Author’s response to reviews

Title: Older persons' existential loneliness, as interpreted by their significant others – an interview study

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Author’s response to reviews:

Dear Editor,

BGTC-D-17-00056

Requested revisions have been done in the enclosed manuscript entitled Older persons' existential loneliness, as interpreted by their significant others - an interview study. The changes in the manuscript are highlighted in yellow and a point-by-point response to the comments has been provided within this cover letter. We have worked the language through ones more, and as far as we know, the manuscript conforms to the journal style found in the Instructions for Authors on the BMC Geriatrics homepage.

Kind regards,

Helena Larsson, RN, PhD-student

Point-by-point response to reviewer 1:

Thank you for valuable comments, we have considered them all and made requested revisions and commented them.
Reviewer 1

- The abstract has a logical flow of why the study is undertaken, will need to read more about what is known (although sparse) about EL in the background.

ANSWER: We have added more information about EL in the background of the abstract.

- Able to follow through and understand the three categories described. Unsure at this point why elders (>75) themselves were not interviewed and EL of older people was interpreted by their relatives.

ANSWER: We have added more information about the LONE study and also added the information earlier, both in the abstract and in the background section. This study is part of a larger research project on EL, the LONE study, where EL is explored through interviews with frail older people, their significant others and health care professionals. The LONE study is in the development phase of designing a complex intervention.

- In the background, add a reference to support the 1st para (p.4, 12-15) when making a claim about demographic ageing.

ANSWER: A reference has been added.

- Although the background mentions sparse understanding of EL, in the methods section (p.7, 17), you allude the reader to 'description of EL referred to as a deeper sense of loneliness' - a point that is not picked up and can be included in the background.

ANSWER: We have, just as suggested, added more substantial information of EL, in the background section and in the method section.

- Rationale for interviewing relatives to explore older persons' EL provided. However, unsure of reason for excluding the elders' views of EL.

ANSWER: We have added more information about the LONE study and also given arguments in the background section of why we have chosen to listen to the voices of significant others of older persons. Since EL is described as a complex phenomenon it is necessary to use multiple approaches in order to explore and clarify the phenomenon.
-For the methods, your rationale for choice for the use of a descriptive qualitative design is weak.

ANSWER: Arguments for the chosen design and method have been added. Since this study aims to explore human experiences the study is descriptive with a qualitative design. Hsieh and Shannon’s approach was chosen since their method is often used in a health care context, and since it is well described as well as useful in structuring a great amount of data.

-Agree that empirical study is needed for the relatives, as mentioned in the abstract, unsure why elders were excluded, or were their views included in the main LONE study.

ANSWER: This study is part of a larger research project on EL, the LONE study where EL is explored through interviews not only with significant others but also with frail older people and health care professionals. The LONE study is in the development phase of designing a complex intervention. This information we have stated clearer in the manuscript.

-Any other descriptions used to define ‘frail’ other than by age > 75 in need of long-term care (LTC). How define LTC?

ANSWER: The concept “frail older people” was defined as older persons >75 in need of long-term care related to multiple diagnoses, physical disorders and functional impairments. The care was given by formal caregivers from the municipality or the county council. We hypothesised that older persons, who are stricken by infirmity and diseases, and who are likely to have suffered many losses since they have lived for a long time, have experienced EL and therefore we chose to ask them, their significant others and health care professionals about EL. This information has been added in the method section.

-Insufficient information to claim that the care contexts (Table 1) such as 'primary health care centre', 'municipal home care' and 'hospital ward' indicate older persons are in need of LTC.

ANSWER: The table of care context show that we have used different care contexts so that the variation of the phenomenon could appear. We have added more information of ‘frail’ and hopefully this will make the insufficient information sufficient.

-While the majority was a 1:1 interview with the exception of one couple, were there any variation and lack of consistency in the data and approach required, and impacts of the dynamics in the group.
ANSWER: For the majority of the interviews we were three persons during the interviews; HL (the first author), a senior researcher and one informant. Only at one single occasion the informants were a couple. Regardless of if the interviews were with one informant or, at a single occasion with a couple, the data or approach did not reveal differences. According to the chosen method we sought for variation within each category and our intention was to reveal this variation within each category. Quotations were used to exemplify the variation. It was the aim that guided us in the analysis and we sought for all descriptions of the phenomenon. The variation of the significant others we could not influence and the demographics of them we have shown in table 2.

- Include examples of broad interview questions to see how they fit the aim of the study, and how questions about EL were asked to solicit follow-up responses.

ANSWER: We have added information of how we introduced EL and added more of our questions. Hopefully these changes make the procedure during the interviews clearer.

- Relatives' understanding/perceptions of EL and their subjective perception of the older person's abilities may affect their responses.

ANSWER: Therefore, it was important to be two interviewers, one junior researcher and senior researcher familiar with existential conversations, so that one of us could have the role of an observer. This procedure also made it possible for us to discuss our preunderstandings and presumptions regarding the interview situation.

- Using 'relatives' did not really fit when one of the participant was a 'friend' - maybe 'significant others' or other words similar to this may be considered.

ANSWER: We agree and have corrected this and chosen ‘significant others’ to designate the informants.

- For results and discussions, would be helpful to have background information of relatives like age range and whether they were primary carers, how long have they know the elder, etc. to help understand the findings.

This can help to support the preassumption made in the discussion section (p.16, 35) when it was mentioned that 'it is of importance to know the person well, as relatives often do'. Similarly,
some background data for older people like age range, no. of chronic illnesses, physical and mental dependency, etc. will assist understanding.

ANSWER: We have given background information of the significant others like age, gender and relation. We have added information in the method section as; They all characterised their relation to the older person as close or very close. None of them were primary carers. We have also added some more information in table 1, like age and gender of the older person.

-Descriptions for category 1 is fine except, at the outset, when you describe 'decreasing mobility in space' (p.8, line 48) is unclear.

ANSWER: We have added a sentence at the outset to clarify the decreasing mobility in space.

-Can relate to most of the descriptions in category 2 based on the work of prior studies and are appropriately illustrated here.

-For category 3, 'Being disconnected from the outside world', would be better to compare data from across the care contexts to illustrate similarities and differences, if any. Only nursing home was explicitly mentioned here and prior literature have already found disconnection with the outside world exist once older people reside in these places.

ANSWER: The aim of the study was to explore EL and therefore we have not focused similarities and differences related to different care context. However, according to significant others, the disconnection from the outside world is seen regardless of where the older person lived. We have added information in category 3 in order to clarify this.

-Suggest to state some realistic examples how person-centred care (p.17, 17-48) you think would work among relatives, older person and health care professionals in this EL study.

ANSWER: With regard to McCormack and co-workers we have added examples of conditions that make a person-centred philosophy flourish in elderly care. Examples as; being able to sit down and talk for a while in a supporting care environment where personnel feel encouraged and supported by each other and by the organisation.
-The limitations include a section on data analysis which is better placed into the methods.

ANSWER: We have moved the sentence about data analysis to the method section.

-Full 34 references were used. Recheck BMC Geriatrics reference format and ensure consistency for capitalization (e.g. for journal names), abbreviation vs. full journal names, punctuations (; or :).

ANSWER: The references have been rechecked and corrected.

-Reference 27 may be better to provide project funded information as it's official information rather than using 'submitted for publication'.

ANSWER: This comment we had trouble with to understand. Maybe it is confusing that the paper is referred to as a “study-protocol”. Maybe it is clarifying to know that it is a manuscript that is submitted for publication.

-Quality of written English

Please indicate the quality of language in the manuscript: Needs some language corrections before being published

ANSWER: We have worked the language through ones more.

Point-by-point response to reviewer 2:

Thank you for valuable comments, we have considered them all and made requested revisions and commented them.

Reviewer 2

Thank you for this interesting and clearly written publication. Existential loneliness is indeed a crucial but complex and challenging phenomenon in the care for older persons. The choice to study this phenomenon using a qualitative research design and from the perspective of the relatives is appropriate. The study reveals interesting insights from the relatives’ perspective
contributing to a better understanding of the living world of older frail persons. So, this manuscript could be of added value to the existing literature in this area.

However, there are some issues which could be clarified and improved.

-As the authors repeatedly indicated, studies concerning the phenomenon 'existential loneliness' are sparse, resulting in a lack of clear definition of 'existential loneliness'. It is not clearly described in the paper how the researchers addressed this conceptual problem in their research method. How did they introduce and define 'existential loneliness' when interviewing the relatives? How did they relate the relative's experiences to the concept 'existential loneliness'? Did the older frail persons, involved in this study, indeed suffer from 'existential loneliness'? In other words, does this study contribute to a better understanding of older persons' 'existential loneliness' (from the perspective of relatives) or to the impact of age or frailty on the older persons’ well-being (from the perspective of relatives) or ...?

ANSWER: This is an important point and something that we have considered before, during and after this study was undertaken. This study is part of a larger research project on EL, the LONE study where EL is explored through interviews not only with significant others but also with frail older people and health care professionals. The LONE study is in the development phase of designing a complex intervention. This information is vital for the understanding of the study and, has now, been added in the abstract and in the background section. Another consideration we made was to be two interviewers. Since we were aware of the literature which describe the phenomenon as complex and unclear it was vital to be one senior researcher, familiar with existential conversations, so that one of us could have the role of an observer and adding some more questions, if needed. This procedure also made it possible for us to discuss our preunderstandings and presumptions regarding the interviews. Further, we have added information in the method section, procedure, of how we introduced EL to the significant others. “We are, in particular, interested in a deeper feeling of being alone in life, sometimes referred to as existential loneliness, a feeling that can come and go. Can you try to remember any situation when you perceived that your…experienced this kind of loneliness, this deeper feeling of being alone?” If the older persons suffered from EL we cannot know. What we can say is that these findings seem to be central to the experience of EL among frail older persons, as interpreted by their significant others. Therefore, comparing the older persons’ experience with the perception of their significant others’ is an important topic for further research.

-In the discussion the authors reported that they 'had to take into consideration that the concept of EL is not clarified and is seen as a multifaceted phenomenon'. It is not clear whether this statement refers to the methodological issue mentioned here. Some clarification about this methodological issue is lacking in the method section as well in the discussion.
ANSWER: The word ‘multifaceted’ has been removed and we have made some requested revisions in limitations and in the method section which hopefully will give clarification to this paragraph.

- ‘Background section’ can be improved by a stronger focus in view of a solid and clear problem statement (the lack of studies about the relatives’ experiences is not the most convincing argument to investigate older persons’ EL).

ANSWER: We have added a more solid and clear problem statement in the background section. Early detection of existential suffering among frail older people is essential in order to prevent impaired existential health and in this endeavour the voices of significant others could be a valuable resource. Listening to someone who knows a person well, as significant others often do, might be helpful in identifying existential needs at an early stage.

- More information about the research ‘design’ is needed to understand and evaluate the fit between the specific design and research question. Besides, it is not well argued why Hsieh and Shannon’s analysis approach is appropriate in view of the research aim.

ANSWER: Since this study aims to explore human experiences the study is descriptive with a qualitative design. Hsieh and Shannon’s approach was chosen since their method is often used in a health care context, and since it is well described as well as useful in structuring a great amount of data. These arguments have been added in the method section.

- More (convincing) information is needed to be able to evaluate the trustworthiness of the findings

ANSWER: We have added more background information of the participants as well as of the older persons. We have also added information of the process of analysis in order to increase the possibilities to evaluate the trustworthiness of the findings.

- Interviews lasted between 40 and 90 minutes; range = 51?? (page 7, line 40)

ANSWER: This has been corrected (“minutes” has been added after 51 and range corrected to “median”)


Discussion point about "the perception that the older persons' physical impairments lead to EL" (page 16, lines 9-43): the first part of this paragraph is clear and pertinent; the second part is less clear. "With regards to both the experience and the expression of EL, the body is important' (line 21-22). Who is saying this? The relation with Gabriel Marcel isn't clear neither. The authors concluded the paragraph with the message that relatives are a valuable resource in the understanding of the experience of EL (which certainly is true); the relationship with the above addressed discussion point, however, is not clear for the reader.

ANSWER: We have worked this paragraph through in order to make the links clearer. We have removed "With regards to both the experience and the expression of EL, the body is important" and instead described that the idea of the deteriorating body can be related to Gabriel Marcel, according to whom an existential situation can be described as a trial when we, in our body, confront time. We conclude the paragraph by saying that; ‘Thus, the knowledge that the significant others’ possess, regarding for example the older persons’ bodily expressions, may never reach the health care professionals’.

- The authors repeatedly refer to the complex and multifaceted nature of EL; in order to better understand the concept of EL (which is the aim of this research) it would be interesting to clarify what they exactly mean by 'multifaceted' (as revealed by the findings of their study).

ANSWER: The word ‘multifaceted’ is not a correct word of use so we have corrected this and used the word ‘complex’ with regard to referred literature in the manuscript.

- Quality of written English

Please indicate the quality of language in the manuscript:

Needs some language corrections before being published

ANSWER: We have worked the language through ones more.