Reviewer’s report

Title: Making stillbirths count, making numbers talk - Issues in data collection for stillbirths

Version: 1 Date: 12 September 2009

Reviewer: Rachel Haws

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Overall comments
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Overall, this is an extremely important assessment of the current poor state of the world’s data on the compelling yet neglected problem of stillbirth, with broad relevance for epidemiologists, maternal and child health program planners, and clinicians. The paper effectively reviews the multifaceted challenges to obtaining complete stillbirth registration and reporting. This is also the first paper I have seen which proposes a comprehensive system for collecting data on stillbirths globally that is both theoretically implementable in and relevant for low-resource settings, and also flexible enough to capture higher-level and informative data which may be available in higher-resource settings (e.g., placental histopathology, etc). There are some areas of potential overlap in the classification system the authors suggest which could cause confusion, and some difficulties imagining how the cause of stillbirth could be ascertained in the lowest-resource settings at the present time. Still, I largely agree with the logic, organization, and classifications proposed and the framework is a welcome new tool in need of testing. The authors have highlighted some of the logistical and methodological challenges involved in implementing this system globally, as well as the need to adapt the data collected for local program and reporting needs. I would have liked to see actual testing of the classification framework in the settings described in the panels, but the system appears to be relatively nascent and untested. Instead, the panels merely describe the capacity of several low- and middle-income sites to adopt and practice stillbirth ascertainment, including cause of death.

The article is also the only analysis I have seen which systematically assesses the strengths and deficiencies of the ICD-10 definition and classification of stillbirth, and compares the requirements, strengths, and weaknesses of the multiple stillbirth classification systems in existence. The use of these systems has important implications for capturing globally usable and meaningful data on stillbirth incidence and causation, which the authors carefully analyze. The article offers a thoughtful consideration of the potential power of verbal autopsy in settings where stillbirths occur outside of health facilities, and rightly highlights that more efforts are needed to improve the usefulness and accuracy of this tool.
The focus on the continuum of pregnancy-associated deaths, with stillbirths included alongside maternal and neonatal morbidity and mortality, is compelling and much needed to galvanize political and programmatic action.

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Major compulsory revisions

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1) The authors should be applauded for acknowledging that how a woman, her family, and her caregiver experience a stillbirth (and their overall cultural, practical, and financial importance and meaning) may influence data quality on stillbirth incidence. I was disappointed, however, that there are multiple instances where the abstract concept of “culture” is treated monolithically as a barrier to stillbirth ascertainment (rather than a set of factors shaping how stillbirths are viewed and discussed in a society), with few examples given and little attention to the “whys” of stillbirths being sensitive events, etc. Designing effective ways of increasing registration and disclosure rates will depend on the local context and meaning of a stillbirth. These issues and “whys” are left largely unexplored in the paper, therefore making the recommendations regarding incentivizing pregnancy registration and survey measurement somewhat simplistic. The anthropological literature on stillbirth and stillbirth disclosure is limited, and I grant that this is not a social science paper. However, because its focus is interdisciplinary, I would encourage the authors to include a few examples from the social science literature that highlight the gravity of both pregnancy and stillbirth in low-resource settings (and even many high-resource settings), and to use caution when considering the abstract notion of “culture” as a barrier when other more tangible and universal concepts and issues apply. Additionally, the grief and emotional aspects of perinatal loss (which may also impact disclosure in surveys) are essentially unaddressed. Both of these issues are germane to the larger issue of the quality of stillbirth data collection, and require investment in operational and formative research to understand the social dynamics of loss, how these dynamics affect stillbirth ascertainment, and whether the accuracy of measurement methods would improve if data collection were more culturally resonant and sensitive. If the section on underreporting could be better organized and nuanced, the paper would offer a more evenhanded assessment of the social, emotional, and setting-specific context in which measurement occurs, and more constructively suggest pragmatic ways of improving data collection (as it is daunting to try to change “culture”). Some other specific instances where social science literature could be cited to help the reader understand:

a) P. 6, third para. Please flesh out what you mean by “Cultural resistance to registration can be considerable.”

b) P. 9, first para: Would be good to describe and give examples of what you really mean by “strong taboos and cultural barriers” to registration, possibly in light of pregnancy and childbirth often being highly vulnerable periods for the mother and her child, where adverse outcomes suggest activity of malevolent human or spiritual forces (Consider citing Winch PJ et al, Lancet 2005 Aug
c) P. 9 – The assessment of factors leading to underreporting is somewhat weak. Consider the possible local importance of “cultural practices” and appreciate the need for culturally sensitive data collection methods. Also mention both women’s grief responses and cultural proscriptions forbidding mourning of a stillbirth in many settings that could encourage underreporting.

d) P. 9 – Reconsider saying that “religious beliefs and cultural habits” are keeping women from delivering in facilities. Apart from cost and distance issues, rural women may not deliver in facilities because care in facilities is not culturally sensitive or perceived as poor quality, or because laboring women are not permitted to be accompanied in the labor & delivery ward. Policy and bedside manner changes in facilities, attractive incentives to register pregnancies and birth, and respect of privacy and women’s and their family’s emotions and expectations both during pregnancy and surrounding a stillbirth (which are poorly understood and for which more research is needed in different settings) would likely make a bigger impact on our ability to count stillbirths than changing culture.

e) P.9/10, discussion of prenatal registration – important to acknowledge the possibility that in certain settings, registration incentives may have to be extremely attractive if they are to override norms of concealing pregnancy and risks women may perceive they face if their pregnancy becomes public. Otherwise, the denominator may still be an underestimate (Stokes E et al, BJOG. 2008 Dec;115(13):1641-7). Also interesting that you suggest (without citation) that women are more likely to report a stillbirth in hopes that it will prevent recurrence – some studies have found that women keep quiet about stillbirth because publicizing their loss is thought to increase the likelihood of gossip and witchcraft, which is associated with recurrence (discussed and cited in Lawn BMC Preg Childbirth May 2009).

f) P. 12 – Please specify and cite some example of cultural practices and clarify the “lack of understanding” of the importance of the placenta you mention. In many cultural settings (e.g., West Africa) the placenta is regarded as having extreme and even spiritual importance, and is to be immediately buried or eaten, and thus families are unwilling to allow it to be subjected to medical investigation. Birth attendants may similarly appreciate its symbolic power but not its role in the pathophysiology of stillbirth or neonatal morbidities – please clarify this in the text.

2) The paper is acceptably written and very well-organized, but suboptimal word choices, typos, and minor punctuation errors occlude the authors’ meaning in some places. I have suggested some corrections (through about pages 8/9), but I would recommend that the paper be carefully reviewed to minimize these grammatical errors and improve the clarity of the evidence and arguments set forth in the paper.
3) Panels – only Panel 4 is referred to in the text. Given that examples of setting-specific stillbirth registration/measurement are promised in the introduction and that these illustrate the ways in which stillbirths can be registered and analyzed in resource-poor settings, please incorporate these panels into the text. Additionally, some minor editorial changes could harmonize the tone so that these panels are more parallel presentations of the current situation, what is currently measured, and whether the system proposed in the paper is implementable. Has this template been tested/implemented anywhere yet? This would be the strongest evidence to put forth rather than discussing potentialities as these 3 panels do.

Minor essential revisions

1) P. 4 Abstract, first/second line has missing word: “and yet ARE invisible”

2) P. 4 Abstract, last sentence has missing word: “systems, AND effective registration and reporting systems.”

3) P. 5, first para, end of sentence beginning with “Accurately reported stillbirths…”: Change to “the first step toward any improvement.”

4) P. 5, first para.: Change “Millennium goals” to “Millennium Development Goals”

5) P. 5, second para, change “challenges in governance, infrastructure, and workforce in developing countries” to “LIMITED governance, infrastructure, and workforce in low-resource countries”

6) P. 5, last para: add footnote (same as/similar to footnote 1 on next page?) for “For every 50 publications on unexplained infant death…”

7) P. 6, second para, last sentence has missing word: “to serve AS a sensitive indicator”

8) P. 7, first para under international definition: be more specific about what is meant by “different health care planning than those reporting only third trimester stillbirths.” Meaning not entirely clear.

9) P. 7: Citation and preferably more explanation needed for “differences in cultural understanding of pregnancy duration”

10) P. 8: Under identification of stillbirths, should say “Today ninety countries worldwide lack any data on the occurrence of stillbirths.” This is the second instance of this statistic (first on p. 4) – one time may be enough.

11) P. 13 – Even in the most resource-rich settings, the cause of stillbirth remains a mystery in a substantial proportion of cases (which you describe on p. 15). This seems like a very important caveat to consider at the challenges/implications
para at the end of the section on p. 15, as you recommend that stillbirths be classified by cause, but even in the best circumstances, these causes may not be documentable.

12) P. 14 – would be good to explain why under-diagnosis of malformations occurs in low resource settings – generally because the lack of autopsies and other diagnostic assessments allow identification only of gross external malformations.

13) P. 17, under “2)” – “hydranENcephaly” misspelled.

14) P. 18/19 – please include a clear distinction between unexplained and unknown (presumably, in unexplained, all possible diagnostic measures were performed but failed to generate a diagnosis/cause of death, whereas in unknown these measures were not taken?)

15) Figure 1 – 2nd column – this column seems somewhat redundant with figure 5 in terms of both content and organization. This is not inappropriate per se, but is this purposeful or drawn from any particular source? Under the second column, does unknown intrapartum include non-cord fetal hypoxic events – e.g., those linked to uterine hyperstimulation, fetal distress, etc?. In third column, what do you mean by “pregnancy complications?” Additionally, is there a reason why breech is not considered in the third column (it clearly falls under intrapartum malpresentation in 2nd column) somewhere near multiples [which is increasingly linked with assisted reproductive technologies in developed countries but not as frequent in low-resource settings]. Also, use of plus sign and divisor sign on arrows seems non-parallel. Meaning still comes across, but multiplication/division or addition/subtraction signs are better pairs.

16) Figure 2 – please include a color legend for pink (deaths?) and blue (time period?). Also consider moving days of neonatal life and birth/neonatal, which might fit best at the bottom, near or incorporated with pregnancy trimester or pregnancy term (which keeps all time period issues together).

17) Figure 3. For clarity, please reference the discrepancy between stillbirth rates by birthweight and gestation in the figure caption.

18) Figure 4. Template questions: Under delivery/care level, why are general practitioners/licensed doctors who may not be specialists not included? Under maternal characteristics, what is the value of including terminations on this template, given that in most settings (especially where induced abortion is illegal), this outcome is hugely underreported (I appreciate the importance of knowing this discussed on P. 14, but think that its accuracy very importantly depends on setting and on how the information is elucidated)? Under quality of care, would it be feasible to include a box for “month when antenatal visits began”? In many settings, quality of care may be good but starts in the 7th or 8th month.

19) Panel 2. Change the tense “The hospital now moves towards introducing…” to “The hospital is moving toward introducing…”
20) Panel 3. The first-person voice (“we”) throughout this panel breaks from the tone of the rest of the article. Consider changing to third-person.

21) Panel 4. The first-person voice (“we”) throughout this panel breaks from the tone of the rest of the article. Consider changing to third-person. Also important to note that a disadvantage of this system is that while it helpfully distinguishes between fresh and macerated SBs, diagnostic data to determine cause of death are not generally available.

Discretionary revisions

1) Suggest use of “low- and middle-income”/“high-resource” or “low resource”/“high-resource” rather than “developing”/“developed” (e.g., “developing regions” p. 8)

2) Figure 5. Just a technical question - does verbal autopsy allow for multiple contributing conditions, as you helpfully suggest be included in the template (Figure 4)?

3) Throughout the paper, the authors suggest areas for future/needed research. For digestibility and clarity for readers, consider extracting and putting these into a panel to highlight research gaps and priorities (e.g., need to investigate variations in local meaning and management of stillbirth and relationship to ability to capture stillbirths, testing effectiveness of incentivization of pregnancy registration, feasibility and accuracy of placental examination—possibly by birth attendants—in low-resource settings, improvement of verbal autopsy strategies, testing of classification systems and impact on stillbirth prevention/rates).

Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.