Author's response to reviews

Title: Attitudes towards neonatal euthanasia of the general Austrian population: a survey

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Author's response to reviews:

Point-by-point response to the comments

Additional revisions:

- Please could you provide a statement regarding informed consent. Please state in the Methods section whether written informed consent for participation in the study was obtained from participants or, where participants are children, a parent or guardian.

We included the following statement in the first paragraph of the Methods section: “After calling a selected person, verbal informed consent was obtained from all individuals that were able and willing to participate in the study, otherwise calls were discontinued by the interviewer. All information that was entered into the survey was anonymous. Identification based on the provided data was impossible at any time.”

- Please include email addresses for all authors on your title page.

We included all e-mail addresses.

- Please rename ‘Introduction’ as ‘Background’

Section title was renamed.

Reviewer: Georg Kemmler

Major Compulsory Reviews

1. Methods, p. 5, first paragraph: Did the authors check the representativeness of their sample, e.g., by comparison with census data of the national statistical office (Statistik Austria)?

We included: “To ensure representativeness of the final sample, IFES
constructed a weighting variable based on representative values of the basic socio-demographic characteristics of the Austria population.

2. Methods, p. 6: Attitudes towards NE are assessed by one single question only. As the assessment of lay persons’ attitudes to NE is the main goal of the study, this is quite a “minimalistic” approach. One would usually expect that the topic of foremost interest is covered by more items, both for psychometric and scientific reasons. Why did the authors decide to be so sparingly with items on attitudes to NE? Please comment and also mention this as a limitation of the study!

The aim of the study was to describe the general attitude and/or inclination of the public to reject the idea of giving euthanasia to suffering neonates, rather than to assess attitudes concerning euthanasia in very specific (clinical) situations of neonatal suffering. We agree that it would be preferable to use validated psychometrical scales, but in the field of end-of-life attitudes, such scales are rarely available to date. They would have to be developed, which we were unable to do in the present study.

We now mention this fact in the Limitations section.

3. Results, p. 7-8: The authors provide two analyses, a univariate analysis using Chi-square tests and a multiple logistic regression analysis. Which of the two should the reader “believe” in? E.g., political orientation emerged as a significant predictor in analysis 1 (“right” was associated with higher NE approval rates), but not in analysis 2. Is political orientation important for a person’s attitude towards NE or not?

While the results of regression analysis represent adjusted associations that are independent of the other predictor variables in the model, univariate analysis describes unadjusted associations that may result from correlations with other predictors. Therefore, political orientation alone would not suffice to explain attitudes towards NE (as in Table 2), but it is indeed related if no other variables come into play (Table 1), perhaps through the correlation of age.

4. Discussion, p. 11 first paragraph: Withdrawal of care is quite a sensitive issue. It would be useful if the authors could give a reference (or several) for this.

We decided to delete the questioned statement since the reasoning was not well enough documented to be reliable.

Minor Essential Revisions

5. Introduction, p. 4, last paragraph: The authors state that very little is known of the attitudes towards neonatal euthanasia (NE) in the general public. However, the two articles cited in the paragraph before (Teisserey et al.) do deal with
attitudes towards NEs in lay persons. This should come out more clearly.

The limitation of the two studies performed by Teisseyre et al. is the non-representativeness of their data. Thus, to our knowledge, no representative study about public attitudes toward NE exists.

We inserted “…Very little is known about the general public attitude towards NE; only the two studies presented by Teisseyre et al. [16, 17] addressed the public, however, they were not based on representative samples.”

6. Methods, Data analysis, p. 6, last paragraph: The first sentence of this subsection sounds unnecessarily complicated, please simplify! Also please state more exactly how the backward regression procedure worked. The authors wrote that variables with a p # 0.1 (lower or equal) were excluded, which is probably a typo! Moreover, as significance was defined as p # 0.05, what happened with predictors with a p-value between 0.05 and 0.1?

We changed the first sentence to: “Univariate analyses were done by cross-tabulating attitudes by determinants. Associations were tested using Chi²-tests for independence.”

The choice of the exclusion significance level in the backward procedure is a matter of regression model building philosophy. We used the frequently chosen threshold value of >0.1 as exclusion criteria, which results in maintaining “threshold-significant” variables showing p-values between 0.05 and 0.1 in the model. We agree that this approach is not entirely in accordance with the adoption of a general significance level of 0.05. Given the fact that these variables are “near-significant”, their adjustment could be seen as a tradeoff between model building strategy requirements and the adherence to a strict significance level.

We clarified the adopted approach by including the statement “We used a threshold value of 0.1 as exclusion criteria, which resulted in maintaining “threshold-significant” variables showing p-values between 0.05 and 0.1 in the model.”

7. Results, p. 7: This section should begin with a short description of the sample. While Table 1 provides this to some extent, it would be helpful for the reader to have some basic information about the sample distribution (socio-demographics) in the text.

We included basic characteristics of the sample: “The final sample of 1,000 persons (aged 16 to 90 years, mean age 46.3 years) comprised 473 men (47.3%) and 527 women (52.7%).”

8. Table 2: The column with the p-values should be moved to the right-most column of the table. We revised the table as indicated.
Reviewer: Ralf Jox

Minor Essential Revisions

1) Abstract, line 19-20: The last sentence is a conclusion that cannot be drawn from the data. Please formulate this more cautiously.

We clarified by reformulating to: “given the increasing levels of rejection of NE among the younger generations and among people with a higher educational level, it cannot be precluded that the rejection rate might in future increase even further, rather than decrease.”

2) The introduction should address the question why neonatal euthanasia is a relevant question (why not simply withdraw life-sustaining treatment in these children?) and why this should be studied in Austria. There should be some information about the legal, medical and social context in Austria regarding the care of neonates. Do you have any regulations or professional recommendations on how to deal with end-of-life decisions in neonates? What is the practice in neonatal end-of-life decision making in Austria? Is neonatal euthanasia being discussed in the public or in the medial community?

We inserted the following two paragraphs in the background section:

“Supporters of NE argue that there are neonates whose suffering cannot be relieved, even when withdrawing the life-sustaining treatment, and for whom there is no hope of improvement. Their central argument is based on the judgment of the neonate’s quality of life, arguing that in such cases death would be more humane than a continued life. According to this reasoning, life-ending measures can be acceptable in such cases of unbearable suffering, if conducted under very strict conditions [5].

In Austria, active euthanasia is illegal for anyone, including newborn children. In recent years, we find a recurring public debate supporting either the liberalization of euthanasia for adults or the protection of the legal status quo. During the Nazi period, involuntary euthanasia programs were installed in Austria, directed at both mentally and physically disabled adults but also children. [J Child Neurol. 2006 Apr;21(4):342-8. "A cold wind coming": Heinrich Gross and child euthanasia in Vienna. Thomas FP, Beres A, Shevell MI] Due to the historical burden, active euthanasia for neonates is a delicate subject in Austria that is neither discussed in public nor by the scientific medical community. Studies investigating the attitude toward NE among health professionals or lay people in Austria are lacking. Admittedly, only a small number of investigations on this topic can be found in international scientific literature.

3) Methods: Please add the exact date when the study was conducted. Was it in 2009? How can you explain the delay in reporting?
We clarified by inserting: “The cross-sectional survey about attitudes toward euthanasia was conducted among inhabitants of Austria aged 16 years and older in December 2009.”

The primary aim of the survey was to assess the attitudes toward euthanasia in terminally ill adult people, the results of which were published in BMC Med Ethics. 2013 Jul 4;14:26. doi: 10.1186/1472-6939-14-26. As a by-product, an item on neonatal euthanasia was included for the first time in a representative survey but not analyzed until this year.

4) Methods: the central question about the attitude towards NE (line 106ff) is very vague. Notably, it misses the conditions you outlined before in the introduction (unbearable suffering, parents’ consent...). Please give as much specific information about the formulation and any related information you gave to the participants as possible. Discuss this in the limitation section. A major problem is that you interpreted the categories “undecided” and “do not know” as “approve”, which is not justified. You should distinguish this more clearly in the results section.

The aim of the study was to describe the general attitude and/or inclination of the public to reject the idea of giving euthanasia to suffering neonates, rather than to assess attitudes concerning euthanasia in very specific (clinical) situations of neonatal suffering. We agree that it would be preferable to use validated psychometrical scales, but in the field of end-of-life attitudes, such scales are rarely available to date. They would have to be developed, which we were unable to do in the present study.

The item on NE followed the items on various forms of euthanasia in severely ill adults and was introduced by: “ And now for another medical situation that refers to the beginning rather than to the end of life:“

We included: “The question about the attitude towards NE was preceded by items concerning attitudes toward euthanasia for terminally ill adults. The wording of the NE item was: “And now for another medical situation that refers to the beginning rather than to the end of life:“

Concerning the answering categories, we would like to stress that the main target population of analysis were people explicitly rejecting NE. We therefore compared the category ‘disapprove’ to all other answer categories, an approach already adopted in our former analysis of this survey and also in the analysis of Moulton et al. [18]. To make this point more explicit, we clarified this in the Methods section and inserted it in the Results section:

“63.6% of all interviewees rejected NE while the other 36.4% (‘approvers’ by definition) included persons who opted in favor, were undecided, or didn’t answer the item (Table 1).”

5) Study design: The same authors also published a survey on VAE in the
Austrian population (ref. 15): was this the same survey or a different one? If it was a different one, it is more problematic to compare both results, and it would have been better to ask the same citizens on both topics. (Address in discussion part)

It was the same survey that was cited in the reference (BMC Med Ethics. 2013 Jul 4;14:26. doi: 10.1186/1472-6939-14-26.) Therefore, a comparison of results seems reasonable.

We included the addition “…a relationship that we found in a previous analysis of the same survey data” in the first paragraph of the discussion section.

6) Line 183ff: Why is the argument from unbearable suffering not applicable in neonates? Please discuss whether and what difference it makes when suffering is inferred from observation of behavior or clinical data in contrast to the situation when the patient expresses his suffering.

The statement in line 183 is not correctly formulated. Of course, the argument of unbearable suffering is controversial but central to supporters of NE. We clarified the statement in line 183.

We think that it goes beyond the scope (and aim) of this paper to discuss about the difference it makes when suffering is inferred vs. expressed.

7) Discussion: Please briefly discuss the normative relevance of your results. What can these results teach us about the question whether and how to legalize/allow NE?

We added: “… the question of legalizing neonatal euthanasia along the lines indicated by the Groningen protocol has been very controversially discussed in the medical ethics literature. Approval and disapproval seem to be almost balanced when referring to the number of expressed opinions. Concerning the general public in Austria, a clear reluctance to accept legalization seems to prevail and it may increase even further. Therefore, if physicians involved in neonatal care would intend to introduce regulations such as the Groningen Protocol, strong and comprehensible arguments would be needed in a first step to gain wider public acceptance.”

Discretionary Revisions

1) Abstract, line 15-16: Please state more clearly in what way the age, educational level and experience with end-of-life care affects attitudes towards NE.

We clarified and corrected the statement: “Regression analysis has shown the respondents’ educational level (p=0.005) and experience in the care of terminally
ill persons (p=0.001) to be factors that are positively associated with the rejection of neonatal euthanasia, whereas a higher age was associated with a lower degree of rejection (p=0.021)."

2) Line 40: Does the Groningen protocol not primarily aim to give guidance on how to properly conduct (not only report) NE?
Yes, for this reason we described reporting as “one of the main goals”.

3) Lines 41ff: Could you maybe give some examples for these 3 groups, especially for the latter who was the group you focused your research on?
We included examples for each group.

4) Line 60: redundant phrase (“if it is ethical and if it can be justified”).
We deleted “if it is ethical and”.

5) Line 38 and 62: Please use past tense for events in the past or past projects such as the EURONIC project.
We corrected the wording as indicated.

6) Line 77: What is Computer-assisted telephone interviewing?
We included: “Computer-assisted telephone interviewing … is a telephone surveying technique in which the interviewer is guided by a script provided by a software application.”

7) Line 78: Why did you choose to include citizens aged at least 16 years? What is the age of legal maturity in Austria (18)?
Age of legal maturity in Austria is 18, but most population surveys (e.g. health surveys) start with the age of 15 or 16. In Austria persons aged 14 or older have almost complete capacity to determine whether they may make binding amendments to their rights, duties and obligations, such as entering into contracts, making gifts, or writing a valid will.

8) Methods: Were there any further inclusion or exclusion criteria? Could you verify language comprehension
There were no further inclusion or exclusion criteria. Language comprehension was a requirement for conducting the interview and checked after calling.
We included the following sentence in the Methods section: “Persons unable to communicate in German were excluded before starting the interview.”

9) Line 94: Educational level is not clear (what is difference between high school diploma and university? What is apprentice/vocational?). How did you ask about socio-cultural ideology? It can be doubted whether the self-perceived labels
“conservative” and “liberal” as well as “left-wing”, “right-wing” are meaningful categories in a current democratic society where classic political schemes are no longer applicable.

High school diploma in Austria corresponds to an education of at least 12yrs, and university of at least 15yrs. Compulsory school is an education of 9yrs, apprentice training resp. intermediate vocational degree are degrees that are awarded after 10 and 12 yrs of education. We included years of education in the description of categories for clarification in the Methods section.

We are aware of the problems associated with the self-labelling in political schemes and agree with your doubts. For the situation of a telephone survey, where the number of questions is very limited, we chose this kind of assessment as a tradeoff between practicability and validity.

10) Line 98: How did you define “experience in the care of severely ill” or in end-of-life care? Did you ask about care for severely ill children or neonates? Did you distinguish between professional and private care experience?

Care experiences were assessed by self-reporting. We were not able to distinguish between different kinds of care or persons concerned due to financial limitations in conducting the study.

11) Line 99: The self-rating of health is a very crude measurement, a 10-point numerical rating scale would have been better.

We used a 5-point scale with named categories, a practice very common in health surveys. We clarified this in the description of variables.

12) Results p. 7 and 8: Better use other subheadings for the results that have to do with the content of the results. On both pages there is much redundancy between the text and the tables (here you could shorten the paper).

We shortened and renamed the subsections.

13) Line 130ff: It makes more sense to state this results positively (approval rates instead of rejection rates), as the approval is the new and surprising result.

We changed the wording as indicated.

14) Line 205: Why should knowledge of prenatal care and predictive testing explain more rejection towards NE? Wouldn’t it be plausible to think that people who are more ready to accept an abortion are also more ready to accept NE? See also line 218f. (does not seem consistent).

We added: “thus consider NE to be highly avoidable by a more widespread use of prenatal prevention techniques.”
The statement in line 218 is deleted because it is not consistent and very speculative in nature.

15) Line 222ff: End-of-life care experience of the surveyed citizens probably largely concerned older adults. How can this explain attitude towards NE?

As a result of regression analysis, the effect of end-of-life care experience is established as an independent predictor of attitudes, i.e. it includes independence from the age group variable. Both variables show an effect, but in opposite directions.

16) The whole manuscript needs careful editing for language mistakes (grammar, style, commas).

The paper has now been reviewed by a professional translation agency.