Author's response to reviews

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

Authors:

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Version: 3 Date: 14 May 2012

Author's response to reviews: see over
Dear editor,

Thank you for the comment on our paper. We also thank Tracy Schroepfer and Stephen Workman for reviewing the paper and providing comment, permitting us the possibility to improve the paper.

We have adapted the title of the paper. In the present form it is more representative of the content of the article.

The comments have been used to revise the manuscript. A point-by-point response to the concerns is attached.

We hope you will find the concerns to be satisfactory addressed,

Sincerely,
Also on behalf of Ad Kerkhof, Gerrit van der Wal and Bregje Unwuteaka-Philipsen,

Cees Ruijs, presenting author

REACTION TO REVIEWER REPORTS

Reviewer’s report

Title: Unbearable suffering in end-of-life cancer patients A cross-sectional study in primary care in the Netherlands
Version: 2 Date: 31 March 2012
Reviewer: Tracy Schroepfer

Reviewer's report:
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.

Comment:
The Methods, Results and Discussion sections have been rewritten with the objective of making the document easier to read. Grammatical issues have been solved using comment provided by a colleague, who is a native English speaker. Missing words have been added.
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.

Comment:
*Psychometric analysis of the instrument has been performed previously, and is described in the article in which the instrument was presented.*

We added in the text (page 8, lines 10-11): “The development of the instrument, including analysis of validity, is described in detail elsewhere [26].”

Furthermore, additional information on the development is now provided in the section “Measurement instrument” (page 8-9).

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.

Comment:
The ratings 2 and 3 have been added in the text (page 9, lines 5-7): “A uniform 5-point scoring scale is employed, with a description of scores: 1-not at all; 2-slightly; 3-moderately; 4-seriously; 5-very seriously, hardly can be worse.”

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.

Comment:
Combining table 1 & 2 into one table would make the table too big. We did change the names of table 1 and 2 to table 1A and table 1B, to make clear they belong together. Further the text was made more explicit, according to the literal text of the domains in the instrument.

The domain of “medical signs and symptoms” is implemented in the framework, and is part of the comprehensive design of the instrument. The objective of explicating the domain of medical signs and symptoms was to assess the position of traditional medical aspects in the spectrum of suffering (which has clinical implications).

This was made explicit in the text (page 8, lines 12-14): “Assessment of suffering requires a framework of suffering [32], which was required to include the domain of medical signs and symptoms, to assess the position of traditional medical aspects in the spectrum of suffering. A framework consisting of the following five domains provided a practical, functional construct: (I) medical signs and symptoms; (II) loss of function; (III) personal aspects; (IV) aspects of environment and (V) nature and prognosis of the disease.”
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 do not feel fits into either the environment or support domain).

Comment added:
Page 8, lines 20-23: “The domain of environment included (lack of) support and aspects of social interaction, such as experiencing to be a burden to others and experiencing symptoms to be embarrassing, resulting in withdrawal from social interaction.”

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.

Comment added:
Page 8, line 23 and page 9, lines 1-2: “Fear of future suffering, due to either progression of symptoms, or impairment of strength to bear the suffering, constitute two aspects which are frequently mentioned in Dutch literature concerning EPAS.”

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.?

Comment added:
More details have been provided:
Page 9, line 14: “Exact phrases of the answers were immediately written down by the interviewer.”

Page 10, lines 6-8: “All literal formulations of sources were compiled in a table, corresponding answers were combined, codes were assigned and the sources per patient over all interviews were assessed.”

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?

Comment:
The number of patients in the study was too small to provide further differentiation concerning 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.

Comment added:
The text has been adapted; page 13, lines 4-8: “The other half of the unbearable aspects occurred in the collective domains of loss of function, personal aspects, environment and nature and prognosis of disease. The most frequent unbearable aspects were impaired capacity to perform activities, feeling dependant, help needed with housekeeping, not being able to do important things, trouble accepting the situation, being bedridden and loss of control (27%-55%).”

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.

Comment:
The sentence has been removed.

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

Comment:
The text has been adapted, page 14, lines 5-6: “The use of a largely untested instrument is another limitation.”

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.

Comment:
Grammatical comment was provided by a native English speaker and the text has been adapted throughout 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.

Reviewer's report
Title: Unbearable suffering in end-of-life cancer patients A cross-sectional study in primary care in the Netherlands
Version: 2 Date: 23 March 2012
Reviewer: stephen workman

Reviewer's report:
This is a well written study examining an important element of end of life care and one that is indirectly relevant to considerations of euthanasia and assisted suicide. It should be published. I believe a palliative care journal is the appropriate venue. Regarding the points 1-9: Yes to all with one proviso
The title includes the term "Unbearable suffering" In the article "unbearable suffering" is defined as : A subjective experience of suffering that it is so (Omit it?) serious and uncontrollable that it overwhelms one's bearing capacity"
I think overwhelming would be a better title descriptor than unbearable?

Comment:
"Unbearable suffering" is medical terminology which is frequently used. The terminology and as such was formulated in the developmental set-up of this study, and therefore cannot be changed. The formulation "unbearable suffering" also is part of legislation concerning euthanasia and physician-assisted suicide.
This has been addressed in the text (page 4, lines 8-11):

"In the contemporary debate about euthanasia and physician assisted suicide (EPAS) unbearable suffering is a frequently mentioned component [3-5]. Legislative criteria formulated in relation to EPAS require physicians to assess whether unbearable suffering is present [6]."

To my way of thinking unbearable suffering would result in a patient asking to die or to receive euthanasia, or want symptom control to the point of being rendered unconscious if necessary--that is death or sedation is a better alternative than an unbearable degree of suffering--as in a level of suffering that cannot be withstood or borne. Conversely, one could argue that overwhelming suffering designates a level of suffering similar to overwhelming but does not carry the same connotation in terms of demanding or implying that there is a desire that relief from suffering be provided at any cost.

Comment:
Unbearable suffering is frequently associated with euthanasia and physician-assisted suicide, due to the frequent relation which is provided on the subject in literature. However, unbearable suffering has other clinical implications, which are frequently overlooked. Asking the patient whether unbearable suffering is present provides
direction for adjustment of palliative interventions. Text has been added (page 4, lines 4-8):

“For physicians, relief of suffering is an important goal of the care they provide [2,3]. Sometimes palliative interventions do not take away the suffering. An important question for physicians is to ask their patients whether the suffering is bearable. If unbearable suffering is present, physicians need to assess which aspects are unbearable, to adjust palliative interventions.”

Level of interest: An article of importance in its field
Quality of written English: Acceptable
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.