Author’s response to reviews

Title: The second patient? Family members of cancer patients and their role in end-of-life decision making

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The response letter as well as cover letter are also uploaded separately as a supplementary file on the 'Attach Files' page.

Answer to reviewers

Thank you very much for your very helpful comments and suggestions as well as for the literature tips. We have read all recommended articles carefully. Especially, it was very enlightening for us to look at our study results and methods in the light of the Sandelowski’s paper. In the following we addressed all your comments. All changes to the initial reviewers’ comments were accepted and we have used track changes to indicate the new changes in response to your new comments. The manuscript was revised by a native speaker.

Technical Comments:

Editor Comments:

1. Comment: In the abstract the focus is on demanding family members while in the body of the paper the theme is “Strong Family wish for Further Treatment”. I suggest using exactly the same phrasing every time a theme is listed within the paper, abstract and headings.
1. Answer: We have changed the phrasing in the abstract to have the same name for the theme throughout the abstract and the paper. Furthermore, we have adjusted further themes and themes’ order in the abstract to have the same order and themes in the paper.

P. 3. Line: 42-53

Four major themes played a central role in the perception of the medical staff in regard to family members. (1) Family impact on patients’ treatment preferences. (2) Strong family wish for further treatment. (3) Emotional distress of the family related to the involvement in end-of-life decision-making. (4) Importance of knowing family structures

2. Comment: Both reviewers raised concerns about the lack of evidence that grounded theory was truly used in this study. While you have added description in the methods section that is consistent with a grounded theory approach, the results section does not demonstrate this approach. For example, in the methods section you provided two lists of examples of codes/categories: advisory role of family members, emotional support to the patient, impact on patients’ treatment preferences, pressure on patients, family preference for life-prolonging treatment etc. and reasons for non-involvement of the family into decision-making; involving patients step by step into decisions to limit treatment etc. These codes/categories should be completely (do not use etc.) and explicitly described in your results as wherever they fall within the four existing themes, NOT in the methods section.

2.1. Answer: We have removed codes/categories from the methods section.

2.2. Comment: The first paragraph in the results section should give an overview of your findings in terms of the core concept or process that was identified and then the categories within that core concept. This section currently begins with a summary of responses to particular questions from the interview guide. Simply summarizing responses to questions indicates a qualitative description approach was taken to the analysis (see Sandelowski 2000: DOI 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G) it does not demonstrate that the data was analyzed using grounded theory methods in the way you have described in your methods section.

If you have used grounded theory then it should be relatively easy to re-write your results section to clearly demonstrate the use of grounded theory.

You may want to carefully review other papers that have describe the use of grounded theory in research to see how results are presented: DOI 10.1186/s12904-017-0214-z or http://onlinelibrary.wiley.com/doi/10.1111/j.1547-5069.2010.01335.x/epdf. Note that there is
often a figure to depict the findings and show the relationships among the core concepts or processes.

If after reviewing the Sandelowski paper and the examples of grounded theory, you decide that what you really did was qualitative description then change your methods to describe that approach and write your methods section to also reflect that approach.

2.2. Answer: Thank you very much for your comment and very helpful and interesting literature references! We have read Sandelowski paper as well as papers describing the use of grounded theory method with a great interest. Though in our paper we tried to adhere to the grounded theory especially in our methods, after having studied the suggested literature carefully we have realized that what we actually did in our results’ part corresponds more to the method of a qualitative description. And actually, after having read the Sandelowski’s paper, this method of qualitative description turns out to be more suited to our primary research aim. Our primary study aim was to get answers to questions that are high relevant for oncologists and oncology nurses integrating with family members near the end of life and to describe their experience in involving family members in the decisional process of treatment limitation. Following your suggestion, we have re-written the method part using the more suitable name for the methodological approach that is a “qualitative description” approach.

P. 7-10. Line: 118-2018

2.3 Comment: The title of your paper refers to “the second patient” but this idea is not mentioned again in the paper. I wondered if “family as the second patient” is actually the core concept of your work. Something to think about…

2.3. Answer: We have addressed this idea of “second” patient in the paper: in the results section and in the discussion.

P. 14. Line: 280-284. “Relatives were often compared by oncologists and nurses with second patients. They were perceived not only as patients’ informants and supporters but also as affected by a crisis situation due to a life-threatening disease of their beloved one. Therefore, they needed to be taken care of too.”

P. 18. Line. 377-378 “However, relatives were also often perceived as second patients who could be traumatized by a patient’s situation and needed special attention, care and time investment.”
3. Comment: You have added to your description of the methods used to enhance the rigor of your work. In your third point you clearly indicate that you are describing how you enhanced analysability. It would be helpful to similarly label each of the points made in terms of linking to credibility, transparency, analysability and usefulness.

3. Answer: We have labelled each of the points and changed the points order according to the first sentence in this paragraph: “The following techniques were used to assess credibility, transparency, analysability and usefulness of the data.”

“The following techniques were used to assess credibility, transparency, analysability and usefulness of the data [34].

Credibility: The interviewer was not an employee of the hospital where the study was conducted to guarantee neutrality. However, the interviewer had experience in working with oncological patients as well as expertise in qualitative research methods. Researchers’ participation in interviews and in data interpretation were constantly reflected to reduce personal bias in research. For this reason, field notes were written in which emerging thoughts during the research process were documented. Furthermore, regular interdisciplinary team meetings served as a platform for reflection and acknowledgement of researchers’ previous experience and background on a theory development process.

Analysability: All interviews were digitally recorded, transcribed verbatim and checked by team members. After each interview we wrote case-based memos that helped us to analyse data. To increase analysability researcher triangulation was used. Through regular meetings of the interdisciplinary team, with expertise in oncology, social science, and medical ethics, multiple researchers were involved in the analytical process. Emerging discrepancies of the analysis were discussed in order to increase the validity and reliability of the study.

Transparency: We discussed results in the context of current research as well as limitations of the study and how they may impact the results.

Usefulness: Interview participants were selected with a maximum variance in working experience, positions and age in order to increase the representatives of all aspects of the topic in terms of participants [33]. For our research question it was important to search for the maximum variation in perspectives, ranging from the experienced oncologists to nurses working at 4 hospital units.”

4. Comment: A section on limitations has been added to the paper but it should be placed just before the conclusion rather than after it.
4. Answer: We have placed a section on limitations before the conclusion.

Page 21-22. Line: 454-470

5. Comment: A minor point to improve the readability and flow of your work would be to remove “n=” wherever you have included it outside of brackets. For example it is used correctly here within the brackets: “Qualitative in-depth interviews were conducted with oncologists (n=12) and nurses (n=6) working at the Department of Hematology/Oncology at the university hospital in Munich, Germany.” However, in the following instance: “In a cross-sectional interview study with n=130 patients who were diagnosed with incurable disease…” it is easier to read without the “n” and simply say “In a cross-sectional interview study with 130 patients who were diagnosed with incurable disease…”

5. Answer: Thank you for this hint. We have removed “n” in all the cases where it was used outside of brackets.