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. Pagnini,

Thank you for giving us the opportunity to revise our manuscript according to the reviewers’ helpful suggestions.

We now submit the revised version of our manuscript. We detail in the following how we have incorporated the reviewers’ helpful suggestions and addressed their concerns. Both reviewers had very reasonable suggestions which we hope to have included satisfyingly into the text. We tried to shorten the resulting text in some places, but currently the manuscript is about 7500 words. If necessary, we would be happy to take editorial advice on space limitations and would remove information as deemed appropriate.

Current additions to the manuscript and tables are marked in blue.

Sincerely,

Inga Steppacher

Review Comments to the Author

Boris Kotchoubey (Reviewer 1): A famous study of Gray et al (2011) demonstrated that US-Americans ascribe patients in UWS (syn. "vegetative state") even less cognitive facilities than to the dead. The present authors intended to replicate or to check up this result in a European (German) population. Their main result is that Germans, in contrast to Americans, ascribe UWS patients slightly MORE cognitive facilities than to the dead. Moreover, the negative correlation between religiosity and the ascribed cognitive abilities found in the original study was not replicated here.
This observation is very important from both points of view of applied medical sociology and philosophical ethics. Also the discussion of the results is clever and ingenuous. Thus I strongly argue for publication of these data.

Thank you very much for the general positive response!

However, I find that the manuscript needs further improvement.

First of all, the authors must be highly cautious in the interpretation of the obtained USA/Germany differences. The reason is simply that there are very many different aspects of the American and German cultures are histories that might, eventually, account of the differences in the relation to UWS. Although the authors discussed many of such potential factors, there are much more. One of them is the experience of the T4 action than may have made Germans particularly reluctant to value any living condition worse than the death (this hypothesis could be tested in a comparison with another European culture having no history of national socialism, e.g. in a French population).

Indeed this is a valid point which we now have incorporated into our discussion.

Likewise, the fact that Germans see the UWS situation as less tragic as compared with Americans may not need any deep cultural explanation in terms of Hofstede's dimensions, but simply result from different systems of health insurance in Germany and the USA.

In order to avoid participants to rate UWS more negative exclusively because of the costs that arise, Gray et al. pointed out to their participants that all expenses of the UWS (as well as of burial) would be covered by an insurance. We kept this notion for our study. Therefore, we think that differences in health insurance systems between US and Germany should not directly contribute to differences in ratings.

The data clearly contradict to the interpretation that Americans ascribe less abilities to UWS than to the dead because, being (implicit) religious dualists, they ascribe more of the mind to the separated "souls" of the deceased. If the implicit dualism is the explanation, Germans would ascribe less abilities to the died than Americans do, but this is not the case: rather, Germans ascribe more abilities to UWS patients than Americans do.

Thank you for stating this point so clearly. We have taken the liberty to include this into our discussion.

Concerning the correlation between the ascribed mind and the severity of the outcome (which is negative in the American sample but positive in the German one), both directions can be justified. On the one hand, if suffering is negative, the complete loss of the mind implies the inability to suffer, and therefore a better outcome than the partial loss with retained ability to suffer. On the other hand, the entire human existence is related to suffering. Therefore, the ability to feel anything (including suffering) means to remain a human subject, which can be regarded as a better outcome than to lose everything that makes a human. Therefore, neither positive nor
negative correlation is "paradoxical"; rather, the sign of the correlation depends on the general system of values in which the two correlated variables are embedded.

Thank you for pointing this out. We erased the 'paradoxical' from the text.

If the authors discuss the issue of possible active or passive euthanasia for UWS, p.5, they should not ignore the paradox that there are actually two main arguments pro euthanasia: (i) salvation from unnecessary suffer and (ii) a patient's free will and authonomy. Since, however, properly diagnosed UWS patients per definition (i) cannot suffer and (ii) possess no authonomy, they should be - as far as our ethical decisions are rational - the LEAST eligible group for euthanasia! This obviously absurd result builds the logical basis for the contradiction discussed by the authors that UWS patients are attributed "the right to die" although (or even because) they have no rights whatsoever!

We now include the point of unnecessary suffering in more detail in the introduction as well as in the discussion section and added appropriate literature on the topic.

Finally, I am convinced that no contemporary discussion about the ethical aspects of UWS can be successful without taking into account breakthrough findings of T. Yu et al (2013, 2014). They found in 2013 that the MAJORITY of UWS patients (and not a single patient, which might be attributed to a diagnostic error!) respond to other people's cries of suffering, thus revealing signs of emotional empathy. They further demonstrated that UWS patient's Wernicke and Broca areas differentially respond to correct and wrong sentences (although they admit that this may not prove that patients consciously perceive the semantic inhalt of the sentences).

This are indeed important findings. We now include Yu et al., 2013 in our background as well as in our discussion section.

Minor remarks:

p.21, line 19 "participants " => "participants' "

We corrected this error.

Discussion of the differences between medical experts and laymen might profit from the comparisons with the data from many Western countries demonstrating much more negative attitudes of doctors toward active euthanasia as compared with lay population of the same countries.

We added this informative point within the discussion.

Luigi Trojano (Reviewer 2): The authors report the findings of an on-line survey investigating the perception of Unresponsive Wakefulness Syndrome (UWS) patients in a large German sample (N=919). Participants were presented with one story describing the condition of a person
who after a car accident, was either alive, in UWS or dead, and thereafter were asked to rate the mental abilities of that person. The authors explored the effect of religiosity, of subjective knowledge and exposure to UWS patients, and of the medical background.

The authors also compared their findings with those collected in an US sample in a previous study in which the same stimuli were used to assess the perception of UWS.

The study has merit since it investigates a delicate issue that could be relevant for several ethical and health policy decisions in different countries. However, I believe that the manuscript has several weaknesses that preclude publication in its present form. Below I will summaarize my major concerns.

Thank you for the generally positive response!

1) The authors did not consider the potential effect of demographics (age, gender, educational level) on participants' responses. I believe that data should be analysed in this respect, as, for instance, gender might affect attitudes towards death and religiosity.

Thank you for this idea. We include now a backward regression analysis with the proposed factors to calculate the amount of mind ascription variance that can be accounted for by age, gender, socio-economical status, familiarity with the syndrome and religiosity. We found that the factors age, religiosity and socio economic status result in a significant regression model. Age and religiosity had individually significant effects with more mind ascription by younger and more religious people and no gender difference. The model is able to explain about 15% of the overall variance. This is now included in the results section as well as discussed in the Discussion.

2) The authors devote many efforts to compare their own and the previous results from the US sample. The authors even choose parametric statistical analysis to keep the studies as similar as possible, notwithstanding the fact that parametric statistical analysis is not appropriate for some of the present data, not respecting normality assumption.

This is true, however, as pointed out, the more appropriate non parametrical test have also been performed. They resulted only in numerical changes but the main results were the same.

However no comparison is made on possible demographics differences between the two samples. In this case, not only age, gender, and educational level, but also socio-economics and cultural background matter. The reader has no means to establish whether differences between the responses in the two samples can be at least partially accounted for by differences in these variables. I acknowledge that the reader might be reassured by the fact that no significant difference was found on some responses between the two samples, but it is obvious that the responses differed in several crucial aspects.
This is also true. In fact, not only the reader but we have also little possibility to evaluate differences in the sample other than mean age and gender. We now compare the samples on these factors: Gray's sample is younger and includes more male participants. Within our sample we found significant correlations for younger people to ascribe more mind, which suggests that we may have underestimated rather than overestimated the differences between the two samples. Additionally we found no gender differences in mind ascriptions in our data which suggests that the gender differences in the samples might not have a large impact. However, this point of concern is now included as a study limitation within the discussion section.

In their discussion section the authors take into account that linguistic differences might have yielded differences in response patterns, but it would be important to underline that the different procedures used for performing the survey (on-line vs. paper and pencil) might have introduced clearly divergent selection biases in the two studies, with a different composition of the two samples.

We now included this concern within the discussion section.

3) The authors interpret the differences between their own and the US study within a theoretical model postulating six dimensions characterizing different cultures. This part of the manuscript strongly relies on the assumption that the samples included in the two studies are highly representative of the population of the countries characterized by the theoretical model. The authors should made explicit this assumption and demonstrate its plausibility before adopting this peculiar theoretical model for interpreting their results.

We point out that assumption, its requirements and why we think we met them, in the method section. We describe the sampling methods of both studies in more detail now. The concern is also discussed in the Discussion. We think and point out that our data is consistent with this assumption, but that other factors should also be taken into account and further research is needed. In fact, previous experience has taught us that scientists can be very reluctant to the idea that some results may not replicate and can be more open to the idea that cultural differences may play a role. Whereas we are not in a position to judge conclusively where the differences between our findings and Gray et al’s come from, the present data are at least clearly consistent with a cross-cultural explanation. Other factors are likewise addressed via additional analyses and discussion.

In conclusion, I believe that the present study has merit and provides interesting results as far as the issue of the perception of (UWS) patients in a selected German sample is concerned. In this respect I would only suggest exploring the potential role of additional demographic factors in this sample. I believe that, instead, the authors need to tone down their emphasis on cross-cultural issues on the basis of available data.

As explained above, we now additionally include a regression analysis to explore the potential roles of the available factors in our sample. This resulted in a highly significant regression model but only explain about 15% of interpersonal variance in mind ascription. However, the differences we found between the German and US sample are well in line with the assumed
differences due to cultural differences. That is why, for now, we have not removed any of the cross-cultural statistics and discussions. However, if deemed appropriate we will remove or shorten the cultural focus.

I would encourage re-submission of the manuscript after major changes.

Thank you very much. We hope to have met your expectations.