Author’s response to reviews

Title: Social autopsy: Providing evidence on failures in the pathway to survival, and increasing awareness to empower communities and engage health programs

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Author’s response to reviews: see over
Managing Editor  
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Re: Manuscript ID 3515478435358576

We are pleased to submit our revised paper, “Social autopsy: Providing evidence on failures in the pathway to survival, and increasing awareness to empower communities and engage health programs,” to be considered for publication in the special thematic series on verbal autopsy of *Population Health Metrics*. This was an invited submission, which is based on the oral presentation on social autopsy that I made at the “Global Congress on Verbal Autopsy: State of the Science” meeting recently held in Bali, Indonesia.

The revised manuscript responds to the concerns raised by the journal referees. Please find our detailed point-by-point response to these concerns immediately below. We hope that our responses and the revised paper satisfy all concerns, and that we may look forward to publication of our paper in the special thematic series on verbal autopsy of *Population Health Metrics*.

Sincerely,

Henry Kalter

**Referees’ concerns and authors’ responses**

**Reviewer 1:**

Overall comments:

*In particular the paper would benefit from further explanation of the quantitative results presented in table 1:*

As suggested in the reviewer’s detailed comments (see below), we moved several quantitative results from the Discussion section to the Results section. We added text on the “social diagnosis” outcome variable to ensure that all five objectives were covered. We also provided further explanation of how these findings differentiate the Pathway from the non-Pathway child studies, and the non-MAPEDIR from the MAPEDIR maternal studies. These results reference the findings in table 1. In addition, additional table 1 provides details of the variables presented in table 1 that were not possible to include in the main table due to space limitations. The text also puts all this in context by explaining the intent...
of the outcomes variables, e.g., from the Methods section: “Data were extracted to assess whether the study met five key objectives of social autopsy…”

**Also the paper would benefit from a more detailed explanation of the content and field work procedures required for the administration of the maternal and child social autopsy tools. Clear references and web links to the actual tools would be most beneficial; this will also assist in expanding the use of these tools.**

We agree that the questionnaires and supporting tools should be made freely available to encourage their use. The BASICS Pathway Analysis social autopsy questionnaire is currently available online as part of a manual that provides detailed explanations and tools to support implementation, analysis and use of the collected verbal and social autopsy data. This manual is reference #31 of the current manuscript. We have added the web link to the reference. We plan to make the CHERG social autopsy questionnaire and supporting tools freely available on the CHERG website once they have been more fully piloted and finalized. Regarding the UNICEF maternal verbal/social autopsy questionnaire, UNICEF will need to decide whether to make this instrument and its supporting materials available online.

**Specific comments:**

**Abstract:**

*# Paragraph 2 line 5 and line 14. A major aim of the paper is to describe the development of maternal and child social autopsies, thus the chronology of the implementation of these tools should be clear even in the abstract. However, only the chronology of the maternal death audit is clear. The same level of detail is needed for the pathway analysis (described in line 5) and the new maternal social autopsy (described in line 14). For example the authors should describe when these tools were first developed and implemented.*

The second sentence of the abstract’s second paragraph has been modified to read: “The Pathway Analysis social autopsy format, based on the Pathway to Survival model designed to support the Integrated Management of Childhood Illness approach, was developed in 1995-2001 and has been utilized in studies in Asia, Africa and Latin America.” The last sentence of the paragraph already states the timing of the new maternal social autopsy: “From 2005-2009 ten high mortality states in India conducted community-based maternal verbal/social autopsies…”

**Introduction:**

*# Paragraph 1 line 12. I suggest that the wording should be changed to “Two complementary objectives of social autopsy are to increase awareness of maternal and child interventions to empower ….” My opinion is that the social autopsy does not increase awareness of maternal and child mortality; the main parts of the verbal autopsy does this. I consider that a major objective of the social autopsy is to increase awareness of interventions / pathways to reduce maternal and child health. The authors also seem to imply this elsewhere throughout the paper.*

The empowering information is that which conveys that the deaths can be prevented, i.e., the social autopsy data on mortality determinants demystifies the causes of the deaths, empowering the community to devise interventions to overcome the identified problems. We have changed the wording of the sentence to match that in the abstract, which is “Two complementary objectives of social autopsy are to increase awareness of maternal and child mortality as preventable problems to empower…” We think this appropriately addresses the reviewer’s concern.
# Paragraph 2 line 20. The date of development or implementation of the pathways model should be described here to help the reader understand the developmental process and contrast with the maternal health models.
We have added the date: “…culminating in the development of the “Pathway to Survival” framework in 1995 [4].”

# Paragraph 4 lines 3-8. These objectives are repeated and written more clearly in the discussion in paragraph 3 lines 1-9 thus there is redundancy here. I suggest that the information is cut from the discussion and that it replaces the information written here.
The Methods section includes a detailed discussion of the objectives for a social autopsy study, in the context of describing our plan to assess whether the studies achieved these objectives, which we believe is appropriate for the Methods section. We don’t think this information is needed in the Introduction, and so deleted this. The introductory paragraph now reads: “This paper further reviews the concept of social autopsy, the development of the methodology and the quality of its execution in the pursuit of five key objectives. The paper focuses on seminal efforts in which the authors have participated, while also undertaking a comprehensive search of related work in order to assess how widely and successfully the social autopsy method has been adopted.” The redundant lines in the Discussion section have been replaced with a specific discussion of the achievement or non-achievement of each of the objectives. So, the key objectives of a social autopsy study are now listed only in the Methods section.

**Methods:**

*In general, the field work procedures required for the administration of the maternal and child social autopsy tools were not clear. For example it is not clear how much time it takes to administer these tools, the cadre of health worker required for administration and if the tools allow collection of data on care seeking from more than one provider. Clear references and web links to the actual tools would be most beneficial; this will also assist in expanding the use of these tools.*

Several of these points were also raised in comment 6 of reviewer 2. We have added a paragraph on these points to the Technical Issues sub-section of Discussion section. In addition, the CHERG social autopsy questionnaire and supporting materials and tools will be made freely available on the CHERG website once they have undergone adequate field testing. UNICEF will need to decide whether to make its maternal verbal/social autopsy questionnaire and supporting materials available online.

# Paragraph 2 line 5. I would prefer that 5 years is written as 59 months in line with other CHERG documents.
The age limit in the Methods section is described in accordance with the methodology we used, i.e., the search strategy and the limits available in the databases that were searched; for example, Medline’s age groups relevant to our search are birth-1 month, 1-23 months and 2-5 years.

# Paragraph 2 line 9. It is noted that only French and English articles were reviewed. This should be highlighted in the discussion section.
The first sentence of the Discussion section has been modified to read: “The comprehensive review of English and French literature found that…”

**Results:**

Social autopsy manuscript ID 3515478435358576 – cover letter for revised manuscript
This section would benefit from additional explanation of the available quantitative results. Additional discussion of the results in table 1 i.e. the quantitative data before the qualitative would also be most helpful. For example, some of this quantitative data is presented in paragraph 2 lines 1-16 of the discussion. If this is moved to the results section this will both improve the results sections and improve the flow of the discussion.

We moved the data from the Discussion to the Results section and also separated the Pathway and non-Pathway child studies as well as the MAPEDIR and non-MAPEDIR maternal studies. This improved the description of the Results and shortened this part of the Discussion. We thank the reviewer for this suggestion. We also added text on the “social diagnosis” outcome variable to the Results and Discussion sections to ensure that all five objectives were covered by the text.

In addition, table 1 provides information on the age of children studied but there is no description of the importance of knowing different age groups and the different care seeking patterns across the age groups either in the results or in the discussion.

In fact, the Results section does discuss this, and we have added some detail to the existing sentence: “In 2009 the WHO/UNICEF-supported Child Health Epidemiology Reference Group (CHERG) [33] undertook to review and update the pathway analysis social autopsy format. The main issues considered were: 1) in response to the increased contribution of neonatal deaths to overall child mortality resulting from recent decreases in post-neonatal deaths [34], to improve the format’s assessment of stillbirths and neonatal deaths and related care seeking issues by adding modules on maternal and newborn care, including care seeking for maternal complications;…” We believe that this sentence makes clear the importance of considering the age group being studied by a social autopsy questionnaire.

# Paragraph 1 line 4. Please describe when the pathways to survival model was first created / implemented.

The sentence now reads: “Only three child studies were conducted prior to the development of the Pathway to Survival model in 1995, which…”

# Paragraph 9 lines 1-12. The authors make reference to the CHERG documents but it would be very good if a weblink / clear reference could be provided in this paper.

As described above, the questionnaire and supporting tools will be made available on the CHERG website after they have undergone appropriate field testing.

# Paragraph 10 line 2. What does prefecture or provincial level mean? Is this the same as district? A description of the size of the prefecture of province would be useful.

‘Province’ is a commonly used word for an administrative jurisdiction above the district level, similar to ‘state’ in many countries. ‘Prefecture’ is often equivalent to ‘province,’ and is how we meant it to be understood, but the term has different meanings in different countries so we are dropping it and just retaining ‘province.’ We believe that ‘province’ is a sufficiently widely used and understood word such that it is not necessary to define or describe this word in the paper.

Discussion:

It would be useful to add a paragraph on limitations of the review for example a discussion about the limitations of a predominately qualitative approach to data synthesis and the reasons why a quantitative or meta-analytic approach was not used (eg the limited number of papers). Also the fact that only English and French articles were reviewed should be mentioned.
The paper’s analytic method is to assess outcomes of the social autopsy studies in terms of whether they achieved the five objectives that we describe in the methodology section and table 1. This necessarily requires a qualitative approach to the review. In addition, we did quantify and compare the reviewed papers’ achievements of these objectives according to whether they were a Pathway or non-Pathway paper (child SA) or a MAPEDIR or non-MAPEDIR paper (maternal SA), i.e., how many of each type of paper achieved each objective. A meta-analytic approach might have been appropriate if we were attempting to combine or compare the actual quantitative findings of the reviewed papers, but that was not the purpose of our review. We do not view any of these as limitations of the review, rather that we selected the analytic method that was most appropriate to achieve our paper’s purpose. As stated above, we added mention of the languages of the reviewed articles to the Discussion section.

A paragraph on the limitations or difficulties with the social autopsy approach should also be included. For example, the fact that social autopsy relies on self reports from families who have suffered a severe event should be discussed and how this may affect recall. A discussion about understanding and contrasting the social autopsy approach with assessments of care seeking for other types of health care e.g. non fatal severe illnesses, preventative care, delivery care and how the barriers and constraints vary would be useful. For example much information can be gained from understanding situations where care seeking is successful eg the “Near miss” approach.

We have added a Limitations sub-section to the Discussion section where we cover these issues. The reviewer raises other important study methods for discussion; however, these are beyond the scope of the current article, the focus of which is the review of social autopsy studies and methods and not these other study methods. Nevertheless, at least one type of care that the reviewer mentions (delivery care and constraints to careseeking) is already covered by a social autopsy study of stillbirths and neonatal deaths, but only for women who suffered a stillbirth or neonatal death.

Some discussion about the length of the social autopsy interview is also needed. The verbal autopsy interview in itself is lengthy (usually 30-60 minutes). Adding a social autopsy module to this interview can be difficult as the family are often getting tired by the end of the interview and may answer the questions less accurately. Also the family may have time pressures and may not have sufficient time to answer all questions. A case has been made for administering the two components separately for this reason.

Several of these points were also raised in comment 6 of reviewer 2. We have added material on these points to the Technical Issues sub-section of the Discussion section.

In addition, the following items were not clear and would benefit from revision # Paragraph 2 lines 1-16. As described above, most of the first paragraph (i.e. lines 1-16) should be moved to the results section as this is quantitative data that hasn’t been presented earlier in the paper. This will both improve the results sections and improve the flow of the discussion.

This suggestion was taken, as described above.

# Paragraph 3 lines 1-9. As described above these objectives are a repeat of that written in the background section paragraph 4 lines 3-8 but written more clearly. I suggest the information is cut from here and that it replaces the information written in the background section.

We replied to this same comment above.
Reviewer 2:

**General comments:**
Also, none of the studies included in the review meet the inclusion criteria of representativeness or ‘large area’; either in terms of geography; or sizeable sample size. This is not unusual, since ‘social autopsy’ enquiries till date have been implemented as research studies, rather than through routine data collection programs. Hence, the detailed review of individual studies only serves to underscore the utility of such data collection, and could be summarised.

Representativeness and large area were not inclusion criteria, but rather were study characteristics that were examined by the review. And, in fact, some of the studies did achieve these objectives, as well as several other desirable objectives that the review examined and contrasted between the more and less successful studies. We believe that the review is a valuable feature of the manuscript and that it should be retained. The issue of representativeness is further addressed in our response to comment 3, below.

**Major Revisions:**

I suggest that the manuscript should preferably be recast as a commentary on the need for social autopsy in the light of various issues in its implementation. The commentary could focus on the following issues:

1. Till date, social autopsy has mainly been implemented in the area of maternal and child health, and not for a routine enquiry into population level cause-specific mortality; which is the main driver for implementation of verbal autopsy in developing countries.
2. The article could present a concise summary of the specific experience in implementing social autopsy in different countries; to accompany Table 1. The detailed methodology of and findings from individual studies can be followed up through the references.

We believe that the current approach taken by the manuscript of a comprehensive review with an emphasis on the key work that we have conducted in the field is the appropriate one, and believe that the manuscript should retain this approach.

3. A note of the potential quantitative bias in all these studies should be made, since there is no information (at least from this review) of the actual generalisability of the study sample to the overall mortality in the study areas, to be able to infer the generalisability of findings regarding social determinants.
4. Nevertheless, despite the absence of generalisability from a statistical perspective, the studies have identified social determinants along with specific examples of uses of such information, which indicates the utility and benefits from these investigations; and this point should be highlighted.

We have incorporated these points in new paragraph 3 of the Discussion section.

5. The authors should discuss the potential for extending such enquiry into TB, HIV, suicide and other injuries. The manuscript could comment on the potential value/limitation of social autopsy for NCDs.

While we appreciate the reviewer’s interest and concerns, our manuscript is on the use of social autopsy for child and maternal deaths, with a focus on the most important causes of these deaths. Most are due to acute illnesses or injuries (already covered by the current methodology), which
lend themselves to a Pathway analysis. Even chronic diseases of children, not to mention adults, would be difficult if not impossible to analyze with the existing tools. We believe that new tools based on totally different conceptual frameworks would need to be developed to assess these conditions, and that a description of this methodology properly belongs in a separate, complete manuscript.

6. The manuscript should discuss the considerable challenges in implementing integrated verbal / social autopsy interviews at the population level; in terms of availability /training of human resources; community participation (length of interview, negotiating feelings of guilt/shame in respondents, regarding failure to prevent death etc), and challenges in data analysis.

Several of these points were also raised by reviewer 1. Discussion of these issues has been incorporated into the Technical Issues sub-section of the Discussion section.

7. The manuscript could make the case for nested social autopsy projects as follow up case studies based on a selected representative sample of deaths from biological causes determined through verbal autopsy. This will remove the potential for sensitivity and stigma from the social autopsy component that could influence the disclosure of information related to the biological ‘VA’ component of the interview. At the same time, the follow up study will provide opportunity for separate specialised training of interviewers; a more elaborate informed consent process; strengthen the quantitative inferences on social determinants, all through judicious use of available human, financial and technical resources.

We have incorporated a discussion of many of these issues into the Technical Issues sub-section of the Discussion section. However, given the sample size needs for a social autopsy study, the suggested sampling strategy appears unrealistic, so we did not include this in the discussion.

Reviewer 3:

We thank the reviewer for her thoughtful and important comments. While we don’t believe there is a need to revise the manuscript based on her comments (and we also don’t think that the reviewer intended this), we would like to provide the following responses to be shared with her:

3-delays model: We agree that this is an imperfect model for the very reasons described by the reviewer. The delays simply describe the more outward manifestations of the careseeking process, and not the underlying reasons for the delays, many of which may overlap between the outward three delays. Nevertheless, the model is a useful community teaching tool. It provides the basis for a clear graphical presentation of the steps that need to be taken in order to effectively seek care. This can stimulate a discussion of the underlying reasons for the delays, and a search for solutions to overcome these problems. The SA questionnaire asks about the delays and also the constraints to careseeking, which can then be related back to the delays.

No blaming: Even in settings where quality of care issues are the major contributor to child mortality, we believe that it is best to take a no-blaming approach unless the problems are due to a few isolated health care providers. If not, then this implies that there are systemic problems leading to widespread poor quality care, in which case the solution must be to approach the systemic problems. Facility-based death reviews would be needed in such situations, to involve the providers (and perhaps also the directors and managers) in identifying the problems and solutions.
The two points made by the reviewer raises another interesting question for consideration: Why is it that in settings where most children who died at home had been seen by a doctor and there are apparent serious problems with the quality of health care, caregivers continue to bring their sick children for health care? Perhaps this does lead to some hesitation and an increased first delay, which may in turn contribute to the children being more seriously ill once care is sought. So, the reasons for the delays and outcomes become even more interwoven. The solution is to break the chain by simultaneously examining and dealing with all the links. This requires conducting both community-based and facility-based death reviews.

Reviewer 4:

No reviewer comments – No response required