Author's response to reviews

Title: Social autopsy: INDEPTH Network experiences of utility, process, practices and challenges in investigating causes and contributors to mortality

Authors:

Karin Källander (k.kallander@malariaconsortium.org)
Daniel Kadobera (dkadobera@yahoo.com)
Thomas N Williams (twilliams@kili.kemri-wellcome.org)
Rikke Thoft Nielsen (rikke.thoft@gmail.com)
Lucy Yevoo (lyevoo@gmail.com)
Aloysius Mutebi (amutebi@musph.ac.ug)
Jonas Akpakli (jaselasi@gmail.com)
Clement Narh (iteetee@gmail.com)
Margaret Gyapong (margaret.gyapong@4u.com.gh)
Alberta Amu (alberta.amu@gmail.com)
Peter Waiswa (pwaiswa2001@yahoo.com)

Version: 3 Date: 16 May 2011

Author's response to reviews:

Editors-in-Chief: Christopher JL Murray, Institute for Health Metrics and Evaluation; Alan D. Lopez, University of Queensland

Issue Editor: Dr. Rafael Lozano, Professor of Global Health at the University of Washington’s Institute for Health Metrics and Evaluation.

RE: Social autopsy: INDEPTH Network experiences of utility, process, practices and challenges in investigating causes and contributors to mortality

Please find enclosed a revised version of the manuscript entitled "Social autopsy: INDEPTH Network experiences of utility, process, practices and challenges in investigating causes and contributors to mortality" for consideration for publication in the special thematic series on verbal autopsy.

We have significantly revised the manuscript by addressing each of the two reviewers’ comments as well as the comments provided by the handling editor (see annex 1, 2 and 3).

We look forward to your response.
Sincerely yours,

Karin Källander, MSc, PhD
Malaria Consortium.
P.O Box 8045, Kampala, Uganda
Tel: +256 772 744126

Annex 1- Reviewer 1 report

Title: Social autopsy: INDEPTH Network experiences of utility, process, practices and challenges in investigating causes and contributors to mortality

Version: 1 Date: 1 April 2011

Reviewer: Maria de Fatima Marinho de Souza

Reviewer’s report:

1. In general, I would suggest that the article be shortened. Considering the significance of the article’s contribution, revision and editing are essential. The text could be more objective, since there are too many details in the methods, results and discussion portions that could be edited so the text overall could gain more flow to it. The excess of repetitive words makes the flow of the different sections of the paper more difficult. This way, the reading and comprehension of the text becomes harder. For example, in methods it is not relevant to the readers to know that “the results from the literature search were compiled by the lead author (KK)…” or if the workshop was in Nairobi or other city. In the results there are similar issues with too many details. Other example is “A second SAWG meeting, sponsored by the INDEPTH network, was organised in Pune, India in 2009, to finalise the analysis plan for the SA data collected…” It could be more objective summarizing the amount of meetings, the goals and results.

Action 1: The article has been shortened significantly and as suggested by the reviewer and the details around the process has been reduced to allow for more focus on the methods of implementation and results.
2. The article shows that in the path to a child death there are barriers in the access to health care services such as cultural, geographic and institutional barriers. It is a fact that any delay in a child death pathway contributes to a fatality. Even worst is a sequence of delays. In the social autopsy attributing the child death to these delays could generate bias in the social interpretation.

Action 2: I am not entirely sure what the reviewer means by this statement. We are not sure if she means that she is worried about the sequence of delays generating bias or that the child death pathway generates a bias to the social interpretation of illness. We have tried to address both issues in the discussion section on page 23 and 25.

3. In the social autopsy, it would be important to explain the culture related delay and the experience in perceiving symptoms as well as the gravity signs for a child at home. For example, in the case of Uganda a high variance (Mean 24.5 days; SD 50.3) was observed in the delay to seek the care, which could be related to different cultural perceptions. Even delays at a facility level could be explained using a social-cultural approach.

Action 3: The recognition (and interpretation) of illness is the most difficult part to assess using social autopsy and even well-developed SA tools cannot elucidate the contribution of culture related delays unless they are complemented with qualitative methods. This is now discussed on page 23. The high variance observed in timing of treatment seeking between Uganda and Ghana was due to some outliers and we now used median number of days instead.

4. Understanding cultural issues is fundamental to local health authorities in order to improve policies, programs and services when taking into account cultural issues related to premature deaths.

Action 4: Point taken. A section on this will be added in the discussion on page 23.

5. It is important to be careful with some of the conclusions. It is too easy to attribute to the caretaker a poor behavior when seeking care. In Ghana, for example, the geographical and institutional barriers were so difficult to overcome that the result was the same for the child who stayed at home or not. Moreover, it is important to deepen more the cultural barriers and knowledge to explain better this problem. For example, if there is a social belief that is common to a community, seeking care or staying home would not make a difference since the child would not survive it according to this belief. Therefore there would be no outside expectations for the caretaker to act on it.
Action 5: Point taken. Will adjust the conclusion accordingly and bring out the limitation of SA to bring out the cultural related delays. As above this is included in the discussion on page 23.

6. To deepen the cultural issues related to premature deaths is an important contribution that a social autopsy research could bring.

Action 6: point taken but only if the SA tool is complemented by qualitative methods. Could be valuable to conduct in-depth interviews with a sample of deprived caretakers to understand cultural related delays in relation to various disease conditions. This is now mentioned on page 23.

Annex 2 – Reviewer 2 report

Title: Social autopsy: INDEPTH Network experiences of utility, process, practices and challenges in investigating causes and contributors to mortality

Version: 1 Date: 11 April 2011

Reviewer: Morten Sodemann

Reviewer’s report:

Major compulsory revisions

1. With a focus on delays in the care seeking process the methods section is not clear enough. It does not describe the exact methodology behind the evaluation of delays: who, when, how, guidelines etc. As it is it would not be possible for somebody else to repeat the study. This could be the source of important bias

Action 1: The methodology has been revised significantly to better describe how the data was analyzed and the delays were evaluated. Table of results from both countries have been added to back up the process.

2. It is not explained why a dataset with 434 deaths is compared to a data set with only 40 deaths in a different country. The comparison is not necessary and it creates more questions than answers.

Action 2: The reasons for the big difference in numbers are that Uganda included
deaths over 18 months whereas Ghana reported deaths over 12 months; that the study in Uganda covers a bigger population and that Uganda has a higher child mortality rate than Ghana. We did not set out to compare the two countries; rather to report on the results of implementation of the new tool in two different contexts. We have tried to clarify this in the methods section on pages 9 and 15.

3. If the comparison was justified it still lacks a range of confounders and co-variates: disease/mortality pattern, geography, logistics, ethnic diversity, referral policies, transport access, malnutrition rates, chronic vs. acute illnesses, formal/informal user fees, constellation of evaluating physicians. Are the two study areas comparable?

Action 3: The aim was to present the data from the two countries separately, not to do comparison (which correctly so would require analysis of co-variates etc). We have toned down the comparative angle and are now emphasizing that we are reporting the results from the two countries separately (see page 15).

4. By not including information regarding care sought between first and last visit valuable information is lost that could explain behaviour - it is not clear why this information is omitted

Action 4: This decision to only include first and last source of care came out of the discussions in the expert group based on experiences from data collection in Bandim HDSS and from previous experiences using the SA tool in its old format (Bolivia report by Aguilar 1998). Both Bandim and Bolivia results showed that it was too complex to analyse the care seeking information using more than 2 sources, that data collectors would not be able to collect such complicated data, that mothers tended to mix up the providers seen and because the tool got too lengthy. It was concluded in the group that what is most important is the first and last source of care. This is indeed a limitation of the SA tool and is discussed on page 26.

5. It is not clear how symptom severity was assessed but it is still a crucial parameter in the analysis. This could also be a source of important bias.

Action 5: One limitation of the tool we developed was that it did not include a question on the severity of the child’s condition at the time of first care-seeking. This was later added in the final version. This limitation is now discussed on page 27.

6. Inappropriate decision making (p. 17) – patients and care takers are always rational on their own grounds – was there any effort to explore their grounds? –could it be that the child temporarily improved because of treatment given and
then deteriorated?

Action 6: Point taken and text has been modified.

7. p. 19 first paragraph last sentence important but does not make sense – missing words?

Action 7: The sentence has been fixed.

8. Not clear why SA tools for newborns and for maternal deaths are given so much attention in the introduction while no data are presented regarding the tools.

Action 8: Point taken. The work on the neonatal and maternal tools have been toned down and the focus is now on the child death tool.

9. Sounds as if more than the two sites reporting results in the present paper have evaluated the tools. What were their experiences – the study being exploratory and pilot testing of the SA tool?

Action 9: It has been clarified in the methods section which sites contributed to the tool development and which ones contributed with data.

10. The statement regarding the findings from Ghana (“While the results from Ghana compare with most many other studies which link child deaths to poor care-seeking behaviour”) is incorrect. There are many studies that demonstrate appropriate care seeking in fatal childhood illness.

Action 10: Point is taken and the wording has been changed in the discussion.

11. It would be informative with some additional results from the other sites that tested the SA.

Action 11: It has been clarified in the method section that only two sites contributed with data. The other site which provided information (Bandim HDSS) only tested the newborn tool and the results from this site will be presented in another publication.

12. The discussion should include a discussion of the obvious factors that influence care seeking mentioned under 3.). and the conclusion should be
adjusted accordingly. It is not reasonable to conclude as the authors do based on their findings.

Action 12: The text has been carefully reviewed and the discussion and conclusion have been revised accordingly to address this comment.

Annex 3 - Handling Editors’ comments

1. There is no possibility to assess causality in this study. The conclusion should be association, not causality.

Action 1: Point taken. Wording has been changed throughout the document.

2. The literature review needs to be improved.

Action 2: An attempt to improve the literature review has been done by reducing the text and making it more concise.

3. The methods section describes a process, and it is not a methodological description. It is not clear how you analyzed the data

Action 3: The process has been reduced and the more focus has been added on the data collection and analysis.

4. We do not feel you should be comparing two countries with such unequal numbers of cases.

Action 4: We have removed the aspects of comparing the countries and are instead reporting on the two countries separately to show implementation results from two different country contexts.

5. We request that you add a table of your results

Action 5: One table from the Uganda results and one table from the Ghana results have been added.

6. It is not clear to us whether your method has been standardized.
Action 6: The intent by the social autopsy working group was to reach consensus around the SA method and to standardize its tools and methods to suit implementation in the 32 field sites in 17 countries under the INDEPTH network. A brief description of the process on how this was achieved is explained under the background and method section.