Author’s response to reviews

Title: Prevalence and profile of unrecognised palliative patients in hospitals

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Author’s response to reviews: see over
Dear Editor

You can find the answers to your questions and those of the reviewers.

*English*

The English has been revised by 2 native English speakers (one American and one English).

*Ethics and Informed consent*

The fifth paragraph of the section Method mentions these topics with more details. It appears in blue. Indeed, we have confirmed in the article that a positive advice was given to this research work by the Ethics Committee of our university hospital and that this Committee had checked that the work was done according to the Belgian laws (see the sentences on ethics committee approval).

The president of the Ethics Committee considered that this survey did not correspond to a experimentation "on the patient" because it was an interview of the caregivers and not an interview of the patient himself. The caregiver was of course allowed not to participate. Moreover, every patient hospitalised in our hospital signs a document called ‘regulation of internal order’ where he agrees that the data and samples (under certain conditions) may be used for research works -except of course if the patient does nor agree-. This document indicates that the research work has to be approved by the Ethics Committee (with a scientific background and the respect of confidentiality).

*Highlight changes*

The changes introduced after the first review appear in red.
The changes introduced after the second review appear in blue.
Dear Mrs Gott

Thank you for your remarks.
The English has been revised by 2 native English speakers (one American speaker and one English speaker).

Dear Mrs Becker

Thank you for your remarks.

Dear Mrs Bernacki

Thank your for your remarks. Here the answers to the last one (first and second review)

Remark at the first review:

Also, is it possible to provide to agreement between the three nurses involved in the study, ie. If three of the RN all evaluated the same 20 or 30 patients, then you could provide a kappa statistic for your method of defining patients (“incurable, progressive, life-threatening disease”) which would improve the scientific validity of the study. Finally, please describe the experience or training of the nurses.

It is not possible to provide a K statistic. The timing proposed by the Health authorities sponsoring the project was short. Moreover, due to their own work, the study nurses have not begun to work in our team at the same time. Each study nurse has been trained individually. The preparation of the survey is described in the 11th paragraph of the Methods section.

Remark at the second review:

‘The authors have clarified all of my questions, except regarding the degree of agreement-disagreement between study nurses for identifying patients with “incurable, progressive life threatening disease”. I think if the authors addressed this, and selected a smaller sample of patients, it would lend better confidence to their data.’

I think there is some misunderstanding. The study nurses must not identify the patient as palliative or not (they may not do this). The patient must be identified as palliative by the caregiver (physician and / or nurse) mainly in charge of him. The study nurses must only ask to the caregiver ‘are you in charge of patients suffering from an incurable, progressive, life-threatening disease, with no possibility of obtaining remission, stabilization or improvement of this illness’. The study nurses did not evaluate any patient nor have any access to the patient’s record. Moreover the study nurses must not control in the medical record if the caregivers’ answer was correct or not.

If I transpose your remark, the agreement-disagreement should be done between the caregivers of the participating hospitals.
Rosenwax et al (Palliative Medicine 2005; 19: 556-562) also tried to evaluate the palliative patients’ population. They worked on retrospective data with 3 proxy:
- 10 conditions identified in the literature,
- ‘patients who were hospitalized for some period in the 12-month period before their death, with the reason for admission matching the underlying cause of death on the death certificate’.
- ‘including all but sudden deaths’.

Among the 10 conditions they selected, there were no cardiovascular diseases except heart failure.

I am afraid that a very precise definition implies necessarily a limitation in the study depending on the criteria used in this definition. Indeed a list of diseases will never be exhaustive and an estimated prognosis will never be perfectly correct. Moreover a focused criteria implies that patients who do not meet this criteria would not be palliative. The aim of our study was to measure the number of palliative patients without any exclusion on the underlying diseases.

So, we just verified that study nurses conduct the interview on the same way. As they did not begin their work at the same time, these verifications were made 3 times. Changing these criteria implies that we must re-do the study or do another study.