Author's response to reviews

Title: European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion

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

First, we would like to extend our gratitude towards the reviewers for their efforts and well-found comments. We concur to the reviewers’ and editor’s main criticism that we should not treat the texts we refer to as the EAPC framework as a uniform body in the way we do. We have tried to revise the text accordingly and tried to adapt the level of ambition. Instead, we focus on the latest framework (Cherny NI, Radbruch L, The Board of EAPC. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med 2009, 23:581-593. Henceforth: the EAPC framework) and discuss two issues in particular with reference to that text.

The English has been checked by the professional copyeditor Roger Tanner: Roger Tanner <roger.tanner@ordvaxling.se>

In the following, we give a point-by-point response to the reviewers’ comments.

“Reviewer: a a
Reviewer’s report:
Thank you for giving the opportunity to read this paper. This paper presents some interesting thoughts on palliative sedation. Notwithstanding, many questions raised after reading of this text. For the purpose of this review, I will restrict myself to the major items that are of critical importance for this paper (in my opinion).

1. The title of this paper suggests that the recently published EAPC framework for palliative care will be discussed. As far as I know, this is also the only authorized text of the EAPC on palliative sedation. However, this official EAPC-publication is only explicitly discussed on 2 (out of 10) pages, namely in the section on ‘refactory symptoms’ and in the section on ‘intending death’. In the background section the authors state that: ‘we will focus on texts that explicitly set out to make policy recommendations leveled by the EAPC or some of its representatives’ (p1). However, my critique is that most of the papers referred to by the authors, although published at the forum site of EAPC, seem intended (by the EAPC) as discussion papers and not as formal position papers. The publication of De Graeff & Dean consists of a literature review and, although supported by an EAPC consensus panel, it does not seem to be a formal EAPC paper also. In my opinion, it is highly problematic to present this collection of papers as a more or less coherent EAPC framework on palliative sedation, as suggested both in the title and in the background section. This is also confusing because there is an explicit EAPC position paper with the word ‘framework’ in the title (the publication of Cherny et al). This raises serious problems for the remainder of the paper. For example in the discussion on terminology the authors wonder ‘What terminology and definitions are actually proposed and used within the EAPC framework of palliative sedation?’ and continue their discussion with citations from other papers. At the end of that analysis they argue that one of the most important tasks of the EAPC seems to ‘fend off any accusations that palliative sedation is even remotely related to euthanasia’. But this conclusion is clearly not retrieved from the official framework publication of Cherny et al. which is not even cited in this paragraph.”

Cover letter

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2. It seems that the authors want to combine two perspectives in their article, namely to start an ethical discussion on the difference between palliative sedation and euthanasia (1) and to analyze the EAPC framework on palliative sedation (2). As a reviewer, I am of the opinion that the current attempt of the authors to combine these two perspectives is problematic (see also the remarks above). I would suggest that the authors clearly choose one perspective. The first perspective will require more detailed (ethical) analysis, the second perspective requires a thorough analysis of the EAPC framework publication of Cherny et al.”

We have chosen to discuss two of the most controversial ethical issues the EAPC framework addresses and have expanded on these issues, namely on 1) intolerable suffering and refractory symptoms, and 2) the debate on slow euthanasia. The aim to analyze the text is therefore dropped (although we have to interpret what is said in the framework in order to discuss it, which makes some level of analysis unavoidable).

“3. The authors conclude that ‘according to this reasoning, abstaining from shortening the dying process if it contains unbearable suffering is unethical’. Unfortunately ‘this reasoning’ is not very clear to me. Does this imply, according to the authors, that the dying process of patients who suffer unbearably can or should be shortened, regardless of their consent? Also, I do not agree with the suggestion of the authors that the EAPC position that rejects the deliberate hastening of death through palliative sedation does not make sense. For example, I think that many persons, both those who accept and those who do not accept euthanasia, would agree that ‘normal’/’standard’/’regular’ palliative care programs should not aim at hidden or slow euthanasia.

The reasoning referred to is eliminated in the current version. As regards the deliberate hastening of death, we never claimed that the position does not make sense, nor that it is unreasonable to claim that standard palliative care programs should not aim at slow euthanasia. What we did claim, and still claim, is that it is unclear what the border between slow euthanasia and palliative sedation is more specifically, in what sense this border can be formulated in terms of intentions and what the moral difference between deep continuous palliative sedation in the end of life and euthanasia is. We have tried to clarify this in the present text.

4. It is not clear what is meant with the claim in the summary and in the abstract that the EAPC takes ‘a less patient-centered stand than what is defensible’. Also, it is not clear how this relates to the conclusions from the autonomy section.

We agree that the autonomy-claim in the summary should have been substantiated further. However, since the present text focus upon the EAPC framework, which does not explicitly discuss autonomy, we have eliminated this part. We have instead focused upon the discussion the reviewer found interesting, which is also included in the summary.
"Reviewer: Bert Broeckaert
Reviewer's report:
Major Compulsory Revisions
1. The article overstates the unity of the texts that according to them constitute "the EAPC framework" on sedation. The origin, intention and status of each of the texts discussed is very different. For this reason it would be better, for each of the different items you want to discuss, to make a detailed and strict comparison of each of the texts (and it would be better to limit the number of texts you want to compare)."

We agree and have changed the text as to focus on the EAPC framework.

"2. There are very few references to the rather large literature on sedation (including specific articles on the issues you want to discuss) in your text. In this way you isolate the papers you discuss from the (scientific) context in which they have been written. See a.o. Claessens ea in Journal of Pain and Symptom Management for an overview of the clinical studies. This paper should include more references to the wider (and already much older) discussion (e.g. the discussion on slow euthanasia; the definition; the terminology of sedation; the life-shortening effect of sedation; food and fluids...) and thus put the papers discussed here into perspective." 

We certainly agree and have added several references to the older discussions (e.g. ref. 6-9). However, since the text has been made more concise and many parts of the text have been eliminated, the total number of references is still less than in the original version.

"3. The paper would be stronger if it would address fewer issues regarding sedation but discuss them more in depth; now it discusses each of the issues rather superficially."

We have tried to rectify the text in these regards by focusing on 1) intolerable suffering and refractory symptoms, and 2) the debate on slow euthanasia. The discussions on these topics have been extended.

Minor Essential Revisions
"1. background: specify which texts you are referring to when you write 'those published on EAPC's official website'

This part is eliminated in the present version.

"2. the decision to withhold or withdraw nutrition and hydration is a different decision than the one to sedate. You are essentially talking about two separate decisions. Your discussion is not clear on this."

We certainly agree that these are two different decisions and tried to make this as clear as we could. However, since we have no objections to the discussion about nutrition and hydration in the EAPC framework, we have eliminated this part, together with the comparison between the decisions.

"3. euthanasia does intend death; sedation does not (and usually doesn't have a
life-shortening effect either) - these are important differences. Of course physicians do not perform euthanasia because they enjoy killing their patient but because they want to relieve unbearable suffering. But that is not enough to conclude that the intention of both acts is identical. Though I am not impressed by the article in its present form and though the argumentation offered does not convince me (but this is not the reason not to accept the article in its present form), I think that after a serious revision this challenging article can be accepted.

We have not claimed that “the intention of both acts [euthanasia and sedation] is identical”. What we did claim, and still claim, is that the difference is not as great as might be the first impression and that this first impression somewhat fades when one is clear over an ambiguity in the term “intention”. We have tried to clarify this position.

Reviewer: JUDITH RIETJENS
Reviewer’s report:
General
“The authors reflect in their paper on the EAPC framework for palliative sedation. They focused on texts that explicitly set out to make policy recommendations for palliative sedation, leveled by the EAPC or some of its representatives. These texts include texts about palliative sedation posted on the EAPC forum (written by several authors), De Graeff & Dean’s recommendations for standards, the recent EAPC recommended framework for palliative sedation, and 2 papers written by Materstvedt et al about euthanasia and physician assisted suicide on behalf of the EAPC ethics task force.

Overall, the paper raises several interesting issues for discussion, and appears to be well thought through and clearly presented. There are a few suggested changes that would help to further focus and clarify things for readers.

Major Compulsory Revisions
1. The aim of this paper is to provide a critical appraisal of some of the underlying principles of these texts. However, while there are indeed several common elements in these documents, there is also variety in viewpoints and in arguments that are used, eg with respect to term, judgment of refractory symptoms, sedation for existential suffering, and the use of the doctrine of double effect. Apparently, the EAPC recommendations are not that straightforward or comparable across these documents (which can be understood because these documents have different aims, were written by different people, in different points in time). Commenting on the different documents in one paper results in a rather long and unfocussed paper that could gain strength, in my opinion, by focusing e.g. on the sedation documents (leaving out the euthanasia papers, because that does not seem the focus), or even by choosing to comment only on the most recent EAPC publication about their suggested framework. As it seems to me, the main points the authors want to make could also be made while only focusing on this recent EAPC publication. In any case, the authors should in my view better motivate the choice of the documents, the fact that there are differences between these documents (and what this means for their use), and also it should be motivated how and according to which criteria they identified the themes they wanted to comment on.”
We agree and have adopted the reviewer’s recommended strategy to focus on the most recent EAPC framework.

“2. In definitions the authors discuss the fact that the definition of continuous PST includes normative elements that distinguish it from euthanasia/assisted suicide. They acknowledge that such a definition might, however, be of use for empirical research. It can also be argued that such a definition might not be suitable for empirical research because empirical research would be better served with descriptive definitions, see e.g. JPSM 2008; 37:e10-1.”

We agree. However, since the EAPC framework does not elaborate on the question regarding the definition of palliative sedation, we have eliminated this discussion from the present text.

“3. Paragraph intolerable suffering and refractory symptoms. The authors state that de Graeff’s definition does not include psychological/existential suffering; however, their definition does not specifically address the source of suffering, thus therefore does not exclude psychological/existential suffering.”

We agree, but we tried to make another point, namely that de Graeff’s definition holds refractory symptoms to be something else than mere intolerable suffering, so existential intolerable suffering in the end of life would be an insufficient indication for palliative sedation, according to the definition. We have tried to make this explicit.

“4. Same paragraph. The authors argue that the EAPC is apparently not concerned about life-shortening when this concerns the forgoing of nutrition or hydration. However while the recent EAPC framework does indeed not specifically address this issue, de Graeff does pay attention to it, although not in a very concrete way (“If the sedation is intended to be transient or if deep sedation is considered for a patient with a life expectancy of longer than a week, then hydration may be medically indicated”).”

We agree, but we have eliminated this discussion (see answer 2 to the second reviewer for an explanation).

“5. In the remaining of the paragraph, the authors address the question whether proportional sedation should also be used when there is a risk that this might hasten death. While the authors claim that the use of sedation could in fact hasten death, this is not acknowledged by the EAPC. For the EAPC therefore there is no reason to compare the life-shortening effect through the forgoing of nutrition/hydration versus through the use of sedating medications. The argument that sedation can shorten life needs therefore, in my view, some more foundation and clarification.”

As we read the EAPC framework, we find that it does acknowledge that sedation, although likely very rarely, may hasten death (p. 582). They even add a reference where empirical data supports this. We have tried to clarify this in the present text.

“Minor Essential Revisions
Two times, the issue of intent is discussed, in a partly overlapping way (terminology and intending death). The paper will gain focus if this could be
We agree and have integrated these parts in Intending death.

“Paragraph nutrition, hydration, and sedation. Please add a reference for “With patients suffering from brain tumors […]” and for “In other cases, where nutrition and hydration is provided […]”.

These passages are eliminated in the present text.

“Discretionary Revisions
The authors raise several questions but in general refrain from suggesting alternative solutions or recommendations. Doing so could make their points stronger.”

This point seems correct but, in all honesty, we do not think that we are able to present any concrete recommendations. However, we hope that we convey a message about the spirit in which we would like to see frameworks on palliative sedation written: that considerations regarding the best interest and autonomous decisions of the patients should guide the characterisation of the refractoriness of symptoms and overrides considerations about the possible intentions of health care professionals. We have therefore added this point in our Conclusions.

Since the manuscript has been entirely restructured, we were not able to highlight the changes without highlighting the whole manuscript. We hope that the reviewers can see the similarities and differences in content anyway.

We still think the article merits publication, since it makes a contribution to the ongoing discussion about contested ethical issues regarding palliative sedation in the end of life. The EAPC framework should be further discussed in relation to these issues.

This manuscript has not, in parts or as a whole, been published previously and is not under consideration in any other journal. Nor has its content been presented in any conferences. All the authors have read and agreed to the content of the manuscript.

Best regards,

The authors
(Niklas Juth, Anna Lindblad, Niels Lynöe, Manne Sjöstrand, Gert Helgesson)