Author’s response to reviews

Title: A mixed methods investigation of surrogate end-of-life decisions among older adult partners

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Author’s response to reviews:

Dear Prof Gummlich,

Thank you for taking the time to examine our manuscript and considering it for publication. The suggestions that the reviewers and yourself made were very helpful in strengthening our work. We have taken them into consideration and edited our manuscript accordingly.

We have provided a response, point by point, to each of the concerns and included the corresponding changes. We hope that we have been able to address them appropriately.

We look forward to hearing from your regarding our revised submission.

Your sincerely,

Eleonore Batteux

Eamonn Ferguson

Richard Tunney

Reviewer reports:

Elizabeth K. Vig (Reviewer 2): Thank you to the authors who have responded to the comments from the original reviews. The manuscript is much improved. I think the details added to the Methods are especially helpful to help readers understand how the research questions were approached. The Background and Results sections could be shortened, but I will defer to the Editor on this.
Thank you for your comment. We have made some adjustments to the wording in the Background and Results sections to make them slightly shorter and easier to read, but did not cut specific points or arguments to avoid changing the substance of the paper.

Natalie Christine Ernecoff, PhD, MPH (Reviewer 3): Thank you for addressing the comments. I have no additional concerns.

Thank you for your comment.

Amber Comer (Reviewer 5): 1. Reviewer 4 Comment: "A major conceptual challenge is presentation of the idea of risk: that surrogates are more likely to take certain risks for others than for themselves. In the introduction, the authors discuss this phenomenon but do not always make it clear which risk they are talking about. There are usually two risks involved in the decisions: risk of death and risk of poor quality of life. Why do they think that the risk of low quality of life is more salient to the surrogates? This may be the case, but cannot be assumed."

Response: "Thank you for your comment. We have made it clear in our introduction that surrogate decisions have tended to avoid a risk of death, rather than a risk of poor quality of life."

Commentary: I think the point of reviewer 4's comment was that some surrogates tend to avoid risk of death, while others avoid risk of poor quality of life. The way you have phrased your response, you say that you are now focusing on avoiding "risk of poor quality of life RATHER than poor quality of life." Surrogates tend to focus on one or the other - so rather is not the appropriate word. A better word would be "either". So, this section should be rephrased to discuss that either of these positions are possible and must be taken into account.

Thank you for your comment. As reviewer 4 points out, we discuss the experimental research which shows that surrogates take less risk for others than they do for themselves, but we had not originally specified which type of risk we were talking about (Background, page 4 line 23 to page 5 line 17). We understand the reviewer’s comment as asking us to clarify which type of risk we are referring to, or whether we are referring to both. We have now clarified this by detailing that the evidence suggests that surrogates focus on reducing the risk of death for others, rather than the risk of poor quality of life. At present, we are not aware of experimental evidence on risk preferences suggesting that self-other differences reflect the contrary. We do not make the claim that surrogates ignore the patient’s quality of life when making a decision for them, but only that differences between the decisions they make for themselves and for a patient do not seem to be attributable to a greater avoidance of the risk of poor quality of life for the patient. We have therefore left the text as it is as we think it is suitable to explain our point.
2. You say on line 40 "The ethical framework of surrogate decision-making was developed almost three decades ago and remains representative characteristic of the current legislation in many western countries current legislation1 (Buchanan & Brock, 1990)." I am not sure what you mean by this. There are papers which have explored that legislation for surrogate decision making is actually quite different between different states within the United States for instance and there is not one accepted standard for making decisions (some states use substituted judgement and others use best interest, and that there is not standard for who can make decisions) (Link to paper: http://journals.iupui.edu/index.php/ihlr/article/view/21709/20901 Comer AR, Gaffney M, Stone C, Torke A. What do you mean I cannot consent for my grandmother's medical procedure: key issues with state default surrogate decision making laws. Indiana Health Law Review. 2017;14(2).

Thank you for pointing this out. What we mean is that the principles underpinning the ethical framework developed by Buchanan & Brock can still be seen today in legislation across western countries, albeit with variations. Using advance directives, taking into account the patient’s wishes and their best interest are still characteristic of many US states and other countries’ legal requirements, even though their precise implementation varies from country to country or state to state. We have made this clearer in the text as well as a footnote.

Background, line 40 onwards: “An ethical framework of surrogate decision-making was developed almost three decades age, of which the underpinning principles remain representative of the current legislation in many western countries1 (Buchanan & Brock, 1990). The ethical framework stated that if an advance directive is available, it should be followed. Otherwise, the substituted judgment standard should be applied, whereby the surrogate must decide based on their knowledge of the patient’s preferences – i.e. make the decision that the patient would have wanted. When little is known about the patient’s preferences, the best interests standard applies whereby the option which provides the best possible outcome is chosen. Although the exact use and implementation of these principles varies from country to country, they are recurrent throughout and are worth assessing.”

Footnote: 1The specific legislation regarding the conditions under which surrogate decision-making occurs and the procedure it follows varies from country to country, although similar ethical principles are applied in westernised countries.

3. On line 44 you say "If an advance directive is available, it should be followed. Otherwise, the substituted judgment standard should be applied, whereby the surrogate must decide based on their knowledge of the patient's preferences" This is not accurate. In fact, the standard in the US has moved away from substituted judgement and toward best interest in the past few years (see citation given above). Most states now have laws that say best interest is the standard. Substituted judgement became very hard to implement given that many people do not have these conversations. Best interest is also an easier standard to apply because it does not require you to forgo what the patient may have wanted when making your decision as to what is best.

Thank you for highlighting this to us. In that paragraph, we are simply detailing the text by Buchanan & Brock, which we do say is not necessarily applied as such in every country or
state. It is interesting that the US is moving more towards the best interest standard now (although we are struggling to find that point in the citation given and would be interested in other citations too). Nevertheless, we write the paper for a readership that is not specific to the US and the substituted judgment standard is still relevant in other countries too. Therefore, we think the substituted judgment standard is still worth discussing, as is building an evidence base to evaluate it, which our paper aims to contribute to.

4. In the section on "psychological theories of surrogate decision-making" you give a lot of information. I am not sure why this section is relevant given the following: 1) you do not use these theories in your qualitative analysis; 2) you do not include all theories on surrogate decision making, just some of the theories available; and 3) you do not tie your findings back to the theories you present. As you seem to state the theories and move on, it makes the paper rather long and hard to follow.

Thank you for your comment. The reason we present these psychological theories is because we refer to them throughout the rest of the paper. Tunney and Ziegler’s model is essential to the paper as we conduct a theoretical qualitative analysis based on the model, as specified in the Methods section (page 11, lines 10-12). We then use its concepts and terminology throughout our results section. In the discussion, we write a section on theoretical implications which evaluates the model alongside the other psychological theories we discuss in our introduction (page 27, lines 2-19). Given that our paper makes claims about the psychological process of making a surrogate decision, we think it is crucial that we discuss previous psychological theories in the Background section.

5. I am not sure why you moved Table 1 to the methods section. You should not report research findings in the methods section. Only in the results section. Just as you would not discuss results in the discussion that you do not report in the results.

Thank you for pointing this out. We have moved Table 1 back to the results where it was originally.

6. Under "Theoretical implications" you begin talking about how your findings "lend support to predictions made by Tunney and Siegler". The problem is that you write as if the reader knows what these assumptions are, but make no effort to explain what they mean. Also, should this literature be introduced under the background? It seems to come out of nowhere in the discussion.

Thank you for your comment. We have detailed Tunney and Ziegler’s model in the background section, as discussed in response to point 4 above (Background, page 5-6). We have specified this in the discussion to direct the reader back to the background section for clarity (Discussion, page 27, lines 2-3): “Our findings lend support to predictions made by Tunney and Ziegler’s (2015) model (detailed in the Background section).”