Author's response to reviews

Title: Incidence and changeability of explicit requests for euthanasia in a palliative care hospital

Authors:

Frédéric Guirimand (frederic@guirimand.fr)
Etienne Dubois (etienne@live.fr)
Lucy Laporte (laporte@adc.asso.fr)
Jean-François Richard (jfrichard@adc.asso.fr)
Danièle Leboul (dleboul@adc.asso.fr)

Version: 5  Date: 11 October 2014

Author's response to reviews: see over
Author's response to reviews

Title: Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files

Authors:
Frédéric Guirimand: fguirimand@adc.asso.fr
Etienne Dubois: etiennedubois@live.fr
Lucy Laporte: llaporte@adc.asso.fr
Jean-François Richard: jfrichard@adc.asso.fr
Danièle Leboul: dleboul@adc.asso.fr

Version 4: October 2014

Author's response to reviews: see over
Reviewer's report

Title: Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files

Version: 3 Date: 19 August 2014

Reviewer: Melanie M Smith

There are no Major Compulsory Revisions

Minor Essential Revisions

<table>
<thead>
<tr>
<th>Reviewer</th>
<th>Response</th>
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</thead>
<tbody>
<tr>
<td>1 - There is a grammatical error in the second sentence of the methods section of the abstract. It should read “an euthanasia-like practice”</td>
<td>This sentence has been deleted from the new version</td>
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<td>2 - In the third paragraph of the background, there are two periods at the end of the first sentence</td>
<td>Corrected</td>
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<tr>
<td>3 - In the first paragraph of the Background, the article states that there is an impression that caregivers are rarely confronted by euthanasia requests. I believe this is referencing the third citation but it isn’t completely clear. I simply think it should be more explicit. Who are the caregivers and what is the origin of this impression?</td>
<td>No reference was associated to this impression that caregivers are rarely confronted by ER. This idea and the corresponding sentence have been deleted from this most recent version.</td>
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<td>4 - In the Discussion section, the first paragraph entitled “Persistent of inpatients’ request for euthanasia,” does not address whether or not the response to these requests influences persistence. The previous paragraph briefly mentions that doctors’ attitudes may influence demands. Doctors’ attitudes may also influence persistence. If a doctor’s attitude could influence a patient’s request, couldn’t legality and availability of euthanasia also influence patient requests for euthanasia and the persistence of these requests? Perhaps in a country where physician-assisted-suicide is legal, the request would be more persistent as the patient would get a favorable response from the caregiver</td>
<td>We agree with these remarks. To reinforce this idea, we have added a sentence about the fact that patients who expressed an ER may continue to desire ER after their requests were refused but they may subsequently be silent about it (Pasman et al., 2013). A sentence about the possible consequences of the legislation on euthanasia or physician-assisted suicide on the persistence of the requests has been added.</td>
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5 - I believe table 1 lists all of the search terms but it is far from exhaustive, for instance it doesn’t contain terms like “end my life” or “kill myself.” This could lead to significant under-reporting of all three categories and should be addressed in the discussion.

We think that this is an issue arising from translation. We used a large panel of French words as indicated in box 1 “with all combinations bringing together the following two groups of terms: 1 Leave, die, death; 2 Request, want, quickly, wish, desire”. We also took into account the typographic errors and spelling mistakes in the carers’ notes. We excluded 84% of the extracted notes (see table 1) after reading the context. We think the risk of under-reporting is very low.

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

**Quality of written English:** Acceptable

**Statistical review:** Yes, but I do not feel adequately qualified to assess the statistics.

**Declaration of competing interests:** I declare that I have no competing interests
Reviewer's report

Title: Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files

Version: 3 Date: 19 August 2014

Reviewer: Bregje D Onwuteaka-Philipsen

This is an interesting study on a difficult to study and not studied much, especially in countries (most) where euthanasia is not allowed. However, I have several suggestions to further improve the manuscript.

Major compulsory revisions

<table>
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<tr>
<td>1 - The research questions are not described very precisely in the introduction and therefore do not exactly reflect the data presented. One is about the incidence of death wishes, suicidal thoughts and requests for euthanasia (table 2). Another one is about patient characteristics related to this wishes (table 3). Finally you want to study changes over time. This is very interesting, but with the methods of your study I doubt whether it is possible to quantify how many people changed. I think I would limit the question to explore how these requests can evolve (in some that are reflected in patient files and that you describe in table 4)</td>
<td>To respond to the referee’s comments here, the introduction has been rewritten to precisely describe the aim of the study. The article focuses on the incidence of wishes to die (WD) with various expressions. Changes over time are reported more qualitatively than quantitatively. “The aim of this study was to evaluate what carers reported about what the patients said them about their WD. The originality of our work is that it distinguishes between, and quantifies, WD which require an act (ER, or ST) and the other wishes to die (OWD), and considers how they change”.</td>
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<tr>
<td>2 - You distinguish wishes to die, thoughts of suicide and euthanasia requests. I would think that all these group have a wish to die, with two subgroups that you can distinguish because they express it in a way that includes an action (euthanasia or suicide). In line 15 and 16 you seem to also have this view: ‘... distinguish clearly between ER or TS and OTHER wishes to die’. However, in describing the results (and discussion of the results) this notion is not always followed. The incidence of death wish should then be 9% (195/2157; in table 2 mistakenly you put 43% in the table). This group can be divided in people who expressed it (only) as a death wish (147-26-2?), people who expressed</td>
<td>• We agree with this major remark: all the three groups defined in the earlier version are WD. The three groups have been renamed as suggested: ER (euthanasia request), ST (suicidal thought) and OWD (other wish to die). Each note was attributed to one group according to an order of priority: ER first, then ST and finally OWD. The 195 patients were then classified into three groups according to the same order of priority. We have as a consequence modified the whole text, the tables and the statistics according to these three groups.</td>
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|                                                                          | • The mistake in table 2 has been corrected.  
|                                                                          | • In the new figure 1B, the distribution |

thoughts of suicide (17-2?; if you let euthanasia request prevail over suicidal thoughts) and people who requested euthanasia (61). It would also mean that figure 1 could change into one big circle with death wishes in which there are two overlapping circles of euthanasia requests and suicidal thoughts expressed.

The tables have been redesigned in line with the reviewer’s suggestions:
- The titles are more concise and at the top of the table
- Table 1: Classification of the patients into the three groups of WD
- Table 2 : Characteristics of the patients
  - The number of notes in the column heading of notes and the number of patients in the column heading of patient.
  - In a footnote : * 33024 and 195862 notes from medical and paramedical staff, respectively
  - Various categories of “other” have been deleted. The vast majority (84%) of withdrawn notes are reported in the last line.
- Table 3 (= table 2 now): we have changed “hospitalized patients” to “all patients”
  - The column “repeated ER” has been deleted.
  - As suggested, the other columns have an overarching heading “wish to die” subdivided in four columns: total, ER, ST, OWD
  - We prefer to keep the ST group: as mentioned in the discussion, this small number could be related to the lack of communication about assisted suicide in France, unlike in Switzerland.

4 The limitations of the methods used should get more emphasis because they have implications for the interpretation of the study. I would place them more in front

The discussion has been rewritten to respond to these points. The limitations of the methods are more clearly emphasized; this appears at the beginning of the
of the discussion (after a few lines in which the results are summarized for instance). The main limitation of studying patient files is the risk of underrepresentation. Not all conversations will end up in patient files, certainly when it concerns this type of subject and something that does not need a clear action / decision-making to follow. Certainly when somebody repeatedly requests euthanasia or expresses a death wish I can imagine it will not be written down every time (thus making changes difficult to quantify). Another limitation is that the staff writes down their interpretation. This stems from the limitation that you did not ask the patients themselves. Another, more important, consequence of this is that only the death wishes and euthanasia requests that are expressed to staff could have end up in the patient file (a second reason for underrepresentation). This should be mentioned in the limitations section, and can also be taken into account in the manuscript by avoiding talking about ‘having a death wish’ but about ‘expressing a death wish’. Especially for euthanasia requests it can be likely that people do not request it, because they know it cannot happen. With regard to repeatedly requesting euthanasia or talking about death wishes, a recent study showed that after a refusal of a request communication about it often stops (Pasman, 2013 patient education and counselling).

The beginning of the discussion highlights the risk of underrepresentation of ER: the reviewers’ comments have been taken into account in the revised manuscript. “First, the resistance to speaking and writing about ER...”

“Second, carers may feel helpless in response to such demands: they do not lead to any clear action or even decisions”.

“Third, the collection of ER depends upon the sense of WD the carer gave to what he / she heard...”.

As suggested, we now refer to “expressing a death wish” and never “having a death wish”.

The fact that people do not request euthanasia because they know it cannot happen is also discussed: “Possibly, in a country where euthanasia or physician-assisted-suicide is legal, requests would be more frequent and persistent as the patient is more likely to receive a favorable response from caregivers...”

The question about the influence of a refusal following an ER is also addressed: “By contrast, patients who express an ER may continue to desire ER after their requests have been refused but they may subsequently keep silent about it [Pasman 2013”]

Minor Essential Revisions

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<tr>
<td>1 - The title should include both euthanasia requests and death wishes. I would prefer a title that includes the method of the study. In light of my previous remarks on changeability I would</td>
<td>We agree and have changed the title as suggested: “Death wishes and explicit requests for euthanasia in a palliative care hospital: an</td>
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</table>
not emphasize that in the title. Suggestion: Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patient files

| 2 - Better to call table 1 a box | Table 1 is now a box. |

**Level of interest:** An article of importance in its field

**Quality of written English:** Needs some language corrections before being published

**Statistical review:** Yes, and I have assessed the statistics in my report.

**Declaration of competing interests:** I declare that I have no competing interests