

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study
AUTHORS	van der Steen, Jenny; Heck, Sten; Juffermans, Carla; Garvelink, Mirjam Marjolein; Achterberg, Wilco; Clayton, Josephine; Thompson, Genevieve; Koopmans, Raymond; Linden, Yvette

VERSION 1 – REVIEW

REVIEWER	Emel Yorganci Cicely Saunders Institute, King's College London, United Kingdom
REVIEW RETURNED	22-Oct-2020

GENERAL COMMENTS	<p>Abstract - Does the aim of the work include development of the QPL? If so, please make it clear. If not, it doesn't need to be in the methods section.</p> <p>Line 14-17 is a finding, not methods.</p> <p>Conclusions lack reflection on QPL's design.</p> <p>One of the biggest limitations of this work is that it's not asking perception from the patients and families, which should be highlighted in the summary section. I understand that patients and families were involved in the development phase yet this is not the same as formally evaluating the perception to them. Also, it mentions older people - did any of them have dementia or family members who have dementia?</p> <p>It would strengthen the introduction to explain several more physician-related barriers to ACP, as the only one you have mentioned is the timing.</p> <p>It's not that clear from the abstract that the patients will be the one that will use the QPL to ask the questions and not the physicians.</p> <p>Box 1 - Nice to see an overview but the majority of the negative feedback was around the length of the tool. Please include the QPL tool and provide the number of questions.</p> <p>I found the incentive of €30 gift card interesting. I understand that there was no ethics committee involvement but why did you feel the need to offer this to the survey participants? Was this to enhance participation? I wonder if it is ethical as many studies with people with dementia would not have this kind of incentive.</p>
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	<p>In the interview analysis section, it is stated that the thematic analysis is inductive. However, by looking at your interview guide (detailed and many closed-ended questions) and given that you did have several topics in mind that you wanted answers based on the survey I believe your thematic analysis was a combination of deductive and inductive.</p> <p>How did the people who responded to the survey differ from the ones who did not? (e.g. where there geographical differences, number of patients the practice sees etc.) I reckon you have this information. It would be useful to see this, to be able to evaluate possible respondent/selection bias in the sample.</p> <p>Table 1 - Estimation of dementia patients dying in the past year is not useful. We have the information around how frequently they see dementia patients, but not how many.</p> <p>Table 4 - Again, not very useful as we don't know the number of questions.</p> <p>Data saturation - Who were the last three interviews with? Given that you had a mixture of interviewees based on their acceptability scores.</p> <p>Not sure if this study has a mixed-methods design. I think this is a multi-method study which employed a survey and interviews in a sequential manner. The integration of the two study components was not needed or did not really add anything that wasn't revealed previously.</p> <p>While the physicians thought the questions in the QPL were acceptable, it doesn't seem as in its current form that it would be feasible to implement it. Please discuss this further in your discussion.</p> <p>Please provide a reference (p11, line 34).</p> <p>The discussion section needs to be developed. It brushes off majority of the findings regarding acceptability of the QPL and how it might need further modifications.</p> <p>It might be useful to give a bit of context around dementia end of life care in the Netherlands (e.g. hastened death).</p> <p>Supplement 1 - Did you observe any floor/ceiling effects? There is no changes in the direction of the questions, so a lot of people might have just picked in one way or another for a lot of the items. Please address this potential limitation.</p> <p>I think this is a thorough piece of work and QPL might have potential to improve advance care planning conversations. A lot of data was collected but I am not sure if all the tables are needed. However, there is room for further thinking which should be put into discussion.</p>
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REVIEWER	Lara Pivodic Vrije Universiteit Brussel, Belgium
REVIEW RETURNED	17-Nov-2020

<p>GENERAL COMMENTS</p>	<p>Thank you for the opportunity to review this paper. Please find below a few suggestions where additional information or discussion is needed or where it would be helpful to present results differently.</p> <ul style="list-style-type: none"> • I would appreciate more information about the contribution of older people and experts in grief and bereavement to the development of the QPL – how were these stakeholders selected, in which respects did they change the initial draft of the QPL? • Please indicate the sampling frame for physicians; for which population was sample aimed to be representative? • The integration of survey and interview results seems somewhat incomplete. The respective section in the results addresses only the topic of physicians not feeling able to answer people’s questions. But participants also expressed other concerns about the QPL, e.g. possible effect of hastening death, the list being too long...a systematic integration would require that these aspects are also integrated (and described) in the context of the contents of the interviews. • Related to the point above: why was physicians’ concern about answering questions selected for the secondary analysis of the survey results and not also the other problems raised by physicians? • The very low response rate (even if common for physician surveys) requires a more thorough discussion of the impact it may have had on the findings of this study. The physicians appear to be rather experienced in caring for people with dementia and still express not very high acceptability of the QPL – what does this imply? What could be other systematic biases introduced by the low response rate? • Please report results in Tables 2 and 3 separately for the different groups of physicians so the reader can interpret differences between them. Now this is only indicated by non-significant p-values which are not a suitable indicator for differences, especially in sample sizes of 18 vs. 46. • The ‘iterative approach’ is referred to as a strength in the discussion, but it is reported only briefly in the results and seems incomplete (selection of one particular theme only). Please expand this analysis and reporting in the results or remove the focus on it from the discussion and summary • The implications and conclusions in the discussion address mainly training to increase physicians’ confidence in answering questions. But physicians also expressed other concerns that warrant discussion about how they would be addressed in further development work for the QPL and implementation strategies, especially the length and concerns about hastening death. • Overall, acceptability and intention for use of the QPL seems not very high, especially in light of this being physicians used to working with people with dementia. Somewhat more discussion is needed on what specifically this means for implementation of the QPL in its current form and whether any changes may be needed next to physician training. <p>Minor issues:</p> <ul style="list-style-type: none"> • The conclusion of the abstract is not a clear answer to the question stated in the objectives in the abstract, please adapt • The first two points of the article summary may be difficult to understand for a reader who has not read the entire article first
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	<ul style="list-style-type: none"> • Section “Results-interview themes – theme 2” states “nursing home residents with dementia and family may have had more opportunity to think about EOL.....” – what does ‘more than’ refer to? more than which group? • Please report numerators and denominators alongside percentages, given that the total N is below 100
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1, Emel Yorganci

1. Abstract - Does the aim of the work include development of the QPL? If so, please make it clear. If not, it doesn't need to be in the methods section.

Response: we agree that it was unclear whether the development was part of the aim of the research, which was indeed to evaluate an initial version of the QPL that we had developed. We had included in the methods some background to the QPL but we can understand this is confusing. *We rephrased.*

2. Line 14-17 is a finding, not methods.

Response: we feel that the recruitment strategy and the main outcome with cut off assessed in previous work is best placed as part of the methods conceived ahead of the study.

3. Conclusions lack reflection on QPL's design.

Response: we have clarified the aim of the study (your first point) which did not include the development phase, but we agree that the Conclusion of the abstract and perhaps also the Discussion section of the manuscript may be improved by clarifying the next steps to be taken with this particular QPL.

In the meanwhile, we have used the findings from this evaluation study along with subsequent input from family caregivers through informal interviews (not part of research) to improve the QPL. We feel that the adaptations improved the contents, but that we need to work on feasible implementation strategies before making further changes to the contents. Regarding its length, findings with another QPL under study (not for dementia) reinforced that a long version is preferred above dropping contents to reduce choice of sample questions. In parallel, our evaluation study resulted in adding more questions and tips than dropping items. The main point from the evaluation was concerns of healthcare providers that could hinder its implementation, and therefore we had provided recommendations to avoid gatekeeping and increase self-efficacy to conduct ACP conversations through training.

In the abstract, we noted that self-efficacy is the important term here, and therefore we used “feeling confident” which is closer to the concept of self-efficacy than “confidence”. Further, we expanded the Discussion in the manuscript referring to findings with the other QPL and observing that self-efficacy may be improved through training and we provided concrete suggestions for the training to include practicing conversations. Finally, for transparency and for use in practice, we added a Supplement that shows changes made to the questions in the 2018 pilot version used in the evaluation study.

4. One of the biggest limitations of this work is that it's not asking perception from the patients and families, which should be highlighted in the summary section. I understand that patients and families were involved in the development phase yet this is not the same as formally evaluating the perception to them. Also, it mentions older people - did any of them have dementia or family members who have dementia?

Response: Indeed, family caregivers were involved in the development phase, as were older people some of whom had experience with dementia in several ways, for example, through volunteering in an Alzheimer café. We felt that evaluation of the QPL by persons with dementia and family caregivers would require another study, preferably a study where the QPL is actually being used by them in practice; a new study with evaluations of use in practice by family is in the protocol stage. Before undertaking such study, we preferred to understand to what extent use of the QPL would be supported by the health care disciplines responsible for engaging them in ACP conversations. The limitation of the study to professional caregivers was already included in the Discussion.

In the Methods, we added description to the panel of older people, avoiding detail that might render persons recognizable: "many of whom had experience with dementia in various roles." Further, we added explicitly to the Summary of strength and limitations, where we pointed out that we studied practitioners' perceptions only, that this does not include perceptions of persons with dementia and family. To the paragraph on Implications and conclusions, we added: "Further research should include evaluations of use in practice, including formal evaluations from persons with dementia and family."

5. It would strengthen the introduction to explain several more physician-related barriers to ACP, as the only one you have mentioned is the timing.

Response: We agree that the barriers we mentioned referred to timing only and this does not do justice to the breadth of barriers identified in the literature.

We added two barriers that may be underlying the concerns about the right timing and referred to literature about moral dilemmas and GP conceptualisations of what ACP in dementia entails.

6. It's not that clear from the abstract that the patients will be the one that will use the QPL to ask the questions and not the physicians.

Response: we can understand that this should be crystal clear as the concept of a QPL is not well known and being misunderstood easily.

We clarified in the first sentence of the abstract, inserting "with sample questions for patient and families" ("...patient question prompt lists (QPLs) with sample questions for patients and family increased patients' involvement..")

7. Box 1 - Nice to see an overview but the majority of the negative feedback was around the length of the tool. Please include the QPL tool and provide the number of questions.

Response: thank you for your suggestion. The 2020 version (also in Dutch) has just been published open access online at the university webpage. We asked a professional translator to translate the QPL's main elements, which comprises its sample questions, tips and points to consider and think about (not including the background information). The 2020 version additionally provides the sample questions as a separate list to bring selected questions. The version evaluated in the study was a first version in 2018, for evaluation only. A 2019 improved pilot version was improved again with help of family and professional caregivers (not part of formal research), which resulted in the 2020 version which is the first version posted online. The 2018 version comprised 76 questions. We added 9 questions suggested by physicians as a result of the evaluation study, and we only deleted one, combining another one as the respondents suggested adding more than deleting questions. We also rephrased suggested additions as tips.

We added to the Methods the number of questions and we uploaded the translation of the evaluated version and the two revised version and we suggest this can be published as a Supplement to the article. We also added to the Discussion reference to other work in which those evaluating another QPL did not want to drop any question despite its length, and we mentioned the increased number of questions and tips.

8. I found the incentive of €30 gift card interesting. I understand that there was no ethics committee involvement but why did you feel the need to offer this to the survey participants? Was this to enhance participation? I wonder if it is ethical as many studies with people with dementia would not have this kind of incentive.

Response: compensation of lost income for time spent contributing to research is not uncommon for physicians. There are many methodological articles that found that incentives for physicians participating in research increase response rates somewhat, for example, studies on whether a financial versus another type of incentive matter. Fewer studies have examined incentives for patients or healthy volunteers such as a coffee voucher (for example, Pieper et al. BMC Med Res Meth 2018 <https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-018-0544-4>). Ethical considerations about undue influence concluded that coercion, participants taking more risk, is unlikely because effects of incentives on research participation are often modest (Singer et al. 2008 in reference list Pieper et al.). There are differences between countries, for example, in Portugal, practice seems to not compensate physicians for study participation (Basilio et al. Portuguese Primary Care physicians response rate in surveys: A systematic review, Rev Assoc Med Bras 2018). It is debatable if the same compensation for work time provided to physicians would be appropriate in terms of equity or would be regarded coercion for patients and family. In our studies, we often provide incentives for patient and family representatives who contribute to the research, but more commonly in the form of, for example, fine chocolates.

9. In the interview analysis section, it is stated that the thematic analysis is inductive. However, by looking at your interview guide (detailed and many closed-ended questions) and given that you did have several topics in mind that you wanted answers based on the survey I believe your thematic analysis was a combination of deductive and inductive.

Response: We did not use a particular theory or frame to derive codes and synthesize codes as themes. There were many interview questions indeed, and not all were asked or not exactly this way in each interview, and we coded across the full transcript, not by question. The 188 codes derived from the transcripts were assigned to transcripts inductively and therefore they do not line up with the interview questions as in a structured interview.

Further, consistent with open and semi-structured interview methodology, almost all questions that could be answered with yes or no were followed by prompts, questions asking for explanation (“If yes...”; “if no...”; see interview guide). We invited interviewees to elaborate with the prompts after questions that as stand-alone might be perceived as closed-ended.

Moreover, the interview was not only about a concrete product (the QPL) but we invited interviewees to speak about how they discuss end of life with patient and family more generally (Introduction of interview guide: “about your views on openly discussing end-of-life care and palliative care in dementia in general.” The QPL was a concrete tool to talk about the practitioners’ approach to ACP while codes and themes emerged from both asking about the QPL and end-of-life conversations more generally.

To the Methods section, we added explanation about not asking all questions, while also asking more about personal strategies in later interviews. We also explained that in the discussions of the topics in the interview guide, the QPL as a concrete tool and end-of-life conversations more generally were both instrumental in inviting interviewees to elaborate about strategies to ACP they employed personally which helped to understand how a QPL would or would not fit with these strategies.

10. How did the people who responded to the survey differ from the ones who did not? (e.g. where there geographical differences, number of patients the practice sees etc.) I reckon you have this information. It would be useful to see this, to be able to evaluate possible respondent/selection bias in the sample.

Response: Adhering to the GDPR meant that we as researchers were not allowed to see names or addresses from practitioners who received a survey unless they disclosed to us by returning a completed questionnaire. Mailings were supported by teachers and secretaries of the two academic centers who had access to databases with names of practitioners connected with the academic center. We know that response rates by academic center were similar (21% and 20%). Assuming that practitioners with connections to an academic center may not be representative of practitioners nationwide, and the respondents may have been more interested in the topic, the need for training and concerns about being unable to answer patients’ and families’ questions is all the more concerning.

We added the response rates by academic center to the first paragraph of the Results. In the Discussion, we inserted in the last sentence of the first paragraph: Physicians, although associated with an academic center and probably with an interest in the topic, may not feel comfortable” Further, we elaborated on limitations, adding “The concerns we identified from responding, probably interested physicians connected with an academic center, may not generalize but even underestimate concerns in physicians caring for persons with dementia.”

11. Table 1 - Estimation of dementia patients dying in the past year is not useful. We have the information around how frequently they see dementia patients, but not how many.

Response: we have used this item about how many persons with dementia die under their care in previous studies among physicians (van der Steen et al., J Palliat Med 2011, <https://doi.org/10.1089/jpm.2010.0484>; Brazil et al., BMC Palliat Care 2015 <https://doi.org/10.1186/s12904-015-0019-x>). The item was useful in indicating different populations cared for in different countries and by different disciplines. In the current study, for some elderly care physicians, but not for any GP, caring for persons with dementia in the terminal stage is daily work (the footnote to Table 1 says “more patients with dementia died in their practice in the past year (e.g. 20 or more 17% vs. 0).”). We feel that seeing patients with dementia in all stages including providing care in the terminal stage may be relevant in how a QPL about anticipatory palliative care that includes sections about dying and bereavement is being perceived, beyond how often physicians see persons with dementia (which is possible without ever providing care in later or terminal stages such as in a memory clinic and also in some general practices).

12. Table 4 - Again, not very useful as we don't know the number of questions.

Response: we agree that to interpret comments about length, the number of questions in the QPL is relevant. However, we feel that perceived need for training and ability to answer the questions relates mostly to the content of the questions. The situation anticipated by the physicians was patients and families selecting the questions from the list they are interested in during a regular consultation, not a situation of being tested for knowing the answers to all questions.

We added the number of questions in the 2018 evaluation version to the Methods (per your point 7).

13. Data saturation - Who were the last three interviews with? Given that you had a mixture of interviewees based on their acceptability scores.

Response: the last three interviews were with a pair of supervisor and trainee in elderly care medicine who responded being unable to complete the survey because they felt there were basic issues with the QPL and they would rather present their critiques in a face-to-face interview, and the only geriatrician who responded and who found the question prompt list acceptable according to the score she provided.

We added to the Results where we indicated saturation was reached with the last interviews, that these were conducted "with very critical elderly care physicians and the only geriatrician"

14. Not sure if this study has a mixed-methods design. I think this is a multi-method study which employed a survey and interviews in a sequential manner. The integration of the two study components was not needed or did not really add anything that wasn't revealed previously.

Response: much has been written about typologies of mixed-methods research based on timing and compatibility of research paradigms and integration of the designs. We indeed used a sequential mixed-methods design, the explanatory rather than exploratory sequential design, which is one form of mixed-methods studies according to the well-known work of Creswell, Plano Clark et al. We integrated the findings obtained with more methods not only at the level of interpretation to which integration is often limited, but also at the level of analyses, going back to the quantitative data as a pattern emerged from the qualitative interviews (described in the Results section "Integration of survey and interview results")

In the Methods, we added references including to an article in which various mixed-methods designs from a book by Creswell are being reproduced as journal articles are more easily accessed.

15. While the physicians thought the questions in the QPL were acceptable, it doesn't seem as in its current form that it would be feasible to implement it. Please discuss this further in your discussion.

Response: according to the criteria determined in advance and used in earlier work, the acceptability is adequate though not great. Regarding length, we hardly received any specific suggestions about what content should be omitted, similar to a finding in an evaluation study of another QPL. In principle, a QPL is meant to inspire question asking and should offer choice.

See also your point 7; we added to the Discussion reference to other work in which those evaluating another QPL did not want to drop any question despite its length. See also your point 3; to the Discussion we provided concrete suggestions for the training to include practicing conversations.

16. Please provide a reference (p11, line 34).

Response: Thank you for your suggestion. (This refers to page 11 number in Word document; "The response to the survey was low although usual for physician surveys").

We added explanation on the rather low response rate and we added references to literature on response rates and referring to trends of declining response rates.

17. The discussion section needs to be developed. It brushes off majority of the findings regarding acceptability of the QPL and how it might need further modifications.

Response: thank you for seeing merit in a fuller discussion of the findings to improve the QPL or its implementation, and your suggestion to expand the Discussion is allowed now that BMJ Open just relaxed the earlier word count limit of 3000.

In addition to our responses with points 3, 7 and 15, we added to the Discussion, paragraph on Implications and conclusions "They should be offered choice from a collection of structured sample questions, but if overwhelming, they may decide in advance with their professional caregivers which topic to discuss (first)."

18. It might be useful to give a bit of context around dementia end of life care in the Netherlands (e.g. hastened death).

Response: a better understanding of concerns about a hastened death may be helpful in the context of a national debate on concerns around euthanasia in dementia in the Netherlands.

To the Methods section, we added reference to inclusion of the euthanasia topic in the earlier booklet when adapting the original Canadian version for the Netherlands, and to the debate and discrepancy between what is or should be possible according to general public versus physicians' views. We also added a reference to a study among GP's concerns around euthanasia in dementia to the Discussion.

19. Supplement 1 - Did you observe any floor/ceiling effects? There is no changes in the direction of the questions, so a lot of people might have just picked in one way or another for a lot of the items. Please address this potential limitation.

Response: as you can see from the means and SD (Supplement 2, former Supplement 1), there were no floor or ceiling effects. The statements were phrased in a positive way, but the scale started with DISAgreement emphasized. Negatively phrased statements risk the "not" being overlooked. The instrument has been used in previous work and also in this study, Cronbach's alpha was adequate (footnote to table in Supplement).

20. I think this is a thorough piece of work and QPL might have potential to improve advance care planning conversations. A lot of data was collected but I am not sure if all the tables are needed. However, there is room for further thinking which should be put into discussion.

Response: Thank you for your comment. Reviewing the tables, Box 1 and Table 1 describe the QPL and the sample, respectively. Table 2 addresses the main research question as it describes an evaluation of acceptability and the contents. Table 3 might be perceived as additional as it describes perceived barriers and benefits of use of the QPL, but this connects to the third main theme that emerged from the interviews and which is relevant in preparing for implementation of the QPL. We are particularly fond of the brief Table 4 as going back to the quantitative data after having conducted the qualitative interviews means we clearly benefitted from the mixed-methods design which allowed for identifying and quantifying a major concern some physicians have when patients and family indeed would be more leading in which topics are being discussed in ACP conversations.

Reviewer 2, Lara Pivodic

Thank you for the opportunity to review this paper. Please find below a few suggestions where additional information or discussion is needed or where it would be helpful to present results differently.

1. I would appreciate more information about the contribution of older people and experts in grief and bereavement to the development of the QPL – how were these stakeholders selected, in which respects did they change the initial draft of the QPL?

Response: thank you for your request for more background. Developing the QPL was not part of the evaluation research, but because the QPL itself was not available in English, it may be helpful to provide some more background about its development and contents beyond the topics in Box 1. The older people participated in a PPI panel affiliated with the Leiden University Medical Center or the Radboud university medical center.

In the abstract, we clarified that the development of the QPL was not part of the evaluation study we report on in the article. To the Methods paragraph on PPI involvement in the development of the QPL, we added various experience with dementia of, in fact, two panels of older people affiliated with the two academic centers. We also expanded text from just mentioning we improved it based on the feedback we received, to include detail per your suggestion: "We provided the three goals we wanted to achieve with the QPL and solicited for any feedback. We collated and discussed their feedback which was used to improve the QPL, in particular the information provided, simplifying it and addressing the reader more personally and empathically (Box 1)."

2. Please indicate the sampling frame for physicians; for which population was sample aimed to be representative?

Response: we sampled from two academic centers (paragraph Evaluation procedures: "The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted

access to residents and supervisors in elderly care medicine and general practice.” We did not aim at a nationally representative sample. Rather, we aimed for variation in experience with sampling from both residents (trainees, novice physicians) and their supervisors from the two disciplines with primary responsibility in the care for persons with dementia. We felt that having or not having much experience could be relevant and we thus ensured variability in experience. In particular, we believed that perceptions on acceptability of a QPL that would increase autonomy of patient and family would be relevant as provided by both the future generation of physicians and highly experienced physicians. Further, oversampling of physicians with an academic interest or interest in the particular topic could actually help improve the QPL more as they are more likely to be future users of the QPL. *In the abstract, we removed geography of the two academic centers (west and east) to avoid any suggestion of sampling representative of the nation.*

We added to the Methods, Evaluation procedures: “Further, we thus sampled for large variation in experience and a population of practitioners who may be early adopters.”

To the Discussion, first paragraph on Main findings and interpretation, we referred to the sampling strategy, adding that these were findings among those “associated with an academic center and probably with an interest in the topic.”

3. The integration of survey and interview results seems somewhat incomplete. The respective section in the results addresses only the topic of physicians not feeling able to answer people’s questions. But participants also expressed other concerns about the QPL, e.g. possible effect of hastening death, the list being too long...a systematic integration would require that these aspects are also integrated (and described) in the context of the contents of the interviews.

Related to the point above: why was physicians’ concern about answering questions selected for the secondary analysis of the survey results and not also the other problems raised by physicians?

Response: We had also used the survey results to inspire question asking in the interviews (Methods section, paragraph Interviews: “If relevant, specific questions were asked based on reviewing participant’s survey responses in an open manner.”). Indeed, a fuller integration of analyses of the survey and interviews would have been possible if we created more hypotheses from the interviews and examined these in the survey data. However, the concerns about not being able to answer questions appeared prominent in the interviews. Creating more hypotheses and testing these in data already collected might impress as cherry picking from a large number of exploratory analysis and we would rather use this study to generate hypotheses and examine in explicitly confirmatory follow-up studies. We feel that the balance in data presented may be good as is, as the other reviewer suggested reducing the number of Tables, and we had also provided a Supplement with more detailed results.

We added to the Discussion, where we mentioned benefits of the iterative approach: “additional to interviewing about completed surveys.” We also added the term “prominently” to the Discussion, Strengths and limitations, where we report on the iterative approach, as the theme we analysed further, emerged prominently from the interviews.

4. The very low response rate (even if common for physician surveys) requires a more thorough discussion of the impact it may have had on the findings of this study. The physicians appear to be rather experienced in caring for people with dementia and still express not very high acceptability of the QPL – what does this imply? What could be other systematic biases introduced by the low response rate?

Response: The response rate was low even for physicians. However, we found, also in the interviews, that even physicians affiliated to academic centers who may have a specific interest in the topic, and novice physicians but also the experienced supervising physicians expressed concerns about question-asking on part of the patient and family. (See also our response to point 2, about the sampling frame.) We do expect the responding physicians to represent a selected sample, but this suggests the concerns physicians have may be underestimated rather than overestimated.

Of note, in the qualitative part of our mixed-methods study, bias by directive interviewing or failing to bracket own ideas could occur in different ways such as introduced by the interviewer or by the analyst. A team of three researchers with different backgrounds was involved in interviewing and in analysing the interviews which helps in critical feedback and reflection on the interviews and analyses.

To the Discussion, paragraph on Strengths and limitations, we added reference to literature about declining response rates in healthcare professionals. We also added that the concerns we identified in our sample of physicians affiliated with academic centers may not generalize but even underestimate concerns in physicians caring for persons with dementia.

5. Please report results in Tables 2 and 3 separately for the different groups of physicians so the reader can interpret differences between them. Now this is only indicated by non-significant p-values which are not a suitable indicator for differences, especially in sample sizes of 18 vs. 46.

Response: we acknowledge that there are important differences in practice patterns between elderly care physicians and GPs. However, the number of 18 GPs was small and to examine difference between the groups of physicians to present to an international audience that mostly does not understand the exact differences, was not a main goal. We had considered presenting all data for the professions separately, but we felt that adding all results by profession would inappropriately emphasize differences and may too much. (Further, note that the other reviewer felt a lot of figures are presented already in the tables).

6. The 'iterative approach' is referred to as a strength in the discussion, but it is reported only briefly in the results and seems incomplete (selection of one particular theme only). Please expand this analysis and reporting in the results or remove the focus on it from the discussion and summary

Response: mixed-methods studies often integrate findings at the level of interpretation but less often, findings from a qualitative instrument are used to conduct additional quantitative analyses or are reported as such rather than as part of a preconceived analytic plan. We found that the concerns about not being able to answer questions appeared prominently from the interviews and we felt this could also be an important barrier to adopting the QPL in practice (see also our response with point 3).

We added references to mixed-methods methodological articles in the Introduction and Discussion. We added the term "prominently" to the Discussion, Strengths and limitations, where we report on the iterative approach, as the theme we analysed further, emerged prominently from the interviews. To the last paragraph of the Results, where we report on the additional analyses, we added "This emerged as an important issue that could affect adoption of the QPL. Therefore..."

7. The implications and conclusions in the discussion address mainly training to increase physicians' confidence in answering questions. But physicians also expressed other concerns that warrant discussion about how they would be addressed in further development work for the QPL and implementation strategies, especially the length and concerns about hastening death.

Response: We agree that training alone will probably target only part of the potential barriers we identified in this study. Length was a concern, however, in contrast, we received more suggestions to add sample questions than to omit particular questions of content, a finding consistent with another study evaluating a generic palliative care QPL. In fact, a revised version comprised more questions about euthanasia as suggested by physicians in the evaluation study.

To the Methods, we added reference to euthanasia which in the Netherlands is more acceptable to the general public than to physicians. To the Discussion, we added reference to findings about length in the other study. We added the sample questions of the QPL as a supplement, also indicating which questions were added or omitted in the later versions in response to the evaluations.

8. Overall, acceptability and intention for use of the QPL seems not very high, especially in light of this being physicians used to working with people with dementia. Somewhat more discussion is needed on what specifically this means for implementation of the QPL in its current form and whether any changes may be needed next to physician training.

Response: Acceptability was lower than for a booklet on palliative care in dementia for family of nursing home residents with dementia. It may relate to the QPL's different target population, to include persons with early-stage dementia and family of community-dwelling persons with dementia as well as to the format with sample questions which could be a powerful tool to bring sensitive questions to the table.

To the Discussion, we added more specific suggestions about training and a suggestion to select together, in advance, to discuss only part of the QPL.

9. Minor issues:

9a. The conclusion of the abstract is not a clear answer to the question stated in the objectives in the abstract, please adapt

Response: Thank you.

We now start the conclusion of the abstract with acceptability.

9b. The first two points of the article summary may be difficult to understand for a reader who has not read the entire article first

Response: we learnt that the points should refer to methodological issues only and we can see that the first point was too short to provide clear background to the study.

We removed the first point and we shortened the second one.

9c. Section “Results-interview themes – theme 2” states “nursing home residents with dementia and family may have had more opportunity to think about EOL.....” – what does ‘more than’ refer to? more than which group?

Response: thank you for pointing out that it was not clear that the settings in the sentence before referred to community and institutional settings.

We added the comparator: “than persons (still) living in a community setting,”

• Please report numerators and denominators alongside percentages, given that the total N is below 100

Response: we feel that regardless of the total N, numerators and denominators should be included or readers should be able to derive these. We opted for the last, providing total numbers and any missing values in footnotes to the tables. Because the denominator is smaller than 100, anyone interested in the numbers is able to derive any number with the proportion/percentage and the denominator in the methods and titles minus the number of missing values for each item. This option makes for better readability than adding columns with numbers.

Other changes: in Box 2, we adapted the table of contents to line up with the translation of the professional translator in the Supplement, and we consistently used the phrasing in the 2018 evaluation version used in this research.

VERSION 2 – REVIEW

REVIEWER	Emel Yorganci Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care King's College London
REVIEW RETURNED	31-Jan-2021
GENERAL COMMENTS	The authors addressed all the concerns and comments I have previously raised. The manuscript reads well and will be a valuable addition to the field with clear direction for future research for QPL's adaptation and implementation in practice, and for

VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

Dr. Emel Yorganci , King's College London

Comments to the Author:

The authors addressed all the concerns and comments I have previously raised. The manuscript reads well and will be a valuable addition to the field with clear direction for future research for QPL's adaptation and implementation in practice, and for

Response: thank you so much for verifying the changes and appreciation of the work.