Author’s response to reviews

Title: Autonomy and Couples’ Joint Decision-Making in Health Care

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Author’s response to reviews:

REVIEWER 1:

This is a well-articulated and quite thoroughly analyzed contribution on a clearly clinically relevant topic. The very clear teasing out of the forms of rightful and wrongful influences over personal decision-making would have almost been enough to recommend publication, and the authors provide clear practical distinctions in addition.

Response:

Thank you for this comment.

Nevertheless, a few points would merit clarification or complements: As a clinician I could not help asking myself how I would assess when a situation resembled different ones that the authors describe. A few words either to clarify this or to exclude it from the scope of the paper would be welcome.

Response:

We recognize that clinical assessment of these different scenarios may be challenging. Unfortunately, how to assess clinical situations that resemble the different ones we describe is beyond the scope of the current paper. We do suggest that statements about joint decision making cannot be taken at face value and that assessment has to take into account “…the specific cultural, ethnic, religious, and personal context and background of the individuals in question” (p. 16, line 348). We also call for further discussion and empirical research. We have expanded this sentence on page 16 to clarify these points. In the future, we hope to develop a framework and propose methods for clinical assessment.

Some of the aspects of shared decision-making within a couple are still a little vague:

a) Is there such a thing as free autonomous delegation of decisions to a partner? The authors sometimes seem to imply that there is (page 14), sometimes that there isn't (page 4). My position would be that there is, but in any case I would urge them to be clearer on this
point. And if there is such thing, then is it truly (as stated on page 14) "less than the theoretical ideal"? Why?

Response:

We agree that an individual can freely and autonomously delegate decisions to a partner. We have clarified this in the sections the reviewer refers to. Although some may argue that autonomous delegation falls short of the Western or theoretical ideal of individual autonomy, it acknowledges the fact that, in real life, there are many relationships in which one partner relies on the other or one partner has more power or holds more sway than the other depending on the issue being addressed. It also acknowledges that consistent with respect for cultural norms in some societies delegating decisions may be the actual preference. We deny the view that joint decision-making by a couple can never be truly autonomous or ethically acceptable because it allows the considerations of another person to influence decisions for one individual. Rather than those influences necessarily reducing autonomy, it is possible that they support autonomy, particularly when couples act as partners.

b) What is meant when the authors say (page 13) that the components of autonomy need to be present in the couple as a unit? Surely it is insufficient if only one partner demonstrates all components, but then what is meant by this?

Response:

We meant that if the standards of intentionality, understanding and lack of external control are met by the couple as a couple without one person’s preferences being imposed on the other or one person being controlled by the other person, then the decision can be viewed as acceptably autonomous. We revised the sentence on page 13.

c) The third option on page 15 justifies lesser participation by some women on the grounds that respecting their own view of their role does actually respect their autonomy. This requires a little more argumentation. Situations that take away options also tend to take away expectations. Is autonomy really such a subjective entity and if so is there a limit to how much a situation can result in domination before it becomes too much?

Response:

The third option on page 15 makes the argument from the perspective of respect for the woman (usually the less dominant partner) and her concept of what it means to be acceptably autonomous. While situations that take away options also tend to take away expectations, the situation we describe is reflective of and respectful of cultures with a perspective of decision making and autonomy that differ from the Western concept. We do not think that autonomy is so subjective as to mean almost anything an individual decides it means but we also want to expand the notion of autonomous decision making beyond the typical Western concept. Finding the ethically acceptable space between these two positions is at the heart of this manuscript.

REVIEWER 2:
This is a most welcomed paper which focuses on the principle of respect for patient autonomy, an (non-universal) ideal which in a way disregards that most human beings are "forced" by material conditions but also by our (for many of us willed and wanted) dependency on others, be it emotionally or for other reasons. As the authors claim: not all influence is controlling. Therefore respect for autonomy as a leading principle in decision making should indeed be problematized. However, with a gender imbalance in power almost worldwide, as doctors and also ethicists we meet this issue particularly when treating women coming from non-western cultures / continents. I miss a paragraph answering how one should approach these patients, in particular when serious decisions are to be made, e.g. end-of-life decisions, organ donation, serious prognostic information etc. How is power imbalance dealt with? This question is in particular important to address in these serious decisions, but it may be very difficult to deal with in a clinical setting!

Response:

As we noted above in response to the first reviewer’s concerns, we recognize that how to approach these issues clinically and how to clinically assess the status of the power and decision making dynamics between two persons comprising a couple is not straightforward. When faced with serious decisions such as end of life choices, organ donation, etc., the stakes are high for the individual and so we tend to seek greater confidence in our assessment of decision making and decisions. These assessments are not easy under any circumstances. We do recognize that assessment of the contributions to decision making of each individual in a couple has to take into account “…the specific cultural, ethnic, religious, and personal context and background of the individuals in question” (p. 16, line 348), and we call for further discussion and empirical research. This is an area that certainly needs additional attention, and hopefully our paper will lead to further debate and attention.

It is a well written paper, and easy to follow, and I hope this paper will start a necessary debate. The example of breast reconstruction functions very well.

Response: Thank you.

I have but a few comments / questions:

The structure of the paper is a bit strange: first background, and then "Main Text"? Should the field of family ethics be referred to?

Response

The headings made the structure look rather unusual. We have now reworded the headings.

What about hidden power which can be present in "persuasion", persuasion then indeed becomes controlling. Hidden power exists in our part of the world as well.

Response:
We agree that hidden power in persuasion can indeed make it controlling but we believe this would be difficult-to-impossible to detect in most situations since it takes place outside the view of third parties (such as clinicians or ethicists). In such situations, claims of “couple joint decision making” are suspect as we argue on page 16 of the manuscript. We have now added some text to address this issue.

Reference # 6 is incomplete.

Response

Thank you. We have completed Reference #6.