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 potentially accepting it for publication. We have taken the helpful reviews 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 you regarding our revised submission.

Your sincerely,

Eleonore Batteux
Eamonn Ferguson
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Reviewer reports:

Amber Comer (Reviewer 5): Although I appreciate and agree with the authors response about substitute judgement still being utilized in many countries, I strongly believe that the best interest standard should be at least mentioned. My reasoning is that the authors give an outdated source on the subject (Buccan and Brock) which was written before most states in the US started making major changes in surrogate laws. Although this paper is not going to a US audience
specifically, the paper as written misrepresents the standard used in the US, because almost all states have moved away from substitute judgement toward best interest (this is easily found in the literature). I also think when speaking about surrogate decision making, it is hard to get around discussing best interest in addition to substitute judgement. I am not suggesting that you take out what you have written about substitute judgment, I am merely suggesting that you add a sentence or two about best interest.

Thank you for your comment. As you suggest, we we have made our mention of the best interest standard more explicit and emphasised how legislation is changing (Background, page 3, lines 18-23): “When little is known about the patient’s preferences, the best interest standard applies whereby the option which provides the best possible outcome is chosen. The exact use and implementation of these principles varies. For example, legislation in the UK combines the substituted judgment standard with the best interest standard and states in the US are moving towards the best interest standard. Nevertheless, the substituted judgment standard continues to be used and is worth assessing.” We also refer to it later on in our introduction (page 6) and in our results.

Also, I still think the background is rather confusing and hard to follow. To that point, I made an entire comment about how something seemed to come out of nowhere that you mentioned in the discussion section because it was so hard to follow in the background (trust me I read the background multiple times before I wrote that comment and as a novice to your theories section, it was hard to follow). I think that making the background more concise will help you keep readers attention as it is rather hard to follow as written. I am only giving these comments to help improve the readers experience and understanding of your hard and important work.

Thank you for clarifying this. We have made the background more concise where we could. We have also clarified the theory section as much as possible without extending it further (Background, pages 5-6): “Tunney and Ziegler’s (2015) model puts forward that surrogates engage in various forms of perspective taking when making a decision. The importance they give to each perspective depends on the nature of the decision. For end-of-life decisions – highly significant decisions for which the surrogate can be held accountable – the model predicts that surrogates focus on what is required of them. If the best interests standard should be followed, the surrogate will engage in benevolent perspective-taking (i.e. decide based on what the recipient should do). If the substituted judgment standard should be followed, the surrogate will engage in simulated perspective-taking (i.e. predict what the recipient would do and decide accordingly), particularly if they are close to the recipient and know their wishes. However, the surrogate might also engage in an egocentric perspective (i.e. decide based on what the surrogate wants) to preserve their own interest. If the surrogate has incomplete knowledge of the recipient’s preferences, they might rely on a projected perspective (i.e. decide based on what they would do if they were the recipient). Although the model expects a next-of-kin to focus on a simulated perspective, other perspectives might come into play and prevent strict adherence to the substituted judgment standard.

Other theories make predictions regarding when self-other differences occur. The presence of a hot-cold empathy gap between the surrogate and the recipient would lead surrogates to underestimate the intensity of the recipient’s emotional state, such as a patient’s pain
(Loewenstein, 2005). The risk-as-feelings hypothesis expects reduced emotional reactions to the prospect of a risk when deciding for someone else (Loewenstein, Weber, Hsee, & Welch, 2001). Both assume that surrogate decision-making is no different from one’s own decision process – self-other differences are only a reflection of the psychological distance between the surrogate and the recipient, i.e. how close they are to each other (Trope & Liberman, 2010). Finally, social values theory suggests that social values are the key factor taken into account when making surrogate decisions and self-other differences should arise when taking a risk is socially valued or frowned upon (Stone & Allgaier, 2008). None of these accounts are able to capture the intricacies of making surrogate end-of-life decisions, which is likely to be a much more complex and reflective process. Tunney and Ziegler’s model (2015), in assuming that surrogates engage in perspective-taking, is more able to support an understanding of how surrogates navigate such complex medical decisions. It can conceptualise the tensions felt by surrogates when needing to abide by the substituted judgment standard and is therefore well suited to analysing surrogate decisions.”