Author's response to reviews

Title: Patient Preferences for Communicating Risk Estimates

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PDF covering letter
Reviewer Mazur:

Comment 1. “Abstract: The authors use the phrase ‘complex risk information’ in their Abstract. But they will need to explicitly define the concept in their Introduction.”
   Response: The definition of ‘complex risk information’ has been explicitly mentioned in the Background section on page 5.

Comment 2. “Abstract: The authors will need to clarify in their Discussion section why their study was based on 40 women.”
   Response: Clarification as to why the sample size was limited to 40 is mentioned on pages 6 and 12: "Our sample size was small because focus groups and 1-on-1 interviews were originally conducted to discuss HRT and decision-making issues. When convergence was reached on these broader topics, we ceased recruitment and analyzed data from these respondents."

Comment 3. “Abstract (Conclusions): The authors in their Abstract (Conclusions) state that ‘simple bar charts depicting absolute lifetime risk estimates appear to be the preferred format for communicating health risks to patients.’ The authors need to clarify that these format the preferred format based on one measure: patient preferences for format, as contrast to use of format in decision making tasks. This is not a criticism of the manuscript, but ‘preferred formats’ can be preferred for reasons other than preferences for format. The authors did not systematically study the reason these formats are preferred by their study participants. This ties in with the authors’ Background section.”
   Response: This clarification was made on page 2. Additionally, we added discussion concerning not systematically assessing reasons formats are preferred on page 13: "Although we did not systematically study the reasons for participants’ stated preferences, participants were asked open-ended questions to understand these preferences."

Comment 4. “Background: The authors state that ‘The challenge to clinicians is how to present risk information to patients in a manner they can use.’ Again, I believe that the issue of how study participants use information is a different question from what format of information they report they prefer.”
   Response: The wording has been changed to reflect this point (page 3).

Comment 5. “Background: The authors need to be more careful with their terminology regarding ‘more favorable’ treatments vs. ‘risks of treatment’. They state that ‘Framing the benefits of treatment in relative rather than absolute terms tends to make the benefits of a treatment look more favorable, but can conversely emphasize its risks.’ The authors need to remember that both concepts, ‘favorability’ and ‘risk’ have dimensions in the short-, medium-, and long-term. Two treatment survival curves may have the same or different profile of ‘favorability’ and ‘risk’ in the short-, medium-, and long-terms.”
   Response: The phrasing has been changed on page 3 to more precisely reflect the intended meaning: ”Framing the benefits of treatment in
relative rather than absolute terms may emphasize the short-term benefits of a treatment. Conversely, framing the risks of treatment in relative rather than absolute terms may emphasize its risks.”

Comment 6. “Background: The authors need to be careful about their use of the term ‘survival curve’. Their own survival curve in Figure 1 has an atypical y-axis (Chance of Not Developing Heart Disease). Many survival curves have as a y-axis: a patient’s chance of surviving. So, the authors will have to further clarify their survival curve discussion and why they use a less typical y-dimension.”

Response: Explanation for using the atypical y-axis has been included on page 7: "The survival curve was atypical in that its y-axis presented a patient’s chance of not developing a disease instead of the more standard “chance of survival”. This modification was made to keep the data presented consistent with data presented in the other graphical formats since survival was not presented in the other graphs (the chance of not developing a disease is the closest equivalent to survival, which is the chance of not dying)."

Comment 7. “Background: The authors state ‘The aim of this study is to determine patient preferences for the presentation of complex benefit/risk information, including preferences for graphical format, time horizons, multiple outcomes, and metrics.’ It would add to the clarity of the manuscript if the authors in the Methods section have separate subheadings of each preference task: graphic format, time horizons, multiple outcomes, and metrics, and how their methodology was designed to assess each of these preference task dimensions.”

Response: The requested subheadings have been added to improve clarity.

Comment 8. “Discussion: The conclusion should also include discussions of limitations of their study design, e.g., what are the limitations of focus groups and their study size of 40 study participants. There are also limitations of the presentation of lifetime data as contrast to five-year survival data. The five-year survival data has been routinely used in clinical trial research for years and that the scientific literature is fixed up to the present in terms of the data at being discussed in the scientific medical peer-reviewed literature as specified points in time. It may not be easy to go back and ask for expanded temporal data sets when the published literature, e.g., is discussed in terms of five-year survival frames. Also, quality-of-life information may be wholly unavailable in the scientific medical literature because studies did not systematically address quality-of-life in the data collected in the original research study. For further development of these concepts, I refer the authors to the following books: Mazur DJ, Shared Decision Making in the Patient-Physician Relationship: Challenges Facing Patients, Physicians, and Medical Institutions, Tampa, FLA.: American College of Physician Executives, 2001; Mazur DJ, Medical Risk and the Right to an Informed Consent in Clinical Care and Clinical Research, Tampa, FLA.: American College of Physician Executives, 1998.”

Response: Discussion of study limitations has been developed on pages 12 and 13 to address:
a. Study size and focus group discussions: “Our sample size was small because focus groups and 1-on-1 interviews were originally conducted to discuss HRT and decision-making issues. When convergence was reached on these broader topics, we ceased recruitment and analyzed data from these respondents. While these results may not be generalizable to all women, our sample included a diverse group of women with respect to race, income, and educational background. Recognizing that focus group discussions might lead to "group think", we control for this by asking participants to privately write down their personal preferences before they were discussed.”

b. Timeline of survival data: “…since scientific literature traditionally presents 5-year survival data, it might be difficult to compare our data, based on 10-year, 20-year and lifetime horizons, to that in the current literature.”

Reviewer Siegrist

Comment 1. “Data from focus group discussions and one-to-one interviews were used. In a focus group discussion people may influence each other, therefore, I’m bothered that observations are treated as if they were independent from each other. A more detailed description of the group discussion might clarify this point (e.g., Were the preferences assessed before participants discussed the presentation form?).”

Response: Details about the focus group discussions have been clarified on pages 6 and 12: “To avoid ‘group think’ resulting from focus group discussions, participants were asked to privately record their preferences on a worksheet before the group discussion convened. These worksheets were collected after the discussions and data were extracted and analyzed.”

Comment 2. “For non-Caucasian women, smaller differences were observed than for Caucasian women (see Table 2). Is it possible that this result can be explained by the fact that non-Caucasian women were tested in one-to-one interviews?”

Response: This possibility has been addressed on page 10: “There was a smaller difference in mean preference rating among non-Caucasian than among Caucasian respondents. It is possible that this was due to the fact that these discussions were conducted 1-on-1 as opposed to focus group discussions. However, this is not likely as the 1-on-1 discussions were time-constrained and highly focused.”

Comment 3. “The study did not test which form of presentation is best understood by patients. Should we use the preferred presentation form or the presentation form that is best understood by most people. Do the authors expect that these two criterions are correlated? Some more elaboration could be helpful in assessing the relevance of the results.”
Response: Clarification of the benefits of assessing both comprehension and patient preferences has been added on page 12: “Presentation formats that are not understandable may be misinterpreted; formats that are unappealing may be ignored. Therefore, future studies might test both comprehension and patient preferences simultaneously to develop future risk communication tools.”