Author’s response to reviews

Title: Perspectives on disclosure of the dementia diagnosis among primary care physicians in Japan: A qualitatively driven mixed methods study

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Version: 1 Date: 25 Apr 2019

Author’s response to reviews:

April 26, 2019

Editor-in-Chief
Dr. Tovah Honor Aronin
BMC Family Practice

Dear Dr. Tovah Honor Aronin,

Thank you for the opportunity to revise our manuscript, "Perspectives on disclosure of dementia diagnosis among primary care physicians in Japan: a qualitative study" (FAMP-D-19-00023). We have revised the title in response to reviewers’ inquiry to, "Perspectives on disclosure of the dementia diagnosis among primary care physicians in Japan: a qualitatively driven mixed methods study."

We greatly appreciate your comments, and the comments of the reviewers. We have considered these carefully in our revision. We provide a point-by-point explanation of our response below.

Also, stimulated by the reviewers’ comments, we also felt that the methods section would be clearer by minor restructuring. The changes we have made for this purpose are highlighted in green. In the restructuring, we have followed a more traditional format, and used sub-headers to highlight the methodological steps.
Response to the review comments:

For comments by Editor, Dr. Tovah Honor Aronin

1. I did not quite understand that also primary care physicians working in hospitals were interviewed. Could you please explain because in some countries, primary care physicians do not work at all in hospitals which are considered to be secondary or tertiary level of healthcare.

<Response> Thank you for your question. Some physicians in hospitals were included in this research because Japan has a free access system to hospitals so that patients may visit physicians in a hospital for primary care services. We agree that it should be stated for international readers and added the following sentence on page 5, line 4-7.

“Physicians based in local hospitals were included because they are also considered providers of primary care services in Japan. The word for hospital in Japan, byouin, has a much broader nuance than English as even a single physician’s office workplace may be called a “hospital” rather than a clinic.”

2. You also used the quantitative evaluations but this has not been described in the methodology section. Please, add. I would also be interested in knowing why you chose also the quantitative evaluation. The title of the manuscript mentions only qualitative.

<Response> Thank you for sharing this concern. In the interview design, the comfort level was to be asked orally in order to explore the reasoning behind their choice. So we gathered that information through a qualitative process. We agree that our initial description may be misleading about the process so the following 2 parts in Methods section were revised accordingly.

“Design and setting: We employed a qualitatively driven mixed methods design organized through conduct of semi-structured interviews with 24 primary care physicians, and rankings of their comfort disclosing dementia. A qualitatively driven design overall relies on a qualitative approach, but incorporates with a lesser emphasis quantitative data collection as well” (Methods-Design and setting section, page 3, line 13 to 17.)

“Mixed data analysis: To merge participant responses about their level of comfort with disclosing dementia, and the reasoning behind their rankings, we used joint display analysis, the process of linking the quantitative and qualitative findings in a table or matrix according to constructs held in common between both types of data. The final step involves drawing interpretations or what mixed methods research methodologists term “metainferences” based on both types of data that we organized in a final column.” (Methods-Mixed data analysis section, page 4, line 26-32.)

Also, based on above minor restructuring, we have changed the subtitle of our manuscript from “a qualitative study” to “A qualitatively driven mixed methods study.”
For comments by Dr. Hakan Yaman (Reviewer 1)

Thank you for the comments in detail. We have made corrections as follows according to your advices.

1. Spelling errors need to be corrected.
   <Response> Thank you for the comment. They have been corrected.

2. abstract: <Background> The number of dementia patients in Japan (Please rephrase this sentence).
   <Response> Agreed. “In Japan” was missing in the <Background> of the body. It is added on page 2, line 16.

3. ...standardized in a published guideline in Japan (3), (Please add in Japan).
   <Response> Agreed and corrected on page 2, line 20.

   <Response> Agreed and replaced the reference.

5. culture differ from those of Europe and the Americas. (Reference?).
   <Response> Thank you for the confirmation. We have added the following 2 references to support our interest on page 3. Line 2.


6. Participants and interview procedures (Could you please explain items 7 and 8 of COREQ list?).

<Response> Thanks for pointing out this information was missing. We added as follows on page 4, line 3-6.

“Prior to the interview, the participants had no relations with the interviewer. The interviewer explained the purpose of the research and her background as a qualitative researcher, and that she was not a medical professional and participants may share their experience without being judged or evaluated.”

7. ...addressed primary care physicians' goals in managing multimorbid dementia patients; (Multimorbid patients with dementia?).

<Response> Agreed and revised as advised on page 3, line 25-26.

8. The institutional review board of the home institution of the investigators in Japan approved this research. (Date and no?).

<Response> Thank you for confirming. “December 27th, 2016 (No.16-233)” is added on page 3, line 21, and under declaration section on page 11, line 7.

9. As illustrated in Table 1, a total of 24 primary care physicians... (How are female participants distributed?).

<Response> Thank you for confirming. We distributed as “Seventeen (71%) of the participants were male and 7 (29%) were female.” on page 5, line 3. Table 2 is also revised with the number of female participants.

10. ...while six (25%) worked in hospital settings. (This is primary care setting?).

<Response> Yes, Japan has a free access system to hospitals so patients may visit physicians in a hospital for primary care services. We agree that it should be stated for international readers so added the following sentence on page 5, line 3-6.

“while six (25%) worked in primary care hospital settings” “Physicians in local hospitals were included because they are also considered providers of primary care services in Japan. The word for hospital in Japan, byouin, has a much broader nuance than English as even a single physician’s office workplace may be called a “hospital” rather than a clinic.”

11. decision-making
12. communication-based

13. ...environment as a reason FOR not disclosing the ...

14. ...family members for a clear diagnosis ARE usually stronger than in ...

15. ...to always include family members... (always to include).

16. ...the degree patients understand provided information...

17. Also, the majority of the dementia patients that they care for have Alzheimer's dementia. (appropriate verb is missing; reference?).
For comments by Dr. Antonija Poplas Susic (Reviewer 2)

1. It is very interesting study focused on communicating/ disclosing dementia to patients and family members and describes feelings, meanings and attitudes of physicians being involved in person/community-centred care. In general, the core of the study is illuminating communication skills of physicians talking about disclosing bad news to patients which is otherwise very usual topic. Also, in this manuscript it is mentioned that similar has been happening while disclose cancer to patients.

The authors state themselves that some aspects of study differ from results of other countries. The reason they consider to be important for that difference is well developed long-term care in Japan. If study compared situations and circumstances from different countries, it would be much more interesting for publishing at the international level. The study is specifically important to Japan but less to other countries.

<Response> Thank you for your comment. We discovered disclosure of dementia in primary care requires consideration of multiple dimensions and had different considerations from disclosure of cancer. We now elaborate on this point in the manuscript.

We also identified issues not limited to the situation in Japan, and we clarified this point as well. With such speculation, we consider our findings illustrate unique aspects of disclosure of dementia in primary care setting. We hope our report will be beneficial to international readers/investigators in this field, not just readers with an interest in Japan.

2. The methodology is qualitative but you also involved qualitative tool which assessed comfort level of participants in disclosing dementia on a scale from 1 to 10.

<Response> We understood this is a common concern as seen in your Question 6. Please see our response for item 6 below. We have clarified the study is a qualitatively driven mixed methods study.

3. I think that at least one limitation discussed in the article (not involving patients) is not in line with the topic of the study.

<Response> We understood that you have described this issue more in detail in Question 12. Please refer to our response under item 12 below.

4. Page 3, line 24: …and reviewed for the appropriateness of the language and the substance of the inquiry for a Japanese context. Who did the revision and how?

<Response> We agree that it should be stated more clearly. We revised this as follows on page 3, line 30-32.
“For use in Japan, a professional service translated the interview guide into Japanese and two bilingual senior investigators (MI, MF) reviewed the content and confirmed the language and substance of the inquiry to be natural and appropriate for the Japanese context.”

5. Page 4, line 11-12: For each of the major themes, we developed additional sub-themes to finalize the coding scheme. I am interested on sub-themes related to "disclosure" (which is a topic of this article) to be presented/gathered at one point.

   <Response> Agreed. We have presented the themes for disclosing dementia in Table 1 and added the sentence below on page 4, line 19 to 20.

   “The main themes and sub-themes related to ‘disclosure’ are presented in Table 1.”

6. The method section describes the qualitative methodology as using semi-structured interviews being conducted with 24 primary care physicians by purposeful sampling. But on page 6 (line 53), you describe a quantitative tool as to rate their comfort level in disclosing dementia on a scale of 1 to 10. This part is not described in Method section. According to Results section, the Methods section needs to be revised and clarified.

   <Response> Thank you for sharing this concern. In the interview design, the comfort level was asked orally in order to explore the reasoning behind their choice. So we gathered that information through a qualitative process. We agree that our initial description may be misleading about the process so the following 2 parts in Methods section were revised accordingly.

   “Design and setting: We employed a qualitatively driven mixed methods design organized through conduct of semi-structured interviews with 24 primary care physicians, and rankings of their comfort disclosing dementia. A qualitatively driven design overall relies on a qualitative approach, but incorporates with a lesser emphasis quantitative data collection as well (20)” (Methods-Design and setting section, page 3, line 13 to 17.)

   “Mixed data analysis: To merge participant responses about their level of comfort with disclosing dementia, and the reasoning behind their rankings, we used joint display analysis, the process of linking the quantitative and qualitative findings in a table or matrix according to constructs held in common between both types of data. The final step involves drawing interpretations or what mixed methods research methodologists term “metainferences” based on both types of data that we organized in a final column (20).” (Methods-Mixed data analysis section, page 4, line 25-31.)

   Also, based on above minor restructuring, we have changed the subtitle of our manuscript from “a qualitative study” to “A qualitatively driven mixed methods study.”

7. Page 6, last line (58) …., and then analyzed the characteristics of each group.
How these characteristics were analyzed/interpreted?

<Response> Thank you for the confirmation. We added “thematically analyzed” on page 7, line 31.

8. Page 7, line 31, subtitle: Rural versus urban considerations

The section misses results/quotes.

9. Page 7, lines 33-37: Although access to additional resources differs between rural and urban physicians, the differences in attitudes of disclosing dementia seem to vary based on individual beliefs of the primary care physicians rather than their practice environment.

This statement belongs to the Discussion section not to Result section.

<Response> Thank you for your comment. Regarding comments No.8 and 9, we fully revised the result section of Rural versus urban consideration (page 8, line 16-31) and moved the sentence of No.9 to Discussion section (page 10, line 14-18).

10. Page 7, line 52 until page 8, line 4: We find that, for a number of participants, …is not necessarily the patient but collectively the patient and his/her family members… Therein lies the rationale for physicians to always include family members when disclosing dementia.

Inconsistency in the same paragraph. Needed to be clarified.

<Response> Thank you for your advice. We revised this paragraph as below to present our point more clearly, on page 9, line 1-6.

“For a number of participants, the target of disclosure of dementia was collectively the patient and his/her family members. While recent ethical discussions conclude that disclosure of the diagnosis serves the best interest of patients (4, 5, 7, 22), our participants always included family members when disclosing dementia. The findings of this study illuminate how primary care physicians in Japan consider the cooperation and well-being of patients’ family members as crucial factors in maintaining dementia patients’ quality of life.”

And more discussion follows until page 9, line 13, to compare our findings to Western ethical perspective by referring additional literatures (No.23-28).

11. Page 7, line 58, page 8, line 3: You wrote: ….psychological stability of patients' family members as crucial factors in maintaining dementia patients' quality of life.
What do you mean with psychological stability? Was it mentioned in results of the study?

<Response> Agreed that this point should be stated in the result section. We added a sentence “It is often the family members who are troubled with and suffer from the patients’ symptoms of dementia and need care.” on page 6, line 3-4, and presented a quote as a rational. Also, we rephrased the word “psychological stability” to “well-being” on page 9, line 14.

12. Page 8, line 57: Limitations of this study include, first, that the study participants were all physicians.

The title "Perspectives on disclosure of dementia diagnosis among primary care physicians in Japan: a qualitative study" is focused on physicians. The title guides the reader to be informed on physicians' views. Why did you compose the study from physicians only if you know in advance that it is a limitation? Why do you think that following the title is a limitation?

<Response> Agreed. This point should not be the limitation of the study since our aim was to explore primary care physicians’ perspectives on disclosure of dementia diagnosis. We deleted the paragraph from page 10, line 19.

13. Page 9, lines 12-17: “It remains unclear if the years of clinical practice or the environment in which physicians work affect physicians' perspectives on disclosure. Future research using probability sampling could delineate associations between physician characteristics, the work environment, and physicians' attitudes and anxiety about disclosure.”

Other statistical methods should be used to assess factors influencing physicians to disclose dementia.

<Response> Thank you for the suggestion. We have a plan to develop this topic as a mix methods research investigation in the future. So that we restated the approach as “Future research using a survey among a larger population” on page 10, line 25.

In summary, we have substantially revised the manuscript based on the comments received and we think it is greatly improved.

We look forward to your decision regarding acceptance for publication.

With best regards,

Michiko Abe

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