Author's response to reviews

Title: Knowledge, Attitudes and Practices survey on Organ Donation among a Selected Adult Population of Pakistan

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Author's response to reviews: see over
For the Reviewers

First of all, we would like to thank you all for your valuable suggestions and recommendations.

Point by Point Reply to Mr. Leonardo D. de Castro’s Recommendations / Comments

Title: Knowledge, Attitudes and Practices survey on Organ Donation among a Selected Adult Population of Pakistan
Date: 23rd March, 2009
Reviewer: Leonardo D. de Castro

• Major Compulsory Revisions

Q1. As this is meant to be an ethics publication, I consider it necessary for the authors to indicate the implications of their findings for ethical issues related to organ donation. What ethical issues will their findings help to clarify or resolve? How will their findings contribute to the clarification or resolution of those issues?
Authors: We have tried to address this in the Strengths and Limitations section.

Q2. The authors can be clearer and more substantive in their discussion of the findings. For example, on page 18, last sentence of the second paragraph, they say that “This difference can be explained by the reasoning that the patient population is expected to know more about this particular aspect of organ donation” without making clear (a) whether they were referring to the patient population in their study or in the earlier Pakistani study, (b) what particular characteristics of that patient population indicated that they were expected to know more . . . , and (c) what particular implications this finding had for the clarification or resolution of ethical issues.
Authors: We have tried to address this point.

Q3. Significance of the study—In the first paragraph of the section on Strengths and Limitations, the authors say that “the results of our study are likely to create a greater motivational impact.” However, they do not explain how that is going to happen. It is not clear how the information in itself can be expected to generate “greater motivational impact.” The paper could benefit from a more thorough reasoning to support its conclusions. In the second and last paragraph of the Conclusion, the paper says that measures should be taken to educate people with relevant information, . . . so that people can make informed choices in the future. Did it have to take this study to find this out? Doesn’t everybody know this already? Perhaps the authors can explain why the conclusion is not trivial?
Authors: These points have been addressed in the Conclusion and Strengths and Limitations section.
Q1. Introduction: Please provide a more in-depth description of the ordinance promulgated in 2007. For example, does the ordinance define brain death as human death? We have heard that in Pakistan, brain death did not equate to human death. Also, does the ordinance stipulate something about living donor protection (such as means of obtaining consent)? Does it stipulate developing an organ distribution system like UNOS in the US?
Authors: These points have been addressed in the introduction section. However, we have mentioned the salient features with brevity as we plan to write a commentary on the Ordinance in greater detail in the future. Interested readers may perhaps read that paper in the future for a better understanding of the Ordinance and its drawbacks. We thank you for bringing up these important issues.

Q2. Please explain the current situation regarding organ donation from living and brain dead donors in Pakistan by providing data on numbers of cases and organ transplant facilities.
Authors: Available information regarding this has been provided in the introduction section. As mentioned, information on this subject is scarce in the absence of an established national registry.

Q3. Methods: It is generally considered that motives for donation are completely different for brain dead and living donors. However, these two types of donors were not differentiated in the questionnaire used in this study. It is possible that answers for subjects who imagined being brain dead or living donors are mixed together, and therefore the results may lack validity. If this suggestion is relevant, you should add this as a limitation of the study in the Discussion section.
Authors: Thank you. We have added this as a limitation in the relevant section of the manuscript.

Q4. Discussion: The percentage of people who want to donate their organs to a family member is compared to previous studies (p. 18, third paragraph), but more deliberate arguments and careful citations are required. As mentioned above, answers for subjects who imagined being brain dead or living donors may be mixed together in the result regarding motives for donation in this study.
Furthermore, references (reference 14-17) are cited without distinguishing those involving organ transplants from brain dead donors and living donors. Given that motives of donation for brain dead and living donors are different, simply comparing numbers from these previous studies is inadequate.

**Authors:** Some possible reasons for this finding have been mentioned. Where this information was available from the references, we have mentioned the living or brain dead donors. Kindly note that failure to mention such information is because of unavailability of this information from the aforementioned studies.

**Minor Essential Revisions**

**Q1.** Results: Please rewrite the results regarding replies to the question in Section 3 (Part A) of the questionnaire (“16. Who would you like to donate your organs to?”) to improve clarity. You state in the main text, “A sizeable majority of the people reported that they would donate their organs to a family member (39.7%)” (p. 12, second paragraph), but Table 4 inconsistently indicates that 51.1% of people would donate their organ to a family member.

**Authors:** We apologize for the oversight. The correct figure is 51.1% and has been corrected in the main text as well. We also hope that the results are clearer now.

**Q2.** The Discussion section indicates that socioeconomic levels are categorized based on eight variables (p. 22, first paragraph). These variables should be defined in the Methods or Results section.

**Authors:** These variables have been defined in the methods section for a clearer understanding of the readers.
Point by Point Reply to the Suggestions and Recommendations of Mr. Stuart Youngner

Title: Knowledge, Attitudes and Practices survey on Organ Donation among a Selected Adult Population of Pakistan
Date: 23rd March, 2009
Reviewer: Stuart Youngner

Reviewer’s report:

Q1. Background: The reader needs more details about Pakistan that may seem obvious to the authors but are not to readers, at least from the Europe and the United States. For example, in the introduction, there is no mention of how many transplants take place in Pakistan every year, how many are live donors and how many deceased. Are the deceased donors brain-dead or is donation done after cardiac death? You mention the 2007 Ordinance. What did it address? What exploitation of human rights issues did it address? What were these problems, if any, in Pakistan? On page 4-5 you make the assertion that “most of the undesirable practices…are due to insufficient public awareness… Is there any data to support this assertion? How do you know it is so? What are examples of undesirable practices?

Authors: Information about transplants in Pakistan is generally very scarce. Whatever data was available has been incorporated now. However, please note that information on organ donation from Pakistan is scarce in the absence of an established national registry. Therefore, we sincerely hope that your future critique will take this very important point into consideration.

More information has been provided about the 2007 Ordinance. However, we have not discussed it in too much detail because of the increased length of the introduction may deter some readers from reading further. We are hoping to discuss the Ordinance and its shortcomings in a separate paper in the future and feel that the information we currently mention in our manuscript should be an adequate summary of the subject. Interested readers may follow up on that publication in the future. Secondly, because we were not able to support our assertion about “most of the undesirable practices…are due to insufficient public awareness”, we have rewritten the paragraph so as not to give this impression.

Q2. Materials and Methods

In your questionnaire, questions 18 and 19 ask about informed consent using the word “can” not “should”. Does this mean you are asking subjects what is permitted by law or what they think should be permitted? Perhaps, this is a translation problem, but it should be clarified. “Can” would make it a factual question. Do they know the law? “Should” would make it an opinion question.

Authors: We apologize for the oversight. It was a translation problem on our part. It is certainly a “should” question asking the opinions of the respondents; not
a “can” or factual question. We have made the correction in the questionnaire so that the readers are not confused.

**Q3. Results**

Tables 1 and 2 do not mention the self identified religion of subjects. You asked the question, why not report the data? The data reported on page 12 is very confusing to me. The data in the first paragraph seems different from that reported from Table 4 at the bottom of the page. For example, at the top you report that 32.1% would donate to a person of their own religion (and, does this mean only to a person of their own religion?) while at the bottom of the page 29.6% made religion most important. I think I see the difference, but juxtaposing the two results without clarification confused me.

At the top of the page you say a “sizable majority” but give data that except for drinking is not indicative of a majority.

On page 16, you say religion didn’t have an association… To which of the religions you asked about in your questionnaire do you refer? All of them?. And when you say “religion” here, was it the person’s self-identified religious identity or their answer that religion told them not to donate.

Top of page 17: Only 3.5% had themselves donated. Only??? That seems like an incredibly high figure to me. Considering that Pakistan has 160 million people, that would mean that 5,600,000 Pakistanis have donated. Even allowing for children and people who have not heard of organ transplant, the figure is unbelievably high. How do you explain this?

Bottom of page 19: Again, you mention religion. You say “none of the religions”—but the reference is to Islam. Explain.

Bottom page 20: What do you mean by “effective legislation?”

**Authors:** The self identified religion of the respondents has been provided in the manuscript now, in tables 1 and 2 and appropriate chi square test was run for this in table 3 as well so that this information is complete.

Regarding the data before Table 4, we want to clarify for you. As per questionnaire, these are two separate questions. One question asks the respondents to pick one option from each set. So, 32.1% is out of one set that is limited to religion and considering religion as a variable at that point in time without consideration to other factors. The next set in the same question is for age and so forth for many other variables. However, in a separate question that comes afterwards, we then enquired what is the most important factor out of [Religion of recipient, Relationship to recipient, Age of recipient, Health status of recipient, Drug Abuse by recipient, assurance of respectful treatment of donated...
organs and None of these factors]. Now, here respondents have picked one option out of all the options, so we can say here that only religion is the most important consideration out of all the variables in the latter question but not for the former question.

Regarding the mention of a “sizable majority” while giving data that except for drinking is not indicative of a majority; we have removed the phrase “sizable majority” to avoid confusion.

The two variables “religion” and “perception of allowance of organ donation in religion” should not be mixed. A person’s self-identified religion is a separate variable which didn’t have an association with organ donation scores as shown in table 3. 97% of the people in our survey were Muslims. Perception that religion allowed to donate had a significant association with motivation to donate. We hope that this clarification is helpful.

Regarding the actual practice of donation, please note that when we state “only 3.5% had themselves donated”; this means the population in our survey; not the population of Pakistan. 3.5% out of 408 is only 15 individuals; not 5,600,000 Pakistanis. We can’t say this for the whole Pakistani population because the sample of the study was 408; not 160 million people. We have clarified this in the text now so that no more confusion with regards to this point exists.

The reference made is to Islam. Most of the people in our survey were after all Muslims. We have avoided using the statement “none of the religions object to organ donation in principle” so as not to arise confusion. All statements are for Islam.

Effective legislation has been alluded to in the methods section.
Point by Point Reply to the Suggestions and Recommendations of Dr. Syed Ali Anwar Naqvi

**Title:** Knowledge, Attitudes and Practices survey on Organ Donation among a Selected Adult Population of Pakistan  
**Date:** 23rd March, 2009  
**Reviewer:** Syed Ali Anwar Naqvi

**- Major Compulsory Revisions**

**Q1:** The authors have used a quantitative analysis to assess perceptions and attitudes. This approach has limits and can actually be misleading, as was obvious in this manuscript. A qualitative approach or at least a combination of qualitative and quantitative analysis would have been more appropriate for the topic.

**Authors:** We have tried to provide reasoning for the different findings in our study and hope that it will help in making the approach from qualitative.

**Q2:** Here are some observations:
· On page 4, last paragraph, the authors say “Wider public awareness of this Ordinance is crucial for its reinforcement and implementation. Moreover, most of the undesirable practices related to organ transplantation are due to insufficient public awareness regarding organ transplantation and pertaining policy and legislation, low motivation for organ donation, misconceptions related to health risks for donors and religious constraints”. This statement needs to be substantiated by references.

**Authors:** Unfortunately, we could not substantiate this statement of ours. It was also pointed out by another reviewer. We have therefore rephrased and omitted the major portion of this statement from our manuscript now.

**Q3:** The authors are equating blood donation with solid viscera donation. There are major differences between donating blood (a renewable substance) and a Kidney. A person may be willing to donate blood every few months to complete strangers and may be reluctant to give a kidney. The two cannot be compared. In order for the study to be meaningful, this distinction must be made.

**Authors:** We have clarified this point in the Limitations and Results section of the study. We appreciate that you broached this distinction. Since we had collected data regarding all organ and tissue donations, we decided to report the blood donation along with the solid organ donation in our survey. The difference between solid organ and blood donation was clear to the respondents of this survey.

**Q4:** The authors state that “with the exception of a few open ended questions, the interview was based on prompted questions”. In order to assess attitudes and perceptions, surveys only tend to skim the surface and a much better tool is a qualitative analysis which the authors have not employed or done so sparingly. This weakens the study.
**Authors:** We have tried to provide explanations for why we found what we found in the survey. This should hopefully rectify some of the shortcomings of the study.

**Q5:** On page 11 the authors mention “Eighty one (50.1%) people knew that organs for donation can come from people who have recently died...”. It is unclear as to what the authors mean when they say “recently died”. There is a very specific spectrum of individuals who qualify as deceased donors and the term “recently dead” can indicate a variety of situations. This cannot be assessed without actually examining the question related to this bit of information.

**Authors:** The term recently died alludes to “cadaveric donation” which is a very standard term in organ transplantation. We have replaced the word to avoid future confusion so that all readers can understand this standard parlance. The definition of death has been provided in the Transplantation Ordinance 2007.

**Q6:** On page 15, the authors are lumping together a variety of disparate entities together when they speak in one breath about “.....organ donation is out of compassion/sympathy, for money and as a responsibility”. Organ donation driven by altruistic reasons of compassion is entirely different from vending a kidney because of poverty and a lack of other options.

**Authors:** These entities are indeed disparate but we have not intended to lump them together. We asked the respondents why they thought organ donation is done. Some replied that it is done as a responsibility, others though that it is done for monetary gain while others still thought that it is done out of compassion and sympathy. In principle organ donation driven by altruistic purposes is different from vending a kidney and that is exactly the kind of understanding we were hoping to gauge through this question which we successfully did as respondents chose different reasons for organ donation; each individual chose an options nearest to his understanding for the reasons that drive organ donation. Monetary gains were juxtaposed with altruism by respondents.

**Q7:** On page 16, the authors say that “With regards to consent, 76.1% respondents thought that the donor should be the one who can give consent for a living donation”. That implies that, regarding living donations, 24% respondents were of the view that no consent was required from the donor? This response needs further exploration.

**Authors:** The necessary clarification has been provided in the Results section. Thank you for bringing this up sir.

**Q8:** In the same paragraph, further down the authors say that “In the case of unclaimed bodies, a majority (35.2%) felt that the charitable organizations should have the right to decide on this issue while 22.3% felt that no one has the right to
make such decisions”. In framing the question, it is unclear what the authors mean by “unclaimed bodies”. Those that are left in morgues or of a homeless person found dead on the street? If this is what the respondent understood, then this was a flawed question. As stated before, not all individuals qualify to be deceased donors. Clarification is needed.

Authors: This clarification has been added and substantiated by the reference we took our definition of unclaimed bodies from.

- Discretionary Revisions

Comment:
I feel that in addition to the above mentioned points, since the authors addressing a very important area in organ transplantation in Pakistan, they need to strengthen their literature review by going beyond the solitary paper they quote which they themselves indicate as a weak one due to its limitations. I suggest that the authors review the following papers that address some of the issues that the authors have studied:

Authors: We have added new references to provide a more solid background and improve the discussion of the subject.

We earnestly hope that you will be satisfied with our efforts to rectify our manuscript’s faults. As mentioned, this study is an important step in the future direction of organ donation in Pakistan and its publication is important to disseminate our findings to a wider audience.

Thank you

Authors