Author’s response to reviews

Title: Shall parent/patient wishes be fulfilled in any case? – A series of 32 ethics consultations: from reproductive medicine to neonatology

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Dear editors,

Thank you very much for the reviews of our manuscript. We understand that there is a list of points to be clarified and try to live up to this goal. Also, we appreciate the effort and time that the reviewers invested into our paper.
Niklas Juth (Reviewer 1):

This study certainly has merits. It brings new interesting findings into the discussion about ethical consultations (EC) and has a clear area of focus, thereby filling a knowledge gap. However, due to several unclear passages and methodological considerations, it has to be substantially revised before publication. Here are my main concerns.

Introduction

1. In the beginning of the article, it is said that the article aspires to "give insight into ethical reasoning in a particular area of medicine [i.e. reproductive medicine, obstetrics and neonatology] with unique ethical questions and challenges." This is done (partly) by investigating ethical consultation (EC) records. But if this is done, and especially if it is done by using qualitative method, one wonders why the "focus and research question of the study concerns whether or not the respective wishes of the parents (-to-be) were supported". Surely, there must be all sorts of ethical considerations in the EC records. The authors need to explain why they choose the narrow focus they did. By doing so, they also made the choice of in practice to make this into quantitative research (see below).

We supplemented the introduction to clarify this point.

Method:

2. Row 94: "retrospective qualitative analysis of a series of cases was carried out…" It is unclear what qualitative method of analysis is used more specifically (there are several to choose from), why the method used is used (i.e. the rationale of choice of method) and what makes it qualitative. The main results (rows 133-139) are all quantitative by definition (since they are about counting the occurrence of something, e.g. support for patient's wishes).

Our qualitative approach is based on the work of Mayring. We added this in line 106.


Although in the results you refer to (as of line 150) we listed the rates of how many times wishes were rejected or accepted, we consider the approach of our work to be basically qualitative. As described by Mayring the analysed aspects are deduced closely from the studied material inductively. According to this we created categories that display the wishes of the parents (to-be). After this structuring process we then went back to the documentary sheets to identify the wishes in every case. Only as a second step we conducted a quantitative analysis in those qualitatively compiled categories.

3. Row 99-100: "… relying on a systematic change of perspective thus avoiding subjective bias." Please clarify what is meant by "a systematic change of perspective" (recurs in row 106) and why it avoids "subjective bias" (by the way, is there objective bias? This phrase should be changed or explained as well.) Row 107-108: "Further central elements are the comparative analysis and evaluation of different diagnostic and therapeutic options under ethical aspects." This sentence needs clarification in several respects. First, central elements of what? Second, please clarify what "the comparative analysis and evaluation of different diagnostic and therapeutic options under ethical aspects" means. What comparative analysis? What evaluation? What ethical aspects? The mentioned four principles or something else (the word "Further..." in the beginning of the sentence suggest something else)?

We tried to improve this paragraph to clarify those questions, see row 120-127.

Discussion:

4. The discussion in rows 205-221 about "medicine as a wish-fulfilling institution" is puzzling. In order to take a few examples: "Although, as illustrated before, each of the main subgroups has its unique characteristics, there is a red thread: the appeal to medicine as a wish-fulfilling institution." Who makes this appeal: the patients, the authors or someone else? The fact that the patients have wishes could not be sufficient in order to make the subgroups into "medicine as a wish-fulfilling institution". After all, it is the choice of the author to focus on the wishes of the patients.

5. Second, "medicine as a wish-fulfilling institution" is defined as "any sort of medical treatment carried out without direct medical need". But surely there are proper medical needs to address within reproductive medicine, obstetrics and neonatology, or? Do they conceive of all the cases as cases lacking medical needs? Then one would like to see a definition of medical needs (as opposed to wishes), which, as the authors notice, difficult to produce.
6. Third, it is said that "In wish-fulfilling medicine the process of shared-decision-making and the application of a patient's autonomy is different from the onset." Is it? Why? How? The authors continue: "The patient may opt for a treatment and may skip important steps in the decision process such as sharing information and counselling about options. They execute "… autonomy far more directly and with a greater impact than in usual clinical situations". [34]" Really? May they? Do they? Why? How?

7. Fourth, it is then said that "When applied to ethical questions concerning unborn or newborn children respectively, this way of executing one's autonomy receives a new dimension." What new dimension? Why? How?

8. Fifth, it is said "Throughout the analysed cases EC was only requested in extremely conflicting decisions." What characterizes "extremely conflicting decisions"?

9. Sixth, it is said that "In these situations EC can certainly be beneficial to distinguish between options and the most appropriate ethical justification." What is this distinction about? Is it simply noting that what one could do in a certain situation (one's options) will also include options that are not ethically justified? It is hard to see why anyone could fail to make this "distinction". If the authors mean something else, it has to be clarified.

This is only a few examples of writings that needs to be clarified.

We have adjusted this paragraph.

Conclusion:

10. In the beginning of the conclusion, one can read: "We illustrated that ethically challenging parent / patients' wishes should not be fulfilled automatically without ethical deliberation. A connecting link between all the cases appeared to be the principle of respect for autonomy." There are at least two problems here. First, what the authors really have illustrated is some of the EC expressed that "patients' wishes should not be fulfilled automatically without ethical deliberation". But perhaps patients' wishes SHOULD be automatically fulfilled without ethical deliberation. This is a normative position requiring normative argument. The article does not present any such argument - it is an empirical and not a normative study that the articles build on. What is expressed in the first sentence in the quote is a classic example of a violation of Hume's law. It needs to be rephrased. The other problem is that the connecting link is a result of the focus of the authors, namely to focus on "whether or not the respective wishes of the parents (-to-be) were supported" (see above). Then, by definition, the principle
of autonomy becomes relevant. But this is not a conclusion, but part and parcel of the design of the study.

We do not intend to derive an Ought from an Is. Thus, we have tried to improve the section Conclusions in this regard.

Reviewer 2 (Reviewer 2):

PEER REVIEWER COMMENTS:

GENERAL COMMENTS: The research question is interesting, and the investigators have done a good job of designing an effective review with some interesting insights.

However, the writing is a bit of a mess. I gather that the authors might not be native English speakers, which is understandable. There is a need for some heavy editing to provide greater clarity, and the moving of content from one section to another.

REQUESTED REVISIONS:

11. This is essentially a systematic literature review without meta-analysis. It should be transparently stated as thus. Line 50: PRISMA is checklist for the conduct of systematic reviews and meta-analyses, yet this sentence begins by saying the LITERATURE REVIEW was conducted according to PRISMA. This does not logically follow.

As there were only 14 eligible studies with no obvious common denominator no meta-analysis was conducted. We have supplemented this paragraph to make this more transparent.

12. Line 36: referring to the space between "conception and birth" as a "life period" is politically problematic, unless the authors are overtly stating that life begins at conception.

We have rewritten this sentence.

13. The entire manuscript is peppered with sloppy grammar like this, and needs a once over from a high quality editor. For instance, in line 40, EC is used in the plural ("Not only DO EC...."), but in the same sentence it is used in the singular ("IT has even been shown to...")
Similarly, there is a need for better paragraph separations. For example, lines 36-48 can easily be 2 or more paragraphs.

For better readability we have divided the introduction into more paragraphs. In addition, we revised the whole text to distinguish between the singular and plural form of EC and in addition an experienced scientific author checked it for any other grammatical flaws.

14. There is a great deal of confusion about what goes into the Methods section and what goes into the Results section. For example, lines 59-91 seem mostly relevant to METHODS, yet they appear in the LITERATURE SEARCH SECTION. The literature search is a portion of the methods, and should not be separate.

As requested the literature search is now part of the methods section.

15. Similarly, in the Methods are listed the numbers of studies reviewed. These numbers are in fact the RESULTS of the search process, so would be reported in the RESULTS section.

We don’t understand this complaint. To prevent misunderstanding: Those aren’t studies we reviewed per se but sources where the approach of our ethics consultations and our method are based on.

16. On line 163 there are two commas and an ellipsis followed by a phrase in round parentheses.

I don’t know what the two commas signify or if this is a typographical error or a type of grammatical nomenclature with which I am unfamiliar. The parenthetical phrase should be in square brackets, though.

Corrected.

17. Lines 168--180 is expressing two different ideas that are entangled. Some rewriting for clarity would be appreciated.

There are already two paragraphs where we elaborate on cases from different subgroups which are named at the beginning of each paragraph. How are the ideas entangled?

18. Line 206: I am unfamiliar with the phrase "red thread". Please describe the meaning.
By red thread we mean the common theme that links all subgroups. We have rewritten this phrase.

ADDITIONAL REQUESTS/SUGGESTIONS:

19. The authors should strive for clarity. The core of the research is fine and interesting. As this is a systematic review, some mention of how the conclusions were landed upon would be useful: was a narrative synthesis employed, a thematic analysis, or is the purpose of the paper to simply describe the contents of the studies that were identified?

See point 2.