Author's response to reviews

Title: Concepts of decision making capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying.

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Author's response to reviews: see over
Dear Editors,

Many thanks for your efforts in ensuring peer review for this manuscript and to the reviewers for their considered and thorough feedback. We have addressed the reviewers’ comments point by point beginning with the major revisions and then the minor revisions. Where appropriate we have indicated where we have made corresponding changes to the text and highlighted changes to the text using tracked changes.

**Essential major revisions (Reviewer 2):**

1) The authors use “decision making” and “mental capacity” interchangeably, which may not be appropriate especially for such topic. Decision making is influenced by mental capacity and the other factors mentioned in the manuscript such as voluntariness, motives, and autonomy. The distinction between decision making and mental capacity is important as it appears that the disagreement among the invited experts is in a major part related to what constitutes “sound” and thus acceptable decision making rather than adequate mental capacity.

*We thank the reviewer for this observation and have amended the text to improve consistency of the terms used throughout.*

2) It appears that the disagreement among the experts is on two issues: 1) in the context of assisted dying should everybody be assumed competent unless proven otherwise OR incompetent unless proven otherwise, and 2) in accepting or rejecting an assisted dying request should we only assess mental capacity or in addition, voluntariness, motives, emotions, etc? Although the experts were invited (and thus may not represent “current thinking”), it would be useful to the reader to know how many took one view or the other and whether this was related to their background.

*We have reviewed the submissions and attempted to address the points above in the results section under the headings ‘Definition and boundaries of mental capacity’ and ‘Presumption of capacity’.*

3) There is some inconsistency in what was analyzed: 35 transcripts of oral evidence and five pieces of written evidence (abstract) vs. 36 transcripts of oral evidence and five pieces of written evidence (methods) vs. 36 transcripts of oral evidence only (results and table 1). This needs to be clarified.

*Thank you for pointing out this inconsistency. This has now been reviewed and revised in the manuscript and abstract. We have also added an extra column in table 1 to make it clear who provided written as well as oral submissions to the Commission and added some detail to the text about the submissions in the results section. During this process of review we noticed that we had not included some of the written evidence that was analysed and this has now been added to the table as well.*

4) If the invited experts did not listen to each other/discuss with each other, it is possible that they were addressing different things (or talking imprecisely), rather than having disagreement. It is not clear what questions the experts were asked to address. For example, were they asked specifically to define mental capacity? Apparently they were not, since 4 of the 36 transcripts did not include reference to mental capacity. The authors did not have direct contact/discussion with the
experts. They base their conclusions on the authors’ interpretation of the transcripts (we do not even know how much agreement the authors had among themselves). This interpretation does not necessarily represent “current thinking”. Thus the conclusions of the authors do not appear to be supported by the presented data and need to be softened.

We acknowledge the point that the experts did not discuss their ideas with each other and therefore were not having a disagreement and have amended the text to reflect this. The experts were not asked to define mental capacity and this has been added to the text (see section ‘Definition and boundaries of the concept of mental capacity’ paragraph 1) We have made amendments to the conclusions as suggested.

5) The manuscript is essentially addressed to UK voters or parliament members. A wider perspective on the ethics/regulations of assisted dying worldwide and putting the results in context of medical decision making and mental capacity assessment in general may make the manuscript more appealing to a wider audience. [for example, is medical capacity presumed until proven otherwise when a patient refuses life saving treatment or donate an organ while alive, and are the other factors that may affect decision making such as motives, voluntariness, etc assessed in addition to mental capacity in such situations?]

We acknowledge these points and have attempted to address the issue of international relevance and wider perspectives highlighted above in the discussion section.

6) 4 out of 36 transcripts did not mention mental capacity. This is unexpected and needs more discussion. What is the background of those contributors? Why did not they address mental capacity?

On reviewing the four transcripts we found that one did make a brief reference of the ability of a person to make a genuine decision and has therefore been added to the total of transcripts mentioning capacity. The others on review did not make reference to mental capacity at all and we have described these contributions in the text (in the results section paragraph 2)

Essential minor revisions:

1) The topics “what is mental capacity” and “the boundaries of the definition of mental capacity” appear to be almost the same and may better be presented/discussed together.

This change has been made as suggested

2) The sentence under discussion about the impartiality of the Commission on Assisted dying is not referenced and is not related to the study. Consider omitting.

This sentence has been omitted as suggested.

3) The sentence under discussion “This study analyzed ..... using rigorous qualitative methods from an atheoretical perspective...” is rather self credentialing and may be too strong. More detailed description of the methods used and their validity would be useful.
We acknowledge that this may be too strong and have removed this from the discussion whilst adding a section on reflexivity.

4) The manuscript needs editing. See for example the third sentence under results under abstract.

We have clarified the sentence that has been identified as requiring editing and reviewed the document and made further similar editorial changes as suggested.

5) The information about the “Bill” needs to be updated.

This information has been updated (please see page 2 paragraph 1)

6) The three paragraphs under presumption of capacity under results don’t flow well. The authors seem to go back and forth to the two options with some redundancy and confusion.

This section has been reworked with the intention of improving clarity and flow as suggested. We have also further analysed the relationship between presumption of capacity and support for use the Mental Capacity Act and added this data in table 2.

7) Because this is a piece of sociological research and not a theoretical paper, there should be a section on strengths and limitations of the methods, findings and conclusions. This is really important in this case as the submissions were never intended as critiques of capacity nor may indeed have not intended any ethical argument for a submission concerning the law; so this is secondary use research in every sense. Given this fact, the authors need to be cautious in how they impute intent, use and definition of capacity by the authors. It is quite likely that were they to interview the authors directly, they might obtain completely different answers and draw different conclusions. Having said that, a strength is also that these uses of the notion of capacity are not consciously done as an end in itself and it is very useful indeed to examine how people do use these concepts in real life.

We acknowledge this point and have discussed these issues under a new section entitled ‘strengths and limitations’ towards the end of the discussion.

8) I thought there was a slight problem in the approach of the authors in that they did not very clearly distinguish between several different issues: a) the ethical basis of argument regarding the authors’ position on assisted suicide, and whether and how this appealed to capacity; b) the authors’ own (apparent) conceptualisation of the notion of capacity; c) the authors’ own interpretation of the legal concept of capacity as contained in the Mental Capacity Act; and d) whether the MCA could indeed support b) or c) or indeed a). It should be relatively simple to tease these apart but important not to confuse them.

We appreciate this request for clarity in our position and have attempted to address this in the discussion.

9) As I assume BMC Ethics is an international journal, it would be worth putting in
more context than is provided regarding British legal process, the MCA and so on, so that an international reader from a different jurisdiction can relate to the debate and understand what the context of these submissions are.

*We acknowledge this point and have added a paragraph in the discussion section about alternative processes for capacity determination and added some new references to support this.*

10) I think the conclusion is too strong - to conclude from a single secondary use study that 'current thinking about mental capacity as it relates to assisted suicide is inconsistent and problematic' is too strong. The research certainly shows inconsistency which is problematic, and the authors can indeed argue that given the high profile and supposed expertise of the people submitting arguments this points to particular problems, but they cannot generalise quite as easily. They should also highly the problem with qualitative research in general and this rather skewed sample in particular in claiming representativeness in any way in terms of reflecting balanced spread of thinking regarding assisted suicide, let alone capacity.

*We have amended the conclusion in line with the issues raised above.*

We hope that these amendments are satisfactory and look forward to hearing the outcome of the ongoing review process.

Yours faithfully,

Dr Annabel Price (on behalf of all authors)