometimes need to make this distinction clear in North America."

I think you have tackled a subject that is really important today not just for your local area but worldwide, so I hope your article will receive wide publication.

Good Luck
Reviewer #2: I found this article to be a thoughtful and interesting description of a valuable project which had a high level of engagement of caregivers. Overall, I feel the length of description of the data is not so relevant for a journal of this type but of more valuable to a journal more widely read by those in the dementia field. I have some questions/suggestions for the authors to help them refocus this article.

1) did the team consider involving people with a diagnosis in these discussions? caregivers are commonly involved in projects regarding care of people with dementia and in the spirit of caregiving partnerships and coproduction a perspective of what a person with dementia feels a caregiver would benefit from might be interesting.

"We really kept our focus for this project on the family caregiver as our purpose was to partner with caregivers to develop the Caring for the Caregiver program. As we have evolved in our work, we are now conducting a project where we are also including the person with dementia and the family caregiver (to create a dementia-friendly acute care hospital)."

2) given that those with a diagnosis were not involved in the project I suggest altering the description at the bottom of p2 from 'people who are affected with dementia' to something more accurate.

"You are correct and we have revised this to: “family caregivers of those with dementia”.

3) how diverse were the caregivers you involved? Some demographic information would be helpful along with discussion of thought placed in this.

"We have added a brief description of the caregivers included in the project to show their diversity in gender, ethnicity, and kin relationship to the affected person."

4) in the first para of the background I suggest changing 'affected individual' to 'person with a diagnosis'. Caregivers are affected by the diagnosis so this should be clearer. I feel this background can be shortened also.

"We have revised as above and have removed less relevant material from the background to make it more accessible."

5) typing error at bottom of p9 penultimate word of para. 'About caregiving fro families'

"corrected"
6) top of p10 it should be made clear that at least one caregiver has end of life experience as a former caregiver as this strengthens the disease trajectory representation. I didn't think there was such a participant until I read it later on.

"This has been added."

7) consider shortening the quotation middle p13

"We have removed some of the quotation that was redundant."

8) I'd like to see more methodological discussion and reference to where this project's methods sit within PPI im dementia research.

"We have added a few sentences to demonstrate PPI in the area of family caregiving for persons with dementia – while PPI is quite extensive related to the person with dementia, the literature is sparse related to the family caregiver."

Eg how was disagreement between stakeholders recorded and discussed and dealt with? Any challenges or strategies which helped?

"Challenges and strategies have been added to pages 15 and 16."

9) suggest starting new para p15 for JLA reference as the discussion para feels long and slightly muddled.

"As noted."

Also, reference to work ongoing on transitions I'm dementia care, eg murna downs?

"Thank you – we had not previously come across this publication related to transitions and it has been added as it well describes what we were seeing in the group work."

10) in description of challenges it's unclear why need to learn about strengths in regards to family caregiving. Do you mean the value and depth of their caregiving experiences?

"What we meant here was to identify the specific strengths of the organization for family caregiving but we have removed as it is confusing."

11) it would be good to know more about how the relationships built in this project developed to funding applications.
"This is briefly discussed on page 16 as one of the outcomes of our community partnerships."

12) repetitive sentence in conclusion p16 quoting 80% figure. Not necessary.

"We agree and this sentence has been removed."

Reviewer #3: Though this paper primarily appears to describe an intervention, rather than a research study as such, I think it is of value to readers of RIE.

As stated, the conclusions are consistent with those produced by the James Lind Alliance study. I would like to see more detail about research methods, especially in relation to interviews with caregivers, and an acknowledgment of issues and limitations of the research. I'd like to know more about any similarities or differences in perspective between the different stakeholders, particularly since the authors express an interest in diversity issues.

"Page 10 has been revised to include this information. We have also added information about limitations in the discussion on page 17."

There is scope in the discussion section to consider how these findings relate to the literature on family caregiving more generally.

"We have briefly added information about the state of science in family caregiving and need to continue PPI in this area on page 17."

There is already a considerable literature on caregiving for people with dementia; it would be helpful to consider whether this research might be relevant to caregiving for people experiencing other problems involving severe mental distress.

"We are not able to comment on the relevance of our findings to other caregiving areas but certainly support our process of PPI for identifying needs and gaps for building a program of support for family caregivers in other area."

Reviewer #4: Summary. The authors report on the two main ways in which they engaged with communities of caregivers to develop a program called "Caring for Caregivers" at University of Texas Health San Antonio. The program provides support to caregivers of people with dementia. The first phase of engagement constituted a kind of needs assessment and involved the researchers identifying and establishing relationships with the relevant communities via meetings (both as organizers and as attendees) and by attending other community events. The second phase was a community-academic forum that involved many stakeholders. The authors used the forum to create small groups discussions to elicit views on barriers and facilitators to effective family caregiving and to identify the relevant supports that could be created for them. The authors conclude that these activities were crucial to the success and relevance of the Caring for the Caregivers Program.
GENERAL COMMENTS

The authors describe a very resource intensive and seemingly successful approach to establishing collaborative relationships with caregiver communities to identify and address the support needs of the caregiver community. I think the example provided here will be of interest to other health centers and regions looking to use community engagement to develop similar support programs. It also nicely describes what might be missed if this kind of engagement is not done.

The authors could provide a little more detail on how the environmental scan was conducted. The list is described as being "systematically developed". Via internet search? Or by a registry of such groups? Something else? All done by one person? How was the "community of interest" defined for the purpose of developing the list?

"This is important information and we have added this to page 7. The community of interest is defined as agencies and individuals involved with family caregivers of persons with dementia."

Since the authors appear to use qualitative research methods to gather and analyze the information at the academic forum, more detail on these methods would be helpful.

"We have added information related to credibility and to the analysis on page 9."

Relatedly, since qualitative methods seem to have been employed in data gathering and analysis, there should be some mention of techniques used to ensure credibility and transferability, etc., of the findings.

"As above."

For example, how might the authors position and role may have influenced the interpretation of the data?

"We have added this to the limitations on page 17."

What factors might be relevant when thinking about how relevant this is to other settings? E.g., socio-economic or education status? Is it possible for the researchers to comment on this? We can’t really comment on this.

"We didn’t collect information on the education or socioeconomic status of our participants so are unable to comment. Our sample was, however, quite diverse representing a less-advantaged group in the rural focus group and a more affluent group among those we individually interviewed."

SPECIFIC COMMENTS

Summary. The authors describe the forum as an opportunity to identify and discuss priorities; however, the description in the full text does not describe an activity that would allow the
researchers to identify priorities. I suggest you remove this word or say more about how this was done in the full text and actually list the priorities identified.

"We agree and this had been revised."

Background, line 29. I think sentence should be "…can be particularly challenging because of the related cognitive decline…"

"revised as suggested"

Background, line 56. "We are increasingly dependent…” Please specify who is referred to by "we“? The health center? The United States population? Globally?

"We have actually removed this as suggested by another reviewer to shorten the background."

p. 7. There are various frameworks for conceptualizing public engagement and the various obligations at each step. Can the authors say a little bit about why Rowe and Frewer were chosen? Why not IAP2 (which is similar)?

"We selected the Rowe and Frewer framework as it has been used in North America in the past and was familiar to our team."

-p. 7. The last sentence of the Background doesn't seem quite right: the methods and results don't lead to the implementation plan. The methods were used to gather the information that was then used in the development of the plan.

"Revised"

-p.7. Phase one seems to be a kind of assessment of the needs of caregivers. Is it not?

"It was a needs assessment but was also an assessment of the resources in the community."

-p.7. How was the information about the purpose communicated? Did the researchers have an introductory letter and an information package of some kind? How was the information provided consistently?

"We didn’t have an information package at this time as we were collecting information from our community of interest about their services. This information was used to inform our mission statement and purpose."

-p.8. Were the researchers invited to speak at events or did they request to speak at community events?

"As community members and groups became aware of our program, we were invited to come and speak about the program development at their events. As we became known in the
community we were also invited to speak about Alzheimer’s disease and family caregiving as members of our team have expertise in these areas."

-p.8. Who funded the community-academic forum? How was it advertised? How were individuals/groups invited?

"The funding is identified in the acknowledgements section. Owing to the length of the paper, this has not been explained in detail but participants were invited by email, through mailing lists of our collaborators, and in person. We had flyers that announced the events."

p.8. line 5 and 9. Who does "we" refer to? All the authors? If not, perhaps say "one author" or "two authors" etc.

"This was an effort of the caring for the caregiver team and we were all involved in a variety of these activities so it is difficult to state specifically how many team members for each of the activities. We have revised this to make it a little more specific and have noted that the caregiver team is the authors of this manuscript."

p.11. The themes "Making the invisible visible" and "you don't know what you don't know" don't seem to adequately capture what the authors describe. Could the authors use themes that are more specific and descriptive as they have for the other two themes? For example, why not "Increasing awareness of caregiver role" for the first? Or "Unrecognized role as caregiver"?

"Thank you for this suggestion – we are reluctant to revise as these were the themes that were identified from the team analysis and described what the group at the community academic forum was reporting."

-p.15. The authors mention that it was time consuming to establish relationships with the groups, but no timeline is given. Can the researchers better describe this? Can they say something about whether and how this might have been done better/more efficiently?

"This has been added to page 17 and we also commented on the time frame in the limitations. While this may have been done more efficiently, the time that we invested to establish these trusting relationships and partnerships has been extremely important to our ongoing work."

-p.16. I mentioned this point earlier. The authors should describe how they prioritized the activities and list them. Might also be helpful to say what they mean by "prioritized" in this context. Is it perceived importance or use to caregivers or in terms of ease of planning and execution ("low hanging fruit"), or something else?

"We have removed priorities as our goal was not to identify priorities but rather to address gaps in the system of care for family caregivers."

Conclusion: The author's conclusion seems disconnected to the rest of the study. It also introduces a number of new claims. The conclusions should relate in a very general way what the authors can infer from the material they have provided. In this case, I think the conclusions
should say something about the importance of identifying and establishing relationships with stakeholder groups to ensure relevance of support programs and perhaps something about the challenges this raises and how overcome (via environmental scan, forums, etc.). Perhaps 5 sentences and no more.

"We have revised so that the conclusions do reflect the results from this project."