Reviewer's report

Title: Unbearable suffering in end-of-life cancer patients A cross-sectional study in primary care in the Netherlands

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Reviewer: Tracy Schroepfer

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Reviewer's Comments

This paper addresses an important topic, and does so in a well-written paper. The introduction and background are clear, succinct and provide the reader with a very clear idea as to the goal of this study. Attention needs to be given, however, to the Methods, Results and Discussion sections, as well as to grammatical issues, missing words, etc.

Major Compulsory Revisions

1. Page 8: The authors talk about developing the SOS-V due to an instrument being available. Since this is a newly developed instrument, it is important to address issues of reliability and validity (face validity? expert panel validity?). How was the instrument developed? How were the items chosen? More information needs to be provided on the instrument.

2. Page 9: Since the response set for the SOS-V was dichotomized, it would be helpful to know what a rating of 2 & 3 represented. The authors note that 1 is “not at all”, 4 is “seriously” and 5 is “very seriously” but do not note within the text (I see it in the table) the meaning of the values 2 & 3.

3. Tables 1 & 2: I feel these tables should be combined into one. The authors note on page 8 that “suffering compromises a broad spectrum, divided over physical, psychological, social and existential and therefore to measure suffering a comprehensive instrument is required.” I agree with the authors and it fits with the holistic approach that is palliative care. To divide the domains into medical and other, takes away from the holistic approach. This same issue also holds true for Figure 1.

4. Table 2: The authors do not talk in the text about how variables were chosen for the domains. It is not clear why the aspect of shame was included under the environment domain. In addition, it seems that the environment domain is really a support domain (except for shame, which I am do not feel fits into either the environment or support domain). Why does The Nature and Prognosis of Disease domain have only two items, both of which focus on fear of future suffering and fear of future failing strength to bear suffering? Based on the literature written on prognosis, it seems other items would be included. I think these questions could be answered by responding to point 1 above.

5. Page 9: Under the Analysis section, the authors note that bearing capacity
was an “inventory study of sources and influences.” The authors need to provide more detail regarding how the analysis was conducted. Did they use a directed content analysis, etc.?

6. Page 10: It would be useful to the reader to have some idea of the demographics associated with the results reported. Were respondents who reported more unbearable suffering in one domain of a different age than those reporting unbearable suffering in another? What age, cancer type, etc. was associated with the overall unbearable suffering, etc. What about the sources of the capacity to bear suffering: were there any interesting findings concerning demographics? Were there any interesting findings with regard to the results and respondent demographics?

7. Page 12: The authors note that “The most frequent unbearable aspects in the collective other domains were loss of control, being bedridden, trouble accepting the situation, not being able to do important things, help needed with housekeeping and impaired capacity to perform activities (27%-55%).” In listing “loss of control” first, it would seem that this item would show up on the table as the most frequently mentioned and yet it was fourth. In addition, loss of control is noted in the discussion section but not the results section. This discrepancy also holds true for the item bedridden.

8. Page 12: The authors state that the, “low number of reported additional unbearable aspects may indicate comprehensive measuring”; however, it could also mean that asking respondents lists of pre-determined unbearable aspects prior to giving them an opportunity to list what they felt were aspects influenced them.

9. An additional limitation is the use of an untested instrument to measure unbearable suffering.

Minor Essential Revisions
None

Discretionary Revisions
1. A number of sentences throughout the manuscript lack punctuation that assists the reader in reading the material correctly. For example, on page 4, second paragraph, the sentence that begins with, “In primary care world-wide tens-of-thousands…” requires a comma after the word “world-wide” in order for it to make sense. Grammatical issues are prevalent in the paper.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Not suitable for publication unless extensively edited

Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:

I declare that I have no competing interests.