**Author’s response to reviews**

**Title:** Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: A pilot study

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**Author’s response to reviews:**

Birgit Jaspers (Reviewer 1):

1. The fact that a hypothetical wish was assessed twice is stated in the limitations section (page 15: Furthermore, the main survey was not validated and thus, all answers should be interpreted as hypothetical desires only. We do not assume or infer any correlation of the hypothetical desires expressed by our participants with actual decisions to pursue or complete MAID). Nevertheless, in the manuscript the term "personal desire for PAD" was used. This seems to be too strong for the question about a hypothetical consideration of PAD for oneself in the future.

   Thank you very much for your comment. All instances of “personal desire for PAD” have been replaced with “hypothetical consideration of PAD for oneself”

2. In the discussion section, the authors state that participants had a higher personal desire for PAD and that the wish to hasten death is independent of pain control. This is misleading, as a wish to hasten death is not measured in this study from the data we can only conclude that a hypothetical consideration of PAD for oneself may not be dependent on pain control (and why should it?).
We appreciate your insight. This has been changed to “Prior studies have shown that the desire for hastened death increases over time despite pain control [21, 23]. Our results, although hypothetical, suggest a similar pattern, with the desire for PAD increasing from baseline to follow-up for all three groups.” (Discussion, Page 13, lines 9-12)

3. Also, there is no description of palliative care 'interventions' (term used on page 8 and 15), it is only known that 2 groups had palliative care service involvement at some point.

Thank you for your comment. We have changed “palliative care interventions” to “initial palliative consultation” (Methods, page 7, line 5) for the new palliative care group. It is stated in the limitations section that “interventions were not standardized, and management varies significantly between providers.” for the prior and ongoing palliative care group. (Limitations, page 16, lines 11-13)

4. Therefore, the full title ("The impact of palliative care…") seems to be too strong for this study, given that there are a) two measurements with ESAS and PPS and b) is no information about treatments and no qualitative data on factors that may have influenced ESAS outcomes.

We recognize your concerns and changed the title changed to: Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: A pilot study.

5. The conclusion drawn from the study that "the role (of palliative care) should be reframed as primarily supportive rather than preventative" is not justified (neither by the design of the study nor the research question or the results).
We agree with your comment and this conclusion has been removed.

6. Table 1 is titled Baseline characteristics but also shows data covering the second assessments (ESAS und PPS at time 2 for which no n is stated in the table).

Thank you for observation. This has been corrected by creating a new table for ESAS and PPS scores at baseline and follow-up. (Primary Outcomes, page 11)

7. A cross-check with the data shown in Figure 1 (Study flow chart) shows inconsistencies regarding the numbers of participants in survey 1 (102) and 2 (70) and makes it impossible to understand the analysis. According to the flow chart the first survey was completed by 102 patients (new palliative care: 64, no palliative care 21, prior palliative care 17), the second by 70 patients (new palliative care: 43, no palliative care 14, prior palliative care 13). However, baseline data are shown for 81 patients (new palliative care: 43 - matching the number of the second survey, no palliative care 21 - matching the number of the first survey, prior palliative care 17 - also matching the number of the first survey).

Thank you for noticing this error. The table now reflects the number of participants at baseline: No palliative care (N=21), New palliative care (N=64), Prior palliative care (N=17).

8. It is unclear, what 18% missing data means, usually missing data refers to missing answers in completed questionnaires. This should be explained and is not clearly addressed (page 6).

This statement is misleading and has been removed.
9. Though the primary objective suggests a clear hypothesis, it is not formulated statistically. Instead, many primary outcomes are mentioned. Primary outcomes are not statistically defined and therefore it is not possible to assess how many tests regarding statistical significance have been performed. This is vitally important information, as the possibility of statistical artifacts (a p-value under 0.05 which has been generated not by real differences in the population, but by chance) rises with each test. Therefore, the level of significance, which is not mentioned in the manuscript, should be adjusted to the number of tests performed to test hypotheses.

There was also no a priori power calculation which suggests that this was an exploratory study. An exploratory study does not justify testing of significance, as it does not allow the formulation of a hypotheses before data analysis. Instead, it is recommended to present descriptive data only. The small group sizes also lead to questions regarding the validity of the statistical analysis.

I would recommend including an additional statistical review.

Thank you for your comment. The study has been reframed as an exploratory pilot study presenting only descriptive data. All measures and reports of statistical significance have been removed and the methods and results sections have been adjusted accordingly.

10. a) references

Ref 1: Error, goes to https://www.cma.ca/En/Pages/error.aspx Thank you. This concern has been addressed.

Ref 12: Error, goes to https://www.ipsos.com/en-us/news-and-polls/overview?id=6626 Thank you. This concern has been addressed.

Ref 17: Error, goes to a table showing data of 2013; data of 2011 are shown at http://www.statcan.gc.ca/daily-quotidien/140128/t140128b001-eng.htm; only data for cancer, not for HIV; however, the latest data available, it seems, are causes of death in 2013, showing 29.8% for cancer - hardly a difference;
therefore - unless other and more recent data are available somewhere else - the sentence (page 5, line 14-19) "These data, however, are out-dated and no longer accurately represent patients dying in Canada; cancer and AIDS accounted for only 29.9% and 0.1% of deaths in 2011, respectively [17]." should be changed, because it gives the impression that more recent data on causes of death show considerable changes. Thank you. This concern has been addressed.

Ref 34: Error, cannot be found. Thank you. This concern has been addressed.

11. b) appendices

Appendices are titled Appendix 1 and Appendix 2, in the manuscript is a reference to Appendix A (page 6, line 32) Thank you. This concern has been addressed.

12. c) figures and tables

Figures and tables need to be checked for missing explanations of abbreviations and axis labelling (e.g. 2b, 2c, 3b, 3c - Likert scale). Figures and tables have been rechecked and edited as needed.

Julia Downing (Reviewer 2):

13. It should be written as a pilot study due to the limitations of the study

We appreciate your comment and have re-written this as a pilot study.

14. Abstract
You need to include some statistics in the abstract - also put in % e.g. 70 our of 102 participants completed both surveys - what about drop out rate, results etc.

Thank you. Descriptive statistics were added to the abstract.

You should include ethical approval

A line about ethical approval has been added under Methods in the abstract. (Page 2, line 20)

I think your conclusions are too strong based on what is really a pilot study

We recognize your concerns. We have edited the conclusions.

15. Background

I think the objectives are too big for this study, which is in effect a pilot study due to the size of the sample. The secondary objectives (i.e. determining whether patients are aware that PAD will be legal in Canada; whether patients are comfortable discussing their views on PAD with family, friends, or their health care providers; and which health care professionals patients would want to provide PAD.) are more realistic from this study than the primary objective.

Your observations are appreciated. Our primary objective has been rewritten as “to explore both general and personal attitudes toward PAD in patients with life-limiting illnesses with varying involvement of palliative care.” (Background, page 5, line 23) Secondary objectives have remained the same.
16. Methodology

- In the abstract you mention three groups of patients i.e.: one with new referrals to palliative care; one with no palliative care involvement; and one previously and currently managed by a palliative care team, whereas later in the text you talk about the third one being prior PC - I think you need to be clearer - maybe it prior/existing palliative care - but it needs to be clearer.

Thank you for your comment. We have clarified this definition. Prior palliative care has been defined as “having prior and ongoing palliative care involvement” (Methods, page 7, lines 6-8).

- The time frame is very short - two weeks apart, and those new to palliative care will have probably only had one appointment and we know the importance of ongoing and follow up appointments, so I don't think it is realistic to make conclusions as to the impact of PC on and individuals perspective on physician assisted suicide in this time frame.

Thank you for your comment. The time frame was chosen to mirror the proposed wait period between an initial assessment and a second assessment for PAD eligibility. We have edited our conclusions on the impact of palliative care accordingly.

- The questionnaire - you use some validated tools e.g. the ESAS and PPS, but your questions with regards to PAD are not validated and I don't think that they are sensitive enough to show change over a two week period i.e. 1) Do you think physician-assisted death should be available to patients with serious diseases, illnesses, or disabilities that cannot be cured and who cannot tolerate their suffering? 2) Given that you have a serious disease, illness, or disability, in the future, would you consider physician-assisted death for yourself? Whilst you mention they are not validated in the limitations this should be expanded and discuss issues re sensitivity to change etc.
We have considered your concerns. We have omitted the split-plot ANOVA as we are unable to speak to the validity and sensitivity of our measures.

- The sample size is small with small numbers in each group - did you do any sample size calculations??

Thank you for your comment. Though we preformed rough sample size calculations, we have rewritten this study as a pilot considering the small sample size, and the absence of more robust power calculations.

- You should include ethical approval here and not just at the end of the manuscript Added. (Methods, page 6, lines 20-22)

17. Results

- There should be some discussion re the questions and whether they are sensitive to change etc - was a pilot done before this or is this in effect the pilot? I think the wording of the questions need changing so they are sensitive to change.

We acknowledge these concerns and have re-written this as a pilot study. We also recognize the limitations regarding validity and sensitivity to change and will discuss this as a recommendation for a future study.

- You also ask about whether they would be comfortable discussing their options with family or friends - does this differ if they would like PAD or if they don't want it - it may be easier to talk about it if they definitely don't want it.
Your insight is much appreciated. We have added this as a discussion point, but due to the small sample size and limited power, would be unable to comment on a significant relationship between comfort discussing PAD and hypothetical considerations of PAD for oneself. (Discussion, Page 15, lines 5-8)

18. Discussion

  o This is very short and should be expanded - there is more to talk about.

Thank you, we have expanded this section as suggested.

19. Conclusions

  o I think your conclusions are too strong for such a small study, and without ongoing exposure to palliative care.

We thank you kindly for your comment, we have significantly modified our conclusions to reflect the limitations and the nature of this study as a pilot.