Author’s response to reviews

Title: The living dead? Perception of persons in the unresponsive wakefulness syndrome in Germany compared to the USA

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Author’s response to reviews:

Dear Dr. Hickey,

Thank you for your positive response and for giving us the opportunity to further revise our manuscript.

We now submit the edited version of our manuscript. We detail in the following how we have incorporated the reviewers’ and your helpful suggestions and addressed the concerns as well as the missing supplemental file.

As asked, I provide the revised manuscript as a single clean copy.

Sincerely,

Inga Steppacher

1. Under your Ethics approval heading in the Declarations section, please clarify whether informed consent obtained from participants was written or verbal.

I added the following explanation: Participants were informed about general study content, anonymity, data storage and data security on the first page of the online survey. They have to check the consent box in order to begin with the survey.

2. Please note that in the case of minors, members of a study are not capable of providing ethical consent to participate for themselves. As research for this manuscript includes participants as young as 17 years old, we would expect a parent or legal guardian to provide consent to participate in their stead. Please add a statement to the Ethics approval and consent to participate
subheading to reflect that the parents or legal guardians of these participants provided consent on
their behalf.

Alternatively, please provide relevant legislation or national guidelines that state that members
may provide consent for participation in research after the age of 17 in this context.

The front page clearly stated that participants have to be 18 years old in order to participate. However, there were 9 participants under the age of 18 years. We now exclude these nine participants from the analysis. Given the remaining 910 participants, no changes in results occur.

3. Thank you for including a Funding heading for the Declarations section. Please also state the
role of the funding body in the design of the study and collection, analysis, and interpretation of
data and in writing the manuscript. Please note that the role of the funding body specifies any
function beyond the direct funding of aspects of the research or presentation of the manuscript.

I added the following statement: The BMBF played no role in the design of the study, data
collection, analysis and interpretation of data, as well as in writing the manuscript.

4. Please upload a secondary English language version of supplemental file “S1 Text. Original and translated scenarios” where all sections have been fully translated. Please do not remove the original file from the file inventory.

The file is named S2 Text and is now uploaded as an addition to S1 Text.

5. Please add a “Supplementary files” section where you list the following information about
your supplementary material:

- File name
- Title of data
- Description of data

I added the Supplementary files section above the Declarations and under the List of abbreviations.

6. When submitting your revised manuscript please ensure you do so as a single clean copy
without any tracked changes, colored or highlighted text, as these are no longer required at this
stage of the editorial process.

I submitted a single clean copy.
Reviewer reports:

Boris Kotchoubey (Reviewer 1): All critical comments (from my point of view, also those of the other reviewer) have been appropriately accounted for in the revision

Thank you very much!

Luigi Trojano (Reviewer 2): The authors revised their manuscript following Reviewers' comments and suggestions.

I believe that the present version of the paper is actually improved with respect to the original one. In particular, the authors reported some novel analyses about the possible relationships of demographics with participants' responses (age but not gender was significantly related to responses), and addressed some of the issues raised by the comparison of their data with those gathered in a similar previous study on a sample of US people.

I am still convinced that following the approach of the previous US study did not allow focusing analyses and interpretation on the data available in the present German sample. In this sense, the comparison with the US study informed by Hofstede's theoretical model posed several constraints that limited exploiting study's potential.

For instance, the effect of age on consideration of UWS (higher mind ascription in younger participants) is indeed interesting, and might be related to higher religiosity in younger people, or easier access to media information about UWS, or higher cultural and socio-economic background. The authors did not focus on these aspects, but only pointed out that their sample was younger than that reported in the US study, thus excluding that the different responses in the two studies could be accounted for different mean age of the samples.

This is indeed a good idea. However, beside the correlation between mind ascription and age, there is no further significant correlation. Age does not correlate with religiosity (single question, I am a religious person r(221) = .122, p > .05; as well as with the religiosity index). There is also no correlation between age and the subjective feeling of being informed about UWS r(218)=.129, p>.05 or between age and gender r(218)=.08, p>.05. We now include this information within the discussion.

Another aspect that seems to warrant more attention is the discussion about possible shortcomings of assessing mind ascription via written vignettes. Indeed the authors commented on the possible role of wording, particularly in comparison with the US study, but did not comment on the fact that 72/991 participants failed the manipulation check (i.e. did not understand David's conditions). This figure seems to be quite high, if one considers that the sample was composed by relatively young, educated healthy people. The authors might assess whether failures on the manipulation check were equally distributed across conditions, and comment on this finding.
We added the following analysis in the discussion: Concerning the manipulation check, we excluded 72 participants who had given the wrong answerer to the question of what happened to David in the vignette story. In the death vignette one was excluded because he stated that David was alive, 9 thought he had survived with severe brain damage (which would be the correct answer for the PVS vignette). In the life vignette 15 were excluded because they said David survived with severe brain damage. In the PVS vignette however, 43 participants (42.5% of all participants failing the manipulation check) answered that David had died. Fischer's exact test confirms that this is significantly more than in the other vignettes (p<0.000). Given the description of the PVS vignette with the very severe brain damage and no hope of recovery, stating that David was dead might not have been a real mistake. Maybe some of the participants actually thought that, while the body was still alive, the person David had died. This is of course a speculation, but if so, the practice of excluding these participants from the study might have actually excluded mostly participants that engage in active dualism. Further studies could address this issue by asking the participants to explain their choice of answer.

The authors might discuss to a greater extent the role of participants' religion (not considered in the present version) whereas the authors only considered a 'religiosity index' in analogy with the US Study. It would be interesting to contrast atheists vs. followers of any religion, a comparison that could provide cues about the possible role of religion on ethic choices when dealing with patients in UWS (incidentally in Table 1 I suggest replacing 'Religiosity' with Religion' to avoid ambiguities).

This would indeed be interesting if we had sufficient numbers to compare atheists with various religious believes. However, our data would only allow for a comparison between atheists and Christians which would basically resemble the analysis with the religiosity index. Given the composition of the religiosity index, atheists are those with the lowest religiosity index while those actively believing in any religion would be those with the high index. Therefore, we feel that with our data such an analysis would not provide much new information.

A last but not secondary aspect is the personal experience with a patient in UWS. This is a particularly delicate issue, as patients' caregivers are in the special position of deciding what is best for their relatives, and therefore their opinion is of paramount importance. Recent evidence (Moretta et al., Rehabil Psychol 2017) would demonstrate that caregivers tend to ascribe more interaction abilities to their relatives than physicians do. I believe that these findings are relevant for the discussion of the role of contact with the patients in increasing the likelihood of ascribing them mental capacities.

We include this interesting result now in the discussion.

In synthesis, I understand that the authors are willing to maintain the general structure of their paper in which a close parallelism is made between the present and the US study. Even though they do not want to reduce emphasys (and dedicated space) on cross-cultural issues, they might nonetheless enrich the discussion section by taking more advantage from their own data, and addressing some interesting questions elicited by the present study.
A last comment about the sentence on Yu et al.'s data (page 20). I wonder whether UWS patients' response to other people's cries of suffering, can be really considered 'consistent with signs of empathy'. I suggest a more cautious interpretation such as 'thus revealing some kind of emotional responses.'

We use now the cautious interpretation as was suggested.