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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Version: 1 Date: 29 Nov 2017

Author’s response to reviews:

Answer to reviewers

We would like to thank the Reviewers (Tieghan Killackey and Sandra L Bradley) for the constructive, valuable comments and advices that were of a great help for us and allowed us to improve our manuscript considerably.

We hope that all reviewers’ concerns were addressed and answered in the revised version. Below you will find the reviewer’s comments in normal font and our answers in italic font. Revised parts from the manuscript are red marked with page numbers (See attached document). In the manuscript all changes are in corrector mode.

1. Reviewer Tieghan Killackey: Comments to Author:

Background

1. Comment: Paragraph 1: In the sentence on Line 12-14, I wonder if it would make more sense as "family can facilitate or hinder a patient’s decision to pursue supportive care". I would also suggest removing "best" from "best supportive care" (Line 14) as it is not clear what "best supportive care" means in this context.
1. Answer: Thank you for this suggestion. However, we think that “best supportive care” is a more appropriate term in this context as it is an established expression in a palliative medicine. On the contrary, “supportive care” can be used to describe a supportive therapy that can be used additionally and also parallel to a chemotherapy in order to reduce patients’ nausea for example.

However, we have specified this sentence in order to make it clearer what the expression “best supportive care” means in this context.

P.5 “Furthermore, family can facilitate or hinder a patient's decision against further cancer-specific treatment in favor of best supportive care (BSC) with a focus on symptom control and quality-of-life [9,10].”

2. Comment: Paragraph 1: The phrase "communication regarding treatment limitation" is unclear - this makes me think of the limitations of specific treatments as opposed to the idea of limiting curative pursuits (which is what I think you are trying to say) - perhaps instead "treatment options" could be used?

2. Answer: Thank you for this suggestion. We have changed the sentence accordingly.

P.5 “Empirical evidence demonstrates that patients place a great importance on communication regarding treatment options within their family [12].”


I think that what makes this paper distinct is that the authors may be focusing on decisions regarding 'treatment limitation,' however it is unclear what the authors mean by treatment limitation. I would suggest the authors incorporate a definition and examples of what this into the introduction so it is clear what is the focus of this study.

3. Answer: You are right. There are some studies on the family role in treatment decisions, however they mostly focus on the decisions regarding treatment options in general but not on
forgoing cancer treatment. In our study, as you have mentioned above, we aimed to put our focus on a specific context--decisions to limit a cancer-specific treatment (i.e. chemotherapy) as well as transferal to ICU and DNR near the end of life. We have specified in our paper the notion “treatment limitation” in order to make it clear what was the focus of our interview study. We have also added the literature you suggested indicating that previous research focused on family role in treatment decisions in general.

P. 7 “Therefore, we conducted a qualitative interview study with oncologists and oncology nurses in order to gain in-depth understanding of the family role in decision-making for the specific context of a treatment limitation. These interviews focus on forgoing cancer specific treatment, but also touch on topics such as referral to ICU and “Do not resuscitate order” (DNR). The focus of our study was on the role of the family in decision-making when the patient is able to communicate and make decisions.”

P.6 The previous research has mostly focused on the family role in the decisions regarding treatment options [22–25]

Methods

4. Comment: Design of study and participants: It is important in qualitative research to outline what type of qualitative methodology specifically (i.e. grounded theory following which theorist?) was used and why grounded theory was chosen as the most appropriate method to answer these questions as opposed to other qualitative methods (many would argue that all types of qualitative research are relevant for exploring complex phenomena and understanding people’s experiences). Grounded theory is also generally known for having the overall goal of theory development - was this a goal of this study?

4. Answer: We added more information on the used approach and on the reasons for the chosen approach. We aimed to provide an explanatory framework for the family involvement into decisions to limit treatment by patients with advanced cancer.

P. 7 “A qualitative research design based on the classic grounded theory (CGT) method according to Glaser and Strauss and Glaser [28,29] was applied because it was most appropriate for the explorative nature of our study. We aimed to provide an explanatory framework for family involvement into decision-making process on limiting treatment near the end of life when patients are capable to communicate.”

5. Comment: Sampling strategy: I wonder if the authors could provide more information in regards to the "theoretical sampling" used and provide a better description of the sample -i.e.
How the authors chose the number of each healthcare provider group that is represented? Did participants self-identify to researchers and was there any participation incentive? What type of setting and what population of oncology patients do these providers work with?

5. Answer: We provided a better description of the sampling strategy as well as of the type of the setting and population of oncology patients. There was no participation incentive—we have only promised to share the final results when the analysis is completed. However, we have not mentioned it in the paper as it seems to us a superfluous information.

For detailed sample description see our answer to comment 6.

6. Comment: Sampling Strategy: If theoretical sampling was indeed used, it is important to state specifically how participants were recruited in relation to the theory development process. Theoretical saturation is used when the goal of the work is theory development - this is different than "thematic saturation," or the idea that no new themes are emerging from the data. I would recommend an alternative reference to [24] such as:


6. Answer: Thank you for this helpful comment and the literature suggestion! We tried our best to use a theoretical sampling strategy as it is commonly used in a grounded theory. Our intent was a profound understanding of a family role in decision-making with a final target of theory development. However, we have to admit that further studies are needed for this intention—we addressed this issue in the “limitations of the study”.

P 8. “Sampling strategy

We used “theoretical sampling”, developed from the grounded theory approach [29]. It is an iterative process using a continual sampling and data analysis until a “theoretical saturation” is achieved, when the categories are developed and the relationships between them are well established [30].

Purposeful sampling and developing of the interview guide

For the first step we used a purposeful sampling to identify oncologists for the first interviews. Participants were first contacted by email with a detailed study description and were re-contacted after one week by telephone and invited to participate in the interview study.

For our first interviews we developed a preliminary interview guide. It was developed in three steps: 1) in the first step, review of the existing literature was conducted; 2) in the second step, generated questions were discussed in an interdisciplinary team meeting; 3) the interview guide
was discussed with the experts in oncology and social sciences. It included open-ended questions about end-of-life communication with patients and family members and their role in the decision-making process.

The preliminary interview guide included questions such as:

- Tell me about your experience of decision-making on treatment limitation by patients with advanced cancer near the end of life;
- What role do the family play in these decisions?
- What is your opinion on family involvement in decision-making to limit treatment near the end of life?
- What challenges do you face by family involvement in decisions to limit treatment?

These questions served to start the conversation and were followed up by going into more detailed discussion.

Theoretical sampling

After completing n=8 interviews with oncologists and analyzing our first data, more participants needed to be selected to clarify the emerging categories and concepts. We used theoretical sampling to determine the next participants for the study (see Figure 1).

The interview guide was slightly modified and included questions about the best way to involve relatives into decision-making (i.e. What is the best way to integrate relatives in decision-making to limit treatment? What factors might hinder family involvement?). For this reason, we approached oncologists with a special expertise in palliative care and in communication with family members.

Furthermore, we modified questions in order to interview oncology nurses too as they could provide valuable insight into relatives’ involvement and, according to interviewed oncologists, often turned out to be a contact person for families at the care unit. Theoretical sampling added n=6 interviews with oncology nurses and n=4 oncologists to the data.

A total of n=18 participants – oncologists (4 male and 8 female, aged 30–65 years) and nurses (all female, aged 30–50 years) with different working experience and position (fellows and seniors) were recruited. All participants work at 4 general cancer wards caring for hematological and oncological in-patients.”
7. Comment: It is unclear how many interviews were conducted, how long they lasted, if supplemental field notes were taken, etc. I suggest a statement regarding the authors' decisions related to amount of data collected be included in the methods section.

7. Answer: We added more information on the conducted interviews as well as on supplemental field notes.

P10. “A total of n=18 participants – oncologists (4 male and 8 female, aged 30–65 years) and nurses (all female, aged 30–50 years) with different working experience and position (fellows and seniors) were recruited. All participants work at 4 general cancer wards caring for hematological and oncological in-patients.

Demographic data was collected at the end of the interview. The demographic characteristics of participants are presented in table 1.

Interviews lasted for 30 -100 minutes.

Memo-writing

During the whole research process, we wrote both descriptive and reflective case-based memos on the interviewing process, documented participants’ reactions on the asked questions and also documented our emerging new ideas during interviews. Data from the memos was integrated into analysis.”

8. Comment: Was there any need to modify the interview questions in an iterative fashion as data collection took place?

8. Answer: During the interview we had to modify questions, as after first analysis of the data we decided to include nurses and oncologists with a special expertise in palliative care and in communication with family members, adding some specifying additional questions. Furthermore, we learned that involvement of patient and family in DNR orders is a sensible topic for oncologists and nurses. This changed not so much the topic as the strategy in handling and approaching this topic - we had to be sensible to address patient involvement in order to get interviewees to talk.

P.9 “The interview guide was slightly modified and included questions about the best way to involve relatives into decision-making (i.e. What is the best way to integrate relatives in decision-making to limit treatment? What factors might hinder family involvement?). For this reason, we approached oncologists with a special expertise in palliative care and in communication with family members.
Furthermore, we modified questions in order to interview oncology nurses too as they could provide valuable insight into relatives’ involvement and, according to interviewed oncologists, often turned out to be a contact person for families at the care unit.”

9. Comment: I would recommend the authors provide examples of some interview questions, and/or attach an appendix with the interview guide.

9. Answer: We have provided core questions of our interview guide as well as information on its modification.

P. 8 “The preliminary interview guide included questions such as:

• Tell me about your experience of decision-making on treatment limitation by patients with advanced cancer near the end of life;

• What role do the family play in these decisions?

• What is your opinion on family involvement in decision-making to limit treatment near the end of life?

• What challenges do you face by family involvement in decisions to limit treatment?

These questions served to start the conversation and were followed up by going into more detailed discussion.”

10. Comment: I would suggest an examination of the role of the researcher in relation to the study and the participants in order to fulfill the need for reflexivity as a key measure of rigour within qualitative work.

10. Answer: We have added a paragraph describing a role of the researcher in relation to the study.

P.12 “5) The interviewer was not an employee of the hospital where the study was conducted. 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.”

Rigour

The authors mention using both theoretical and maximum variation sampling. If maximum variation sampling is used, it is important to outline why this is relevant to the research question. Was participants’ previous experience working with family members of cancer patients included in the concept of ’maximum variation’? Finally, if this is a maximally diverse sample, would the authors feel comfortable translating the results? How far and wide would these results be applicable to other settings?

Answer: We have explained the reasons for maximally diverse sample. Furthermore, we have discussed the applicability to other settings in “study limitation”.

P.11 “2) We used both purposive and theoretical sampling strategy: 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 [35]. 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.”

P.23 “Our findings are not necessarily transferrable to other care settings. We searched for a maximum variation sampling in order to increase the transferability. Our interviews were conducted in a big university hospital that is characterized through a high staff rotation and a considerable time pressure on oncologists and nurses. So, the results might be representative only for university hospitals.

In order to generalize these findings to all hospital settings further quantitative, and complementary qualitative research involving other hospitals and geographic settings is required.

Hence, this qualitative study is a first step towards understanding of family involvement in decision-making to limit treatment near the end of life and more needs to be done (i.e. investigating different settings) to get a deeper insight into such a complex phenomenon.”

Results

11. Comment: The lack of details regarding the results is a weakness in this manuscript. I wonder if the results could be more thoroughly discussed, as there is a depth of analysis that is missing in this section. It would be helpful to provide more quotes to demonstrate the
saturation of themes that was previously discussed. The current presentation of results does not demonstrate that these results have emerged from an analysis of many interviews (i.e. Heading #3 in the Results section which is supported by only one quote). I would also recommend that the authors shorten the quotes (to allow for more quotes) and contextualize the quotes. It is challenging to know exactly what question or topic the participants are responding to - perhaps the authors could state something like: When asked about the challenges of discussing treatment options with family members, participants often stated: "insert quote"

11. Answer: We elaborated the results part. We added some more quotes to demonstrate the saturation of themes (Please see the results). However, we normally don’t do that in reporting our qualitative research– instead we thought it is more helpful to use paradigmatic examples of typical quotes

12. Comment: There is a significant difference between the involvement of family members in decision making when the patient is capable compared to when the patient is not capable. There are also significant legal differences. This should be clearly stated and outlined in your introduction - are the authors interested in the role of family members in decision making when the patient is capable, or when the family member is required to be a substitute decision maker because the patient is incapable?

12. Answer: Thank you for this helpful comment. We have outlined the aim of our study in introduction.

P.7 “The focus of our study was on the role of the family in decision-making when the patient is able to communicate and make decisions.”

Discussion/Conclusion

13. Comment: In this section, the term 'oncologists' is frequently used when describe the perspective of interviewees - it is unclear whether this is an opinion that is specific to only the oncologists in the sample (if so this should be clearly stated in the results) or that the term 'oncologist' is being used to represent the whole sample despite the fact that nurses made up 30% of the sample. Using this term is therefore inaccurate and should be broadened to account for all the participants of the study.

13. Answer: Thank you for this hint. The term “oncologists” has been used incorrectly to represent the whole sample. We have changed this term to “oncologists and nurses” or “study participants” or “The interviewees”
14. Comment: I would recommend that the authors condense the discussion in order to add analytical depth to the presentation of results.

14. Answer: We have tried to elaborate the presentation of results. However, we think the discussion against the background of the literature and the debate in medical ethics is important for better evaluation of results.

15. Comment: The conclusion does not fully reflect the overall results of the study. I would suggest that the authors clearly state what the goal of the study was and what this knowledge contributes to current practice.

15. Answer: We have re-written our conclusion adding information on the goal of the study and our contribution to current practice.

P. 22 “Conclusion

The findings of our study address the existing gap in the literature on the role of patients’ family in decision-making to limit treatment near the end of life when patients are able to make decisions and to communicate with their oncologists and nurses. Although, participants recognized the important role of the family in decision-making, they also acknowledged certain challenges such as possible psychological burden of the relatives, the challenge of knowing family structures, and a strong family wish for further treatment that would seem to account for the reluctance of oncologists for a proactive position regarding family involvement in decision-making.

Strong reasons exist for involving the family early on — patient authorization of family involvement provided — in order to help them to cope with the situation as well as to empower and prepare them for the task to act as surrogates and co-helpers. Not only is early involvement of relatives often in accordance with patient preferences; it also allows for a better understanding of eventual disagreement regarding treatment decisions. Moreover, early integration could assist family members to gain a better grasp of futile therapy situations so that they might be less inclined to insist on non-beneficial anti-cancer treatment or life-sustaining measures for their dying loved-ones [50]. The inclusion of additional consultation services such as clinical ethics, pastoral care, psycho-oncology, and clinical social service together with the family, might offer patients and relatives an important aid in processing and mastering disease-specific problems. However, some requirements need to be implemented before early integration is initiated: obtaining the approval for family involvement by the patient, and developing and establishing a systematic assessment of family members’ needs and their wishes in order to provide specific-tailored support.”
Limitations

16. Comment: I would recommend the authors provide a discussion of the limitations of this study.

16. Answer: We have provided a discussion of the limitations of our study.

P. 23 “Limitations of the study

One limitation of this study was that we could not return the interpreted data to participants to check for accuracy and to see if concepts were created adequately and reflect the participants’ experiences due to the lack of time resources of oncologists and nurses.

Our findings are not necessarily transferrable to other care settings. We searched for a maximum variation sampling in order to increase the transferability. Our interviews were conducted in a big university hospital that is characterized through a high staff rotation and a considerable time pressure on oncologists and nurses. So, the results might be representative only for university hospitals.

In order to generalize these findings to all hospital settings further quantitative, and complementary qualitative research involving other hospitals and geographic settings is required.

Hence, this qualitative study is a first step towards understanding of family involvement in decision-making to limit treatment near the end of life and more needs to be done (i.e. investigating different settings) to get a deeper insight into such a complex phenomenon.”

17. Comment: Overall, I would suggest the authors carefully check the paper for grammatical errors to enhance the flow of the manuscript (specifically verb tenses and some sentence structure issues).

17. Answer: The revised manuscript was proofed once more for English language by a native speaker. All the changes are provided in paper in a corrector mode.

Reviewer Sandra L Bradley: Comments to Author:

Comment: Overall, it is an interesting paper with relevant findings. However, the authors don’t describe the type of grounded theory methodology they used or produce evidence that the way they have used GT in analysis is consistent with the type that they used. For example, was it classical GT or constructivist GT? From the way that the coding was done, it suggests it was classical, but there is no evidence of codes, categories and how these were combined into the themes presented.
Answer: Thank you very much for your review and helpful comments. We have added more information on the type of grounded theory methodology.

P.7 “A qualitative research design based on the classic grounded theory (CGT) method according to Glaser and Strauss and Glaser [28,29].”

Comment: There was no indication of the various aspects of rigour that are required: credibility, transparency, usefulness, analysability.

Answer: we elaborated our paragraph about rigor adding more information on credibility, transparency, usefulness and analyzeability.

P. 11-12 “Rigor

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

1) 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.

2) We used both purposive and theoretical sampling strategy: 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 [35]. 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.

3) To increase analysability researcher triangulation was used: Through the 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.

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

5) The interviewer was not an employee of the hospital where the study was conducted. 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.”

Comment: The abstract does not provide the themes in a manner that indicates these are themes.
Answer: we have specified the results- part of the abstract using a word “theme”.

P3. “Four major themes played a central role in the perception of the medical staff in regard to family members.”

Comment: Line 24, p. 6 - "about half?" - use specific information
Answer: We have specified information on the interviewed patients.

P.5 “In a study by Hobbs et al. 49.4% of n=5204 surveyed patients with lung and colorectal cancer reported that they would involve family members in decision making [15].”

Comment: Line 29, p. 6 - "could show?" - did Nolan et al. show this or not? How was it shown?
Answer: We added more information on the study conducted by Nolan et al.

P.5 “In a cross-sectional interview study with n=130 patients who were diagnosed with incurable disease, Nolan et al. showed that if patients were unable to decide for themselves in case of severe illness, patients would feel better if they could be represented by their relatives, rather than by their doctors [16].”

Comment: Throughout, there are mistakes in the use of English language and this manuscript would have benefited from editing with someone who had English grammar expertise.
Answer: The manuscript was proof-read by a native speaker in the first place and checked for English language now again

Comment: Lines 36-41, p. 6 - in what way? A bold statement such as this needs examples.
Answer: We have added an example of one study to support the statement.
P.6 “A study conducted by Dionne-Odom et al. with n= 122 caregivers demonstrated that family members who were integrated quite early showed lower depression and distress scores [18].”

Comment: Lines 12 - 15, P. 7 - need to detail which studies, not just by ref#

Answer: We have added a study to support the statement.

P.5 „A qualitative study with n=37 patients with advanced cancer and n=40 caregivers conducted by Zhang et al showed that 65 % of families had disagreements regarding treatment decisions including discontinuation of anti-cancer treatment, thus considerably influencing patients’ treatment choices [11].”

Comment: Lines 24-34, p. 7 - too much subjective language without evidence

Answer: We are sorry, but we could not precisely identify the sentence you meant…Did you mean this sentence: Therefore, we conducted a qualitative interview study with oncologists and oncology nurses in order to gain in-depth understanding of family role in decision-making in a specific context of treatment limitation…?

Comment: Lines 41-46, p. 7 - incorrect grammar - which GT method?

Answer: We have added more information on GT-Method.

P.7 “A qualitative research design based on the classic grounded theory (CGT) method according to Glaser and Strauss and Glaser [28,29].

Comment: p. 8 - there should be an example of the interview guide

Answer: we have provided the example of the interview guide.

P. 9 “The preliminary interview guide included questions such as:

• Tell me about your experience of decision-making on treatment limitation by patients with advanced cancer near the end of life;

• What role do the family play in these decisions?
• What is your opinion on family involvement in decision-making to limit treatment near the end of life?

• What challenges do you face by family involvement in decisions to limit treatment?

These questions served to start the conversation and were followed up by going into more detailed discussion.”

Comment: P. 8 - there should be an example of the sampling strategy. Without the examples it is difficult to know if you have done these stages properly

Answer: We have added more information on our sampling strategy.

P. 8-11 “Sampling strategy

We used “theoretical sampling”, developed from the grounded theory approach [29]. It is an iterative process using a continual sampling and data analysis until a “theoretical saturation” is achieved, when the categories are developed and the relationships between them are well established [30].

Purposeful sampling and developing of the interview guide

For the first step we used a purposeful sampling to identify oncologists for the first interviews. Participants were first contacted by email with a detailed study description and were re-contacted after one week by telephone and invited to participate in the interview study.

For our first interviews we developed a preliminary interview guide. It was developed in three steps: 1) in the first step, review of the existing literature was conducted; 2) in the second step, generated questions were discussed in an interdisciplinary team meeting; 3) the interview guide was discussed with the experts in oncology and social sciences. It included open-ended questions about end-of-life communication with patients and family members and their role in the decision-making process.

The preliminary interview guide included questions such as:

• Tell me about your experience of decision-making on treatment limitation by patients with advanced cancer near the end of life;

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Theoretical sampling

After completing n= 8 interviews with oncologists and analyzing our first data, more participants needed to be selected to clarify the emerging categories and concepts. We used theoretical sampling to determine the next participants for the study (see Figure 1).

The interview guide was slightly modified and included questions about the best way to involve relatives into decision-making (i.e. What is the best way to integrate relatives in decision-making to limit treatment? What factors might hinder family involvement?). For this reason, we approached oncologists with a special expertise in palliative care and in communication with family members.

Furthermore, we modified questions in order to interview oncology nurses too as they could provide valuable insight into relatives’ involvement and, according to interviewed oncologists, often turned out to be a contact person for families at the care unit. Theoretical sampling added n=6 interviews with oncology nurses and n= 4 oncologists to the data.

A total of n=18 participants – oncologists (4 male and 8 female, aged 30–65 years) and nurses (all female, aged 30–50 years) with different working experience and position (fellows and seniors) were recruited. All participants work at 4 general cancer wards caring for hematological and oncological in-patients.

Demographic data was collected at the end of the interview. The demographic characteristics of participants are presented in table 1.

Interviews lasted for 30 -100 minutes.”
Comment: Lines 7-12, p. 9 – Why did you use these in relation to the interviews? Relate the need to do this back to the method of analysis. For example, were you comparing the cohort information to the interview analyses to look for areas of similarities or differences? If so, say so.

Answer: We delete this sentence as it was formulated incorrectly. Our study was motivated by a previous quantitative study on family involvement in decision-making that showed that family was rarely involved. With a qualitative interview study, we intended to get a deeper understanding on the reasons for or against involvement.

Comment: P. 9 - see comments at beginning about what is needed to establish rigor.

Answer: we elaborated our paragraph about rigor adding more information on credibility, transparency, usefulness and analyzability.

p. 11-12 “Rigor

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

1) 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.

2) We used both purposive and theoretical sampling strategy: 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 [35]. 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.

3) To increase analyzability researcher triangulation was used: Through the 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.

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

5) The interviewer was not an employee of the hospital where the study was conducted. 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.”

Comment: Results, p. 9 - what were the categories? How many codes were there? What themes emerged from the categories? A table could indicate all of this.

Answer: We added some more information on codings, including some examples.

P. 10 “Data Analysis

Interviews were audiotaped, transcribed verbatim, and analyzed according to the principle of the classical grounded theory. We applied open, axial, and selective coding [29]. In the first step of open coding, interview data was analyzed “sentence by sentence”, segmented and open codes were created. A code is understood as a meaningful label for the text that expresses the data contents. Through constant comparison, during the axial coding emerging codes were connected by their similarities to categories (i.e. 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.)

The relationships between the categories were then analyzed through constant comparison and core categories were identified and linked into concepts (i.e. reasons for non-involvement of the family into decision-making; involving patients step by step in decisions to limit treatment etc.).”

Comment: At the end of each section in results it is preferable to have a summary sentence, not end with a quotation.

Answer: we added a summary sentence at the end of each section.

Comment: The two quotes on p. 11, lines 19-32 say the same thing - only one is necessary

Answer: We deleted one quote.

Comment: Lines 34-40, P. 13 - what legal requirement? Name the Act under which oncologists are complying.
Answer: We have named the Act and we cut this sentence from the part “4. Importance of knowing family structures” and added it to the sentence in the beginning of the discussion as it addressed the same issue.

P.18 “According to the patient care legislation in Germany relatives need to be officially designated as a proxy decision-maker either by the patient through an advanced directive or by the court in order to decide on behalf of the patients (§1901a.1 of the German Civil Code (Bürgerliches Gesetzbuch, BGB) [36,37].”

Comment: Lines 29-31, p. 16 - recommendations should be produced at the end of the Discussion section under a subheading.

Answer: We deleted the recommendation sentence from this part and added it to the section “Study limitation” as it relates to one of the limitation of our study.

Comment: Lines 41-46 - needs reference

Answer: We have added reference.