

## Peer Review File

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### **Comments & Answers**

#### **Recommended major changes**

- **Comment 1:** First, there has been a change in the legal situation in Germany. Please update the article to reflect these changes.  
**Reply:** Throughout the abstract, the article and in table 4, we have updated the information on the changes in the German legal situation accordingly.
- **Comment 2:** Several suggestions have been made for the review tables.  
**Reply:** We have adjusted our tables according to the reviewer comments. For the individual adjustments, please refer to the separate files for the tables.
- **Comment 3:** In the results you first describe the systematic reviews and then immediately go into the recommendations/results. We recommend you add a summary of these main findings. For example, after the systematic review tables explain there were six findings/results (how would you define them?) and state what these are: Definition of 'desire to die', forms of desire to die, causes, significance and functions of desire to die, ...  
**Reply:** We thank all reviewers for the valuable critique on our result section. We acknowledge that our way of reporting on the process of preparing the recommendations and statements could have been more precise. There seems to have been the conception that all results are based on a systematic literature search, which is not the case. About one third of results are based on systematic literature searches, two thirds are based on expert consensus. Therefore, we completely rewrote our methods section and augmented necessary information which we previously only supplied in our flow-chart. We also added more introductory information to our results, so it becomes immediately obvious where the reported recommendations and statements come from.
- **Comment 4:** Please submit the revision with tables separated from the manuscript, as suggested in the author guidelines for submission.  
**Reply:** Thank you for the reminder about the submission guidelines regarding tables. With this revision, we now follow the guidelines and provide all tables in separate files.
- **Comment 5:** Pay attention to US and/or UK spelling and author guidelines  
**Reply:** We made sure that the manuscript is written in US spelling only and adheres to the author guidelines.

#### **Comments in the Manuscript**

## Abstract

- Line 57: How does this relate?  
**Reply:** “Differential diagnosis” has been removed from the sentence.
- Line 62: How do you know this? Alternative: "The guideline informs health professionals working within the German statutory framework, how to care and communicate with patients who are receiving palliative care and who express a desire to die."  
**Reply:** We accepted the suggested alternative formulation for this sentence.

## Introduction

- Line 67: Need to define this term.  
**Reply:** To acquire a better precision, we changed our wording from “critically-ill” to “patients living with a life-limiting progressive disease”.
- Line 75: What population?  
**Reply:** We added the number of study participants for the annotated study to provide identical information on each of the studies mentioned.
- Line 84: Need to explain what this means. Perhaps the translation direct from the German does not work as well?  
**Reply:** We changed the wording of “termination of life on request”, § 216 German Criminal Code (StGB) and “assistance of suicide with the intent of repeated conduct” (§ 217 StGB) to “euthanasia” and “assisted suicide”, since these terms are more common within the international context. To remain precise in our understanding of these terms, we put the exact German legal wording in brackets when the terms are mentioned the first time.
- Line 85: Replace with may be  
**Reply:** We rewrote the entire paragraph on the legal situation in Germany, as it has been revised shortly after submission of our manuscript.
- Line 87: Is there a reference to support this?  
**Reply:** We provided *Udo C, Melin-Johansson C, Henoeh I, et al. Surgical nurses’ attitudes towards caring for patients dying of cancer – a pilot study of an educational intervention on existential issues. European Journal of Cancer Care 2014; 23: 426-440. DOI: 10.1111/ecc.12142.* as a reference.

## Results

- Lines 167 – 170: This is unclear  
**Reply:** We revised the introduction of our results to clarify the reporting of recommendations and statements based on systematic literature search as well as expert consensus. Additionally, we rewrote our methods section to coherently lead up to the results section.
- Table 2: How many of these papers are included in the SRs ie are you counting the results twice?  
**Reply:** Please refer to our methods section. We searched for RCTs because we couldn’t find any SRs on the topic “Dealing with DD”. Thus, these RCTs are not included in any of the abovementioned SRs.
- Table 2, Main results: Generally in this column simplify ie was there a significant difference and p value? Covered in Sign LoE?  
**Reply:** As suggested, we added p values while trying to simplify the column. ITT-analysis is one of the points of the methodology checklist.
- Table 2, Reference: Add country to this column  
**Reply:** As suggested, we added countries to this column.
- Table 2, Patient characteristics: Give general comment on drop outs ie interpret – no significant difference in drop outs?  
**Reply:** We decided against adding drop out interpretations, since SIGN doesn’t ask for significance of drop outs. A percentage may be indicated (cf. addition). How to interpret this percentage might vary. Usually, a drop out of 20% is judged as acceptable (cf. SIGN

**Reviewer 1**

- Regarding authors: If first and second author are equal, should second author be last in the list?  
**Reply:** The current order of authors corresponds with their contributions to the manuscript.
- The change in the legal situation in Germany needs inclusion now which might be a major change to the paper especially how palliative care will respond but there are some responses out there  
**Reply:** Throughout the abstract and the article, we have updated the information on the changes in the German legal situation accordingly.

#### Abstract:

- Lines 41& 42: unsure what this: “the assistance of suicide with intent of repeated conduct” means?  
**Reply:** We changed the wording of “termination of life on request”, § 216 German Criminal Code (StGB) and “assistance of suicide with the intent of repeated conduct” (§ 217 StGB) to “euthanasia” and “assisted suicide”, since these terms are more common within the international context. To remain precise in our understanding of terms, we put the exact German legal wording in brackets when the terms are mentioned the first time.
- Results section (in abstract): Anything on who created the recommendations? Plenty in the results section on the results of the review but not here?  
**Reply:** To emphasize that the recommendations were created by the expert panel, we changed the first sentence in our results (abstract) to “The expert panel developed and agreed on 21 statements and recommendations on desire to die and related phenomena.”

#### Materials and Methods:

- Lines 134-135: “agreed on key questions during an opening consensus conference.” Key questions about what?  
**Reply:** We reformulate the sentence to answer this question. It now states: “As a first step, the guideline group – a representative panel of experts elected from 61 professional societies, institutions and patient representatives – agreed on key questions to be answered on desire to die within the framework of the guideline. It also stipulated, for which key questions a systematic literature review should be conducted and for which expert consensus should be sought.”
- Page 7, Line 160: “pre-specified inclusion criteria”. What are they?  
**Reply:** We added a reference to our Supplement 1 which now lists all inclusion and exclusion criteria in detail.
- Line 165- 167: what do you mean by “the review results were complimented by...”?  
**Reply:** We now describe in more detail how additional studies to those of the systematic literature search were searched for and integrated into the evidence.
- Line 172: Please write out full acronym for AWMF.  
**Reply:** Upon its first mention in the methods section, the full acronym of AWMF is now written out.
- Line 180: Just refer to developing guidelines rather than guidelines chapter  
**Reply:** Since it is only the guideline chapter on desire to die that we report on, we decided to stay with our current wording on developing the guideline chapter.
- Line 181: What about methods for gaining consensus? From the 61 participants?  
**Reply:** We reformulated and refined the methods section, so that there is now a detailed description about the process of gaining consensus. This information has previously only been supplied by our flow-chart.

#### Results section

- Lines 186-187 “includes 18 recommendations, three statements and explanatory background text regarding desire to die”. Is this all from the literature review?



Author list: I wonder if this " on behalf of the Working Group on desire to die of the German Palliative Care Guideline" needs to be listed if this information is also listed in the disclosures/ financial statement in the Footnotes at end.

**Reply:** All papers reporting content from the German Palliative Care Guideline use this phrasing, therefore, we decided to keep it to remain consistent with the Guideline's reporting style.

Abstract:

- Lines 41 & 42: Are the authors referring to medically administered (called euthanasia in many areas) or self-administered (assisted suicide) forms of assisted dying? Perhaps this is translated directly from the law in Germany? If so, please state.

**Reply:** we changed the wording of "termination of life on request", § 216 German Criminal Code (StGB) and "assistance of suicide with the intent of repeated conduct" (§ 217 StGB) to "euthanasia" and "assisted suicide", since these terms are more common within the international context. To remain precise in our understanding of terms, we put the exact German legal wording in brackets when the terms are mentioned the first time.

- Lines 46 & 47: My understanding is that interdisciplinary includes professionals from many disciplines. Do the authors need to use both 'interdisciplinary' and 'multi-professional' working group? How are they different?

**Reply:** We decided to keep both descriptors as, in our understanding, "interdisciplinary" refers to different disciplines (e.g. oncology or psychiatry) whereas "multiprofessional" refers to different professions (e.g. physicians, nurses, therapists).

- Lines 55 & 56: Sentence needs to be rewritten. Maybe: "A descriptive definition was agreed upon (or - was created?) of desire to die as a complex phenomenon with individual differences related to causes, manifestations, and consequences."

**Reply:** We have adopted the formulation.

Introduction:

- Line 82: The study examined the "desire for death in patients receiving palliative care for cancer" and did not use the word oncological or even oncology. I suggest stating "...377 patients receiving palliative care for cancer..." rather than calling them oncological patients.

**Reply:** We have adopted the formulation.

Materials and Methods:

- Can you just say Methods?

**Reply:** Now the heading is just "Methods".

- Line 137: Doesn't interdisciplinary include multi-professionals? Can you not just say "...an interdisciplinary working group...?"

**Reply:** As stated above: We decided to keep both descriptors as, in our understanding, "interdisciplinary" refers to different disciplines (e.g. oncology or psychiatry) whereas "multiprofessional" refers to different professions (e.g. physicians, nurses, therapists).

- Line 166-167: The statement "the review results were complemented by the working group on further known qualitative and quantitative literature" is confusing. Do the authors mean the review results were 'supported by...? I think the word 'complemented' needs to be replaced with a different word, to help understand what the working group did.

**Reply:** We described in more detail how additional studies to those of the systematic literature search were searched for and integrated into the evidence.

Results

- Lines 187-190: I am wondering if the authors are simply stating how they are reporting the results from the literature review and the expert consensus. If so, can they simply state, "We report on results from the literature review and the expert consensus." ?

**Reply:** We rewrote and added on the introduction to our results section to address also

Response to Revision:

Dear authors,

We thank you for the extensive revisions to your manuscript and we agree that it is much improved. We would like to include this article in the journal, however there are still some edits and revisions that are needed to help bring clarity about what was completed. Please see suggestions below.

1. Can you add the RCT review part to the Methods section?

We added a sentence that the primary studies searched for were RCTs: "Thus, we hereupon conducted a systematic search for primary studies (randomized controlled trials; RCTs) on this special topic in the databases Medline, PsycINFO and Cochrane Central Register of Controlled Trials (CENTRAL) from inception until October 2018,..."

2. At the beginning of the methods number each of the reviews so it is clear what has been done.

We applied the change as suggested. We preferred to use the term "search" instead of "review", because a review includes besides the search also the synthesis of the findings (narrative synthesis), which summarizes all findings of all three searches.

The point on *Search for primary studies* was rephrased as follow:

3. Search for randomized controlled trials (RCTs): For the key question 3) on caring for patients with a desire to die, only a systematic review of qualitative studies could be identified. In order to supplement these findings, we conducted a systematic search for RCTs in the databases Medline (via Ovid), PsycINFO and Cochrane Central Register of Controlled Trials (CENTRAL) from inception until October 2018, according to the recommendations of the PRISMA Statement<sup>21</sup> (for search strategies see Supplement 1). We limited our research to RCTs as we aimed to investigate the effectiveness of interventions.

3. Clearly state the key questions for each review unless they are the same. But numbering the questions will help the reader return to them if they forget.

We numbered the key questions wherever they appear within the text to give more guidance for the reader.

4. Please include separate tables for inclusion/exclusion criteria. (They are included as part of the search tables).

We separated the inclusion / exclusion criteria from the search tables and labeled them "Supplement 3".

5. Please attach tables and figures as separate documents.

We attached tables and figures as separate documents.

6. Abstract:

Change sentence to: This dynamically changing legal situation adds to health professionals reported uncertainty in dealing appropriately with a desire to die.

We applied the change as suggested.

7. Introduction:

First sentence: "Desire to die in patients living with a life-limiting progressive disease can be understood as a broad phenomenon ranging from the acceptance of death and being tired of life on one side of a continuum to the wish to hasten death and acute suicidality on the other end"

Is this the definition you are using throughout the paper? I note later you say there isn't an accepted definition so it would be useful to state what you working definition of desire to hasten death is

We rewrote the beginning of our introduction:

"Desire to die has been object of increasing research interest in recent years. Studies could show a considerable prevalence of desire to die among patients receiving palliative care. Chochinov et al. found in 1995, that of 200 patients living with advanced cancer, 45% experienced an occasional desire to die and almost 10% reported a strong and persistent desire.<sup>2</sup> In a more recent study with 377 patients living with cancer, 18% reported an occasional and 12% a serious desire to die.<sup>3</sup> However, desire to die is not limited to patients with cancer. According to Strupp et al, 22.1% of 573 patients with multiple sclerosis have suicidal thoughts.<sup>4</sup> Patients with multiple sclerosis or other neurological conditions (for example motor neuron disease) are the largest sub-group of those seeking support to end their life prematurely<sup>5, 6</sup> and are at high risk of attempting and completing suicide.<sup>7-9</sup> However, comparison between studies and various patient population is made difficult by the lack of an accepted definition on desire to die.

[...]

By providing systematically developed treatment recommendations based on current evidence and on the clinical experience of a large representative panel of experts, the guideline supports decision-making in practice."

8. Replace this sentence:



Chochinov et al, found in 1995, that of 200 patients living with advanced cancer, 45% experienced at least an occasional desire to die and almost 10% reported a strong and persistent one.

with

Chochinov et al. found in 1995, that of 200 patients living with advanced cancer, 45% experienced an occasional desire to die and almost 10% reported a strong and persistent desire.

We applied the change as suggested.

9. Can you explain what you mean by 'neglect' in this sentence?: "In this context of clinical uncertainty and rapidly evolving legislation,<sup>13</sup> health professionals might neglect or avoid the topic, even if patients themselves raise the issue". Consider deleting 'neglect or' if it means the same as 'avoid'.

We deleted "neglect or" as suggested.

#### 10. Change:

"The guideline was developed and funded within the *German Guideline Program in Oncology* (GGPO) and therefore focuses on patients with cancer from the diagnosis of incurability of their disease. However, the recommendations may also be applicable to other patient groups with advanced diseases. The aim of the guideline is to enable a high quality of life until death for patients suffering from severe symptoms."

to

"The guideline was developed and funded within the *German Guideline Program in Oncology* (GGPO) and therefore focuses on patients with cancer from the diagnosis of an incurable disease. However, the recommendations may also be applicable to other patient groups with advanced diseases. The aim of the guideline is to enable optimum quality of life until death for patients suffering from severe symptoms."

We applied the change as suggested.

#### 11. Methods:

First sentence change to:

"The evidence and consensus based *German Palliative Care Guideline for Patients with incurable Cancer*<sup>1</sup> was developed under the leadership of the *German Association for Palliative Medicine* and within the methodological framework of the GGPO. This program fosters the development and..."

We applied the change as suggested.

## 12. Preparation:

Consider rephrasing these sentences and explain/clarify questions in comments:

“As a first step, the guideline group – a representative panel of experts elected from 61 professional societies, institutions and patient representatives – agreed on key questions to be answered on desire to die within the framework of the guideline. It also stipulated, for which key questions a systematic literature review should be conducted and for which expert consensus should be sought.”

to

“A representative panel of experts elected from 61 professional societies, institutions and patient representatives agreed on key questions to be answered on desire to die using a consensus development method.<sup>19</sup> According to an *a priori* defined criterion, consensus was achieved with the agreement of  $\geq 75\%$  of participants. It stipulated, which key questions could be answered through a systematic literature review and which expert consensus should be sought. “

As we have written on several occasions throughout our methods section, recommendations and statements that answered the key questions were either based on literature review OR expert consensus. This was because there is little literature evidence on the topic as to date. This is part of the method for the development of Guidelines in Germany (AWMF, GGPO). In clinical practice, there is also a need for recommendations on topics, for which only few evidence is available. In those cases, expert consensus (clinical experience) will be used as the base for the recommendations.

We rephrased the paragraph:

“A representative panel of experts elected from 61 professional societies, institutions and patient representatives agreed on key questions to be answered on desire to die during a Structured Consensus Conference, an acknowledged formal consensus development method.<sup>19</sup> According to an *a priori* defined criterion, consensus was achieved with the agreement of  $\geq 75\%$  of participants. It stipulated, which key questions could be answered through a systematic literature review and for which expert consensus should be sought.”

As an explanation, please consider: „Key questions“ refer to clinical questions that are formulated at the beginning of the development of a guideline in order to establish the themes to be treated (see e.g. [https://apps.who.int/iris/bitstream/handle/10665/75146/9789241548441\\_eng.pdf;jsessionid=ADD8C3178902A3A64B2F137A5D6E3A4E?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/75146/9789241548441_eng.pdf;jsessionid=ADD8C3178902A3A64B2F137A5D6E3A4E?sequence=1), WHO guideline development guide). Not all key questions are PICO questions, this is why we don't use here the term “PICO questions”. PICO questions were only formulated for questions that had to be answered by means of a systematic literature search (evidence-based). The representative panel “agreed” on the key questions, it means that a formal consensus process was conducted. See rephrasing.

13. “In addition to ten elected representatives from professional societies and institutions – from the fields of psychiatry, suicidology, palliative care, psycho-oncology and ethics – 20 experts...”

Rephrase to:

“Ten elected representatives from professional societies and institutions – from the fields of psychiatry, suicidology, palliative care, psycho-oncology and ethics – and 20 experts...”

We applied the change as suggested.

#### 14. Section: “Literature search, selection and appraisal”

To help clarify what you have done and guide the reader that you completed three reviews, please begin this section with:

There were three reviews:

1. Review of guidelines about .... which yielded no results
2. Review of review about ....
3. Review of RCTs about ....

We applied the change as suggested. We preferred to use the term “search” instead of “review”, because a review includes besides the search also the synthesis of the findings (narrative review), which summarizes all findings of all three searches.

The point on Search for primary studies was rephrased as follow:

3. Search for randomized controlled trials (RCTs): For the key question 3) on caring for patients with a desire to die, only a systematic review of qualitative studies could be identified. In order to supplement these findings, we conducted a systematic search for RCTs in the databases Medline (via Ovid), PsycINFO and Cochrane Central Register of Controlled Trials (CENTRAL) from inception until October 2018, according to the recommendations of the PRISMA Statement<sup>21</sup> (for search strategies see Supplement 1). We limited our research to RCTs as we aimed to investigate the effectiveness of interventions.

#### 15. Regarding systematic review:

Why did you do PubMed initially for the guidelines and then Medline for the SR?

Thank you for your comment, we specified: Medline (via PubMed) and Medline (via Ovid).

“For the key question on dealing with a desire to die, no systematic review could be identified”

We changed the sentence so that it has the same wording as the key question 3 it refers to: "key question 3) on caring for patients with a desire to die"

16. Page 8:

The literature yielded by the expert consultation was used as background literature for drafting the guideline, but was not systematically appraised with SIGN.

We followed the GGPO method.

17. Page 9

State date: "Consensus Conference (date)..."

We added the date to the sentence: All recommendations and statements went through formal agreement via a Structured Consensus Conference (14.-15. October 2018)

18. "When recommendations are not based on a systematic literature search but only on formal expert agreement, they are marked with "EC" (expert consensus). Since we expected a limited availability of high-quality empirical publications, a close attention was paid to this type of recommendations based on a wide clinical expertise in developing the guideline. In this way, clinical high-relevant topics could be covered by the guideline, even though they are not evidence-based. Beneath recommendations, the guideline also contains statements (ST)."

Change to (delete sentence, and consider deleting more):

When recommendations were not based on empirical evidence but on formal expert agreement, they were marked with "EC" (expert consensus). In this way, clinical high-relevant topics could be covered by the guideline, even though they were not evidence-based. Beneath recommendations, the guideline also contains statements (ST).

We applied the change as suggested but did not delete any more sentences.

19. Statement before results section:

"A statement is an assertion of fact. It can be evidence-based and will be assigned to a level of evidence, or to consensus-based."

We applied the change as suggested.

20. Results:

Delete:

"This is an emerging research topic which has yet to produce a large body of high quality empirical evidence. Therefore, besides recommendations based on literature reviews the guideline group also formulated recommendations on the basis of expert consensus."

We deleted the sentence except for the second part “Besides recommendations based on literature reviews the guideline group also formulated recommendations on the basis of expert consensus.”

Next sentence correct tense to:

“About one third of the recommendations were evidence-based. With the integration of recommendations based on expert knowledge, the guideline group aimed to provide...”

We applied the change as suggested.

21. Page 10:

With additional records from hand searching, a total of four systematic reviews were included (for PRISMA chart see Supplement 2), one addressing the key question on the desire to die phenomenon

We clarified the sentence, now reading: “...one answering the key question 1) on the desire to die phenomenon...”

As no systematic review could be identified to answer the key question on dealing with desire to die, primary studies (randomized controlled trials; RCTs) were searched. We limited our included evidence to RCTs, as we wanted to investigate the effectiveness of interventions. Out of 766 electronic references, four RCTs were included.<sup>26-29</sup> One additional RCT was identified through hand search (for PRISMA chart see Supplement

We deleted the sentence on the method and corrected our statements in the method part (see also point 14). The RCT search supplemented the qualitative results of the SR. We did not search for further quantitative studies besides RCTs, because we looked for the effectiveness of interventions.

22. Page 11:

Suggested rewrite of this sentence:

“Between these two poles, the pressure to enact the desire increases, hoping to die soon or wishing to accelerate the dying phase. This definition of desire to die takes into account the multi-faceted nature of the phenomenon.”

We applied the change as suggested.

23. “Phenomenon of the desire to die” Can you explain what the sub-headings are related to (to help the reader understand?)

We understand that the sub-headings appear to be confusing. Therefore, we reduced and simplified the sub-headings so that they now correspond with the formulations we introduce with key question 1) the phenomenon of desire to die: definition, forms, causes, significance and functions. The sub-headings now read: “Definition of “desire to die”, “forms of desire to die” and “causes, significance and functions of desire to die”.

24. “These concepts from apsychiatric” – do you mean ‘a psychiatric’ or from ‘psychiatric and palliative care perspectives’?

Yes, this is what we mean. In the version of our manuscript we submitted, the sentence reads: "These concepts from psychiatric and palliative care perspective complement each other."

25. Page 12:

*Desire for death and life, dynamics and progression*

Delete "Based on a systematic review....." Begin with

"Desire to die can vary both over time and in terms of its intensity.<sup>22</sup> Additionally, even though it may seem counter intuitive, patients who harbor a desire to die might simultaneously have a desire for life (LoE 3).<sup>22</sup> "

We applied the change as suggested.

26. *Causes, significance and functions of desire to die*

We hope that we understood the question correctly. All text, including all recommendations, refers to one guideline: the German Palliative Care Guideline. They are explained within the manuscript itself, therefore, we cannot link to it.

27. Delete „This descriptive part of the guideline chapter....“

We applied the change as suggested.

When you state „are also in the guidelines“ do you mean everything in the chapter, a particular guideline in the chapter, and if so, what's the difference between a guideline and a recommendation?

If the questions refer to the second sentence after the subheading *Causes, significance and functions of desire to die*, the phrasing is "also described within the guideline". Any reference to a singular guideline in the article means the German Palliative Care Guideline, therefore, we mean everything in the guideline chapter and the guideline in general. Recommendations (as well as statements and informational background text) are presented within the guideline.

28. Page 13

Were they significant differences? If not, then wasn't it hard to interpret if from qualitative research?

We hope we understood correctly to what part of the text the question refers to. If it refers to reference 40 (Rodin, 2008), then yes, differences were significant. We added that information to the text:

"However, those results must be interpreted with caution as statistical differences were significant, but small."

29. Delete „depending on individual...“

We applied the change as suggested.

30. Page 14

3. Screening and assessment

Delete first sentence „Within the German Palliative Care...“. Start sentence with „The thorough...“

We applied the change as suggested.

This statement is based on two systematic reviews with meta-analysis identified via literature search.

We deleted the sentence as suggested.

Rewrite this sentence:

“The guideline group took this indirect evidence gathered among a general patient population and saw it as applicable to patients receiving palliative care with a potential desire to die.”

We changed the sentence to:

The guideline group considered this indirect evidence applicable to patients receiving palliative care and with a potential desire to die.

31. Page 15:

Rewrite sentences:

“It yielded seven tools with the most widely used being the Schedules of Attitudes Towards Hastened Death (SAHD) which is mainly used for research purposes, and the Desire for Death Rating Scale (DDRS) for clinician use.”

We changed the sentence to:

To report and rate the psychometric properties of available assessment instruments for desire to die, Bellido-Perez et al. (2017) conducted a systematic review of 50 studies that yielded seven tools. Among those, the Schedules of Attitudes Towards Hastened Death (SAHD) for research purposes and the Desire for Death Rating Scale (DDRS) for clinician use are the most widely used.

“Professional strategies are based on the fundamental theoretical assumptions about communication in helping relationships.”

We decided to delete the sentence.

32. Page 16:

2nd-3rd lines:

“Five RCTs **were** identified that examine the effectiveness of...”

Toward end of paragraph:

“as these may **also** influence a desire to die (GoR A/LoE 3)”

We applied the changes as suggested.

Bottom of page: “If a patient presents with peracute suicidal ideation and suicidal actions cannot be avoided with other measures, it is recommended to consider admitting the patient to a psychiatric clinic”

No, these recommendations are not affected by the legal changes regarding assisted dying.

33. Page 17/18:

Where you discuss guidelines, and in Table 4 you could mention that the guidelines pre-date changes in the law.

The guideline describes the desire to die and makes recommendations on how to manage it. The legal change has no influence on our description of DD nor on the way to care with the suffering of patients having a DD. We therefore see no need to state that the guideline pre-date changes in the law.

We included the sentence: “The recommendations of the German Palliative Care Guideline continue to apply despite the shift in the legal framework due to the repeal of § 217 and a still pending new regulation of assisted suicide.”

34. Discussion:

You may want to consider looking at this phd thesis focused on issues of suicide and hastened death. See page 144 for a figure on hospice professionals’ interpretations of suicide/hastened death, and when is a death considered to be a suicide:

<https://eprints.lancs.ac.uk/id/eprint/123925/1/2018gersonphd.pdf>

Thank you for suggesting this interesting thesis. Nevertheless, we decided against adding it to our references, since its focus on the distinction of death by natural causes and death by suicide is not the focus of our paper (caring for palliative patients with desire to die).

35. Page 19

“Still, 74% of physicians in Germany state **they** have been asked...”. (delete to, and insert ‘they’)

We applied the change as suggested.

36. Page 20:



“In fact, most of the recommendations are based on expert opinion.” Isn’t expert consensus also ‘opinion’?

This is correct. In the manuscript we submitted, the sentence therefore reads: “In fact, most of the recommendations are based on consensus of expert.”

37. Page 23:

Figure 1 : **Development of the Recommendations about the Desire to Die.** (the original title seems quite lengthy wording)

We chose not to change the title of Figure 1, since it describes not only the development of the recommendations about desire to die, but the development of the whole chapter in the guideline.