Author's response to reviews

Title: Top 10 Health Care Ethics Challenges Facing the Public: Views of Toronto Bioethicists

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To the Editors,

Please consider the revised version of our paper, “Top 10 Ethical Challenges Facing the Public: Views of Toronto Bioethicists,” for publication in *BMC Medical Ethics*. We feel that we have made a sufficient attempt to incorporate the comments from the reviewers into the paper and have responded to the comments where appropriate. Below is our point-by-point description of our responses to the reviewers’ comments. We look forward to hearing back about the revised version.

In addition, as mentioned previously, we would like to coordinate a media release with the eventual publication of this paper. If this revised version of the paper is accepted for publication, we would like to request that you please inform us at least two weeks prior to publication so that we can coordinate the media release. Thank you.

Sincerely,
Jonathan Breslin

**Point-by-Point Responses to Reviewer Comments**

**Reviewer 1**

1. The expertise of the panel beyond clinical ethics is not presented and, therefore, it is questionable how they can address issues of health care policy.
   - The panel was not asked to *address* issues of health policy, only to comment on what they believed to be the top ethical challenges facing the public. Although their experience is focused largely if not entirely in clinical ethics, the fact that they are professional bioethicists makes them more likely to be aware of issues or problems in health care generally that have ethical implications than members of the lay public. One does not need to be an expert in the area of health care policy to be aware of the significant ethical implications associated with, for example, the provincial shortage of family physicians or long waiting lists for services. That being said, familiarity with these issues is in fact the content of the daily work of clinical bioethicists.

2. The experiences of clinical ethicists affiliated with a single centre in the largest Canadian city may not be viewed as representative of the challenges facing the entire Canadian public.
   - Has been accounted for in the “Limitations” section of the paper.

3. Why was the panel not supplemented with hospital administrators, leaders from health care professional organizations, policy-makers, etc.?
   - Has been accounted for in the “Limitations” section of the paper.

4. Several assertions were made without references.
   - We have deliberately avoided using references to support the results and discussion of the paper because the content of these sections has largely paraphrased the comments of the panel members. References have been
included where appropriate but the majority of the material in the results and
discussion is based on comments from the panel members. Since this was not
clear in the initial draft of the paper, we have attempted to clarify this point
throughout the paper.

5. The explanations in the results section provide very little insight into any of the
challenges.
   • We have expanded our discussion of many of the challenges in the “Results”
     section of the paper to provide more insight into the challenges.

6. The claim that the exercise can raise public awareness suggests that the Canadian
public has paid little attention to the debates over the past decade about important
health care decisions and the parties that make them, when in fact many cases have
received considerable media attention, as did the whole process of new legislation on
reproductive technologies adopted in March 2004.
   • Our claim about the exercise raising public awareness has nothing to do with
     the public’s awareness of other high profile ethical challenges or issues, such
     as the ones mentioned by the reviewer. Our claim was simply that the top
     challenge in particular has received very little public attention, and we hope
     that our study will be part of a strategy to bring this challenge to the attention
     of the public. Cases like Sue Rodriguez and Robert Latimer focused on issues
     of assisted suicide and mercy killing, which are only loosely related to the top
     challenge in our study. The issue of reproductive technologies is entirely
     unrelated. While the public may be aware of these other issues, and are
certainly aware of many of the challenges mentioned by the panel, our point
was simply that the public remains largely unaware of the top ranked
challenge.

7. Why the challenge of “disagreement between patients/families and professionals
about treatment decisions” has to be illustrated by the paradigm example is unclear,
and in the context of this manuscript, little benefit is gained from such a narrow
example.
   • We’re not sure what makes the example “narrow” but the purpose of
     including a paradigm example was to give special attention to the top-ranked
     challenge, especially since part of our thesis is that the top-ranked challenge
     has not received nearly as much public attention as it deserves. Although
     health care professionals and clinical bioethicists might be personally familiar
     with the kind of scenario we describe as a paradigm example of a
     disagreement over a treatment decision, other readers may not be. The
     paradigm example would help those readers understand what the challenge is
     all about. The possible narrowness of the example may reflect the fact that it
     is a generic, paradigm example, not one based on the specific details of an
     actual case.

8. The research methodology (Delphi study) does not support the discussion and
recommendations.
   • We believe the modified Delphi is an appropriate methodology for this study.
The purpose of the study was to find out what a group of highly qualified and
experienced clinical bioethicists think are the top ethical challenges facing
members of the public, and a Delphi study is the correct method to achieve
this purpose. The results of the Delphi study then served as the basis for the discussion, which focused on the top-ranked challenge and our recommendations for confronting that challenge. Much of the content of the discussion section did, in fact, paraphrase the comments from the panel members.

**Reviewer 2**

1. The methods section should describe the Delphi process in greater detail.
   - The “Methods” section has been expanded to describe and clarify the process in greater detail.

2. References should be provided for statements describing the challenges.
   - As mentioned above, the reason why there are few references supporting the results and discussion is because we have largely paraphrased the comments from the panel members in those sections. Since this was not clear in the initial draft of the paper, we have attempted to make it more clear throughout. We have made an attempt to add references where appropriate.

3. In the section on surgical innovation, the authors may wish to discuss the ethics of performing sham procedures in a randomized-controlled trial of a surgical procedure (see Moseley et al. NEJM 347 (2002: 81-88).
   - This is a good suggestion but since the results are based on the comments from the panel members, and they did not raise the issue of sham surgery, we did not comment on this in the description of the surgical innovation challenge.

4. The authors should also acknowledge that the challenges and rankings, which represent the views of clinical bioethicists, may not generalize to other groups.
   - Has been accounted for in the “Limitations” section of the paper.

5. The reader might believe, based on the title, that the paper describes the public’s perspective. Perhaps the title should be revised something like the following: “Top 10 health care ethics challenges facing the public: Views of clinical bioethicists in Toronto.”
   - This is a good suggestion; the title has been changed to accommodate this.

6. It might be useful to cite some of the literature on patient/family/physician differences in perspectives regarding goals of care and futility.
   - Again, since we have largely paraphrased the comments from the panel members in the results and discussion of the paper, we feel it is not necessary to support these claims with references. Moreover, the use of the paradigm example was meant to be a starting point for our main focus, the recommended solutions.

7. Do the authors have any ideas regarding how the raising awareness or garnering support might occur? Could this involve a similar process with family members?
   - Suggestions have been made in the “Raising Public Awareness” section of the paper.
**Reviewer 3**

1. A person facing an ethical challenge is in a position to resolve that challenge, or at least to try. Yet the challenges discussed are not ones that patients and families have to resolve, but rather challenges that the health care delivery system and those who govern and serve in it must resolve.

   - The phrase “challenges facing the public” may be somewhat ambiguous. We used this phrase in the sense of challenges affecting or impacting the public, not in the sense of challenges that the public is faced with resolving. To clarify this ambiguity we have added a statement in the “Methods” section of the paper, which explains what was meant by the phrase “ethical challenges facing the public.”

2. It is not clear to this reader in what way medical errors represent an ethical challenge (although it is clear that how errors are dealt with, individually and overall, is an issue that has significant ethical implications). I believe it is essential for the authors to define, at the outset, what they mean by “ethical challenge,” and especially how it was presented to the members of their Delphi panel. They also need to be clear about who is “facing” as opposed to who is being “affected by” these challenges, and why these are best characterized as ethical challenges rather than as serious problems in the health care delivery system.

   - The reviewer raises some good points about the use of the word “challenge”. In fact, this was one of the topics of discussion when the panel met with one another for the second round of the process because it was not clear to some members of the panel exactly what was meant by an ethical challenge. Although it may not be ideal, we felt that it more accurately reflected what we were trying to achieve than other options, such as “issue”, “dilemma”, or “situation”, which we believed were too narrow. The term “challenge” was chosen as one that encompassed all these other possibilities. What we meant by ethical challenge is essentially an issue, dilemma, situation, event, problem, etc., that has ethical implications. This has also been clarified in the “Methods” section of the paper. In addition, the explanation of the medical error challenge has been expanded to help better explain why medical errors represent an ethical challenge.

3. They need to clarify whether these 12 bioethicists represent the entire CEG or some subset of them, and if so how they were chosen as a subset.

   - Has been accounted for in the methods section of the paper.

4. The group appears to have little if any exposure to issues faced in ambulatory care settings. This means that they focus of their experience is in hospital and related inpatient settings.

   - Although it may not be ideal, we felt that it more accurately reflected what we were trying to achieve than other options, such as “issue”, “dilemma”, or “situation”, which we believed were too narrow. The term “challenge” was chosen as one that encompassed all these other possibilities. What we meant by ethical challenge is essentially an issue, dilemma, situation, event, problem, etc., that has ethical implications. This has also been clarified in the “Methods” section of the paper. In addition, the explanation of the medical error challenge has been expanded to help better explain why medical errors represent an ethical challenge.

   - Has been accounted for in the methods section of the paper.
5. Did the authors reword the challenges provided by the panel members? Did they cluster similar statements? How did they go from the panel members’ own words to something around which consensus was achieved? Was there an explicit process for them to discuss their different views? If so, this is NOT a traditional Delphi process.

- This has been explained in more detail in the methods section. While it is true that it is not normally appropriate for panel members to come together to discuss their rankings in a traditional Delphi process, we felt that this was an important part of this process largely because of the ambiguity involved in the research question. The panel discussed some of the issues raised by the reviewers, including what does or does not count as an ethical challenge and distinguishing between challenges that affect the public and challenges that involve the public but primarily affect health care professionals. Moreover, because there are many different ways to describe the same issue or challenge, it was important for the panel members to have the opportunity to explain precisely what they meant so as to reduce the risks of the authors misinterpreting the results and of similar challenges being duplicated on the final list. Thus, the purpose of having the panel members come together was not to discuss or defend their particular rankings, but to make sure all panel members were interpreting the question the same way and to make sure the meanings of all the items were clarified and appropriately specified. Additionally, having the panel members discuss the challenges face to face does help achieve the goal of the Delphi process, which is to build consensus. However, since this is not a traditional Delphi process, we have referred to the process as a modified Delphi.

6. How and when were the comments from the panel members made and gathered?

- As explained in the methods section, the comments from the panel were gathered with their original ranked lists and also during the second round, when the panel members met to discuss the items.

7. The statement about resource allocation at the bottom of page 4 needs some grounding in evidence.

- This statement was made by several members of the panel and is not being presented here as a factual claim. Therefore, references are not needed. We have clarified this statement to reflect that it was a claim made by panel members.

8. Why isn’t the 6th challenge described in terms of pain management and palliative care directly?

- This has been clarified; the challenge is now described directly in terms of pain management and palliative care.

9. It is unclear how the exercise described “be an effective way of bringing these challenges to the public’s attention.”

- Suggestions have been made in the “Raising Public Awareness” section of the paper.

10. The authors actually undermine the validity of their findings in their discussion on page 10 of why disagreements on treatment decisions was the top ranked ethical challenge, by noting that it may be a result of the core experience base of clinical
bioethicists (resolving conflicts). If this is so, what do the rankings really represent besides their opinions? And why should their opinions be the only ones considered?

- As we have mentioned in the “Limitations” section of the paper, we recognize that the results of this study may not be generalizable to other groups since different panels made up of different members may provide different results. However, the purpose of the study was to discover what a group of highly experienced and qualified clinical bioethicists think are the top ethical challenges facing the public. It would certainly be interesting and informative to go through a similar process with other panels, such as physicians, nurses, administrators, and patients and families – but that is outside the scope of this study.

11. The use of the term “survey” is strange at the bottom of page 3.

- The word “survey” has been replaced with “study”.

12. As a non-Canadian reader, it would be important for me to get information on the role of various organizations and groups mentioned, especially at the end of the article, such as the Health Council of Canada.

- In an effort to make the results more widely applicable to contexts outside of Canada, we have reduced the focus on Canada in this section. Instead, we have chosen to discuss the recommendations in general terms.

13. It would be useful to identify exactly how the panel members determined the relative impact of issues on the public. Did they have explicit criteria or were these implicit judgments?

- There were no formal criteria for determining the relative impact on the public of the various challenges. However, the kinds of things that were taken into account by the panel members when ranking the challenges were criteria such as the prevalence of the challenge (ie, how often it arises and is likely to arise in the future), the impact in terms of the number of patients and families currently affected and likely to be affected in the future, as well as the seriousness of the impact on patients and families. A statement explaining this has been added to the “Methods” section of the paper.