Reviewer’s report

Title: Parents of Healthy Children Assign Lower Quality of Life Measure to Scenarios Labeled as Cancer than to Identical Scenarios not Labeled as Cancer

Version: 0 Date: 13 Jan 2019

Reviewer: Justin Newton Scanlan

Reviewer’s report:

Thank you for the opportunity to review this interesting paper.

The overall aim of the study is relevant and novel and overall, the paper is very nicely presented.

I have a few suggestions for revisions that I have outlined below.

The concept of "health utility score" is a tricky one to understand, particularly for those who are unfamiliar with it. If it is possible to give a little further explanation of this concept when it is first presented (page 4, line 4 to 32), I think that this would be helpful.

Related to the point above, the scale from "perfect health" to "quick and painless death" doesn't really seem to be the full spectrum of health outcome from my perspective. Pain was a key feature included in the scenarios, so it seems like "a slow and painful death" may be a more relevant polar opposite to "perfect health." I could not see reference to "quick and painless death" as the "0" anchor point in the other studies using this approach. Perhaps it might be worth adding a little further explanation as to the choice of this anchor point.

I was a bit confused by in the methods section in terms of the sentence: "The scenarios were prearranged in order of severity along with "perfect health" first and "a quick and painless death" last." Firstly, in a later part of the methods section, it was stated that the "worst scenario" was presented to participants first. Additionally, it is not clear how the anchors of "perfect health" and "a quick and painless death" were presented to participants. I think it would be helpful to clarify this a little more.

In the analysis section, Page 7, lines 38 to 48, it is reported that "We used univariate statistics to compare each arm ("cancer" or "serious illness") using the Student's t-test for continuous data and the chisquare test for categorical data. We then compared the median health utilities of each scenario and all scenarios in aggregate using the Mann-Whitney test for medians. We chose a non-parametric test to compare the two arms, since health utilities are unlikely to be normally distributed." It is not clear to me why different analysis methods were used to compare health utility scores across the different scenarios (Student's t-test) and then the aggregate (Mann-Whitney). If health utility scores are non-normally distributed, then wouldn't this be the case across all of the scenarios (therefore suggesting Mann-Whitney tests should be used for all analyses)?
When reporting results in the "health utilities" section, I think it would be helpful to include the Mann-Whitney / t statistic in addition to the p value).

I think that the discussion could be revised to make the implications of this study clearer in the context of the existing literature. This study indicates that parents of healthy children are more likely make riskier decisions when faced with a hypothetical situation that their child has cancer that is not responding to treatment as opposed to a similarly serious illness not labelled cancer that is not responding to treatment. However, results from the other scenarios suggest that the influence of the word "cancer" is not as significant when the prognosis is better. However, the results reported from parents of children with ALL suggest that when parents actually do have a child with cancer, they are more informed about the prognosis and therefore seem to make more "reasoned" or "balanced" decisions. So this suggests that "cancer" may have an emotive influence on parents of healthy children. I think the authors are suggesting that this may influence parental decision making in relation to their children undertaking tests or other treatment that may carry with it a risk of cancer (page 10, Line 26 to 34). I think that restructuring the discussion might be helpful in more clearly making this point.

On page 11, line 14, the authors state that "Significant differences were seen between health utility scores assigned to different scenarios within each set." No analyses were presented in terms of differences within each participant group in terms of health utility ratings for the different scenarios. Therefore use of the word "significant" should be avoided as this suggests that analyses were completed to analyse these differences (and if they were, this should be presented in the results section).

Page 12, Line 51 to 53: there is a sentence that reads "We will also mention that false negatives are almost as bad as false positives (Peasgood et al., 2010)." This needs revision, as it is not clear what is being suggested here.

In the declarations section, I think that "not applicable" should be replaced with "The Institutional Review Board at Indiana University School of Medicine approved the study with expedited status." in the "ethics approval and consent to participate" section. It was also mentioned in the paper that participants were 'consented', so perhaps a brief description of the consent process could also be included in this section (i.e., if the consent was written or verbal). When I initially read this section prior to fully reading the paper, I was concerned that no ethics review process was undertaken and that formal consent was not granted, which does not appear to be the case.

Thank you again for the opportunity to review this interesting paper. I hope my suggestions are helpful in making revisions to the paper.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

Does the work include the necessary controls?
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Yes

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