Author’s response to reviews

Title: Ghent University Hospital's Protocol Regarding the Procedure Concerning Euthanasia and Psychological Suffering

Authors:

Monica Verhofstadt (monica.verhofstadt@vub.be)
Kurt Audenaert (Kurt.Audenaert@ugent.be)
Kristof Van Assche (Kristof.VanAssche@uantwerpen.be)
Sigrid Sterckx (Sigrid.Sterckx@ugent.be)
Kenneth Chambaere (Kenneth.Chambaere@ugent.be)

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Author’s response to reviews:

Dear Editor in Chief,

We are extremely pleased and grateful to learn that our paper entitled, “Ghent University Hospital’s Protocol Regarding the Procedure Concerning Euthanasia and Psychological Suffering” is considered ‘close to acceptance’ provided that we undertake adequate revision on additional comments.

Please find attached our point-to-point reply to both the reviewers’ comment(s) on our manuscript. We have copied all their comments in the attachment documents (bold text) and subsequently addressed each point from each reviewer in turn with text changes in the revised manuscript (in italic).

We also adjusted the references section and fixed the reference section automatically via the software program Mendeley. You will find attached the revised manuscript (one version with all text changes highlighted in yellow and one clean version). I also guarantee that all authors contributed to and approved the final manuscript and re-submission.

We wish to thank you and the reviewers for this opportunity to improve our manuscript further, and sincerely hope it meets the BMC Medical Ethics’ standards for publication in form, content and relevance. We appreciate your time and look forward to your response.
The article is certainly of interest to other people working in hospitals in jurisdictions that allow for euthanasia in psychiatry.

We gratefully thank the reviewer for the positive and constructive feedback that has allowed us to further improve the quality of our manuscript!

1. Still, it would be even more instructive if it could describe which cases are rejected on the basis of this procedure (did it filter out patients, did the HEC, the first, second or third psychiatrist refuse?), and explain how it works in practice. Now it merely describes rules and intentions.

Thank you for this thoughtful comment. We agree that this information would indeed give more insight into today’s practice.

We adjusted our Flow Chart, allowing the reader to see the entire euthanasia procedure and populated it with numbers showing how many requests were made in total, how many of these requests were granted and carried out, and how many were rejected at which stage of the procedure.

We have now included the following sentences into the main text, prior to the introduction of the euthanasia performance in Ghent University Hospital (p. 9, paragraph 2, line 14):

Figure 1 shows the entire euthanasia procedure with numbers of the requests made (N = 12), granted and performed (n = 7), or rejected (n = 5) at a certain stage of the procedure. Up to the present day, the first psychiatrist always functioned as a gatekeeper who decided which patients were eligible to start the procedure in the Ghent University Hospital protocol.

However, it is important to keep in mind that the protocol stipulates that both the second and the third psychiatrist involved should decide autonomously (e.g. independently from the patient, from the attending psychiatrists and from each other) whether or not to grant the patient’s euthanasia request. In theory, it could occur that some patients who are found eligible by the first
psychiatrist are filtered out in the next stages of the procedure. As the first and second psychiatrist are affiliated to the Ghent University Hospital, it is logical that their opinions are crucial in the decision whether or not the psychiatric patient can be euthanased in the hospital. Hypothetically, although this situation has not yet occurred, the opinion of a fourth psychiatrist can be sought when the opinion from the external psychiatrist is negative, if both the first and the second psychiatrist are still of the opinion that the psychiatric patient is eligible for euthanasia. All the opinions of the psychiatrists involved are thoroughly discussed by the HEC at each stage of the procedure, although, in accordance with Belgian law, the advice from the HEC should be considered as providing guidance rather than being legally binding.”

As a consequence, we have changed the following sentence in the discussion section

From: It should, however, be noted that it is unclear how many external requests have been made at Ghent University Hospital, and for what reasons some of these requests might have been refused, since this type of information is not systematically collected.

Into: It should, however, be noted that it is unclear for what reasons some of the external requests might have been refused, as this type of information is not systematically collected.

2. Does the HEC not keep notes of its meetings? To say that nothing can be said about the patients who were eligible for euthanasia also seems a bit too easy. Surely something can be said on age, sex, diagnosis, without compromising patient confidentiality? It is unsatisfying to read 'anecdotal evidence suggests'. Is it really impossible to say any more?

We can reassure the reviewer that minutes are kept, but these minutes are not accessible to us as the HEC applies total confidentiality. Disclosure of patients’ characteristics would indeed give more insights into the implementation of the protocol. However, as the number of psychiatric patients who approach the psychiatrists of the Ghent University Hospital with a request for euthanasia is extremely low, this poses a high risk that these patients may be identified.

After we read your comment, some of us had a discussion with the chairperson and some delegates of the Ghent University Hospital’s ethics committee to discuss what kind of information we are allowed to reveal. We were told that it was paramount for the disclosure of (likely) identifiable data to be avoided and that the anonymity of the patients had to be protected, because they did not give their permission to use their personal data, and also in view of the need to show respect to their relatives who could read the article and the disclosed information. It concerns a topic that is extremely delicate and highly sensitive, especially for the bereaved. Therefore, it was decided to only reveal the following information to you for review purposes by means of aggregate descriptive data, but we do not have ethics approval to also mention this information in the paper itself.
Among the small patient population, the biological sex ratio was 5 M versus 2 F. Patients ranged between 42 and 75 years of age. All patients primarily suffered from depressive disorder, bipolar disorder or psychotic disorder. Comorbidity did occur and concerned personality disorder and/or serious somatic illnesses.

3. Similarly the phrase "this was developed with depressive patients in mind", evokes the question how the protocol doesn't fit the other patient groups?

This is a very pertinent remark. The paper only indicates that the protocol was developed with this patient group in mind at a time when there was a lack of information about what types of psychiatric patients would request euthanasia.

We have now included the following sentences into the discussion section (p. 13, paragraph 2, line 15):

“In this respect, it should be noted that the protocol does not exclude any psychiatric conditions. However, the protocol was developed at a time when there was a lack of information about which patients would be encountered. In the early years after the adoption of the Euthanasia Law, euthanasia on psychiatric patients was virtually non-existent, as on average only 1 psychiatric patient per year was euthanased. This number increased considerably from 2008 onwards. More detailed information on these cases was published in the biennial report of the Federal Control and Evaluation Committee on Euthanasia in 2010, which is precisely the year in which the protocol was agreed and implemented.

Five years after the adoption of the Ghent University Hospital protocol, one quantitative descriptive study (Thienpont et al., 2015) and a recent trend analysis (Dierickx et al., 2017) revealed more details on the characteristics of psychiatric patients in terms of biological sex, age, nature of their psychopathology, and characteristics of the euthanasia procedure and outcome.

Since the Ghent University Hospital developed this protocol before the publication of these studies, it had no information to build on except for their own psychiatrists’ general expertise in psychiatry and personal experience with some cases of euthanasia on psychiatric patients. It turned out that their experiences were congruent with the main findings of these studies. However, these studies describe the most common profiles of patients encountered in practice, whereas other profiles (i.e. in terms of disorder and life context) do occur and can increase the complexity.”

We adjusted the next sentence as follows:

In practice, Ghent University Hospital has already been confronted with euthanasia requests made by a variety of patients, including young patients suffering from anorexia nervosa and patients suffering from autism spectrum disorder.”
Finally, we added the following sentences:

“Although the characteristics of these cases had not been anticipated, they did not necessitate adjustments to the protocol, as the protocol did not exclude any patient group. The protocol made it clear that psychiatric patients might fulfill all the legal requirements for euthanasia, irrespective of age or nature of the disorder. However, due to their expertise in psychiatry (including in end-of-life care for psychiatric patients), the psychiatrists involved in the development and implementation of the protocol were considered to be the most suitable to adequately manage and discuss these requests and to inform the HEC if there would be a need to make adjustments to the protocol, e.g. to insert additional safeguards.”

4. So to sum up, the article is well written and to some extent informative, but the feeling persists that it should be possible to say more about the actual practice, maybe even do some formal evaluation of the guideline that has existed for several years now. That would certainly be a lot more informative for others who wrestle with these issues.

We sincerely hope that we have provided adequate answers to your questions. We also hope for your understanding regarding our position not to disclose sensitive data in the paper in the absence of the consent of the patients and in view of the fact that we have not received ethics approval to disclose these details.

References


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REVIEWER: 2

This is a paper that discusses the brief history of how one hospital in Belgium has responded to that country's evolving practice parameters around decriminalized euthanasia. The authors speak to a particular set of clinical presentations involving euthanasia requests for unbearable psychological suffering, AND that originate from outside of the hospital (that is, not from one of their own patients). The hospital under discussion developed a thoughtful process to handle such
requests that goes beyond what Belgian law requires, in an attempt to build in additional protections for all parties concerned. The paper is well written and generally covers their issue well.

We gratefully thank the reviewer for the positive and constructive feedback that allowed us to improve the quality of our manuscript!

1. However, the paper might be better classified not as "research" but as something closer to a "case study," "notes from the field," or some other publication category that allows for review and narrative discussion of an important topic. If the intent of the "Is the objective acceptable" criteria is to check if there is a statement along the lines of "This paper will discuss X" I would say strictly not quite, but adding such a statement would be relatively easy to do as it is more or less inferred. The reader waits until almost the last page of text to find out that the paper appears to be based on a history of seven (7) euthanasia cases of the type they discuss herein. I would like to see that figure and possibly other relevant numerical facts move up in the paper, as I did find myself wondering all along if the authors are speaking in theory or out of actual practice.

We thank the reviewer for his/her comment. We understand that some confusion has arisen regarding the nature of our article, and we should clarify that our manuscript was submitted under the category ‘debate article’ and could be seen as a theoretical description of a university hospital’s protocol regarding the management of euthanasia requests from psychiatric patients from outside the university hospital.

2. That said, the authors make no statistical claims that would need to be supported by numbers or numerical analysis, but seeing them does offer the reader some context as to what the clinicians actually experienced? In the same vein, it would be interesting to see their process Figure populated with numbers to see how many requests were made, how many made it all the way through (we are told 7), and how many were denied at any of the several off-ramps.

We thank the reviewer for this thoughtful comment.

We have implemented this suggestion and adjusted our Flow Chart, allowing the reader to see the entire euthanasia procedure. We have populated the Flow Chart with numbers showing how many requests were made in total, how many of these requests were granted and carried out, and how many were rejected at which stage of the procedure.

We have now included the following sentences into the main text, prior to the introduction of the euthanasia performance in Ghent University Hospital (p. 9, paragraph 2, line 14):
“Figure 1 shows the entire euthanasia procedure with numbers of the requests made (N = 12), granted and performed (n = 7), or rejected (n = 5) at a particular stage of the procedure. Up to the present day, the first psychiatrist always functioned as a gatekeeper who decided which patients were eligible to start the procedure in the Ghent University Hospital protocol.

However, it is important to keep in mind that the protocol stipulates that both the second and the third psychiatrist involved should decide autonomously (e.g. independently from the patient, from the attending psychiatrists and from each other) whether or not to grant the patient’s euthanasia request. In theory, it could occur that some patients who are found eligible by the first psychiatrist are filtered out in the next stages of the procedure. As the first and second psychiatrist are affiliated to the Ghent University Hospital, it is logical that their opinions are crucial in the decision whether or not the psychiatric patient can be euthanased in the hospital. Hypothetically, although this situation has not yet occurred, the opinion of a fourth psychiatrist can be sought when the opinion from the external psychiatrist is negative, if both the first and the second psychiatrist are still of the opinion that the psychiatric patient is eligible for euthanasia. All the opinions of the psychiatrists involved are thoroughly discussed by the HEC at each stage of the procedure, although, in accordance with Belgian law, the advice from the HEC should be considered as providing guidance rather than being legally binding.”

As a consequence, we have changed the following sentence in the discussion section

From: It should, however, be noted that it is unclear how many external requests have been made at Ghent University Hospital, and for what reasons some of these requests might have been refused, since this type of information is not systematically collected.

Into: It should, however, be noted that it is unclear for what reasons some of the external requests might have been refused, as this type of information is not systematically collected.

3. I think the paper could be strengthened by adding in just a bit of background discussion for non-Belgian readers that speak to how euthanasia practice is paid for, or how any other related financial issues are addressed in their hospital’s experience.

We thank the reviewer for this thoughtful remark, as information on the financial costs can give more insights into euthanasia practice.

We have added the following sentences in the discussion section (p. 15, paragraph 1, line 3):

“It should be noted that, during a roundtable meeting with the HEC, the HEC emphasised that financial costs or gains should in no way influence access to euthanasia, which should only be based on medical expertise, sound decision-making, interdisciplinary reflection, and transparent communication and responsibility. Therefore, during the assessment procedure no additional costs are charged to the patient except for the normal costs of the consultation of the
psychiatrists. If the patient is euthanased, the invoice of that intervention is split into three parts: one part will be borne by the patient’s basic health insurance, the second part will be borne by the patient’s hospitalisation insurance (if applicable), and the third part will need to be borne by the patient. If the patient has no relatives and has not paid in advance, the invoice will only be met after a few years (e.g. from the patient’s estate or, failing that, the patient’s debt might eventually even be paid off by Ghent University Hospital).”