Reflections from a PhD nested in the Every Newborn-INDEPTH study on measurement of stillbirths and neonatal deaths, 2017-2021

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Why do we urgently need good data to measure stillbirths and neonatal deaths?

An estimated 5.1 million stillbirths and neonatal deaths occur each year and many of these deaths occur in low- and middle-income countries (LMIC) in sub-Saharan Africa and Asia. Majority of these countries are reliant on data collected from household surveys, notably the Demographic and Health Survey (DHS). Incidentally, a dearth of data on these outcomes from surveys has variable quality. DHS program uses the full birth history (FBH) as its core module questionnaire; however, a few countries have used the full pregnancy history (FPH). Some previous studies suggested that use of a FPH may improve the capture and estimates computed for these outcomes, however, no prior study had undertaken a direct comparison of these two modules.

What was done?

First, I reviewed the forty-year history of the DHS program focusing on how data on stillbirths and neonatal deaths and data quality aspects within the DHS.[11]

Subsequent studies within my PhD were nested in a recent, five-year collaborative study entitled "Every Newborn-INDEPTH (EN-INDEPTH) study", which ended in December 2020.This was the first randomised comparison of two household survey modules for measuring stillbirth and neonatal deaths, involving over 69,000 women aged between 15 to 49 years of age in five Health and Demographic Surveillance Sites (HDSS) in Africa and Asia (Bandim in Guinea-Bissau, Dabat in Ethiopia, IgangaMayuge in Uganda, Kintampo in Ghana and Matlab in Bangladesh). All study sites were part of the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH Network); they were selected through a competitive request for applications that featured 14 applicants. The five sites were selected based on having a population greater than 30,000 people; recorded annual stillbirth rate (SBR) and neonatal death rate (NMR) greater than 15 per 1,000 livebirths, presence and quality of pregnancy surveillance with stillbirths and neonatal deaths included; and availability of co-funding from the sites.[2] Process and audit trail data dubbed as "Paradata" were examined to draw further insights into how to improve survey methodology and data quality. HDSS systems were reviewed, focusing on pregnancy surveillance and data capture. The EN-INDEPTH data were also linked to the HDSS data to conduct a population-level comparison and HDSS pregnancy surveillance systems were reviewed.

The EN-INDEPTH study's data collection involved both quantitative and qualitative interviews with the mothers and interviewers in various participating sites. The quantitative data was collected using the World Bank's Survey Solutions software. After a rigorous evaluation of the different software and applications available for data collection, the Survey Solutions software was chosen because of its free

1 Joseph Akuze, Simon Cousens, Joy E. Lawn, Peter Waiswa, Vladimir Sergeevich Gordeev, Fred Arnold, Trevor Croft, Angela Baschieri & Hannah Blencowe. Four decades of measuring stillbirths and neonatal deaths in Demographic and Health Surveys: historical review. BMC Population Health Metrics 2020, 19(Suppl 1):8 https://doi.org/10.1186/s12963-020-00225-0

2 Baschieri A, Gordeev VS, Akuze J, Kwesiga D, Blencowe H, Cousens S, et al. "Every Newborn-INDEPTH" (EN-INDEPTH) study protocol for a randomised comparison of household survey modules for measuring stillbirths and neonatal deaths in five Health and Demographic Surveillance sites. J Glob Health. 2019 Jun;9(1):010901

user license, the available support team at the World Bank, and ability to gather survey process and management data referred to as "Paradata".[3]

Our study team members signed a data sharing agreement and upon completion of the study, our data is available and open access. It can be requested for via the LSHTM data campus (https://doi.org/10.1737/DATA.00001556).

What was found?

Our most important and groundbreaking finding was that the stillbirth rate detected by the innovative pregnancy history was higher than the currently used DHS core module in four out of the five sites, although FPH computed estimates were higher than FBH, they were lower the UN-IGME estimated national SBR (Figure 1). Overall (all sites data was pooled) we found that the FPH module captured 21% higher estimate for stillbirth compared to the DHS module (Figure 2). There was no difference in neonatal mortality rates between the two modules. Remarkedly, there was little difference in the average time taken for the two survey modules, meaning that not much extra cost and time would be incurred because of a switch in the implementation of the DHS program with a FPH (Figure 3).[4]

The between-site differences we found might be explained by the variations in the interviewer training and survey implementation. Besides these results we also found that it was crucial to understand the different cultural norms and dynamics and surveillance systems while improving measurement of stillbirth and neonatal deaths.[5]

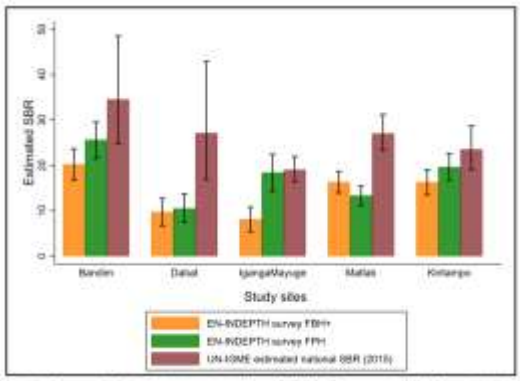

Figure 1: Comparison of stillbirth rate estimates from ENINDEPTH survey and UN IGME national estimates

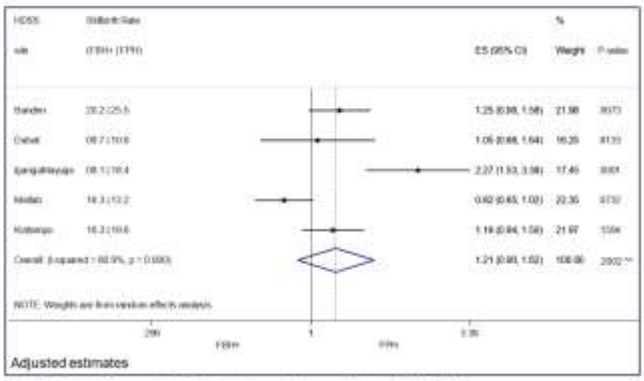

Figure 2: Forest plot Comparing of stillbirth rate estimates between FBH+ and FPH by HDSS

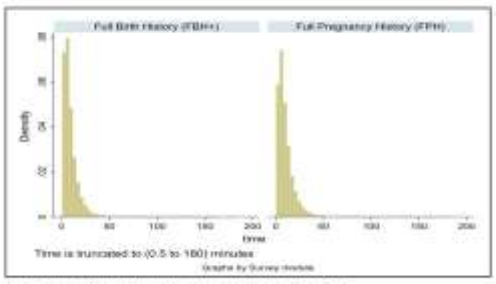

Figure 3: Histogram comparing time taken to complete survey modules with FBH+ and FPH

3 Vladimir Sergeevich Gordeev, Joseph Akuze, Angela Baschieri, Sanne M. Thysen, Francis Dzabeng, M. Moinuddin Haider, Melanie Smuk, Michael Wild, Michael M. Lokshin, Temesgen Azemeraw Yitayew, Solomon Mokonnen Abebe, Davis Natukwatsa, Collins Gyezaho, Seeba Amenga-Etego, Joy E. Lawn, Hannah Blencowe, the Every Newborn-INDEPTH Study Collaborative Group. Paradata analyses to inform population-based survey capture of pregnancy outcomes: EN-INDEPTH study. BMC Population Health Metrics https://doi.org/10.1186/s12963-020-00241-0

4 J Akuze, H Blencowe, P Waiswa,.. J Lawn, S Cousens et al Randomised comparison of two household survey modules for measuring stillbirths and neonatal deaths in 69,176 pregnancies in five countries: Every Newborn-INDEPTH study. Lancet Global Health 2019.

5 Kwesiga D. Qualitative study of barriers and enablers to reporting of pregnancy and adverse pregnancy outcomes in population-based surveys: EN-INDEPTH multi-country population-based study. BMC Population Health Metrics 2020

What was the impact?

This work was aligned with the Lancet and the Lancet Global Health ongoing work focusing on the stillbirth and neonatal deaths, notably The Lancet Stillbirth Series (2011), Ending Preventable Stillbirths (2016), Neonatal Series (2005) and Every Newborn Series (2014), as well as publishing the two most recent WHO stillbirth estimates. With now less than a decade to the end of the sustainable development goals, our findings are timely and reinforce the urgent need to improve data quality of stillbirths and neonatal deaths.

This study further impacted a change in the global policy, implementation and measurement of stillbirths and pregnancy losses in the DHS program. On 10th October 2019, the DHS program announced a major change in the updated questionnaire for DHS-8 "***We held an open comment period in early 2019 and received over 1,000 pages of material from stakeholders worldwide. After careful consideration of each submission, we made numerous changes to better meet existing and emerging data needs in global health. We are especially excited to announce the shift from a birth history to a full pregnancy history….***"[6,7]

Our EN-INDEPTH research has led to development of a 13-paper series supplement on measurement of stillbirths, newborn deaths, birth and death registration, gestational age, termination of pregnancies, child mortality, data linkage and survey implementation. Our supplement articles have diverse authorship groups with southern hemisphere first authorship on majority of the papers. In addition, our diverse team involved many women.

The EN-INDEPTH study has also supported capacity development for scientists from all sites in the area of measurement and two PhDs enrolled at the LSHTM and MakSPH-Uppsala University joint PhD programs. The two young who are doing their PhDs on based on the EN-INDEPTH study also led the coordination of the study. I happen to be one of them.

As both a PhD student and technical coordinator of the EN-INDEPTH study, I have gained exposure to various survey implementation activities, including programming using Survey Solutions, coordination of multi-site teams, complex data analysis and cleaning, and academic writing.

Study partners

This collaborative study was led by London School of Hygiene & Tropical Medicine (LSHTM) and Makerere University School of Public Health (MakSPH) in the five HDSS sites and was funded by the Children's Investment Fund Foundation (CIFF) based in the United Kingdom.

Call to action

Improving data collection remains critical to the success of population-level surveys. Through the EN-INDEPTH study, we have identified opportunities for measurement improvement, around the tools, methods, data quality and interviewers.

Tools

It is critical to have robust data quality assessments for stillbirths and neonatal deaths including accuracy, omission and misclassification. Cultural and religious barriers to reporting, for instance stigma need to be understood before the survey and interviewers prepared for this, as well as for

[6] DHS-8 Questionnaires: https://blog.dhsprogram.com/2019/10/

[7] Link to DHS-8 questionnaires https://www.dhsprogram.com/publications/publication-DHSM11-DHS-Questionnaires-and-Manuals.cfm

handling grief and other psychosocial effects of loss. Furthermore, accurate translations of local terms for different types of pregnancy loss should be done in different contexts and languages.

Operational research is needed to determine which interviewer training methods, materials and supervision tools would improve the quality of data collected.

Finally, many aspects of this study and the papers were led by scientists from the south, with mentorship from both the south and north. We call for further capacity building of southern country scientists to conduct research within their own settings, especially since they often understand their country contexts.

Acknowledgements

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