PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Expectations, end-of-life fears and end-of-life communication among palliative cancer patients and caregivers: a cross-sectional study
AUTHORS	Von Blanckenburg, Pia; Riera Knorrenschild, Jorge; Hofmann, Mareike; Fries, Hansjakob; Nestoriuc, Yvonne; Seifart, Ulf; Rief, Winfried; Seifart, Carola

VERSION 1 – REVIEW

REVIEWER	Christian Schulz Quach University of Toronto, Psychiatry
REVIEW RETURNED	16-Nov-2021

GENERAL COMMENTS	Thank you to the author team for this important contribution. This cross-sectional study using semi-structured interviews aimed at understanding the differences in conversational preferences between seriously-ill patients and their significant others/family members. The authors particularly focused on deepening the understanding on factors influencing verbal communication avoidance. Please consider the following comments as constructive feedback about your original manuscript: ABSTRACT: - "be burdened by such a conversion", I believe you wanted to say 'conversation'? PATIENT AND PUBLIC INVOLVEMENT: - " Cancer patients were involved to see if the semi-structured interview was understandable and comprehensive. Otherwise, there was no direct patient or public involvement." Please rephrase these two sentences. What do you mean by 'to see if'? What was the level of involvement and how exactly did you go about it? Or are you referring to the study participants themselves? Was there any pre-testing of the interview schedule? DISCUSSION - page 11, line 2: You are switching to 'palliative patient' when using 'cancer patient' before. Be careful not to use both labels interchangeably. It might be worthwhile to define your use of either label at the beginning of your manuscript. The implicit assumption appears to be that cancer patients will be dying from their cancer which is not always accurate. If I am reading your manuscript correctly then you are referring to patients with a life-limiting illness of a life expectancy below 12 months who are diagnosed with cancer. - page 11, line 7 ' three out of four' something is missing here. Can

	you clarify what the numbers are referring two? I assume this relates to patients but be precise. - page 11, line 11 'engage or fail to engage' Be careful with your choice of words. Your wording implies that lack of EOL discussion constitutes failure. This could be challenged on many levels. Maybe consider 'chose not to engage' or 'avoided'. - As a general comment on this section, I would encourage you to revisit this section and run it through language editing again. The choice of wording has a colloquial tendency which might lead to misinterpretations. - page 11, line 14-15: "Nevertheless, it is not the frequency of EOL conversations that is most important, but whether important issues are clarified and decisions made." Is that so? What do you base your statement on? From a psychotherapy perspective regular and even repetitive conversations about the same existential dilemma or concerns has much value and can inform a person's decision-making process significantly. Existential-phenomenological or relational psychoanalytical perspectives would inform this argument. Please be careful, again, in not imposing assumptions onto the material which are more revealing of the authors position than the participants understanding. If you wish to add a qualifying statement then you need to justify it. EOL conversations are not a mere clarification and problem-solving process, they are an existential matter of parting, witnessing and leaving behind. - page 11, line 42. 'self-other paradox'. I have difficulty following your description of the phenomenon as a paradox. I wonder whether you are rather speaking to an asymmetry? What is paradox about the fact that de-burdening myself leads to relief (and potentially release) but perceived increased burden on the other? Maybe I need more literature references here to understand what you are referring, but I am not currently convinced that you have identified a paradox. To be clear, I believe you have certainly identified an important finding, but I would urge you to revisit your conclusion on it and develop an alternative explication. page 12, line 41: "The result that negative expectations correlated with negative experiences and positive expectations with positive experiences supports the fact that expectations can develop through personal experiences (learning) [29]." Language editing needed. The sentence is not clear. page 13, line 43: 'conversion' I think you meant 'conversation'? GENERAL COMMENTS - Thank you for allowing me to review this manuscript. The research question is important and relevant. I would like to offer a few points of concerns which I would encourage the authors to address carefully: 1. 'Family' versus 'significant others': Your manuscript is based on a heteronormative idea of family. The research literature is increasingly sensitive to systematic exclusion and biases in reporting research findings, particularly so when they are based on qualitative data. Please consider defining your understanding of the concept of family. Did you mean to include non-tradtiional families, such as the construct of 'chosen family'? Did you actually mean to say 'significant others', meaning those who are important and relevant to a patient from the perspective of attachment and social connectedness? You mentioned 'unit of care' rather late in your manuscript and maybe this is yet another construct that you could introduce much earlier in your introduction. You could well make a case of keeping 'family' as your main category, but you will need to

	explicate your assumptions. 2. 'paradox' versus 'asymmetry' As stated above, I am not convinced that you have identified a true paradox in the philosophical sense of the word. But maybe this is not what you were trying to say? Please take a look at paradox theory and also maybe this reference might be of help: Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. Psycho-Oncology, 22(8), 1688-1704. 3. Language editing: Please consider language editing for your manuscript. You are describing very important and interesting findings but the impact is sometimes 'lost in translation'. I hope these comments are helpful and not discouraging.

REVIEWER	Andrea Züger Medizinische Fakultät Heidelberg, Section of Translational Medical Ethics
REVIEW RETURNED	02-Dec-2021

GENERAL COMMENTS	1. Is the research question or study objective clearly defined? No. Although the authors give some hints (introduction) of what EOL-conversations consist of, a clear definition is lacking. What are the components of an EOL conversation? As a reader, I would prefer a short paragraph on EOL conversations. 3. Is the study design appropriate to answer the research question? No. To answer the question on fear and expectation, a semi-structured interview with more openness and an inductive approach would be more appropriate. Another approach could have been a more structured way of preparing the items for the interviews. It is not transparent enough how the authors have chosen the items they used in the so-called “semi-structured interviews”. Working with focus groups (with patients and HCPs) could have been a good way to prepare the questions and relevant topics for the interviews. 4. Are the methods described sufficiently to allow the study to be repeated? No. Methods: The description of the used methods is confusing. What is part of the semi-structured interviews, and what of the paper-based questionnaire? The two methods should be explained more in detail and apart from each other. The interview description doesn´t fit the characteristics of semi-structured interviews. As it is described, it sounds like a questionnaire. There is lacking information on the following aspects: • Setting • Participants: Method of selection 9. Do the results address the research question or objective? No. The first research question “the degree of participation in EOL care” is not coherent with the results section “Who should decide about end-of-life care”. Are you focusing on participation or decision-making processes? Further comments: I like the idea behind this manuscript, and I support the relevance of this topic. The authors developed a critical research question. However, here are a couple of things that I believe need to be

	addressed: • Wording: In the title, the authors use the term EOL conversation. In the introduction, they are talking about EOL communication, in the results-part about EOL discussions and in the discussion section about EOL talks. Each of these expressions underlines different aspects of communication forms. The author should be more precise and concentrate on one of these expressions. • Patient and public involvement: If the authors mentioned PPI they should elaborate on it. How did they discuss the items? The sentence “Cancer patients were involved to see if the semi-structured interview was understandable” should be reworded. I suggest replacing “semi-structured interview” with interview-guideline or questionnaire. • Table 2: I would reformat the second part of the table (line 14 to 24) to make it more transparent and more readable: First column: question (In which context did you…) Second column: Professional context and informal context as headings • “Patients and family members were asked if they had spoken about EOL topics and with whom.” (p 9/line 54): What are EOL topics? Did the authors ask about what kind of topics they had spoken about? • “Nevertheless, it is not the frequency of EOL conversations that is most important, but whether important issues are clarified and decisions made” (p11/line 14). The authors should elaborate on this statement. • “Of the persons who declined to participate, 42.1 per cent did so out of fear of the emotional burden and 14.5 per cent because the person did not want to talk about this topic” (p12/line 25): How did the authors collect this explanation and data? My main criticism is related to the methodological approach and the data collection presentation. A more transparent presentation could make the study design more plausible and understandable.

VERSION 1 – AUTHOR RESPONSE

REVIEWER: 1

Comments to the Author:

Thank you to the author team for this important contribution. This cross-sectional study using semi-structured interviews aimed at understanding the differences in conversational preferences between seriously-ill patients and their significant others/family members. The

authors particularly focused on deepening the understanding on factors influencing verbal communication avoidance.

Thank you for your warm words.

ABSTRACT:

1. **"be burdened by such a conversion", I believe you wanted to say 'conversation'?**

Yes, this is correct. We now edited the wording from conversation to communication (see reviewer 2, comment 2)

PATIENT AND PUBLIC INVOLVEMENT:

2. **" Cancer patients were involved to see if the semi-structured interview was understandable and comprehensive. Otherwise, there was no direct patient or public involvement." Please rephrase these two sentences. What do you mean by 'to see if'? What was the level of involvement and how exactly did you go about it? Or are you referring to the study participants themselves? Was there any pre-testing of the interview schedule?**

We now changed the paragraph and explained the pretest (patient involvement) in the section assessment instruments: "EOL fears, EOL expectations and the experience with EOL communication were assessed using a structured interview. The interview topic guide was developed by a group of five clinicians and researchers from different professions with expertise in the field. The topic guide was piloted with ten palliative cancer patients from the outpatient chemotherapy centre for comprehensibility and content (pretest). The research group decided to deal with potentially stressful topics in a structured interview instead of a questionnaire, as this was considered a more sensitive approach for the patients and caregivers." (Page 6, lines 18ff) And:

Patient and Public Involvement: During the interview development process, ten patients were asked in a pretest about the interview schedule (priorities, experience, and preferences). Moreover, during the pretest, patients were asked to assess the burden of the interview/ questionnaire and time required to participate in the research. (Page 7, lines 16ff)

DISCUSSION

3. **page 11, line 2: You are switching to 'palliative patient' when using 'cancer patient' before. Be careful not to use both labels interchangeably. It might be worthwhile to define your use of either label at the beginning of your manuscript. The implicit assumption appears to be that cancer patients will be dying from their cancer which is not always accurate. If I am reading your manuscript correctly then you are referring to patients with a life-limiting illness of a life expectancy below 12 months who are diagnosed with cancer.**

Thank you for your valuable comment. We now included a definition clearer explanation of the use of the label: "In our research, the term palliative cancer patients refers to cancer patients with a life-

limiting illness and a life expectancy of less than 12 months.”. (Page 5, lines 15ff). Moreover, we rechecked the wording throughout the manuscript.

4. **page 11, line 7 ' three out of four' something is missing here. Can you clarify what the numbers are referring two? I assume this relates to patients but be precise.**

We now included the words: three out of four patients with advanced cancer (page 11 , line 8)

5. **page 11, line 11 'engage or fail to engage' Be careful with your choice of words. Your wording implies that lack of EOL discussion constitutes failure. This could be challenged on many levels. Maybe consider 'chose not to engage' or 'avoided'.**

We agree with this comment and changed the sentence as suggested. (page 11, line 10)

6. **As a general comment on this section, I would encourage you to revisit this section and run it through language editing again. The choice of wording has a colloquial tendency which might lead to misinterpretations.**

Thank you for this helpful suggestion. We now did a language editing with a critical view on tendencies.

7. **page 11, line 14-15: "Nevertheless, it is not the frequency of EOL conversations that is most important, but whether important issues are clarified and decisions made." Is that so? What do you base your statement on? From a psychotherapy perspective regular and even repetitive conversations about the same existential dilemma or concerns has much value and can inform a person's decision-making process significantly. Existential-phenomenological or relational psychoanalytical perspectives would inform this argument. Please be careful, again, in not imposing assumptions onto the material which are more revealing of the authors position than the participants understanding. If you wish to add a qualifying statement then you need to justify it. EOL conversations are not a mere clarification and problem-solving process, they are an existential matter of parting, witnessing and leaving behind.**

We highly appreciate this comment. We actually approve that statement and now changed the section into:

“Nevertheless, he frequency of EOL communication needed by patients and their carers can be highly individual and variable. For some, repetitive conversations about the same existential dilemma or concern are valuable, can support a person's decision-making process significantly and include parting, grieving and leaving behind. For others, it can be important to clarify issues and make decisions so that they can then focus on matters of life at other times. A helpful framework can be the concept of double awareness [29]. Double awareness is the flexibility of mind between life awareness and death awareness and the possibility of simultaneously switching and tolerating the ambivalence of life and death [29]. Moreover, different EOL topics might be of relevance at different

times or situations: in one time, emotions as grieving and leaving behind can be in the front, whereas in other conversations organizational or care-related topics are the ones to look at. " (page 11, lines 13ff)

8. **page 11, line 42. 'self-other paradox'. I have difficulty following your description of the phenomenon as a paradox. I wonder whether you are rather speaking to an asymmetry? What is paradox about the fact that de-burdening myself leads to relief (and potentially release) but perceived increased burden on the other? Maybe I need more literature references here to understand what you are referring, but I am not currently convinced that you have identified a paradox. To be clear, I believe you have certainly identified an important finding, but I would urge you to revisit your conclusion on it and develop an alternative explication.**

We agree and now changed the wording into self-other "asymmetry". Example: There seems to exist a 'self-other' asymmetry: palliative patients and their caregivers expect substantial personal relief when openly talking about end-of-life issues, but also expect the other person to be burdened by such communication. Professionals repeatedly need to initiate end-of-life communication. (Abstract)

9. **page 12, line 41: "The result that negative expectations correlated with negative experiences and positive expectations with positive experiences supports the fact that expectations can develop through personal experiences (learning) [29]." Language editing needed. The sentence is not clear.**

We now changed the sentence into: The finding of significant correlations between expectations and experiences supports the importance of learning processes in the development of expectations [32]. Thus, if someone experienced positive end-of-life communication in the past, he/she will probably expect positive communication on these topics in the future. Moreover, a vicious circle can occur whereby a negative experience entails negative expectations which in turn lead to negative experiences in terms of a nocebo effect [33]. (page 12, line 29)

10. **page 13, line 43: 'conversion' I think you meant 'conversation'?**

Of course, you are correct. We now changed the typing error.

GENERAL COMMENTS

- **Thank you for allowing me to review this manuscript. The research question is important and relevant. I would like to offer a few points of concerns which I would encourage the authors to address carefully. I hope these comments are helpful and not discouraging.**

The comments were very helpful – Thank you again!

11. **'Family' versus 'significant others': Your manuscript is based on a heteronormative idea of family. The research literature is increasingly sensitive to systematic exclusion and biases in reporting research findings, particularly so when they are based on qualitative data. Please consider defining your understanding of the concept of family. Did you mean to include non-traditional families, such as the construct of 'chosen family'? Did you actually mean to say 'significant others', meaning those who are**

important and relevant to a patient from the perspective of attachment and social connectedness? You mentioned 'unit of care' rather late in your manuscript and maybe this is yet another construct that you could introduce much earlier in your introduction. You could well make a case of keeping 'family' as your main category, but you will need to explicate your assumptions.

Thank you for this important comment. We agree and changed the words "family member/ relatives" into "significant other" and "caregiver". Moreover, we now introduce the concept "unit of care" including a caregiver that can be a relative, a chosen family member, or another significant person.

"In palliative care, patients with an life-threating disease and their caregivers are perceived as "unit of care", meaning that both parts are the focus of a care plan [1]. Caregivers can be relatives or significant others. During the course of illness, there is often a moment when the responsibility for medical decisions shifts from the patient to the caregiver due to patient´s poor condition [2, 3]. However, research shows, that caregivers are often not well prepared for these decisions." (page 4, line 1ff)

And in the methods section: "Caregivers had to be a person close to the cancer patient and a potential surrogate (e.g. partner, child, parent, close friend, family member chosen by the patient etc)." (page 6, line ff)

12. **'paradox' versus 'asymmetry' As stated above, I am not convinced that you have identified a true paradox in the philosophical sense of the word. But maybe this is not what you were trying to say? Please take a look at paradox theory and also maybe this reference might be of help:**

    Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. Psycho-Oncology, 22(8), 1688-1704.

We changed the wording from paradox into asymmetry and added the interesting reference:

"The most notable result is that the interviewed persons expected substantial

personal relief when openly talking about EOL issues in an informal context but expected the other person to be burdened by such a conversion. Notably, this 'self-other' asymmetry applies to both groups, the palliative care patients and the caregivers. This asymmetry was not found in the professional context. On the one hand, persons expect more emotional relief and practical support from communication with loved ones, pointing out the importance and high relevance of informal caregivers in the sense of building a unit of care [1]. On the other hand, concerns about causing negative emotions and burdening the other person were dramatically higher in the informal than in the professional context. Emotion-related factors such as protective buffering can be relevant barriers to EOL communication [11]. The belief that it will hurt the other person to address death and dying seems to be very salient and a relevant barrier to EOL communication. Further research exploring possible interventions involving the dyadic perspective as unit of analysis would be worthwhile [30]. (Badr & Krebs, 2013). (Page 11, lines 31ff)

13. **Language editing: Please consider language editing for your manuscript. You are describing very important and interesting findings but the impact is sometimes 'lost in translation'.**

As recommended we did a further language editing.

Reviewer: 2

1. **I like the idea behind this manuscript, and I support the relevance of this topic. The authors developed a critical research question.**

Thank you very much!

2. **Wording: In the title, the authors use the term EOL conversation. In the introduction, they are talking about EOL communication, in the results-part about EOL discussions and in the discussion section about EOL talks. Each of these expressions underlines different aspects of communication forms. The author should be more precise and concentrate on one of these expressions.**

We highly appreciate this comment. We absolutely agree and we now stated the wording precisely and only used EoL-communication. We chose the broader construct because we wished to include all types of communication about death and dying. (See also comment 8)

3. **Patient and public involvement: If the authors mentioned PPI they should elaborate on it.**

   How did they discuss the items? The sentence "Cancer patients were involved to see if the semi-structured interview was understandable" should be reworded. I suggest replacing "semi-structured interview" with interview-guideline or questionnaire.

As suggested we changed the sentence into: "The topic guide was piloted with ten palliative cancer patients from the outpatient chemotherapy centre for comprehensibility and content (pretest)." (page 6, line 20) and: "During the interview development process, ten patients were asked in a pretest about the interview schedule (priorities, experience, and preferences). Moreover, during the pretest, patients were asked to assess the burden of the interview/ questionnaire and time required to participate in the research." (page 7, line 16)

4. **Table 2: I would reformat the second part of the table (line 14 to 24) to make it more**

   transparent and more readable: First column: question (In which context did you…)

   Second column: Professional context and informal context as headings

We now converted Table 2 as recommended.

5. **“Patients and family members were asked if they had spoken about EOL topics and with whom.” (p 9/line 54): What are EOL topics? Did the authors ask about what kind of topics they had spoken about?**

Thank you for this valuable comment. We now added a new column to Table 2 with the EOL topics patients and care givers talked about.

What kind of topics have you spoken about?	**Medical Care**	**49 (57.6%)**	**47 (71.2%)**
	Nursing Care	34 (40.0%)	42 (63.6%)
	Religiosity/ Spirituality	23 (27.1%)	27 (40.9%)
	Organizational aspects	54 (23.5%)	46 (69.7%)
	Emotions	42 (49.4%)	46 (69.7%)
	Social aspects	24 (28.2%)	37 (56.1%)

Furthermore, we added an explanation to the Method section:

They were then asked whether they had talked about several prespecified EOL topics, such as: medical care, nursing care, organizational issues, emotional issues, social issues or religiosity/ spirituality. Each of these EOL topics was preceded by a list of examples of what this topic might involve. "Medical care": e.g. living will, life-sustaining treatment, treatment of somatic problems like dyspnea, nausea, pain or maintaining quality of life, “emotions”: e.g. feelings like grief, anger, fear or sadness”, “social aspects”: e.g. unresolved conflicts, dealing with relatives and friends, saying goodbye, “nursing care”: e.g. nursing care in the last period of life, place of dying, “organizational aspects”: e.g. financial and legal issues, life pension, inheritance, or funeral, and “religiosity/spirituality”: “talking e.g. about religious beliefs or desires, thoughts about death and the hereafter”. (page 7, line 1ff).

6. **“Nevertheless, it is not the frequency of EOL conversations that is most important, but whether important issues are clarified and decisions made” (p11/line 14). The authors should elaborate on this statement.**

We now changed this section into:

> *“Nevertheless, he frequency of EOL communication needed by patients and their carers can be highly individual and variable. For some, repetitive conversations about the same existential dilemma or concern are valuable, can support a person's decision-making process significantly and include parting, grieving and leaving behind. For others, it can be important to clarify issues and make decisions so that they can then focus on matters of life at other times. A helpful framework can be the concept of double awareness.” (Page 11, line 13).*

7. **“Of the persons who declined to participate, 42.1 per cent did so out of fear of the emotional burden and 14.5 per cent because the person did not want to talk about this topic” (p12/line**

   25): How did the authors collect this explanation and data?

The persons that declined to participate (or who wanted to abort the interview) were asked by the interviewer to share the reason. If the persons gave their permission to include their reasons for not participating or aborting, the answer was noted in free text by the respective interviewer, written down on the questionnaire and then later sorted into one of 7 prespecified categories for computational analysis: "no reason, fear of emotional burden, effort (place/time), doesn't want to talk about the topic/doesn't want to think about the topic, too much of a physical burden, other, emotional burden and doesn't want to talk about the topic". The categories were discussed by the research team and in supervisory sessions to ensure similar code schemes.

8. **Although the authors give some hints (introduction) of what EOL-conversations consist of, a clear definition is lacking. What are the components of an EOL conversation? As a reader, I would prefer a short paragraph on EOL conversations.**

We now included a paragraph on EOL communication:

EOL communication is defined as “a clinical interaction, which includes discussion of death and dying as part of the progression of illness or a potential outcome despite treatment efforts” [5]. In a broader sense, EOL communication can include topics around death and dying such as patient’s wishes about medical treatment (e.g. wished treatment options), but also emotional, spiritual and organizational aspects (e.g. funeral, last will or the wished place of dying) . (page 4)

9. **To answer the question on fear and expectation, a semi-structured interview with more openness and an inductive approach would be more appropriate. Another approach could have been a more structured way of preparing the items for the interviews. It is not transparent enough how the authors have chosen the items they used in the so-called “semi-structured interviews”. Working with focus groups (with patients and HCPs) could have been a good way to prepare the questions and relevant topics for the interviews.**

Thank you for this hint. As suggested we described the development of the structured interview in a more detailed way:

> *EOL fears, EOL expectations and the experience with EOL communication were assessed using a structured interview. The interview topic guide was developed by a group of five clinicians and*

researchers from different professions with expertise in the field. The topic guide was piloted with ten palliative cancer patients from the outpatient chemotherapy centre for comprehensibility and content (pretest). The research group decided to deal with potentially stressful topics in a structured interview instead of a questionnaire, as this was considered a more sensitive approach for the patients and caregivers. All interview questions could be answered on a Likert scale from 0 ("not at all") to 4 ("totally agree" or "very much"). Three questions addressed self-determination in EOL care (e.g. "It is important to me to be self-determined."); seven questions were about persons who should decide about EOL care (e.g. "I want decisions about my medical EOL care to be taken only by myself"); six questions addressed expectations of EOL care (e.g. "I expect… emotional release/ practical support/ emotional burden/…); and five questions were about fears regarding EOL communication (e.g. "I am very afraid of my/ my relatives´ last period of life", "I avoid talking about EOL topics"). Moreover, three questions asked if and whom palliative patients and their caregivers had spoken to (in the informal or professional context; choosing from a list of conversation partners, with the option to add a free text). They were then asked whether they had talked about several prespecified EOL topics, such as: medical care, nursing care, organisational issues, emotional issues, social issues or religiosity/ spirituality. Each of these EOL topics was preceded by a list of examples of what this topic might involve. "Medical care": e.g. living will, life-sustaining treatment, treatment of somatic problems like dyspnoea, nausea, pain or maintaining quality of life, "emotions": e.g. feelings like grief, anger, fear or sadness", "social aspects": e.g. unresolved conflicts, dealing with relatives and friends, saying goodbye,

"nursing care": e.g. nursing care in the last period of life, place of dying, "organisational aspects": e.g. financial and legal issues, life pension, inheritance, or funeral, and "religiosity/spirituality": "talking e.g. about religious beliefs or desires, thoughts about death and the hereafter". Finally, three questions related to the experience of EOL communication ("burdening", "helpful", "satisfying"). (page 5, lines 18ff)

10. **Methods: The description of the used methods is confusing. What is part of the semi-structured interviews, and what of the paper-based questionnaire? The two methods should be explained more in detail and apart from each other. The interview description doesn´t fit the characteristics of semi-structured interviews. As it is described, it sounds like a questionnaire.**

    As recommended we changed this section into two separated parts and explained them in a more detailed way. Moreover, we changed semi-structured into structured interview.

11. **There is lacking information on the following aspects:**

- **Setting**
- **Participants: Method of selection**

We agree and now added more information to both sections:

Setting

All patients who met the inclusion criteria from the outpatient chemotherapy centre of a University hospital were informed about the study by their treating physician. If caregivers accompanied patients to their treatment or consultation there were additionally briefed on the study. After written informed consent, a separate appointment was made to conduct a structured interview and to complete the paper-pencil-questionnaire. Patients and caregivers were interviewed by two psychology Master's *students and three medical doctoral students under the supervision of CS, YN, MH and PB. Interviews took place at doctors' consultation room at the outpatient chemotherapy centre. Participants first filled in the questionnaire and were then asked the interview questions. The interviewers were trained through role plays and also prepared for difficult situations. If patients or caregivers felt distressed by the EOL topics, a psycho-oncological consultation was offered. Participants were free to discontinue the interview or the questionnaire at any time.*

Participants

Inclusion criteria for all participants were sufficient German language skills and a minimum age of 18. For the patient group, a diagnosis of a malignant neoplasm with a limited prognosis judged by the surprise-question ("Would I be surprised if this patient died in the next year?") by the attending physician, was an additional inclusion criterion. Caregivers had to be a person close to the cancer patient and a potential surrogate (e.g. partner, child, parent, close friend, family member chosen by the patient etc).

12. **The first research question "the degree of participation in EOL care" is not coherent with the results section "Who should decide about end-of-life care". Are you focusing on participation**

    or decision-making processes?

We are focusing on the decision-making-process and now changed the first research question: "Therefore, the present study examined a) who should make decisions about EOL care; b) the spectrum of expectations towards EOL communication; c) the level of EOL fears; and d) experiences with EOL communication among palliative cancer patients and their caregivers." (Page 5, line 13)

VERSION 2 – REVIEW

REVIEWER	Christian Schulz Quach University of Toronto, Psychiatry
REVIEW RETURNED	19-Feb-2022

GENERAL COMMENTS	All prior concerns have been addressed sufficiently.

REVIEWER	Andrea Züger Medizinische Fakultät Heidelberg, Section of Translational Medical Ethics
REVIEW RETURNED	07-Mar-2022

GENERAL COMMENTS	Thank you to the author team for the revision of this article. I really appreciate the improvement in the method part. It makes the whole study more precise and transparent. I can only add two small comments (see below). 1) Inconsistent punctuation You used two different styles of quotation marks (e.g. p 7) 2) Patient and Public Involvement I suggest deleting the section "Patient and Public Involvement". What you have done is not really in line with the characteristics of patient involvement. It is a pretest, which is already described in the section "Assessment instruments."