Exploring the Under Reporting of Pregnancy and Adverse Pregnancy Outcomes in Population and Health Surveys

A Multi-Country Qualitative Study

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Abstract
Kambugyiro, D. K. 2023. Exploring the Under Reporting of Pregnancy and Adverse Pregnancy Outcomes in Population and Health Surveys. A Multi-Country Qualitative Study. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 1996. 120 pp. Uppsala: Acta Universitatis Upsaliensis. ISBN 978-91-513-1976-6.

Introduction: Globally in 2021, an estimated 2.3 million newborn deaths and 1.9 million stillbirths occurred, with highest mortality in sub-Saharan Africa and southern Asia. True mortality is likely higher due to under reporting of pregnancies and Adverse Pregnancy Outcomes (APOs). Accurate data are critical for monitoring and preventing these events but many countries rely on Demographic and Health Surveys (DHS), despite measurement challenges. Few studies have explored reasons for under reporting pregnancy and APOs in low income countries, within surveys and surveillance settings.

    Objective: To explore enablers and barriers to reporting pregnancy and APOs during population and health surveys in multi-country contexts, informing measurement improvements.

    Methods: The study was conducted in Uganda, Guinea-Bissau, Ghana, Ethiopia and Bangladesh between 2018 and 2021. Focus group discussions (Study I and II), narratives (Study III) and cognitive interviews (Study IV) were undertaken. Thematic analysis was done for the first three studies and qualitative description for Study IV.

    Results: Methodological challenges included question framing, where double barrelled questions resulted in wrong answers. There were incorrect definitions for miscarriages and stillbirths. Enablers were mostly around interviewers' skills like building rapport, probing and empathy. Community barriers comprised socio-cultural factors that encouraged silence, including fear of witchcraft. Stigma towards APOs was common, with some foetal deaths viewed as not human, thus less reported. Informal reporting of APOs within social networks sometimes resulted in social support. Individually, APOs left women and men with negative psychosocial effects like depression, thus their reluctance to report. Nevertheless, some respondents said interviews left them feeling better, especially if the interviewer comforted them. Respondents accepted interviews hoping to receive health education about pregnancy loss.

    Conclusions: Many adverse pregnancy outcomes are avoidable, but they must be accurately measured before designing appropriate interventions. Surveys like the DHS are globally trusted but this study demonstrates that they have weaknesses and sometimes inaccurate data. Improving measurement requires precise questions, strengthened interviewer training, embedded counseling and health education. Supportive policies encouraging reporting are critical, alongside sensitizing citizens on its importance. Otherwise, APOs shall remain invisible and a continued burden to the mental health of those who experience them.

Keywords: Pregnancy; Adverse pregnancy outcomes; Demographic and Health Survey

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List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I. **Kwesiga, D**., Tawiah, C., Imam, M. A., Tesega, A. K., Nareeba, T., Enuameh, Y. A. K., Biks, G. A., Manu, G., Beedle, A., Delwar, N., Fisker, A. B., Waiswa, P., Lawn, J. E., & Blencowe, H. (2020). Barriers and enablers to reporting pregnancy and adverse pregnancy outcomes in population-based surveys: EN-IN-DEPTH study. *Population Health Metrics*, 19(Suppl 1), 15. https://doi.org/10.1186/s12963-020-00228-x

II. **Kwesiga D**, Eriksson L, Orach CG, Tawiah C, Imam MA, Fisker AB, Enuameh Y, Lawn JE, Blencowe H, Waiswa P, Bradby H, Malqvist M. (2022). Adverse pregnancy outcome disclosure and women's social networks: a qualitative multi-country study with implications for improved reporting in surveys. *BMC Pregnancy Childbirth*. Apr 6;22(1):292. doi: 10.1186/s12884-022-04622-1. PMID: 35387593; PMCID: PMC8988398.

III. **Kwesiga D**, Wanduru P, Eriksson L, Malqvist M, Waiswa P, Blencowe H. (2023) Psychosocial effects of adverse pregnancy outcomes and their influence on reporting pregnancy loss during surveys and surveillance: Narratives from Uganda. *BMC Public Health*. 23:1581. https://doi.org/10.1186/s12889-023-16519-5

IV. **Kwesiga D**, Malqvist M, Orach CG, Blencowe H, Eriksson L, Waiswa P. Exploring women's interpretations of questions from the demographic and health survey: Cognitive interviews on reproduction in IgangaMayuge, Uganda. *Submitted*.

List of related papers

The papers listed below were published within the EN-INDEPTH study. Doris Kwesiga is an author in these papers and while they are not counted as part of the thesis, they are relevant to it and to her work as a PhD student.

1. Akuze, J., Blencowe, H., Waiswa, P., Baschieri, A., Gordeev, V. S., *Kwesiga, D*., Fisker, A. B., Thysen, S. M., Rodrigues, A., Biks, G. A., Abebe, S. M., Gelaye, K. A., Mengistu, M. Y., Geremew, B. M., Delele, T. G., Tesega, A. K., Yitayew, T. A., Kasasa, S., Galiwango, E., … Lawn, J. E. (2020). Randomised comparison of two household survey modules for measuring stillbirths and neonatal deaths in five countries: the Every Newborn-INDEPTH study. *The Lancet. Global Health*, *8*(4), e555–e566. https://doi.org/10.1016/S2214-109X(20)30044-9

2. Blencowe, H., Bottecchia, M., *Kwesiga, D*., Akuze, J., Haider, M. M., Galiwango, E., Dzabeng, F., Fisker, A. B., Enuameh, Y. A. K., Geremew, B. M., Nareeba, T., Woodd, S., Beedle, A., Peven, K., Cousens, S., Waiswa, P., & Lawn, J. E. (2020). Stillbirth outcome capture and classification in population-based surveys: EN-INDEPTH study. *Population Health Metrics*, *19*(Suppl 1), 13. https://doi.org/10.1186/s12963-020-00239-8

3. Biks, G. A., Blencowe, H., Hardy, V. P., Geremew, B. M., Angaw, D. A., Wagnew, A., Abebe, S. M., Guadu, T., Martins, J. S. D., Fisker, A. B., Imam, M. A., Nettey, O. E. A., Kasasa, S., Di Stefano, L., Akuze, J., *Kwesiga, D*., & Lawn, J. E. (2020). Birthweight data completeness and quality in population-based surveys: EN-INDEPTH study. *Population Health Metrics*, *19*(Suppl 1), 17. https://doi.org/10.1186/s12963-020-00229-w

4. Enuameh, Y. A. K., Dzabeng, F., Blencowe, H., Thysen, S. M., Abebe, S. M., Asante, K. P., Tawiah, C., Gordeev, V. S., Adeapena, W., *Kwesiga, D*., Kasasa, S., Zandoh, C., Imam, M. A., Amenga-Etego, S., Newton, S. K., Owusu-Agyei, S., Lawn, J. E., Waiswa, P., & Cresswell, J. A. (2020). Termination of pregnancy data completeness and feasibility in population-based surveys: EN-INDEPTH study. *Population Health Metrics*, *19*(Suppl 1), 12. https://doi.org/10.1186/s12963-020-00238-9

5. Baschieri, A., Gordeev, V. S., Akuze, J., **Kwesiga, D.,** Blencowe, H., Cousens, S., Waiswa, P., Fisker, A. B., Thysen, S. M., Rodrigues, A., Biks, G. A., Abebe, S. M., Gelaye, K. A., Mengistu, M. Y., Geremew, B. M., Delele, T. G., Tesega, A. K., Yitayew, T. A., Kasasa, S., … Lawn, J. E. (2019). "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. *Journal of Global Health*, *9*(1), 10901.
https://doi.org/10.7189/jogh.09.010901

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Operational definitions

Abortion: For the purpose of this study, the ICD-11 definition of abortion is used: "Induced abortion (also referred to as Artificial termination of pregnancy) is a complete expulsion or extraction from a woman of an embryo or a fetus (irrespective of the duration of the pregnancy), following a deliberate interruption of an ongoing pregnancy by medical or surgical means, which is not intended to result in a live birth. Induced abortions are distinct from cases of spontaneous abortion and stillbirth" (1) .

Adverse pregnancy outcomes: For the purpose of this study, adverse pregnancy outcomes refer to all situations where a pregnancy does not result in a live birth, or where the baby dies in the first 28 days of life. This includes all the terms: newborn/neonatal death, stillbirth, miscarriage and abortion.

Miscarriage: Same definition as spontaneous abortion

Newborn / neonatal death: Death within 28 days of birth of any live-born baby (2) regardless of weight or gestational age.

Early neonatal death: Death within the first 7 days of birth

Late neonatal death: Death from 7 days to 28 completed days

Reporting (of pregnancy and adverse pregnancy outcomes): There are various definitions of reporting and this study used a combination of the following:
- In surveys like DHS, data collection includes asking the woman about her pregnancies and their outcomes. Responding to these questions accurately is part of the definition of reporting for the current study
- In the HDSS, reporting is also similar to the DHS, where the respondent shares information on the pregnancy and its outcomes. Sites also have community key informants (may use different terminology) who report the occurrence of births to the HDSS.
- In CRVS, reporting vital events births is a series of events combining notification (declaration), registration (official record) and certification (birth certificate issued). The United Nations defined birth registration as

"the official recording of the occurrence and characteristics of a birth by the civil registrar within the civil registry, in accordance with the legal requirements of a country" (2019). Death certification also requires a death notification and medical cause of death before issuance of a certificate.

Spontaneous abortion / Miscarriage: A condition caused by immunological factors, abnormal ovum or uterine body, maternal disease or infection, or cervical incompetence. This condition is characterized by non-induced embryonic or fetal death or passage of products of conception prior to 20 (*or 22*) weeks gestation or weighing less than 500 grams (1). This definition also includes miscarriage.

Stillbirth: In this thesis, the following definition is used:

A stillbirth refers to a fetal death or baby born with no signs of life – it can be an early gestation stillbirth, that occurs from 22-28 weeks or late gestation stillbirth that occurs from 28 completed weeks of gestation (3) or, if missing, birth weight is ≥1000 g . Stillbirths can be either antepartum or intrapartum.

Antepartum stillbirth: Occurring before the onset of labour

Intrapartum stillbirth: Occurring after the onset of labour and before birth

Abbreviations

ACASI	Audio Computer Assisted Self-Interviews
APOs	Adverse Pregnancy Outcomes
CKIs	Community Key Informants
CRVS	Civil Registration and Vital Statistics
DHS	Demographic and Health Survey
ENAP	Every Newborn Action Plan
EN-INDEPTH	Every Newborn - International Network for the Demographic Evaluation of Populations and their Health
FGDs	Focus Group Discussions
GA	Gestational Age
HDSS	Health and Demographic Surveillance System
HIC	High Income Setting
IDIs	In-depth Interviews
IMHDSS	Iganga-Mayuge Health and Demographic Surveillance System
INDEPTH	International Network for the Demographic Evaluation of Populations and their Health
KIs	Key Informant Interviews
LICs	Low Income Countries
LMICs	Low and Middle Income Countries
LSHTM	London School of Hygiene and Tropical Medicine
MakSPH	Makerere University School of Public Health
MICS	Multiple Indicator Cluster Survey
MNCH	Maternal Newborn and Child Health
NMR	Neonatal Mortality Rate
SDGs	Sustainable Development Goals
SSA	Sub-Saharan Africa
TBAs	Traditional Birth Attendants
UN	United Nations
UNICEF	United Nations Children's Fund
VASA	Verbal and Social Autopsy
WHO	World Health Organization

1. Introduction

Pregnancy and adverse pregnancy outcomes, which include miscarriages, induced abortions, stillbirths and newborn deaths are important events for tracking the achievement of the sustainable development goals and the Every Newborn Action Plan (ENAP). However, there is limited quality data on these events, making decision making difficult. Most Low and Middle Income Countries (LMICs) rely on population surveys for data but these face measurement and reporting challenges. For instance the Demographic and Health Surveys have limited power for sub-national analyses or sub-analyses; demographic surveillance sites have been researched frequently and received various interventions that could influence how representative they are, while a robust civil registration system takes time and resources to roll out nationally and can exclude some groups.

This thesis investigated under reporting of pregnancy and adverse pregnancy outcomes in Africa and Asia, in order to contribute to measurement improvement globally. It was conducted within the Every Newborn-INDEPTH study.

1.1 Overview of mortality estimates

Globally, we continue to see high numbers of adverse pregnancy outcomes including stillbirths and neonatal deaths, despite gradual declines over the years. In 2021, approximately 1.9 million stillbirths (at 28 weeks or more of gestation) occurred worldwide, an equivalent of 5,000 per day, with an estimated global stillbirth rate of 13.9 per 1,000 total births (4). About 45% of these occurred in sub-Saharan Africa, which had the highest stillbirth rate of 21 per 1,000 total births followed by south Asia's 16.2 per 1,000 total births. Uganda's stillbirth rate was approximately 15.1 per 1,000 total births in 2021 (based on 25,855 stillbirths per year), which is still high despite a 34.1 percentage decline and a 2% annual rate of reduction between 2000 and 2021 (4). The same report estimated that Ethiopia had a stillbirth rate of 20.6; Guinea Bissau 31.2; Ghana 21.4 and Bangladesh 20.5 per 1,000 total births.

Newborn deaths in 2021 were estimated at 2.3 million globally, approximately 6,400 every day, with a Neonatal Mortality Rate (NMR) of 18 deaths per 1,000 live births (5). Again, this rate was highest in sub-Saharan Africa at approximately 27 deaths per 1,000 live births, followed by southern and central Asia at 22 deaths per 1,000 live births. Uganda's estimated NMR was 19 deaths per 1,000 live births, which was based on about 32,000 newborn deaths in 2020. The newborn mortality rates for Ethiopia, Guinea Bissau, Ghana and Bangladesh were 26, 34, 23 and 16 deaths per 1,000 live births. In 2013, Uganda's national abortion rate was estimated at 39 abortions per 1,000 women of reproductive age (6).

The true figures of pregnancy and its outcomes are likely higher due to under reporting of births and Adverse Pregnancy Outcomes (APOs), which has been noted elsewhere (7–9), especially in low income settings (6,10–12). In 2016 it was reported that more than 95% of neonatal deaths and almost all stillbirths globally were not registered (13), while the World Health Organisation indicated that most stillbirths and about 50% of newborns had neither birth nor death certificates and so there was no clarity for governments on numbers and causes of deaths, delaying appropriate interventions (14). A review of 157 DHS studies from 53 countries between 1990 and 2020 reported that in 95% of the surveys, stillbirths were under reported (15). Civil Registration and Vital Statistics (CRVS) are considered the "gold standard" for collecting information on births and deaths, when the system is functioning well. Conversely, in countries like Uganda and others in sub-Saharan Africa (SSA), CRVS systems are sub-optimal, resulting in missed and incomplete information on births and deaths (8,16).

There are limitations to the utility of national survey data because of under and misreporting (15). Under reporting of APOs results in data that indicates a lower prevalence of these events, and yet this information feeds into national and local statistics (16) that will be used for planning, priority setting and is important for monitoring progress to achieving the Sustainable Development Goals (SDGs) and Every Newborn Action Plan (ENAP). Vital statistics are critical to ensuring responsiveness of policies to the needs of children and women. Therefore, planning will be based on incomplete data and misinformation, resulting in difficulty in identifying the causes of these deaths, the context around their occurrence and how to potentially avoid them in the future. Furthermore, under reporting of APOs implicitly implies that mothers who have APOs but do not report them may not be seeking or receiving health care. Therefore, they may not find out the cause of the APO and how to avoid it, which is worse for those with repeat occurrences.

Some studies have sought to understand barriers to reporting of pregnancy and APOs that affect the quality of data collected. For instance, an analytical study of fieldwork related issues that lead to poor quality data in DHS processes was done in 39 countries (17). The indicators of data quality that it used were missing or incomplete data, instances of non-response and challenges with reporting age, including age heaping or displacement, inconsistent reporting and unreliable dates. Study findings showed that although the quality of data from various countries was affected by field related factors in different ways, the cross-cutting factors that influenced data quality during the DHS were whether a translator was used during the interview; the sex of the interviewer; language of the respondent, interviewer and questionnaire; place of residence; timing of the interview; and how many call-backs an interviewer had to do to a household (17).

In Tanzania, a study that explored how experiences with pregnancy loss and neonatal deaths may have an effect on quality of data during a survey conducted open-ended interviews with women who suffered different kinds of pregnancy loss (18). Among the findings was that reporting of pregnancy loss was affected by cultures like not publicly discussing APOs, as well as burial practices that prohibit grieving for these babies. Similar findings are reported from a study in Ethiopia that explored attitudes towards stillbirths and neonatal deaths (19). Through focus group discussions with women of different ages, it emerged that these deaths are partly made complex by social and cultural practices and the need to keep them hidden as dictated by their society. Additionally, there are sometimes serious legal concerns around reproductive rights. For instance, reporting of events like induced abortions, in countries (many low and middle income) where it is illegal or restricted plus being politicized or influenced by religious and ethical perspectives, thus under reporting and poor data (20,21). The current abortion laws in America are an example, with the overturning of Roe v. Wade in 2022 that endangers the lives of females and health workers in various ways (22,23).

However, knowledge about the barriers and enablers to reporting of pregnancy and APOs, particularly during surveys and surveillance is still lacking within some settings, including Sub Saharan Africa and South Asia.

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1.2 Global advocacy and planning guidelines

1.2.1. The Every Newborn Action Plan

The Every Newborn Action Plan (ENAP) to end preventable deaths was launched in June 2014 (24). Its vision is a world without occurrence of avoidable newborn deaths and stillbirths, amidst a thriving community of women and their babies. The ENAP set targets of 12 or fewer newborn deaths per 1,000 live births and 12 or fewer stillbirths per 1,000 total births in every country by 2030. These targets necessitate high quality care for mothers and newborns globally, including in emergencies and where referral is needed. ENAP proposed five strategic objectives, the fifth of which focused on counting every newborn. The plan points out that service delivery and subsequently accountability can be improved when managers are able to measure outcomes. It emphasised the need for stillbirths, newborn and maternal deaths to be counted and the improvement of metrics both globally and nationally. Indeed, in order to track progress towards achieving ENAP targets, it is essential to have accurate statistics on these events.

Among the recommended actions for government and associated stakeholders under strategic objective five are:
- Improved registration of all births and deaths, inclusive of stillbirths and newborn deaths
- A basic perinatal dataset with consistent definitions and recording of all birth outcomes
- Institutionalised maternal and perinatal death surveillance and response

Although the ENAP refers to newborns only in the title, it actually has a broader focus, including stillbirths and maternal deaths. This is partially due to being embedded in broader efforts to end preventable deaths of mothers and babies and perhaps it took in to account the broader context in which newborns exist, that is the reproductive, maternal and child health continuum, in which many components cannot be delinked from each other, including the mother-baby dyad. Additionally, addressing the cause of deaths is likely to concurrently benefit newborn death and stillbirth prevention.

A lot of work has been done since the launch of ENAP, under the ENAP metrics streams. Key among these was the Every Newborn-INDEPTH (EN-IN-DEPTH) study.

1.2.2. The Every Newborn-INDEPTH study

The Every Newborn-International Network for the Demographic Evaluation of Populations and their Health (EN-INDEPTH) study had the main objective of improving household survey capture of newborn deaths and stillbirths, with four objectives as follows (25):

1. To undertake a randomised comparison of the reproductive module used in the latest version of Full Birth History plus (FBH+) vs a Full Pregnancy History (FPH) module to examine the variation in capture of stillbirths and neonatal deaths
2. To evaluate the use of existing/modified survey questions to capture the fertility intentions and selected pregnancy outcomes (termination of pregnancy, miscarriage, birthweight, gestational age), as well as birth and death certification
3. To compare the capture of pregnancy outcomes in the survey to that in the routine Health and Demographic Surveillance System (HDSS) data collection
4. To identify barriers and enablers to the reporting of pregnancy and adverse pregnancy outcomes during the survey and HDSS data collection, and particularly if these differ for the two survey questionnaire methods (FBH+ and FPH)

The EN-INDEPTH study was conducted between 2017 and 2021 in five countries across five HDSS sites that were members of the INDEPTH network: Iganga Mayuge HDSS in Uganda, Dabat HDSS in Ethiopia, Kintampo HDSS in Ghana, Bandim HDSS in Guinea Bissau and Matlab HDSS in Bangladesh. Set up with a grant from the Children's Investment Fund Foundation (CIFF) to London School of Hygiene and Tropical Medicine (LSHTM), the study's technical secretariat was a collaboration between LSHTM and Makerere University School of Public Health (MakSPH). The HDSS site team members also led various components of the study. The work was part of the ENAP measurement improvement roadmap.

Within the main survey, which was a randomised comparison of the FBH+ and FPH, a household survey was conducted amongst a total of 69,176 women aged 15-49 years in the five sites (26). These were randomly allocated to receive either a FBH+ or FPH interview. The main finding was that the FPH approached identified more stillbirths and only required an average of 1.4 minutes longer to conduct than the FBH+, potentially increasing stillbirth reporting in settings with high numbers. Subsequently, these results led to the DHS program adopting the FPH module going forward.

Additionally, some variances in results between countries were partially attributed to differences in interviewer training and further research was recommended around this, as well as refinement of survey questions (26). Another study within the EN-INDEPTH survey was conducted on stillbirth outcome capture and classification (27). It reported misclassification, with about 25% of reported stillbirths later found as born alive on further questioning.

In addition to the main survey, over 10 studies were done within the EN-INDEPTH project. These included Birth, stillbirth and death registration data completeness, quality and utility; Birthweight data completeness and quality; Electronic data collection; A historical review of measuring stillbirths and neonatal deaths; Gestational age data completeness, quality and validity; Neonatal and child mortality data comparing retrospective population-based and prospective demographic surveillance; Paradata analyses; Pregnancy intention data completeness, quality and utility; Stillbirth maternity care measurement and associated factors; Stillbirth outcome capture and classification and Termination of pregnancy data completeness and feasibility. The EN-INDEPTH supplement can be found at https://pophealthmetrics.biomedcentral.com/articles/supplements/volume-19-supplement-1.

This PhD study was nested in the EN-INDEPTH study and specifically addressed objective four on barriers and enablers to reporting pregnancy and adverse pregnancy outcomes. The entire PhD took a qualitative methodology approach and in this way complemented the quantitative focus of the PhD of Dr. Joseph Akuze who led the EN-INDEPTH survey. Dr. Akuze's PhD focused on the randomised comparison survey, historical DHS review, paradata and other quantitative components (28).

On the other hand, this PhD project studied barriers and enablers to reporting from the perspectives and experiences of women and interviewers; social networks and their role in reporting APOs; psychosocial impacts of APOs and their influence on reporting pregnancy and APOs; and explored women's interpretations of survey questions on pregnancy and pregnancy outcomes. Therefore, where the quantitative findings show the magnitude of under reporting (or over reporting, misclassification and other measurement challenges), this PhD thesis provides explanations as to why and suggestions for improvement of reporting.

2. Literature Review

This section presents a range of reasons that are likely to or are known to cause under reporting of pregnancy and APOs. Among the starting points for reporting pregnancy includes the fact that a woman may not know that she is pregnant in the first place, which is linked to the bigger health system issues on access to confirmatory tests and family planning. Others are elaborated on below, including challenges with classifying APOs, different methods used to collect pregnancy, birth and mortality data, effects of perceptions and experiences, etcetera. This review provides broader contextual information as well.

2.1. Definitions and classifications of adverse pregnancy outcomes

Adverse pregnancy outcomes have been classified differently globally (29–31). While neonatal deaths are defined in a fairly standardized way, confusion persists around classifying a stillbirth, even within the same country (29,32). This is in spite of efforts to align definitions in ICD 11 (33), and other projects like the Global Alignment of Immunization Safety Assessment in pregnancy (29–31). Indeed, a systematic review to identify different classification systems for causes of perinatal deaths identified 81 varied systems, with most used only in one country and none globally accepted (34). While some were new, others were adaptations of existing ones. Many had limitations, for instance only slightly more than 25% had instructions on how to determine the cause of death.

Multiple definitions of APOs result in confusion in identification (35,36), misclassification and under reporting (29,37,38). Indeed, health workers will classify an APO according to their knowledge and the guidelines in the health facility, not necessarily according to global definitions. This can result in misclassification of an APO into another category, thus under or over reporting by health workers and the parents. A further challenge is that abortion is often used to mean both miscarriage (spontaneous abortion) and intentional termination of pregnancy (39).

Additionally, it is important to know the local definitions of APOs in different communities, because societies may have their own definitions. This is likely to impact on community practices like reporting when APOs occur, depending on whether they are taken as critical or normal occurrences. For instance, still-births are sometimes defined as something useless (32). A study in Uganda explored local definitions, knowledge and coping mechanisms among families that faced stillbirths (40). Through In-depth Interviews (IDIs) with women, men, traditional birth attendants and grandparents, they found that a stillbirth is not disclosed because it is just a "thing". In fact, the definition in *lusoga*, the main language used in the study area is *empunha*, which means that the baby was not valuable. Nevertheless, these local definitions have not been ex plored much in Low and Middle Income Countries (LMIC). Previous studies did not often involve in-depth discussions of local definitions; for instance a study in Uganda looking at APOs was focused on burden and causes (41) and did not include interviews to find out more about definitions and meanings.

It has also been reported that community understanding of APOs may vary from the biomedical definitions used in surveys (18,40). This may result in a lack of clarity about the meaning of the terms in the tools, as shown in a study in Tanzania that conducted qualitative reproductive narratives with women who had an APO and interviews with other females in the community (18). Local language definitions of different APOs overlapped in meaning and were hard to differentiate, thus women often reported having one kind of APO while describing another. One limitation was that the authors later re-catego-rized the APOs as per the narratives given, thus a risk of misclassification. Additionally, they were unable to identify women who had abortions, so data on definition of this often secret process is lacking. That study recommended identification of local terms in order to improve data collected.

An analysis of how to improve the link between gender and health in Africa using DHS data emphasised that DHS gender questions were developed bas-ing on Asian contexts (42). Although this was not specifically about preg-nancy or pregnancy loss, it indicates that some DHS questions were not de-veloped in Africa, thus they may not be easily understood in that context. In fact, a review of measurement challenges in disparities research indicated that cultural differences affect interpretation of tools and that tools developed in one setting may not necessarily apply in another (43).

On the whole, few studies have explored local definitions of APOs in LIC, with most excluding the perspectives of the community (36,41). Understand-ing definitions of pregnancy and of APOs from various stakeholders across countries and their possible influence on reporting of pregnancy and APOs, will be useful in strengthening measurement of these outcomes.

2.2. Measuring pregnancy and adverse pregnancy outcomes

Ideally, all births and deaths should be reported and registered, using the various channels available in a country. Among the types of methods used to collect data on pregnancy and APOs are civil registration and vital statistics; demographic and health surveys; Multiple Indicator Cluster Surveys (MICS); HDSS sites; verbal and social autopsies; audits (perinatal death audits or reviews); World Health Surveys; World Fertility Surveys; Reproductive Health Survey, amongst others. For this study, we focused on three approaches.

2.2.1. Civil Registration and Vital Statistics

Although the current study is about population and health surveys data, it is important to look at this within the broader context of civil registration because some data collected in these surveys e.g. birth and death data overlaps with civil registration data.

Civil registration has been defined as continuous and legally required registration of a population's vital events – births, deaths (including fetal deaths), adoption, marriage and its dissolution, as well as legitimation (44). Birth registration was recognised as a human right by the International Covenant on Civil and Political Rights 1966 (45). While the right to death registration has not been explicitly spelled out, it has been implicitly applied in various human rights documents (46) .

Civil registration and vital statistics, specifically birth and death registration is important because it helps the government know the size of its population and its growth, thus enabling it to better plan for service delivery for its citizens, bearing in mind population distribution and using evidence (47). It also indicates the burden of mortality, highlighting why and when deaths happen, so it can be used for national and global science and policy agendas (48,49). A sound CRVS system is therefore central to government work, donors, international efforts and beneficial to citizens. Goal 16 of the Sustainable Development Goals (SDGs), indicator 16.91 looks at the proportion of under 5 year old children whose births were registered by a civil authority but in 2022, 25% of children below 5 years globally and 50% of children in sub-Saharan Africa had not had their births registered (50).

In Africa, where many countries are low income, there has been a gradual improvement of CRVS systems, including having laws in place. However, CRVS systems in low-income settings are still less than optimal. For instance a UNICEF report in 2019 showed that about 166 million children below 5 years did not have registered births, of whom 43 million were in west and

central Africa, while east and southern Africa had 51 million unregistered, similar to south Asia (51). Death registration is even lower and excludes still-births. As a result, many LMICs rely on data from other sources, particularly the Demographic and Health Survey.

2.2.2. Demographic and Health Surveys

Household surveys like DHS are currently the major source of data on still-births and neonatal mortality for Low and Middle Income Countries (15). The DHS is a countrywide survey focused on key health, population and nutrition indicators (52). It was developed to help countries have good nationally representative estimates of certain selected indicators of population health. These include fertility, fertility preferences, family planning, infant and child mortality, adult and maternal mortality, maternal health care, nutrition, malaria, HIV/AIDS, women's empowerment, domestic violence, housing characteristics, and more. This information is collected through nationally representative surveys that involve structured face to face interviews conducted in households, with both men and women.

A historical review of the DHS reported that between 1984 and 2019, over 320 surveys had been conducted across 90 countries (53). The standard DHS is typically conducted every five years, with sample sizes ranging from 5,000-30,000 households. Occasionally, interim DHS studies are done, with shorter tools and fewer households. The standard DHS has four tools - woman, man, household and biomarker questionnaires, in addition to collection of geographic information, biomarker data and standardized topics of interest for certain countries. With each round of the DHS, some adaptations have been made to these tools, from DHS I to DHS VIII currently.

It ideally takes 18-20 months to conduct a standard DHS, from survey design to analysis. Globally, most data on pregnancy outcomes is from the DHS and for the maternity histories, the DHS predominantly used the Full Birth History (FBH) module, while the Full Pregnancy History had been used in 17 countries only (53). This was the case until the DHS changed to use of the FPH on recommendation of findings from the EN-INDEPTH study.

2.2.3. Health and Demographic Surveillance System Sites

The HDSS sites refer to geographically delineated areas in countries that have been mapped out, right up to household level for regular surveillance of indicators, some of which are similar to the DHS. The HDSS site is a prospective cohort of a selected geographical population, where data on key population and health indicators is regularly collected (54). The residents in the mapped-out households are given identification numbers.

The HDSS sites monitor births and deaths, migration in and out of the HDSS, household socio-economic indicators and wealth, fertility rates and mortality rates, among other health outcomes (55). The frequency of longitudinal data collection in the HDSS sites varies depending on resources, and can be as regularly as every two months or once or twice a year. While each HDSS site operates differently, there is certain data that is commonly collected by all, for instance births and deaths.

The first systematic demographic surveillance studies in Africa were conducted between the 1950s - 1960s (56) and the HDSS sites have evolved overtime. An HDSS site is usually started by conducting a baseline census of all households and members in the population, giving them numbers and following this up by regular surveillance. Membership to the HDSS is through birth and in-migration, while those who migrate out of it for a certain specified period cease to be members (57). The same source further explains that the regular monitoring in an HDSS can be of vital events like births and deaths, demographic variables, as well as other health outcomes. While they provide longitudinal and prospective data and overall have similar surveillance approaches, it is hard to compare different sites because of variability but sites with more frequent surveillance are likely to have better pregnancy and APO capture (28). Nevertheless, HDSS sites also have data quality challenges (37).

2.3. Methodological approaches to studying reporting and other aspects of pregnancy and adverse pregnancy outcomes

Quantitative, qualitative and mixed methods approaches have been used to explore perceptions, experiences and reporting of pregnancy and APOs. For instance a national study was done in the USA to explore the publics' insights on miscarriage (58). Data were collected using an anonymous, cross-sectional online survey. The 1,147 respondents that completed it included both females and males whose partners had a miscarriage. Data were analyzed using statistical methods, including logistic regression. The advantage of that study was that it was able to target a relatively large sample of respondents while ensuring anonymity. They reported a 100% completion rate, and were able to learn about the erroneous perceptions around miscarriage. However, it relied on self-reports without confirmation, and yet it was not face to face so one cannot be sure it was the intended person who responded. More so, the sampling and recruitment strategy were not clearly explained, with authors only indicating the use of an online crowd sourcing web facility. Indeed, the lower responses from blacks and hispanics, who are a different socio-economic class with potentially varying perceptions, is an indication of a sample that was not repre-

sentative. Furthermore, the findings cannot be generalized to the country of study due to these lower responses, yet it was a national survey. Finally, perceptions and experiences are often better understood using qualitative methods, where one has the opportunity to probe for meaning.

Another approach used is qualitative methodology, as shown in a poor, rural part of India where a study explored perceptions and coping mechanisms towards stillbirth by women (59). To achieve this, they conducted key informant interviews and later Focus Group Discussions (FGDs) to validate emerging themes, with patients, family members, health workers, traditional birth attendants, women who had not had stillbirths, respondents of different ages, and two male partners of women who had a stillbirth. Snowball sampling was used to find women who had a stillbirth in the past year. In total, 31 women shared their perceptions and experiences on stillbirth, which was adequate for the study, as indicated by saturation attained. The study applied triangulation by collecting data from multiple groups and using different methods, thus increasing variation. However, snowball sampling was inappropriate, because it is better applied to research among hidden populations, so that one person leads you to another. Therefore, it is likely that the respondents identified through snowball sampling all belong to the same social network. This is a limitation because members of a social network may have similar perceptions, thus the researchers may have excluded the varying views of other people not in that network.

On the other hand, mixed methods approaches combining both qualitative and quantitative methods are also applicable. For instance in Cameroon, a study sought to explore practices and perceptions around pregnancy and pregnancy loss (60). In an ethnographic study that involved anthropological fieldwork over 15 months, data were collected through participant observation activities where the author took part in child care, deliveries and abortions, etcetera. Additionally, informal in-depth interviews, life histories, FGDs and rapid appraisal techniques were done. Furthermore, a reproductive health survey was conducted among 287 women, although the specifics were not explained. Once again, we observe the triangulation of data sources and methods. Most importantly, the fact that the researcher lived with and took part in community activities ensured that she got first-hand information. This is more reliable than self-reports usually given by respondents about events where the researcher was not present. However, it is more expensive and time consuming so may not be done often.

Overall, few qualitative studies were identified that have been done around reporting of pregnancy and APOs in Low and Middle Income Countries (LMICs), a topic shrouded in stigma and secrecy. Moreover, it is a good methodology for answering a research question that requires understanding of cul-

tural norms, gender, perceptions and practices (42), as well as threatening questions (61). On the contrary, many studies used quantitative methods for instance surveys, surveillance, secondary data analysis or review of medical records, among others (62–65). The current study used a qualitative approach and applied triangulation, combining FGDs, narratives and cognitive interviews.

2.4. Factors influencing data collection and data quality in studies on pregnancy and adverse pregnancy outcomes

2.4.1. Interview processes and tools

Approaches used to collect data on pregnancy and APOs vary by mode of administration, frequency of data collection, type of respondent, and other indicators. For instance, some surveys are regularly done every few years, others every few months or even once only; data collection may be in the community or health facility; be conducted face-to-face or online, etcetera.

Among the key influences on data collection are interviewer related factors. On the positive side, the interviewer may ensure collection of better data through probing and ascertaining that the respondent answers all questions. Furthermore, where interviewers are trained to be empathetic and understanding, they win the trust of the respondent (64,66), who may then report more truthfully. On the other hand, the interviewer can negatively affect data collection, through their own interpretation of responses (43), or even their sex (17), where the respondent may be more comfortable with one sex than another. If the interviewer is not a native speaker of the respondent's language or uses a translator, there is potential for misreporting as noted in a DHS review (17).

Supervision, workload and incentives of the teams responsible for data collection can also influence the quality of reporting (67). For example, a study in Mali that used community volunteers to test validity of the community real time mortality monitoring approach had high reporting of infant and neonatal mortality rates (64). Among the reasons for the good data was the regular supervision of volunteers and the incentives received. On the contrary, in Malawi where the same approach was piloted, there was high under reporting of births and neonatal deaths (68). This was partly attributed to a decline in quality of supervision over time, with the need to continuously monitor, train and incentivize the surveillance assistants. In both cases, however, this method was piloted for a short time, and they did not do interviews with these volun-

teers or the supervisors. This would have given a more comprehensive idea of enablers and barriers.

Furthermore, privacy at the interview location is beneficial to the respondent's comfort and subsequent disclosure of sensitive information. Although in the DHS interviewers are instructed to get as private a setting as possible, this has to be balanced with the typical African homestead, where there are often many other people present. Closely related to this is the need for confidentiality, for instance not divulging information previously shared. A study done in Tanzania to find out the percentage of incomplete alleged spontaneous abortions reported women's willingness to confirm that they had an abortion when they were ensured of privacy and confidentiality (66). However, this was a hospital-based study among women already admitted for incomplete abortions, thus possibly a biased sample that will be hard to extrapolate directly to household surveys. It is possible that in the community, reactions may be different.

Collecting information on sensitive topics like sexuality, abortions and pregnancy can be influenced by anonymity and wanting to be socially acceptable. Less accurate reports of abortions have been noted during face to face and long interviews (69), although this was a quantitative study in a high income country that did not try to understand why this was so. Further evidence from Kenya reports reliability in reporting sexual behaviour through use of face to face interviews compared to Audio Computer Assisted Self Interviews (ACASI) among girls (70). Despite some missing responses and higher inconsistencies in ACASI interviews, the findings on premarital sex were more accurate, as well as higher reporting of stigma related actions. The increased completeness in face to face interviews may have been due to the presence of the interviewers who spoke the same language, while the benefit of the online survey is its anonymity. Although the study was not about APOs or pregnancy, it gives us insights into approaches to reporting of sensitive events among adolescents in a similar setting to the study sites.

More so, the frequency of data collection is key in ensuring that vital events like pregnancy and APOs are not missed. For instance in HDSS sites, it has been reported that those which conduct data collection rounds more frequently have a higher likelihood of identifying pregnancies and APOs earlier (37). Although the study reviewed data from five HDSS sites, there were challenges because this was aggregated data and some of the data were missing.

The type of interview tools and wording of questions (67) impact responses and validity of information. In this case, specific reference is made to the two DHS tools – pregnancy history and birth history. There are debates in the literature about which of these collects more accurate data on adverse pregnancy outcomes, although few direct comparisons have been made. A review of

DHS birth histories reported good quality data overall (67), while a comparison of birth and pregnancy histories in Matlab, Bangladesh, found lower reporting for deaths among children in the birth history, although both surveys had low completeness for reporting of neonatal deaths (71). Even though both studies were focusing on DHS tools, it would have been beneficial to get perspectives of the interviewers who actually administered the tools.

Overall, the pros and cons of the various approaches to collection of data on pregnancy or APOs in LICs are not well explored. Knowledge is lacking of people's understanding of the DHS and HDSS tools. Previous studies lack viewpoints of both respondents and interviewers on tools and processes. Indeed, for accurate data to be collected, both interviewers and respondents have to correctly interpret questions in the tools. Inaccurate measurement leads to poor quality data and planning based on erroneous information. Although the DHS has since adopted the recommendation to use the FPH module, a forty year historical review of the DHS, with focus on measuring stillbirths and neonatal deaths indicated that measurement improvement is required through understanding barriers that cause under reporting of pregnancy loss, alongside interviewer training (53).

2.4.2. Perceptions and experiences of pregnancy and adverse pregnancy outcomes

Perceptions are often built or learned through socialization, culture, religion, education and experiences and will influence whether one chooses to report pregnancy or APOs or not. Often, a woman remains silent about her pregnancy except to a few close people (72). In Gambia, a qualitative study reported that this secrecy was to avoid gossip or to prevent evil spirits that may be sent by ill-intentioned people to harm the pregnancy (73). Although the Gambian study included men's perspectives, it was not specifically conducted in a survey setting. In Ethiopia, pregnancy is also concealed because the mother is waiting for the pregnancy to be "safe", that is to get to the point where it is not likely to result in loss (19). Therefore, this culture of non-disclosure could influence reporting during surveys. More so, hiding pregnancy was reportedly high among adolescents and younger people in Gambia (73). This may be due to fear of repercussions of getting pregnant, and possibly not knowing whom to confide in. Therefore, they are not likely to report when asked, increasing cases of under reporting. Unpublished information shows that the Bakiga tribe of western Uganda also do not pride in reporting early pregnancies, because they may not reach full term and sometimes it is seen as showing off and is looked upon with scorn.

The occurrence of APOs also tends to be surrounded by secrecy, as demonstrated by the mourning and burial processes. In Uganda, IDIs to explore local knowledge and attitudes among families that experienced stillbirths reported that culturally they were given quick and different burials predominantly done by women, while many religions also did not administer formal funerals due to the baby or foetus not being baptized (40). The stillbirth was not announced, with greater silence around the macerated ones. This study is critical in helping us understand culture and its effects on reporting especially since it is in one of the same geographical regions as the current study. However, it only looked at stillbirths, while the current study considered more APOs among a wider range of stakeholders, including those who had not experienced them, for a more comprehensive understanding.

Self-blame or blame from other people who accuse them of causing the APO, often their in-laws, is a common phenomenon (58,74,75). In some instances, women may be accused of witchcraft, evil spirits and carrying curses that lead to APOs as reported in Ethiopia (19). Similarly, ethnographic data from Cameroon exploring practices and perceptions around pregnancy and pregnancy loss found that among the cultural reasons allegedly responsible for APOs was witchcraft especially by co-wives, or even by the woman who suffers the APO (60).

Stigma is one of the most common experiences faced by women and men who suffer an APO. Stigma refers to labelling, marginalizing and stereotyping a person due to a "negative trait" that they possess which makes them different in the eyes of others (76–80). All these studies show that stigma is influenced by culture, gender, ethnicity, social economic status, religion, morality, and social inequality and injustice. Stigma can have far reaching effects, for instance, increasing stress, loss of productivity and higher costs to society due to untreated diseases (78). In a study among mentally ill men in New York City, stigma was found to increase rejection by society, even after treatment (76). Similarly, a study on HIV/AIDS stigma in Haiti highlighted the resultant discrimination due to stigma (76). Although these were not done in the context of APOs, they give important lessons on stigma and emphasize that it be viewed in the context of wider social processes, power relations, economic and political issues.

Women who had stillbirths in the United Kingdom encountered stigma that resulted in loss of identity as a mother, guilt, depression and breakdown of social networks and relationships with one's partner (79). Stigma could therefore influence reporting of APOs due to causing isolation and silence on APOs among women. Indeed, a study in rural Vietnam that conducted FGDs to assess factors that influence quality and accuracy of reporting deaths identified

fear of stigma as a barrier (81). However, it focused on all deaths, not just APOs.

Additionally, in a study defining abortion stigma, why and how it occurs and its effects, authors revealed intentional misreporting of abortions, not only by women but also by health workers (82). This was partly due to stigma around abortion, even in contexts with liberal abortion laws. This study helps us understand the negative effects of abortion stigma on accurate measurement of abortion prevalence. However, it did not include actual interviews that would provide first hand community perspectives from a low-income setting, unlike our study. Lastly, an exploratory study in Pakistan, Peru, Mexico, USA and Nigeria reported high stigma towards abortion, difficulty in disclosure of induced abortions and self-misreporting of induced abortions as spontaneous (83). Although they included both men and women, adolescent perspectives were absent, and disclosure which was a major objective was not discussed much. Nevertheless, they recommended more studies across different cultural contexts.

2.4.3. Psycho-social impact of adverse pregnancy outcomes

The loss of a baby results in deep and overwhelming grief that often lasts for a number of years (84). Grief is a controversial concept, especially with regard to its intensity and duration after an APO (84,85). It includes the psychological, affective and physiological reactions when one loses an important person (85) and has also been defined as normal or complicated grief, with the latter reported as more severe (86). Grief after an APO has many effects, including social withdrawal, depression, somatic symptoms, anger, exhaustion, self-blame, and breakdown of relationships (84,85,87,88). Indeed, these effects may lead to failure to report the APO.

In India, grief was influenced by acceptance of social norms that reduce women's autonomy and loss of identity (88). Mothers do grieve internally although other people appear insensitive to their plight and assume that the mother can always have another baby (85,87) . Indeed, a review of literature on grief after miscarriage reported that while extreme grief declines and almost ends in six months, mourning continues (85) and that there are different stages of grief. This implies that reporting could potentially be affected by the stage of grief at which a person is. Another review of literature on grief after perinatal loss highlighted worse grief among women with repeated miscarriage (89). However, it did not highlight what kinds of studies it reviewed, their objectives and target population.

Gender differences have also been noted, for instance depression and anxiety were higher among women than men in the first few years after an APO (84).

However, in that review, few studies were found in non-European cultures. Without a doubt, grief plays a role in reporting of APOs, because a grieving person may not be ready, able, willing, or expected to talk about their loss when asked. Indeed, a study in Canada conducted semi-structured interviews with bereaved couples and reported uncertainties around disclosure - to whom to disclose and how much (87). Although that study used unstructured interviews that are appropriate for exploration of this topic, it was in a high-income setting, so the current study provided insights on grief and reporting from another context.

Other emotions include jealousy, particularly towards pregnant women or those with children, social withdrawal, sadness, pain and fear among both fathers and mothers (90). Depression, anxiety and denial are common, as shown by IDIs in India among women who had stillbirths (75). Again, all these effects are likely to cause one to be reluctant to discuss the loss. However, although that study highlights a lot about stillbirth experiences, it was potentially biased due to the presence of a family member during the interview, which may have discouraged openness. Additionally, in South Africa, narratives with Xhosa women to explore grieving on the death of a neonate revealed anger and confusion at their loss (91). However, authors only focused on deaths among neonates less than eight days old, excluding a broad range of APOs.

Finally, women and men have feelings of guilt, loss, pain, misery, anxiety, depression, negative effects on the relationship with their partner, disbelief, regret, envy, somatic symptoms, dishonor and worthlessness after an APO (92–94). For abortion, semi-structured interviews with Malaysian women revealed embarrassment and feeling sinful (95). However, these respondents were recruited from the same clinic, where women may have certain similar characteristics, thus potential bias and exclusion of those in the community who may have had different experiences. Nevertheless, all these effects noted will likely influence reporting of APOs, because one suffering the psychosocial impact of such unexplainable loss may not want to talk about it at the time the survey or surveillance activity is underway. In conclusion, most studies on the psychosocial impact of APOs are in HICs, with little known from the African or South Asian context, more so how this links to reporting of APOs.

2.4.4. Perceptions of Foetal Personhood

The point at which a foetus is considered a person has long been a subject of global debate (72,96,97). Different schools of thought are held by the medical community, legal fraternity, ethicists, philosophers, religious people, human rights activists, cultural representatives, among others (98–100). The biggest

debate is whether personhood begins at conception, when the baby's heartbeat can be tracked or when foetal movements begin, or on occurrence of a live birth or even later in some cultures. The common thread is the view of personhood as a gradual process, beyond biology and dependent on social recognition. Foetal personhood is defined by norms, gender, social status, developmental stage and culture (98,101,102).

In Israel, a study on foetal personhood reported that being a living organism does not automatically translate into personhood (98). Among Pakistani Muslims in Britain, foetal personhood is bestowed with the azan and naming ceremonies, even if the baby dies shortly after that (97). In South Africa, miscarriage before three months was referred to as clots or delayed menstruation (72), early loss was not considered human, and the unknown were not mourned. This attitude implies that in such a setting where life is considered as starting later, and the "delayed menstruation" is not valued as life, then pregnancy loss is likely to be under reported. That study provided critical information and had a wide range of respondents although it was done in the specific context of a post-apartheid regime. However, in other African studies where foetal personhood is highlighted, we see similar findings. For instance in Ethiopia, a baby is not named or baptized until a specified number of days have passed when they have survived as humans (100). More so, babies that die are buried differently because they are not people, and should not be mourned (19). It was important to further explore foetal personhood in different LICs, to see whether this similarity persists or not and how this in turn may influence reporting of APOs.

Overall, much of the literature discussing personhood has limitations, in that it takes a moral, religious or human rights perspective. It is often focused on the debates on the right to life for the foetus versus women's choices for termination of pregnancy. The current study specifically explored personhood in line with its influence on reporting of pregnancy and APOs, which was a gap in the literature.

2.4.5 Social networks and coping with pregnancy and adverse pregnancy outcomes

Often, decision making in pregnancy and after APOs is influenced by other people, beyond the parents of the baby. Key people in the social networks of the mother and / or father include parents, siblings, in-laws, friends, neighbours, religious leaders, health workers, traditional birth attendants, peers specifically for adolescents, fellow members in a support group, etcetera. These interactions can play either a positive or a negative role, including whether

they decide to disclose pregnancy or APOs. Indeed, a study in Cameroon emphasized that APOs must be considered within the social context in which they occur (60).

Trust is key in interactions between pregnant women or people who experience APOs and those around them, including interviewers during surveys or surveillance. People in the network, through these relationships, may apportion blame, stigma and guilt when an APO has occurred. At times parents may be unsupportive of adolescents who get pregnant, leaving them to deal with the situation on their own. Men whose wives or partners have an APO have also been noted as lacking social support (103), as shown in Ireland but little is known about this in the Ugandan setting. People in the same social network are likely to have similar information and perceptions, developed through social interactions. This directly impacts reporting of pregnancy and APOs. For example, not having awareness of the requirement to report these deaths and to whom has been noted as a barrier (81) and this is likely to be the same within a wider community.

On the other hand, social networks can also be a source of support, encouragement, counselling and sound advice. Therefore, they can assist the bereaved to cope better with the effects of the APO, including being able to talk about it (58,75,104). This includes social support from spouses, mothers and friends (95,104–106).

Health workers play a major role in the wellbeing of people who have suffered APOs. They are the frontline people in charge when a birth or death has occurred within the health facility. When a health worker is positive, open with information and encouraging, then the bereaved is better able to cope and share their experience. However, some studies report frustration with the negative and uncaring attitudes of health workers after an APO (74,90). The bereaved feel neglected, not taken seriously and thus may further slide into depression and inability to discuss or report the APO when asked about it.

Having support, information and sharing experiences is important to increasing disclosure and reporting rates. Sometimes, people who have APOs are able to join support and counselling groups to help them deal with it. However, in Africa and specifically Uganda, not much is documented about this. In fact, African cultures tend to encourage grief suppression, with people told to remain stoic. Often, there is an acceptance of death as inevitable, especially in LICs where perinatal and maternal deaths are common – everybody knows somebody who has had one, and it goes back generations (107). This attitude of fatalism is the norm, and families are expected to move on with life, since that is God's will (107,108). People may turn to religion and traditional prac-

tices to find meaning and comfort for their loss, for example prayer. This normalization of death is bound to affect reporting, in addition to reluctance to revive the memories.

2.4.5. The influence of gender in reporting of pregnancy and adverse pregnancy outcomes

Gender has been defined by the World Health Organisation (WHO) as the characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other (109).

The influence of gender and patriarchy on decision making for women and their health cannot be ignored. This is particularly so in LICs where patriarchy is strong, and men often hold both the money and the decision making power, with females usually subordinate (110). In a study on disclosure of HIV serostatus, In-depth Interviews (IDIs) with HIV positive women and men revealed that gender inequality affects women more, causing them not to disclose their status due to fear of consequences like violence (111). Although this was not focused on pregnancy or APOs, it gives insight into gender and disclosure of sensitive information, which is relevant to the current study. Furthermore, in an editorial discussing the importance of gender analysis in research for health systems, the use of a gender lens was recommended (112). This is because it helps researchers get more holistic information, thus more transformative policies and interventions.

In Pakistan, through FGDs and IDIs with women and men to explore barriers to reporting of stillbirths, mothers in-law were reported to control health care decision making (108). More so, women were dehumanized and sometimes threatened with new co-wives. That study is important because it directly ad dresses barriers and enablers to reporting of stillbirths, including the socio cultural and health system challenges. In a study exploring stillbirths, social iso lation and control of women were reported in India, with women not allowed to talk to neighbours (113). With the restrictive culture, low support from natal family and in-laws, women are expected to conform to the rules, are isolated and lack autonomy to make decisions. Similarly in Pakistan, social isolation of women who had stillbirths was evident in their exclusion from ceremonies celebrating unborn babies (108). Women are often closed up about their stillbirth experience, with suppressed fear and feelings and in such a setting they may not easily report it.

In Uganda, IDIs were held among both women and men to explore men's attitudes and involvement in abortion decisions (114). Men were found to often

be gatekeepers over women's reproductive health, with women requiring their permission before making certain decisions. In such cases, if a woman covertly had an abortion without telling her husband or partner then she may not report it later. Although this study did not highlight what kind of analysis they did, they further show the role of gender in this setting. Nevertheless, gender autonomy is not always perceived as negative. For instance, studies show women viewing abortions as necessary, making their own decisions to have one and going ahead to do so (83,95). Overall, the influence of gender on reporting of pregnancy and APOs has not been explicitly explored in previous studies, with focus mostly on broader reproductive health issues. Overall, the literature gives some indications as to why people may under report pregnancy and APOs.

3. Theoretical Frameworks

It is imperative to recognize the role of human behaviour and how it influences actions, health and other outcomes. Moreover, human behaviour is also influenced by other external factors. A number of theories that explain behaviour and actions have already been developed, that will help us to better understand why people may not report pregnancy or adverse pregnancy outcomes. This study was partially framed on the socioecological model (115). This model was developed focusing on health promotion, with the view that individual and environmental issues are important for health interventions to succeed. It emphasizes that diseases are not only a result of individual lifestyles and behaviour, but also the environmental and social context in which they are. In turn, these components are affected by each other, as well as by human behaviour. A diagrammatic representation of this model is shown in Figure 1.
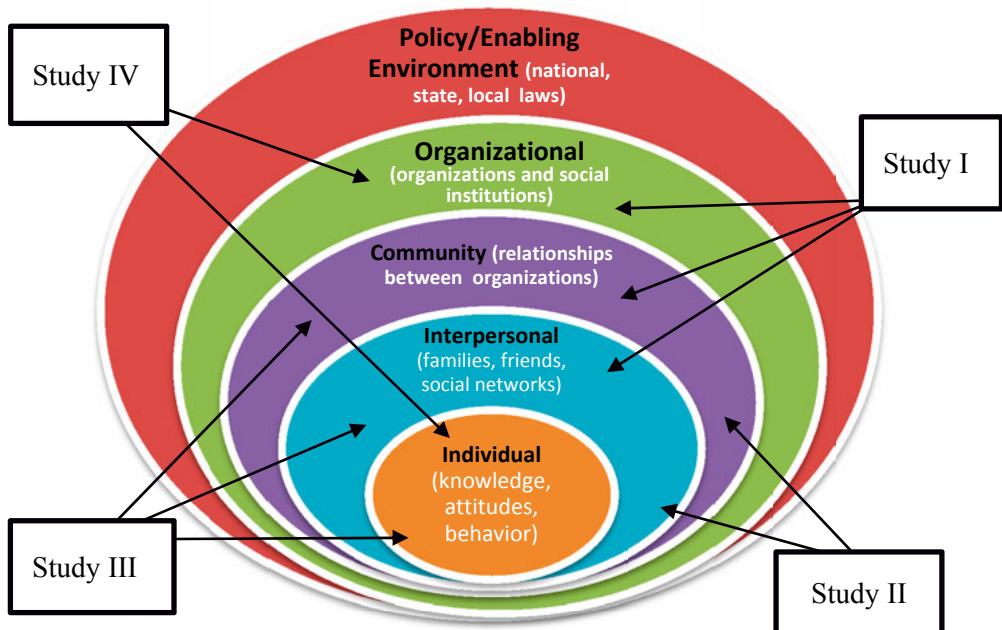

Figure 1: The Socioecological Model (Theoretical Framework)

This theoretical framework was thought to be the most appropriate for this study because issues to do with pregnancy and its outcomes tend to be interconnected from the individual to the society, moving from the micro to the meso levels and it represented this well. It is among the theories that look at individuals within their cultural, social and policy context, which was in line with this study. It looks at the characteristics of an individual that influence behavior and behavior change; social networks (formal and informal) and their influence; community level relationships; the influence of organisations or social institutions and finally policies and laws higher up the hierarchy and their interaction or influence on the other four.

For instance, when this is translated to reporting of pregnancy and APOs, we see that while the women as individuals have knowledge and personal attitudes towards reporting, they are part of a social network, with family, friends and neighbours with whom they interact and influence each other's perceptions and actions. They are also part of a larger community, with specific cultures, religions and geographical settings. These play a role in defining how people handle pregnancy and APOs and influence knowledge, perceptions, practices and reporting. Additionally, there is the organizational and systems level, with everybody being part of an organization, for instance schools, work and other social structures. These also shape people into behaving a certain way, influence them as individuals and as a community. Finally, the legal and policy environment is crucial as well, for instance the legality of abortion, regulations on birth and death registration, and whether these come with any sanctions.

This socio ecological model was applied at different points of the study. A case in point is how it was instrumental during tool development, where I partly referred to the different components to think through potential questions for the guides. At the end of the results section of the current study, further demonstration is made of how this model was relevant and how the different findings fit into it. However in figure 1, mapped on the model are the four studies that are part of this thesis, with arrows indicating the links between the different aspects of the model and the four studies.

Additional theoretical perspectives
Nevertheless, in study II on social networks, two other theories which were not among the initial theories and models that informed this study from the start were introduceed, that is, communication theory and diffusion of innovation theory.

Communication theory
Communication theory regards communication as a constant and multi directional process of sharing information and making meaning of that information

(116). The reason for this additional theoretical perspective was that a key feature of social networks is communication. Despite variations in its definition, the communication process is widely agreed to involve a sender, a receiver and a message. With study II indeed focused on disclosure of APOs, communication theory in this case was an appropriate guide during analysis of how disclosure is done and provided a good framework for categorization and presentation of the three themes and sub-themes. The socio-ecological model could not be applied in that way.

Diffusion of Innovation theory
The diffusion of innovation theory (117) states that when a person is presented with an innovation, they go through five main stages in the innovation-decision process: getting knowledge (about the innovation); persuasion (attitude towards it), decision (to adopt it or not), implementation (using it) and confirmation (reinforcement or reversing from use).

This theory was applied in the discussion of the findings of study II. It was applied to describe how information flow or diffusion in a community can take place and be positively exploited. Specifically for this study, the focus was on how information about the need to report APOs can be shared within a social network. The stages of this theory were appropriate in this case. However, the socio-ecological model was still relevant to this study, particularly the individual and interpersonal components.

4. Problem statement

There is a high number of adverse pregnancy outcomes globally. However, the true figures are likely higher, due to under reporting of pregnancy and adverse pregnancy outcomes (7,15), especially in low income settings (6,10,12,118). Unfortunately, these are the same regions with higher prevalence of adverse pregnancy outcomes. Ideally, all births and deaths should be reported and registered using the various channels available in a country. Civil Registration and Vital Statistics that would provide this data are sub-optimal in many LMICs, resulting in missed and incomplete information on births and deaths (8,16) .

As a result of the weak CRVS, many countries rely on data from the DHS and sometimes from the HDSS sites. However, these also have challenges, for instance the DHS questions often combine stillbirths, neonatal deaths and abortions. Furthermore, DHS is retrospective and asks about data as far back as the five years before the survey, while the HDSS sites often have incomplete data and miss recording of events, despite being prospective (17,37,119).

Possible causes for under reporting have not been widely explored, but a few studies indicate the role of socio-cultural factors including stigma from the community, grief, the need for silence, fear of being suspected of induced abortion and more (18,40,120). However, not much information is available on reporting APOs, particularly from the perspective of mothers who have suffered pregnancy losses, from men, and from the interviewers in surveys. There is also limited information on context specific definitions of pregnancy and the role of gender.

This PhD will help to inform people designing and implementing surveys about possible challenges and facilitators that may be encountered. It was conducted in different HDSS sites, where regular surveillance and data collection for pregnancy and APOs are done. It will therefore also provide feedback to the HDSS sites, highlighting barriers or enablers during surveillance, how to get respondents to disclose sensitive information, and different ways to improve the HDSS interview processes.

5. Research Questions, Aims and Objectives

Research question: What are the enablers and barriers to reporting of pregnancy and adverse pregnancy outcomes during population and health surveys in multi-country contexts?

Aim: To explore the enablers and barriers to reporting of pregnancy and adverse pregnancy outcomes during population and health surveys in multi-country contexts, so as to inform measurement improvements in these surveys. The specific objectives are:

Study I (Paper I)
To explore how community and interviewer perceptions and experiences of pregnancy and adverse pregnancy outcomes affect reporting of these events in surveys

Study II (Paper II)
To examine how social networks influence reporting of adverse pregnancy outcomes in surveys

Study III (Paper III)
To explore the psychosocial experiences after adverse pregnancy outcomes and how they affect reporting in surveys

Study IV (Paper IV)
To explore women's interpretations of survey questions on pregnancy and pregnancy outcomes

6. Materials and Methods

6.1. Overview of studies

This study was a qualitative, multi-methods study using a phenomenological design. It was conducted in five study sites: Iganga Mayuge HDSS in Uganda, Kintampo HDSS in Ghana, Bandim HDSS in Guinea Bissau, Dabat HDSS in Ethiopia and Matlab HDSS in Bangladesh.

This study was situated within an interpretative research paradigm, which believes that human beings think about the world, their behavior, and don't always do things as expected (121). This paradigm was appropriate because it appreciates that there are multiple realities and it is important to understand these from the pespectives of people we are studying and in their own context (122). The interpretative paradigm was relevant since the study sought to explore community and interviewer perceptions, experiences with APOs and interpretations of questions. For example, the results are presented including verbatim quotes from multiple study participants showing their beliefs, practices and interpretations of events.

Table 1 summarises the different aspects of the methods, which we thereafter explain in further detail for each study.

Table 1: Summary of methods used in the four studies

Study	Design	Setting	Sampling & sample	Data collection	Analysis
Study I: Barriers and enablers to reporting pregnancy and adverse pregnancy outcomes in population-based surveys	Qualitative, phenomenological study	HDSS sites in 5 countries • Bandim HDSS (Guinea Bissau) • Iganga Mayuge HDSS (Uganda) • Dabat HDSS (Ethiopia) • Kintampo HDSS (Ghana) • Matlab HDSS (Bangladesh)	• Purposive sampling 172 women • 82 interviewers	• Focus group discussions with women (who had participated in EN-INDEPTH survey) • Focus group discussions with EN-IN-DEPTH survey interviewers	Thematic analysis
Study II: Adverse pregnancy outcome disclosure and women's social networks: a qualitative multi⬜country study with implications for improved reporting in surveys	Qualitative, phenomenological study	HDSS in 4 countries • Bandim HDSS (Guinea Bissau) • Iganga Mayuge HDSS (Uganda) • Kintampo HDSS (Ghana) • Matlab HDSS (Bangladesh)	• Purposive sampling • 147 women	• Focus group discussions with women (who had participated in EN-INDEPTH survey)	Thematic analysis

Study	Design	Setting	Sampling & sample	Data collection	Analysis
Study III: Psychosocial effects of adverse pregnancy outcomes and their influence on reporting pregnancy loss during surveys and demographic surveillance settings in Uganda	Qualitative, phenomenological study	• Iganga Mayuge HDSS (Uganda)	• Purposive sampling • 51 respondents (44 females and 7 males)	• Narratives with women who had experienced an APO and men whose wives / partners had experienced the same	Thematic analysis
Study IV: Women's interpretations of survey questions on pregnancy and pregnancy outcomes: Cognitive interviews in Iganga Mayuge, Uganda	Qualitative, phenomenological study	• Iganga Mayuge HDSS (Uganda)	• Purposive sampling • 20 women	• Cognitive interviews with women	Qualitative description

6.2. Study setting

The five study sites in Uganda, Ghana, Guinea Bissau, Ethiopia and Bangladesh are shown in Figure 2, as well as where the studies were conducted.
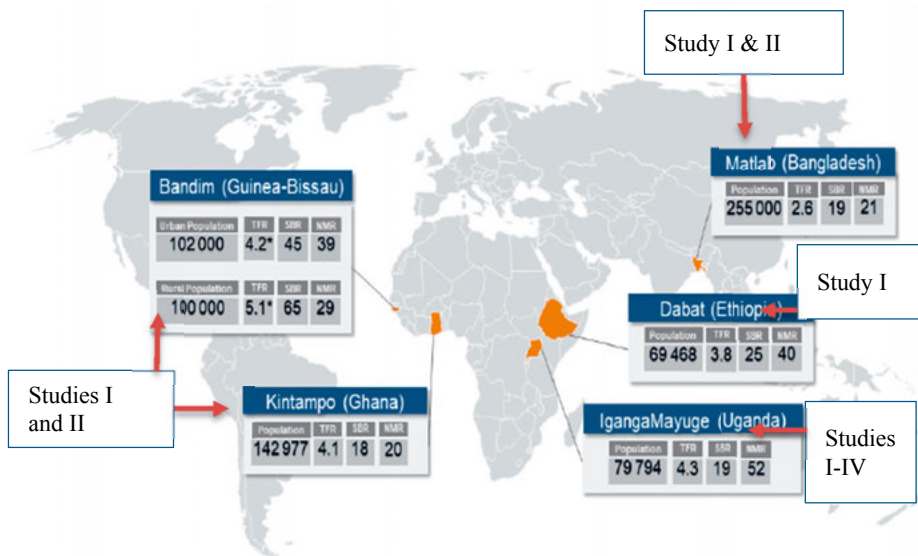
Figure 2: Map of study sites

The map is taken from the EN-INDEPTH protocol paper (25). More information about each HDSS site is shown in table 2 (*Further information on the HDSS sites and their work can be found on their websites*). These five HDSS sites were part of the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH) that had 53 member HDSS sites in 2016, which together were conducting surveillance onover 4 million people in Africa, Asia and Oceania. Many HDSS sites are located in LMICs and contribute to measuring various aspects of population health as earlier explained.

The five study sites were selected for inclusion in the EN-INDEPTH study through an open request for proposals from INDEPTH member HDSS sites, to which 14 applicants responded. Sites were chosen based on various criteria, including the quality of their pregnancy surveillance systems that had to include stillbirths and neonatal deaths, a population above 30,000 people in the

HDSS, an annual neonatal mortality rate above 15 per 1,000 live births, team members with expertise in maternal, newborn health and stillbirths work, as well as availability to provide co-funding for the length of the study.

In addition to the fact that they have a known population under prospective surveillance, HDSS sites have some variations in the way in which they implement surveillance and are not doing things exactly the same way. Therefore, having different sites provided geographical, scientific and other diversities for learning. More importantly, HDSS sites have characteristics which may influence measurement. For instance the different methods of pregnancy and pregnancy outcome surveillance, the frequency of surveillance, how long the HDSS site has existed and the reasons why it was established were potential reasons for the variations in pregnancy and pregnancy outcome capture (28). Having fewer surveillance rounds means that many events occurring between the rounds may be missed, with retrospective registration tending to miss more of the adverse pregnancy outcomes (28).

Table 2 provides further information on the HDSS profiles. Data are collected from multiple sources, including literature (28), the HDSS site websites and verbal information provided during the EN-INDEPTH meetings and refers to different time points. It is not intended for comparison between the sites, but rather to give insights into each site.

Table 2: Profiles of the HDSS sites where the study was conducted

	Iganga Mayuge	Bandim	Dabat	Kintampo	Matlab
Site information					
Location	Uganda: Iganga and Mayuge, 2 districts in	Guinea-Bissau: covering urban and rural	Ethiopia: North Gondar, Amhara region,	Ghana: Bono East Region of	Bangladesh: Matlab Upazila, in Chandpur district, 55km southeast of capital, Dhaka
Year of establishment	2004	1978	1996	2003	1966
Geographical size	• 65 villages • 7 sub-counties • 155 km^2	Urban: 6 suburban areas in Bissau; Rural: 222 clusters of 100 women; total of 182 village clusters nationally	13 Kebeles (4 urban and 9 rural)	7,162 km^2	142 villages; 182 km^2
Population	94,568 (in 2017)	Urban and rural each have approximately 100,000 people	70,000	456,478 (in 2020)	246,893
Households	18,634 (in 2017)	Information unavailable	21,000	32,000	60,400
Birth rate	27.7 per 1,000 population (2017)	21.9 per 1,000 population (2017)	28.2 per 1,000 population (2012)	20.7 per 1,000 population (2016)	7 years crude birth rate: ~22/1,000 population
Total fertility rate	4.3	Information unavailable	3.8	4.1	2.6

Pregnancy identification

	Iganga Mayuge	Bandim	Dabat	Kintampo	Matlab
Main respondent	Any adult member in household if woman is not present	Not applicable	Any adult member in household if woman is not present	Any adult member in household if woman is not present. Or Community Key Informant	Woman main respondent about pregnancy related issues and outcomes. If she died, information about her death obtained from Verbal Autopsy
Methods for pregnancy identification	Has 64 community based "scouts" and Village Health Teams. Both male and female scouts are used	Recently started using community key informants in a sample of rural villages. Each woman is asked about pregnancy status and a pregnancy ID given if found pregnant. Both male and female informants	Local guides report pregnancies and births within 48 hours after they have been identified. 83% of informants are female	Community key informants are used to notify pregnancies. Each woman is asked about her pregnancy status	The women age 15-49 years old missing last menstruation are offered a urine test for pregnancy if pregnancy status is unknown. All enumerators are female

Data capture

	Iganga Mayuge	Bandim	Dabat	Kintampo	Matlab
Average frequency of surveillance rounds	2 per year	Urban: Monthly Rural: 2 per year	2 per year	1 per year (from 2017)	6 per year
Frequency of census or update rounds	Each update round (Twice a year)	Every 2-4 years (Urban), each update round (rural)	Every 7 years	Last census 2003	8 years or more

6.3. Study population

Study I and II: The focus was on women aged 15-49 years old, who had a birth in the last five years and were interviewed in the EN-INDEPTH survey, or those who had ever been interviewed by the HDSS in the routine rounds and were current residents of the HDSS. For study I only, interviewers who had been involved in data collection during the EN-INDEPTH survey were also part of the study population. Study I was conducted in all five study sites while study II was conducted in four - Kintampo, Bandim, Iganga Mayuge and Matlab.

Study III: In this study, the population comprised two groups. The first was women aged 15-49 years old, who had suffered an adverse pregnancy outcome (miscarriage, stillbirth, neonatal death). Within this category, I included women who had been interviewed in the EN-INDEPTH survey; those who had been interviewed about the APO in the routine HDSS rounds and those who were neither interviewed by EN-INDEPTH or in the routine HDSS round but had an APO in the previous four years. The second study population were the spouses or partners of the women who had experienced an APO. This study was conducted in Iganga Mayuge only.

Study IV: The study population was women aged 15-49 years, with secondary or higher levels of education and able to speak English. This study was conducted in Iganga Mayuge only.

6.4. Study design

All four studies were cross-sectional and used qualitative methodology. **Study I and II** were multi-country studies, with Study I conducted in all five study sites and Study II done in four sites. Ethiopia was excluded from study II due to inadequate data on social networks and their influence on reporting adverse pregnancy outcomes.

Studies III and IV were only conducted in Uganda. This was for various reasons, including being the PhD student's country of residence, where I could further do indepth work on the narratives and cognitive interviews at an affordable cost, conveniently and with easier access to participants, while concurrently supplementing the multi-country work and findings.

6.5. Sampling

For all four studies, sampling was done purposively, specifically maximum variation sampling, to ensure that appropriate respondents would be identified. Maximum variation sampling aims to ensure that the sample includes as much as possible the different categories or types of people in the population (121). In the current study, I sought to ensure variation through including respondents in urban and rural areas; younger and older women; those who had suffered APOs and those who had not. This variability was important because in case the different groups had differing opinions and practices towards reporting pregnancy and APOs, then I would not miss them. In all cases, respondents were approached by the HDSS staff and requested to participate.

Study I and II: Women were selected from the household registers that the HDSS used for sampling in the EN-INDEPTH survey, through which they could track those who had participated in the survey. Purposive selection was then done, of women in both urban and rural settings and across different age groups, with deliberate inclusion of adolescents and women who had suffered APOs. Interviewers who collected data in the EN-INDEPTH survey were known and also approached by the HDSS staff to participate as per their availability. Where interviewers were both male and female, both sexes were represented in the FGDs.

Study III: Sampling was done using various sources as shown in Figure 3.
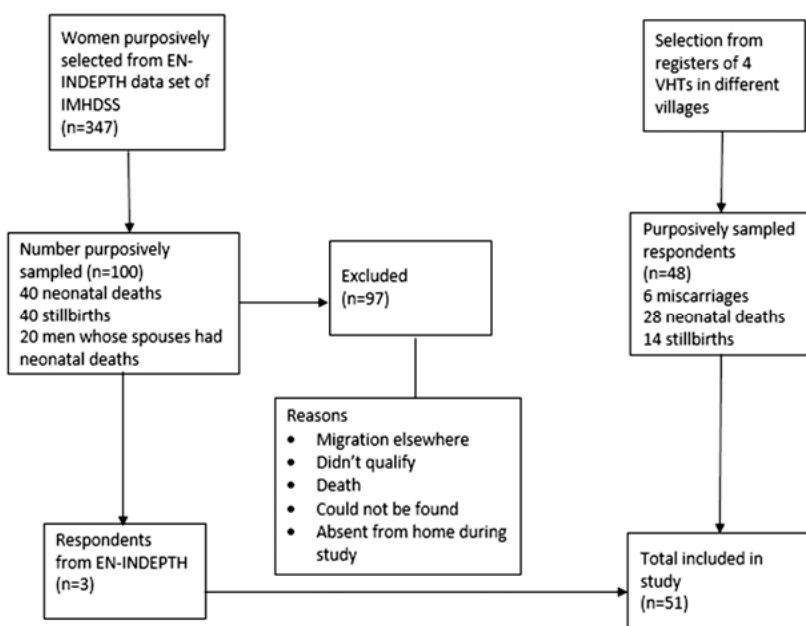
Figure 3: Respondent selection and sampling for Study III

Study IV: Women aged 15-49 years, who had given birth in the past five years, had attained secondary school education or higher, could speak English and were residing within Iganga Mayuge HDSS, specifically in the urban area were purposively sampled

6.6. Data collection

I was the qualitative lead for the entire study and concurrently a PhD student, which I further elaborate on in section 7, showing my role in both instances. At each of the five study sites, there was a research team working on the EN-INDEPTH study, including a multi-site qualitative working group. I coordinated, led and worked with this group for study I and II.

Study I and II: Data were collected between February and August 2018 through FGDs with women (both studies) and with interviewers of the EN-INDEPTH survey and the HDSS site (only Study I). Each FGD was targeted to have 8-12 respondents and HDSS sites conducted a different number of FGDs. To determine the number of FGDs with women, the biggest criterion was to get diversity in respondents to the extent possible, considering the budget that each country had allocated for the qualitative work. For instance,

FGDs with women required women of different ages in both the urban and rural settings of the HDSS site. Therefore, FGDs with women were four each in Bandim, Iganga Mayuge, Kintampo and Matlab and three in Dabat, which started work late due to the delay with various government regulations.

The FGDs with interviewers were two in Bandim, Dabat and Iganga Mayuge, four in Matlab and four in Kintampo. These were premised on getting perceptions from both interviewers who participated in the EN-INDEPTH survey as well as the regular HDSS interviewers involved in routine surveillance. Therefore, each country could do a minimum of two FGDs. Additionally, some countries had both male and female interviewers for the EN-INDEPTH survey and consideration was made to ensure both sexes were represented, as well as the time available to hold these at the end of survey data collection in each country.

I developed standard FGD guides in English for both groups of respondents. This ensured that questions were as similar as possible across the HDSS sites. Nevertheless, the HDSS site research teams had the liberty to make slight adjustments to these guides bearing in mind the need to have data collected in as similar a manner as possible. After the pre-testing, the overall guides were revised and used across all sites. Country teams also translated the guides as needed. Each site translated the tools to the predominant local language except Ghana, which preferred to use the English tool. In each FGD, notes were made by the note taker and with the consent of the respond ents, an audio recording of the discussions done, using a tablet, tape recorder or other recording gadget available.

I developed an FGD training manual, partially adapted from the DHS interviewer training manual. In this case, it was for use by site teams to train moderators and note takers on how to conduct the interviews, including giving them more knowledge on the DHS survey. This was again to ensure that training was standardized across the sites.

Study III: Narratives were held with respondents in September 2021. Narratives give respondents a chance to tell their story, thus providing both the personal and the social, across a continuum of time (past, present and future) and place (123). They are appropriate when a researcher is interested in the life experience of an individual over a period of time.

I developed a narrative guide in English and this was translated into *Lusoga*, the most commonly spoken local language, pre-tested and refined. This guide had three questions – one on the respondent's experience during the APO (interviewers let the respondent narrate her/his story here and probed where important); another on whether they were able to talk to people about the loss,

especially to interviewers, in the past if they were previously interviewed and in the current study and finally they were asked for suggestions on how to improve data collection on APOs during surveys. All interviews were conducted in *Lusoga* and audio recorded on tablets or mobile phones. Each interviewer then transcribed their set of interviews into English. At the end of each day, the field team discussed the activity and observations, which the main author wrote as field notes that supplemented the analysis.

Study IV: Cognitive interviews were conducted with recruited participants in October 2021, focusing on selected items of the reproduction module of the women's questionnaire (English version) in DHS VIII. At the time, the *lusoga* (commonly spoken local language in the study area) version of the DHS VIII tool was not readily available and so we only used one language.

Cognitive interviewing is among the approaches suggested for improvement of survey research (124). Various definitions of cognitive interviews exist, with a lack of consensus or standardization (125,126). One clear definition from Beatty and Willis (page 2) is that *cognitive interviewing entails administering draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends* (125). The focus of cognitive interviews was described by Willis and others as being on the survey questions and understanding the hidden and visible cognitive processes that subjects, chosen according to specific traits of interest, undergo as they answer survey questions (127) .

This process is founded on cognitive theory which has been represented by various frameworks, with the commonly used one developed by Tourangeau in 1984 (127). Tourangeau's framework broadly points out four key areas for the cognitive interview process: Comprehension, Retrieval, Decision and Response processes, detailed in table 3.

Table 3: Cognitive interview processes developed by Tourangeau

Focus area	Sub-components
Comprehension of questions	• Question intent: What the respondent believes the question is asking • Meaning of terms: What particular words mean to the respondent
Retrieval of information from memory	• Recallability of information: The type of information the respondent needs to remember so as to answer the question • Recall strategy: What strategies does the respondent use to retrieve information?
Decision processes	• Motivation: Whether the respondent is applying adequate mental effort to provide thoughtful and accurate responses • Sensitivity / social desirability: Whether the respondent is actually being truthful or simply wants to give answers that make him/her appear better
Response processes	• Matching the response: Can respondent match his or her answer to the available response categories provided for the survey question?

Study IV of this PhD specifically explored women's comprehension of the questions and meaning of key terms in the questionnaire. It was intentionally conducted last, using knowledge gained from the previous three, for example about questions that were problematic to women and potentially influenced reporting of pregnancy or APOs. It therefore specifically focused on these aspects of the questionnaire.

For each respondent, the interviewer would read out the question, note the response, then probe and note down the respondents' answer after the probe. Some of the probes were already indicated and included in the tool, but the interviewer was at liberty to introduce their own relevant probes as well. The interviewer then made a comment on the respondents' verbal and non-verbal behavior during the interview or about anything else they had observed. Finally, the interviewer made a suggestion for revision of the question where they thought it was necessary. An excerpt of the adapted interview tool is shown in Figure 4.

Cognitive interview questionnaire: Reproduction section of woman's questionnaire – DHS 8, English

Interviewer name _____   Respondent ID _____   Interview date: ___ / ___ / ___

(DD/MM/YY)

Time interview started: :

Section A – interview questions from DHS

Original question	Response categories	Probes (Pre-set & by interviewer)	Respondent's answer after probe	Interviewer's comment (on verbal & non-verbal behavior)	Suggested revision
201. Now I would like to ask about all the births you have had during your life. Have you ever given birth?	Yes No (if no, skip to 206)	• Can you repeat the question in your own words? • Any other probe by interviewer			
202. Do you have any sons or daughters to whom you have given birth who are now living with you?	Yes No (if no, skip to 204)	• What does this question mean to you? • Any other probe by interviewer			
204. Do you have any sons or daughters to whom you have given birth who are alive but do not live with you?	Yes No (if no, skip to 206)	• What does this question mean to you? • Any other probe by interviewer			
206. Have you ever given birth to a boy or girl who was born alive but later died? IF NO, PROBE: Any baby who cried, who made any	Yes No (if no, skip to 209 to calculate total births)	• Can you repeat the question in your own words? • How easy or difficult did you find this question to answer? Why do you say that?			

Figure 4: Excerpt from the tool used during cognitive interviews in Study IV

6.6.1. Community engagement and recruitment

For **Studies I and II**, the HDSS teams on the ground sensitised the populations about the EN-INDEPTH study using media like telephone messages for example in Iganga Mayuge before the interviews were done. Recruitment of study participants was done through multiple means, including face to face in all sites, supplemented by written information in Bandim and telephone calls in Matlab and Iganga Mayuge.

For **Studies III and IV** in Iganga Mayuge HDSS only, initial community entry was also done through the HDSS sites, who connected the study teams to the Village Health Team (VHTs). I then worked with these VHTs, who not only assisted with recruitment but also took the research assistants and I to each of the households of the relevant respondents or if they were not home but in the nearby areas helped the team get to them physically and made preliminary introductions about the study and the interviewers.

6.7. Data management

All the audio recorded data were transcribed into English. A few audios were selected and listened to, comparing their content to that of the transcripts, to ensure that the transcripts were a true representation of the interview.

For **Study I and II**, data were shared with me by country qualitative team leads in the form of encrypted files. In line with the data sharing agreement for the EN-INDEPTH study, data were also stored on the centralised database system at LSHTM encrypted, password protected, and only accessible to authorised members of the research team. Data will be stored for a minimum of 10 years following project completion in accordance with the LSHTM's Records Retention and Disposal Schedule and in accordance with INDEPTH and MakSPH procedures.

For **Study III and IV** that were conducted in Uganda only, I stored the transcripts both in a computer folder to which I am the only one with access and cloud storage. In all studies verbatim quotations presented in the papers and this thesis are anonymised, to ensure participant confidentiality.

6.8. Data Analysis

Study I and II: Thematic analysis (128,129) was done using NVivo version 12 software. This involved six steps as recommended: familiarisation; coding;

generating initial themes; reviewing and developing themes; refining, defining and naming themes; and writing up (129). Familiarization involved reading through the transcripts and taking down brief descriptions of potential codes and meanings. This was followed by coding using NVivo software that involved reading each transcript and identifying codes. Initial themes were generated from the codes, by grouping similar codes together, and getting into an iterative process of regrouping the themes alongside further review of the codes under each and their meanings.

A few differences in analysis for the studies are highlighted:

Study I analysis: I developed an a priori codebook to guide the analysis process and try to ensure con sistency across sites to the extent possible. The multi-site qualitative working group reviewed it and made input. This codebook was based on mine and other team members' experiences and published literature.

Thereafter, both inductive and deductive coding were done, a process that involved multiple coders but which I led. Initial coding for each site was done independently by two coders from the qualitative working group in each country who met regularly face-to-face and online to discuss identified codes and themes. These coders were the lead researchers for the work in each site. As the lead of the qualitative work and the PhD student, I was actively involved in the coding discussions for each site. However, in Bandim HDSS site I led the entire analysis and report writing process, supported by one other externally recruited research assistant. The Bandim team lead for the broader EN-INDEPTH survey supported with understanding a few country contextual issues. In Iganga Mayuge, I also led the entire coding, analysis and writing process, supported by one HDSS team member.

As part of the EN-INDEPTH survey work, the multi-site qualitative working group had regular conference calls to discuss and synthesise findings, culminating in a face-to-face analysis meeting in February 2019. In these discussions, I led the teams in discussions comparing coding, cross-country findings and agreeing on generation of themes.

Study II analysis: I led the data analysis, which comprised both inductive and deductive coding. I did the initial coding and was then supported by two researchers in further analysis. We regrouped codes with similar meanings and between which relationships could be established. Thereafter, groups of codes were placed under three pre-defined themes (Sender, Message and Receiver), based on communication theory. On final analysis, all results were subsequently placed under one of these three pre-defined themes.

Study III: Thematic analysis was done, following the earlier explained processes used for sub-study I and II. The major difference was that study III was conducted in Uganda only, thus no cross-country sharing of data. Instead, after transcription, I conducted the analysis process. After the first round of theme generation, I worked with a fellow author to review, refine and agree on the themes.

Study IV: Multiple approaches were used to measure cognition, that is, to identify whether responses given were correct or wrong. The starting point was that I used my knowledge and experience of the study topic. I have worked in the field of maternal and newborn health for many years and I am aware of correct interpretations and common misclassifications of pregnancy outcomes. Furthermore, I had earlier taken part in training the data collectors in Iganga Mayuge for the EN-INDEPTH survey, which used the DHS tool (Version VII). I was therefore aware of the women's DHS tool, the items therein and what a correct or incorrect answer is. Additionally, comparison was made of participant's responses with the instructions in the DHS interviewers' manual, which explains to the interviewer the intention of each question and the kind of answer expected (130). A qualitative description was then undertaken (131), where data are presented in a comprehensive and straightforward way, with minimal inferences from what the respondents shared. I led the data analysis process for this study, and after the initial stages, was supported by other authors in the final analysis and manuscript writing process.

6.9. Ethical considerations

The EN-INDEPTH study was granted ethical approval by the Institutional Review Boards in all operating countries (including Uganda National Council for Science and technology) as well as from the Institutional Ethical Review Committee of the London School of Hygiene & Tropical Medicine. Further approval for the PhD study was granted by the Higher Degrees, Research and Ethics Committee at Makerere University School of Public Health, Uganda.

Every respondent gave written consent/assent after being informed of the study objectives and content, how the interviews would be conducted, benefits and risks of participation, the right to withdraw or stop the interview at will and what the data would be used for.

Throughout the study, we were cognizant of the need for privacy, confidentiality and security of data. For instance, during data collection, interviews were held in private and convenient settings. For those held in respondents' homes, nobody who was not part of the discussion was allowed to listen in. During

the FGDs, numbers were used in place of the respondents' names, so as to avoid having any personal identifiers in the transcripts and audios.

This PhD addressed the issue of adverse pregnancy outcomes and many of the respondents had unfortunately experienced these losses, some more than once. Therefore from study conceptualisation, there was a need to be mindful of the vulnerability of many respondents. The first step was to develop a brief protocol for managing distress during all sub-studies. This provided guidance on how the moderator should respond, for instance if a respondent got upset during an FGD and was also shared for use across all sites.

Secondly, during training of the research assistants and moderators for all sub-studies, beyond understanding the study tools and processes, emphasis was put on ensuring that the research team could identify respondents suffering from trauma of their loss and could respond appropriately. This included noticing for instance that if a respondent started crying, the interviewer needed to pause the interview and firstly commiserate with her/him. After this, they had to ask whether the respondent needed a short break and if they were able to continue with the interview after. Part of the break involved changing the topic briefly or where the respondent offered further information, especially in the narratives, the interviewer could follow up on that angle. Where the respondent said they could not discuss the loss any more, then that section of the interview came to a halt. Interviewers were also taught how to tactfully try to resume the interview, that is, by tackling another less traumatic topic.

For Study IV that involved narratives, part of the design included offering counselling to the respondents. However, on conducting the first few narratives, the team realised that more people were interested in health education. Therefore, the PhD student reflected on this and planned an alternative approach which is elaborated on later in this thesis.

7. My contribution to the EN-INDEPTH study and the PhD study

7.1. EN-INDEPTH study

I was part of the EN-INDEPTH study from late 2015. My role was a Research Assistant in the Makerere School of Public Health team that was part of the study secretariat, together with the team from London School of Hygiene and Tropical Medicine. In that capacity, I participated in the following ways:

I took part in reviewing and grading proposals submitted by various HDSS sites in response to the request for proposals for participating sites, with other secretariat members.

I participated in organizing and coordinating the three main study workshops (protocol development, implementation and the scientific writing workshops), two of which were held in Uganda and one in Bangladesh with other secretariat members. I led writing of the report for the Kampala workshop.

I provided input to the development of the study protocol. In particular, I led the writing of the section defining the qualitative work that would be done, and developed and wrote the research methods component, which was incorporated in to the study protocol and the subsequent protocol publication.

I was the overall lead for all the qualitative work across the five HDSS sites. In Studies I and II, I developed the tools for the various FGDs. I then shared these with other members of the multi-site qualitative working group who provided invaluable feedback and I then finalized each tool, incorporating their input. I also developed the training guide for use during training of qualitative field staff across the five sites, adapted from the DHS interviewer manual. This was successfully adopted and used by the multi-site qualitative team. Additionally, I led training of moderators and note takers in Iganga Mayuge and physically attended all the FGDs in Iganga Mayuge.

For data analysis, I developed the a priori codebook that guided analysis in all the five sites. Kintampo, Matlab and Dabat did their own initial country level coding. However, I was in the loop even in these initial stages, including

through online discussions. I conducted data analysis for Iganga Mayuge, supported by one of their HDSS staff and conducted data analysis for Bandim, with the support of an external researcher. The qualitative research leads from the other three sites shared their work with the rest of the multi-site qualitative working group. After multiple discussions, I led the multi-country generation of themes, collating the data from the five study sites.

Furthermore, I led the writing of both multi-country papers (Study I and II in the PhD). This included writing the initial manuscripts, which other authors reviewed and made input to as indicated in each paper.

I also participated in the writing of five other papers within the EN-INDEPTH supplement series, including the study protocol. On the quantitative side, I was part of the team that led the training of field interviewers for the EN-IN DEPTH survey in Iganga Mayuge.

7.2. PhD study

Concurrently, I was also a PhD student whose work was nested in the EN-INDEPTH study, with my Study I and II being multi-country. In section 6, I highlighted part of my role in this study as a PhD student under the different methods sections, including data collection and analysis. Overall, I conceptualized this PhD study, expanding it from the initial objective it was within the EN-INDEPTH study that was focusing on under reporting, to four sub-studies that included social networks, psycho-social effects of APOs and cognitive interviews. Additionally, I briefly highlight the following:

- For Study III and IV, conducted in Iganga Mayuge HDSS only, I conceptualized the studies and developed the tools supported by my academic supervisory team. This was slightly different from study I and II where I led all components of the work but mostly worked with the EN-INDEPTH multi-country qualitative working group
- For study III and IV, I conducted training of all interviewers and edited the tools. I was present in the field, moved with the VHTs looking for respondents in communities, supervised data collection and ensured daily discussions with the interviewers. For study I and II, I attended all FGDs in Iganga Mayuge. I did not conduct interviews due to not being *lusoga* speaking but I ably followed the discussions.
- In all studies, I led the data analysis and paper writing processes, supported by other authors as indicated in section 6 and in each paper.

Conferences and workshop presentations

- Makerere University Annual Doctoral Convention - February 28th 2023: (Title - "I Wish I Had Also Died": Narratives of Psychosocial Effects of Adverse Pregnancy Outcomes and Their Influence On Reporting Pregnancy Loss During Surveys In Uganda.
- International Stillbirth Alliance 2022, Utah, Salt Lake City, September 15th-17th 2022. (Poster entitled: Barriers And Enablers To Reporting Adverse Pregnancy Outcomes In Population-Based Surveys: EN-INDEPTH Study)
- Makerere University School of Public Health PhD Colloquium – 8th September 2022 (Title: Understanding factors that influence reporting of pregnancy and adverse pregnancy outcomes in population and health surveys)
- Every Newborn-INDEPTH supplement launch 10th December 2020 (Virtual)

8. Results

8.1 Study I: Barriers and enablers to reporting pregnancy and adverse pregnancy outcomes in population-based surveys: EN-INDEPTH study

This study explored challenges and facilitators to reporting pregnancy and adverse pregnancy outcomes in five HDSS sites in Uganda, Ghana, Guinea Bissau, Ethiopia and Bangladesh (https://pophealthmetrics.biomedcentral.com/articles/10.1186/s12963-020-00228-x).

The findings are highlighted in this section, beginning with a narrative and followed by a summary table.

Barriers to reporting pregnancy and APOs
Barriers were remarkably predominantly similar across the five different countries, between East and West Africa and between Africa and Asia. Nevertheless, some examples of differences or perspectives not common to all sites are shown in the text where possible. The current study identified barriers related to survey interview tools and processes; social-cultural and spiritual factors; psychosocial impact of APOs and woman-specific challenges.

Survey interview tools and processes: Many women viewed questions about pregnancy or APOs as irrelevant. They did not understand why data collectors were interested in their pregnancy or how women would benefit from revealing such information. Similarly, information on APOs was deemed to be irrelevant and intrusive, especially since the baby would not be brought back to life. As a result, they did not see why they should tell them about their pregnancy or loss.

> …but musawo [doctor] you have asked a number of times but now look at such questions. The children died and you won't bring them back. Just ask for the ones who are still alive but the dead, miscarriages, stillbirths, how are you going to help us? It is useless and just time wasting to ask those questions (Interviewer narrating what he was told; FGD, in IgangaMayuge, Uganda)

Furthermore, across all sites, the lengthy and repetitive consent form and survey tools reportedly tired out both interviewers and respondents. The exhausted respondents were reportedly likely to give any answer, however inaccurate, so as to end the interview. Interviewers also faced general process-related challenges like inconveniently timed interviews, for instance where the respondent was busy with house or garden chores. This resulted in impatience on the respondents' part, again giving flippant answers and a shorter interview with less time to dig deeper into answers, affecting the quality of data.

> Sometimes when you go to the house, some of them will be in a hurry to go to work so they sometimes do not give us the right responses… (Interviewer, FGD in Kintampo, Ghana)

In Ghana and Uganda, making many call-backs to households in towns and urban areas where people left early for work and returned later was pointed out as a challenge. The need to keep on checking to see if respondents were available was difficult for interviewers, more so when the respondent was eventually found but not willing to be interviewed.

Social-cultural and spiritual factors: Stigma played a big role here; for instance where a woman was unmarried and feared to be judged, or already had young children, she hid the pregnancy so that community members would not discuss her and thus did not reveal it to interviewers either. This was also linked to religious beliefs like Christianity and Islam where pregnancy before marriage is frowned upon. Additionally, women who had APOs were sometimes blamed for them, often by in-laws and this was worse if they had multiple occurrences, leading to a state of shame. This limited disclosure of APOs, as did witchcraft and spiritual beliefs that were common in all sites and detrimental to reporting.

Examples included fear that evil spirits or people with ill intentions would harm the baby if one disclosed the pregnancy. APOs were also sometimes attributed to spiritual harm and talking about it was feared to cause a reoccurrence. In Bangladesh, miscarriage and stillbirth were more specifically attributed to spiritual harm. In Ghana, it was explained that discussing an APO would cause the baby to "come back and worry you," for instance as a stillbirth, meaning a potential repeat occurrence from discussing it.

> Culturally, it's not good to tell everyone about the pregnancy. When you tell one about your pregnancy age, culturally they can take your footstep soil and bewitch you and you get a miscarriage, have caesarean birth or you may die during labour process. Therefore, it is better to keep silent and they just see (Woman, FGD in Iganga Mayuge, Uganda)

The problem may arise from some individuals who may label and say she gave birth while the previous child is an infant or she didn't feed well the already born children but still she is getting another pregnancy. Or they may talk about whether you got the pregnancy from an unknown partner and this may bring another label to you, that the people may say that pregnancy (newborn) is called 'diqala' or 'wofzerash' meaning unknown source or from unknown father, which is very taboo and outlawed. Due to this and other social criticism we preferred to hide our pregnancy (Woman, FGD in Dabat Ethiopia)

Two key things that stood out in this theme were the variation in recognition of the baby's value and burial and mourning practices. Where a woman or society felt that the baby was not yet a human being, neither saw the importance in reporting its loss. Although more value appeared to be placed on a stillbirth since the woman had carried it for a longer time, respondents still mentioned these as not fully human and therefore not easily disclosed.

With regard to a miscarriage, it's not yet developed into a human and you don't see the face but the one I have given birth to and have seen the face and cared for, when he/she dies it will pain me more than the miscarriage. It could be that the miscarriage didn't even last for three or four months compared to the one I will carry for nine months, care and breastfeed. So I will value him or her more than the miscarriage (Woman, FGD in Kintampo, Ghana).

One child of mine has been miscarried. I have seen, it was like a piece of meat. So, what was [there] to love about that piece of meat? (Woman, FGD in Matlab, Bangladesh)

Deaths of babies who had lived for a few days were considered the losses that would most affect the women and were therefore viewed as babies whose existence and loss were more likely to be reported. For instance, people were more likely to report death of an older child, than that of a newborn baby who lived a few hours or days. Often, burials were done differently especially miscarriages and stillbirths, compared to adults, as a result of perceptions of how "human" they were or not. They were often secretive and quick, with little visible mourning. Such cultural secrecy towards APOs translated into silence when it came to reporting them. A few differences in who conducted the burials were seen between sites; for instance in Iganga Mayuge only women buried the APOs and in Kintampo only men did so.

The exception was Matlab, where some APOs were mourned and buried similar to adult deaths and this was the biggest difference between the HDSS sites in Africa and Asia. For instance, burials of stillbirths in Matlab did not differ so much from live born babies. More so, newborn and adult burials had the same cultural and Islamic religious rituals performed. These include use of the burial shroud, "janazah" (funeral prayer), bathing the dead body, arranging

"milad" (group prayer for the dead, usually conducted by the religious leaders), naming the baby and recitation of Quran.

Other socio-cultural factors included cultural descriptions of APOs using terms that had negative meanings, with some equating to a "useless thing" that further stigmatized the mother but also undermined the humanity of the baby or foetus and subsequent need to report it, in addition to gender barriers where some men did not want their wives to be interviewed.

Psychosocial impact of APOs: A major barrier reported in all sites was the emotional and psychological impact of APOs. Women reported not wanting to remember or share this painful experience and being asked directly about it revived sad memories. They sometimes reported hiding APOs during surveys because recollection was too painful.

> As I have told you before, acquiring information is difficult on adverse pregnancy outcomes. Talking about the dead child is uncommon in the community. It is worse when it is neonatal death or when children get older as compared to the miscarriages, abortion and stillbirth because they remember the characteristics that they have seen. Therefore, women will be even tearing when you talk about a newly lost newborn. This makes the data collection difficult in the case of neonatal deaths (Interviewer, FGD in Dabat, Ethiopia)

Woman-specific challenges: A woman's age and her intentions towards the pregnancy affected reporting in many of the sites. Data collectors noted that adolescent girls were often shy about issues to do with periods, pregnancy and sexual and reproductive health, limiting collection of accurate information. Many of them kept quiet when asked. Furthermore, some of them still lived with their parents and were scared to reveal a pregnancy or abortion due to expected repercussions. Other women, as noted in Dabat, Kintampo and Iganga Mayuge, hid their pregnancy because they intended to terminate it, particularly the married or younger women so they could not afford to be found out.

> …Also a woman will not tell you she is pregnant if she has not decided on whether to keep the pregnancy or not. So generally capturing early pregnancies is difficult (Interviewer, FGD in Kintampo, Ghana).

Enablers to improved reporting of pregnancy and APOs
This study also identified facilitators that helped to increase women's disclosure of their pregnancies and APOs. These were mostly identified from the interviewers' FGDs, where they shared their experiences about what they usually do to encourage women to open up to them. A few enablers were also identified in the FGDs with women. In this section, enablers are summarized

into three: interviewer skills and strategies; the interview process; and respondents' understanding and perceived benefits from the interview.

Interviewer skills and strategies: There were key things interviewers did to encourage women to open up. These included building rapport with them; having probing skills; interviewers' understanding of and respect for local culture; empathy and sensitivity in order to obtain information on APOs, including interviewers pretending to have had an APO themselves; patience and humility. Many of these were learned through practical experiences in the field and helped them get more accurate and complete information on such sensitive topics

> There has been a great challenge if a woman had a neonatal death, a miscarriage or still births. She doesn't want to give you the information but to me I always put myself into her picture. Sometimes I confess to God for telling a lie and I pray for forgiveness but I always say to myself that let me pretend. Then i tell her that "even me i had a miscarriage recently and i felt bad'' so she will see that what she is going through is what you are going through then she will narrate the story (Interviewer, FGD in Iganga Mayuge Uganda)

The interview process: Data collectors highlighted the value of a good and clear consenting process at the start of the interview and explained that this prepared women to sit through the interview and participate, even when it could be upsetting. Additionally, when women were assured of the confidentiality of their information and the interview was conducted in a private setting, it was easier to get them to disclose their pregnancies or APOs experienced.

> We conduct a one-on-one interview and there is privacy, so if you read out the informed consent and the person is told why you have visited her, the woman will be sure of confidentiality since the consent brings out all that message. It makes them free and gives us the information… (Interviewer, FGD in Iganga Mayuge, Uganda)

Respondents' understanding and perceived benefits from the interview: In the HDSS sites, many community members often believe that all HDSS staff and researchers are health workers. Therefore, they tend to open up to them, ask about different aspects of health and thus view interviews as a chance to learn.

They are more open in this case and easily share information while also asking questions. This was the same in the EN-INDEPTH survey. Additionally, once women knew what the study was about and understood that they and their children could benefit, they were more interested in participation.

> In my perspective the question about the abortion, stillbirth or dead infant may be very important to link the causes of death. But the way of asking such sen-

sitive questions must take a friendly approach and care must be taken not to disappoint the women who have suffered. If you approach the woman kindly, share condolence and give her time to talk about her worries you can get the right information and these women will be treated well and they will give credit to you. The problem is most data collectors are very speedy and without conscious understanding of the women's grief they started to ask directly about this sensitive issue. Consequently, we end up with the wrong information or a quarrel may be raised (Woman, FGD in Dabat, Ethiopia).

Table 4 provides a summary of barriers to reporting pregnancy and APOs.

Table 4: Barriers to reporting pregnancy and adverse pregnancy outcomes

Major theme	Sub-theme	Barriers to reporting of pregnancy	Barriers to reporting of adverse outcomes
Survey interview tools and processes			• Questions on APOs considered irrelevant, purpose and benefits not clear to women • Intrusive questions on a sensitive topic
	General	• Long and repetitive interview tools and consent forms • Inconvenient time of interviews • Physical distance challenges in locating respondents • High workload for interviewers • Multiple call-backs to a household to locate right respondent	
Socio-cultural and spiritual beliefs	Stigma	• Unplanned pregnancy, fear of judgement	• Blame of women for these APOs • Fear of judgement and stigma from the community
	Religion	• Religion discourages pregnancy before marriage	• Fatalism about APOs or seen as punishment
	Witchcraft and spiritual beliefs	• People with ill intentions will harm the baby • Evil spirits attracted by disclosure	• Miscarriage and stillbirth caused by spiritual harm, or punishment • Talking about it may cause a reoccurrence of APO
	Variation in recognition of the baby's value		• Baby not considered human • Value attached to a baby influences reaction to death
	Burial and mourning practices		• Often different for APOs, especially miscarriages and stillbirths

Major theme	Sub-theme	Barriers to reporting of pregnancy	Barriers to reporting of adverse outcomes
			• Secretive burials
	Trust/ Privacy	• Lack of trust, unsure of privacy and confidentiality of their information	
	Gender & patriarchy	• Men who do not want their wives to be interviewed • More barriers for interviewer of a particular sex	
	Descriptions/Names of APOS		• Names with negative meanings • Same names used to mean different APOs
Psycho-social impact of APOs	Negative psychological and emotional impact		APOs cause grief and sadness. Talking about them resurrects bad memories
Woman-Specific	Age	• Adolescent girls: secretive, scared and shy	
	Individual response to pregnancy	• Woman unsure of pregnancy, and considering termination	

*Where some barriers are in the same box, it means that they were common to reporting of both pregnancy and APOs

8.2 Study II: Adverse pregnancy outcome disclosure and women's social networks: a qualitative multi-country study with implications for improved reporting in surveys

This study examined how and why disclosure of adverse pregnancy outcomes (APOs) takes place within social networks in four Health and Demographic Surveillance System (HDSS) sites in Uganda, Ghana, Guinea Bissau and Bangladesh (https://pubmed.ncbi.nlm.nih.gov/35387593/). Understanding these communication processes within social networks could provide a learning platform to improve formal reporting of APOs within communities.

The study found that communication around APOs was taking place within social networks and was framed around three broad areas, which are the sender, the message and the receiver. Table 5 summarises the results, with themes and sub-themes further highlighted in the subsequent narrative, supported with verbatim quotations from participants. Findings across the four sites were mostly similar but where differences were found, these are highlighted.

Table 5: Summary of themes and sub-themes in Study II

Theme	Sub-theme
Sender	• Identity of the sender • Reasons for disclosure of the adverse pregnancy outcome
Message	• Content of the message • How the message is delivered and why
Receiver	• Identity of the receiver • Why specific people are informed about an adverse pregnancy outcome • Reaction of network members on receipt of the news about an adverse pregnancy outcome

The sender

This refers to the person who shared the information about the APO with other people in the social network. While this was usually the woman who suffered the loss, disclosure could also be done by her partner, family, in-laws or friends. Sometimes this disclosure was done by family or friends because the woman was too distraught to share about her loss. There were various reasons why senders disclosed the APO. These included the fact that it was a common

community expectation and practice to announce the APO that had occurred to key people within the social network. In other instances, people were trying to make sense of what happened, especially with repetitive APOs. For instance, a few people intentionally informed health workers about APOs because they wanted insights into the cause of the baby's death and how future adverse pregnancy outcomes could be avoided. Other times, understanding why the APO had happened was sought through cultural rituals.

> If they [APOs] happen more than once, then one might be forced to share with village or clan members in order to get a solution (FGD in IgangaMayuge, Uganda).

> Those babies that die in the stomach are brought to be buried, those that are born and then die after, other races/tribes say that they are going to find out what it was that killed the baby. Like in the Manjaco tribe, they can say we are going out to … see who killed the baby, to know if it was the guy's family or the woman's family who managed to kill him…. (FGD in Bandim, Guinea-Bissau)

Nevertheless, there were also instances where people did not reveal adverse pregnancy outcomes within their social networks. This was due to the need to avoid blame and rumours, for example with the stigma often attached to induced abortions, people feared accusations of being a murderer and thus did not share with others in the social network. Disillusionment with health care also negatively affected disclosure, with people not seeing why they should bother to report the APO to the same health facility where they had previously been ill-treated.

The message
The message describing the APO could either be delivered directly and clearly as the loss of a baby, or indirectly, often using metaphors. For instance in Balanta villages in Guinea-Bissau, as well as in the Creole language, "*Auor'' (give birth to but not to have) is one of the ways in which a baby born dead is described, while in Kintampo, "w'apon ayinsen'' or "ayinsen no aseɛ'' (the preg- nancy is finished or terminated or spoilt), describes a miscarriage and "w'awo atwene'' (the woman has given birth and thrown it away) refers to a stillbirth.*

In most instances, the message about loss was delivered verbally. However, one respondent explained that since people had seen you pregnant, they eventually found out about the APO since they could see you had returned without a baby, even if you did not speak about it. Therefore, while the news may not have been deliberately shared, it still came to be known.

Direct disclosure to non-clan or non-family members was mentioned by a few respondents in Iganga Mayuge as being done to seek advice when the APOs were repetitive. However, in Kintampo, among the cultural practices described was shaving the heads of the people who suffered APOs, as an indication of the loss. Nevertheless, it was also mentioned that this practice had almost stopped.

After an APO, the message given in response to hearing about the loss was mostly one of comfort in all study sites. People offered words of sympathy and encouragement to the bereaved woman or family. The bereaved were given advice to accept the inevitable and to look to the higher power that was the source of life, with many messages given from a religious perspective, Nevertheless, there were a minority of cases where the message was one of finger pointing, blaming the parents for causing their loss though negligence or carelessness, like not having looked after the baby well.

> … It's not in our hand. It [APOs] is imposed by fate or Allah's wish, that Allah didn't want it. If Allah wanted, it would have survived. People would say this (FGD in Matlab, Bangladesh).

> This generation, girls go for family planning and we hear that the eggs get weakened by the drugs. The fetus may turn to be a miscarriage. So, sometimes, the woman is blamed (FGD in IgangaMayuge, Uganda).

The receiver
Various people received news of the APO, including biological family, in-laws, friends and neighbours, clan members and village mates, religious leaders, clan heads and occasionally health workers, the elders in some sites and the chiefs or their representatives, specifically in Kintampo.

Reasons for telling various people about the APO varied. Firstly, physical and emotional proximity, convenience and having an existing relationship with the receiver were key. Nevertheless, it was revealed that news of APOs was sometimes only shared with close family members, especially the earlier gestation ones like miscarriages. Additionally, other recipients were informed due to their decision making roles in the community, particularly the men, elders and cultural leaders. Among the major roles this group of decision-makers played was planning how to handle the burial. Where spiritual leadership was needed, for instance for burial or prayers, religious leaders were informed. Other reasons for receiving information on an APO included existing community hierarchies, where certain leaders had to be informed about the death.

> Maybe the father of the child [can perform the burial arrangements], but in his absence the father of the woman can do that (FGD in Kintampo, Ghana).

> The religious leaders do conduct prayers [after APOs]. This depends on the religious affiliation of the family. But religious leaders do console the bereaved unlike traditional leaders who go to shrines and carry out their rituals. The religious leaders console the bereaved family saying that it is God who gives and he takes away our loved ones (FGD in Iganga Mayuge, Uganda).

Gender roles were pointed out, for instance in Matlab, women were responsible for bathing and preparing female babies for burial, while the men dealt with the male babies. In Kintampo, elderly women prepared the body for burial.

Typically, when told about the death, people responded with actions of support, including physical presence and keeping the bereaved company, providing them with financial support, helping with tasks in the home of the bereaved, planning for the burial if one was to be conducted and fulfilment of any required cultural practices. This social support helps with comfort and opening up to talk about the loss.

> We just make sure she [mother who had APOs] is never alone. We console her, chat with her and make her lively so that she will not be thinking about her loss (FGD in Kintampo, Ghana)

8.3 Study III - Psychosocial effects of adverse pregnancy outcomes and their influence on reporting pregnancy loss during surveys and surveillance: Narratives from Uganda

This paper shares findings from Iganga Mayuge HDSS, Uganda, discussing the psychosocial effects of adverse pregnancy outcomes on respondents; how people react to interviews about their loss; why the bereaved agree to be interviewed about an adverse pregnancy outcome and finally, respondents' suggestions for improving interviews on APOs. Table 6 provides a summary of the findings, followed by further explanation, supported by verbatim quotes from respondents.

Table 6: Summary of findings from Study III

Theme	Sub-theme
I cried a lot and I still cry (psychosocial effects of the APO on respondents)	• Multiple psychosocial effects after an adverse pregnancy outcome • Physical and economic effects of grief • People unsure what caused death of baby
It is hurting me afresh (people's reactions to interviews about their loss)	• Interviews remind respondents about the loss they suffered • Some respondents okay with being interviewed • Interviews can eventually make respondents feel better and encouraged
You never know, the person can give you some advice (why people agree to interviews about APOs)	• People want advice on danger signs in pregnancy and how to avoid APOs • People want sensitisation on causes of adverse pregnancy outcomes • The need to see tangible benefits from interview after sharing their information
You are supposed to give us counselling and we come back to normal (respondents' suggestions for improving interviews)	• Respondents want interviewers who are comforting and empathetic • A few wanted professional counselling • Notify households ahead of time about the study • Respondents wanted to be asked how they were treated at the health facility

Psychosocial effects of the APO on respondents

After an APO, both women and men suffer from shock, depression, guilt, shame, envy of other people with children, regret, fear of never having another child, withdrawal from society and many other mostly harmful reactions. Grieving is an endless journey that moves along a continuum, from acute grief, to integrated grief and complicated grief, with the potential to easily return to an earlier phase if triggered. Furthermore, these effects manifested regardless of the type of pregnancy loss – whether one had experienced a miscarriage, stillbirth or neonatal death. The difference was that respondents who had suffered multiple APOs appeared to face more intense and longer lasting psychosocial effects, as did those who lost their first baby or who did not have any other living children.

> It hurts me a lot. I was depressed and I even told my husband that I am leaving, going back to my parent's home. Even the things he had bought for his baby I told him that let me take them and give them away because whenever I would look at them, I would feel sadness, but he said no. I cried a lot, I started crying when the water broke and even when they were removing the thing, I was just crying but the midwife said be strong and I save your life (Woman after miscarriage)

While men also grieved, they had further challenges with having to be strong and comfort their wives, amidst anxiety over financial stress brought on by the loss. Most respondents did not know what had caused the APO, having received vague explanations or no communication from health workers, increasing their distress.

> Even up to now I am sad because sometimes, there are certain things that you buy for the child, but whenever you look at them, you feel sad. Whenever you pass near the grave and look there, you feel sad. When you look at someone with their little child, you remember yours, yes (Man after neonatal death)

How people react to interviews about their loss

This theme discusses how people respond to interviews that include questions about APOs. Most respondents shared that such interviews reminded them about their loss and they felt like they were reliving the event. Discussing the loss of the baby was difficult and disheartening. Indeed, during this study, some respondents broke down and cried, a few asked the interviewer to stop asking the questions, while some were silent and unable to talk about what happened.

> …Talking about it that Mrs so and so got a stillbirth…I would not want to hear it. I wanted that maybe if we are seated discussing they should not include that, we discuss other things (Woman after a stillbirth)

A few people said that the loss was in the past and they had recovered. However, this was linked to their intentional effort to pick themselves up and be strong, to avoid being stuck in a state of anxiety and worry.

Interestingly, many respondents shared that at the end of the interview they eventually felt better, especially where interviewers comforted, advised, strengthened and encouraged them and it was an opportunity for letting off steam. In fact, one woman described it as "mourning with her", thus rejuvenating her.

> It is like when you have a problem and confide in your friend, you feel better. It can't be compared to keeping something to yourself. The pain is too much and you feel it alone (Woman after neonatal death)

Why people agree to be interviewed about adverse pregnancy outcomes
This study found that when someone who had an APO consents to an interview, they have certain expectations from the interviewer or the wider research team, which also influences how open they shall be. In this case, most respondents indicated that they wanted sensitization or to understand the cause of pregnancy loss and what to do to prevent the reoccurrence of the APO and hoped to get this advice or other help from the interviewer or the study team. A few expected advice on how to handle the depression they were experiencing.

> I felt happy sharing with you my experience and confiding in you because you can advise me (Woman after stillbirth)

> After telling you, what advice do you give me so that I don't get depressed? So I ask you to advise me and you tell me to do this…. It is you to teach me how to stop the depression (Man after neonatal death)

Beyond this, most of the study participants wanted to see visible and tangible benefits accrue from the study. For instance, they wondered whether reporting APOs was going to result in medicines being brought to the health centers, a better attitude among health workers and improved service delivery in health facilities for mothers and babies or treating the diseases in the body that cause pregnancy loss. This was partly because some linked their loss to poor quality of care they had encountered in the health facilities.

> I had expected that he would give me advice on what to do but he just recorded his things and left. I felt bad (Woman after miscarriage)

Respondents' suggestions for improving interviews on APOs

In this study, respondents were asked to suggest ways in which interviews about APOs can be improved, so as to lessen the pain they cause to bereaved respondents. They made suggestions around the process, by pointing out their preference for interviewers who comforted, encouraged and strengthened them and were polite and calm. A few recommendations were made for interviewers to bring condolences with them, taking a leaf from the practice of Iganga Mayuge HDSS site. A minority asked for professional counselling. At a more general level, a few respondents pointed out how the community entry and household strategies could be improved while one appreciated the use of the narrative approach for interviewing.

> It needs counseling and sensitizing that since she faced that loss, it's better she always visits health professionals in case of any danger signs and you give her such advice so that by the time she gets pregnant, she would be already informed (Man after neonatal death)

They also made content improvement proposals; for instance over half the respondents wanted to be asked about how they were treated while at the health facility, the response of the health workers and other patient care questions. Again, this is linked to their complaints against the system, where they believed it had contributed to the APO.

> Like the way you have come to ask me, it's good to first go through the local council leader of our area and that person mobilizes us and informs us that we will receive visitors. It's good to inform someone in advance that I am going to visit you and this is the purpose for my visit. But there is someone just coming abruptly to someone's home… (Woman after neonatal death)

8.4 Study IV - Exploring women's interpretations of survey questions on pregnancy and pregnancy outcomes: Cognitive interviews in Iganga Mayuge, Uganda

This paper describes findings of cognitive interviews, conducted on an adapted version of the reproduction section of the women's questionnaire of the DHS. Specific focus was placed on the comprehension aspect of cognition, which includes the intent of the question and the meaning of particular terms.

Intent of the question: What the participants believe the question is asking

The study analyzed participants' interpretations of questions to do with births and living children, miscarriages, abortions, newborn deaths and stillbirths, as well as highlighting structural challenges of some questions.

Births and living children: Most participants struggled with questions which asked whether the woman has any sons and daughters she gave birth to who are now living with her or who are alive but do not live with her. For instance, some of the women thought they were being asked how many living children they had; the sex of the children; how many children, including non-biological, her husband's children or grandchildren were living with her and whether she had given away her children to somebody else.

> You are asking me if the children are still alive, if they are still normal and if not sick, like that (Participant's interpretation of 202)

Adverse pregnancy outcomes (miscarriages, newborn deaths and stillbirths): Question 206 asked about newborn deaths in the following way: "Have you ever given birth to a boy or girl who was born alive but later died? IF NO, PROBE: Any baby who cried, who made any movement, sound, or effort to breathe, or who showed any other signs of life even if for a very short time?" While half the participants understood it, the other half misinterpreted it either partially or fully. For example, some thought it was about any child who had died, regardless of age and whether they had first breathed or made a sound at birth.

> Have you ever given birth to a boy or girl who is either alive or dead? (Participant's interpretation of 206)

Question 210 asked: "Women sometimes have a pregnancy that does not result in a live birth. For example, a pregnancy can end in a miscarriage, an abortion, or the child can be born dead. Have you ever had a pregnancy that did not end in a live birth?" Participants faced a challenge with this because the question was long and so some people asked for it to be repeated before they could respond.

> Have you ever lost a child during birth? (Participant's interpretation of 210)

Long questions with multiple concepts

Long questions were problematic, especially those that were double barrelled, asking two or more questions within the same sentence but expecting one answer from the respondent. Indeed some questions had more than two parts. For instance question 204: *Do you have any sons or daughters (statement 1)*

to whom you have given birth (statement 2) who are alive but do not live with you (statement 3)? Some of the responses to this were answering only one part of the question, or the respondent asked the interviewer to repeat the question so they could understand it better. This was frequent also for other long questions with multiple concepts like 210: *Women sometimes have a pregnancy that does not result in a live birth. For example, a pregnancy can end in a miscarriage, an abortion, or the child can be born dead. Have you ever had a pregnancy that did not end in a live birth?*

In conclusion, the questions identified as problematic to participants were 202, 204, 206, 210 and 214.

Meaning and interpretation of key terms

All participants correctly defined abortion as intentional removal of the pregnancy. About half of the participants defined miscarriage, partially correctly, as sudden and unintentional loss of the pregnancy, indicating that it came with blood flow and occasionally the fetus. However, the majority of participants did not indicate the time frame in which miscarriage occurred, except for two who said it happens around 3-4 months. Understanding the term "baby born dead" was understood by all, because nobody struggled to paraphrase or interpret it. For stillbirths though, participants expressed more difficulty, sometimes mixing up the term with newborn deaths.

Table 7 shows the various misinterpretations people had about key terms, in comparison to internationally recognized definitions.

Table 7: Vague interpretations of key terms compared to international definitions

Miscarriage (International definition)	**Miscarriage: vague or unclear definitions from study participants** (quoted verbatim)
• A spontaneous loss of pregnancy (em- bryo or fetus) before 22 completed weeks of gestation • Also referred to as spontaneous abor- tion Source: (126)	• Being sure that you are pregnant and all of a sudden blood starts flowing plus the fetus • …a disease which comes when a lady is pregnant for example due to much malaria • When someone is pregnant and fails to reach the age of birth • Loss, losing a pregnancy • Losing a pregnancy when you didn't want to • Child coming out when it's not the right time

	• A baby coming out when it has not made 9 months • Losing pregnancy either early on or later due to diseases like malaria or heavy work
Stillbirths (International definition) Baby born with no signs of life at 22 ormore completed weeks of gestation. Stillbirth can be further categorized as: • **Early gestation stillbirth:** occurs at 22 to 27 completed weeks of gestation • **Late gestation stillbirth**: occurs at 28 or more completed weeks of gestation • UN IGME uses late gestation stillbirthdefinition for international comparison. This however excludes earlier ones, thus underestimating the true burden (2)	**Stillbirths: vague or unclear definitions from study participants** • Babies who have died • Giving birth to a child who has died • "It was somehow hard to answer because I don't understand that word stillbirths"

Results summary in relation to the theoretical framework

Figure 5 summarises the results across the four studies, mapped against the socio ecological model that was the theoretical framework for this PhD.
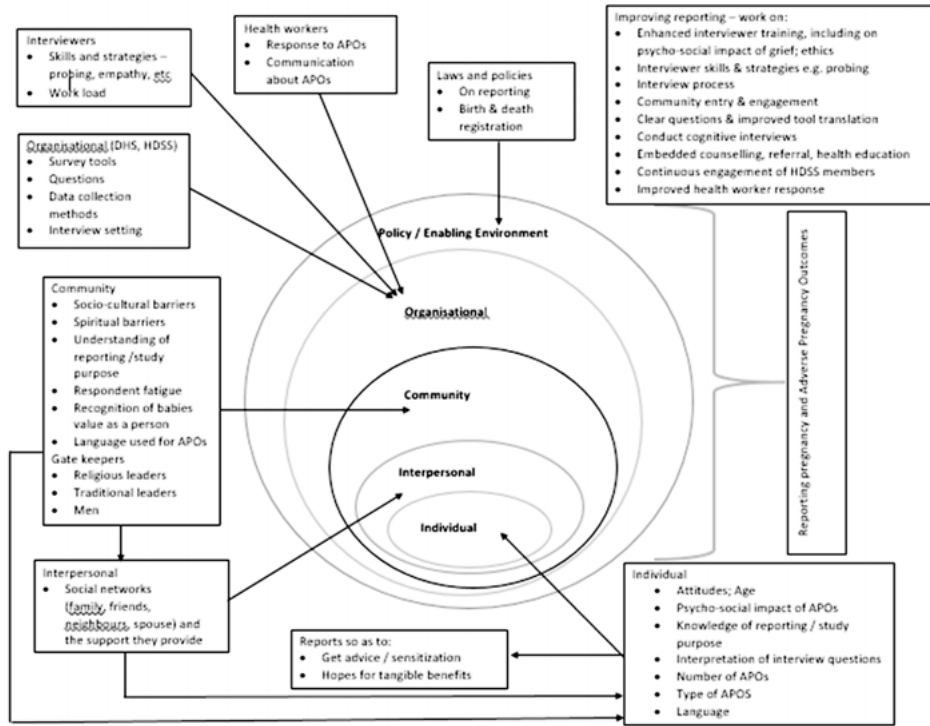
Figure 5: Summary of all study findings

Figure 5 summarises the results across the four studies, mapped against the socio ecological model that was the main theoretical framework for this PhD. The findings indeed fit into the different categories, that is individual, inter-personal, community, organisational and policy/enabling environment. Although there is no category explicitly titled methods, the organisational component represents this.

For instance in study I, the barriers to reporting were to do with survey tools, socio cultural issues, psychosocial effects and the woman-specific barriers. These fit into the socio ecological model under organizational, interpersonal and individual components. Enablers that increased reporting, including inter-viewer skills and processes, plus respondents' understanding and perceived benefits fit in the organizational and individual parts of the theory.

For study II on social networks, themes were the sender, message and receiver. These are represented in the theory under the interpersonal and individual.

Under study III on psychosocial effects, with themes showing the various effects, how people react to interviews and why they agree to them, again the link to the theory is evident with the individual and interpersonal aspects mostly.

Finally for study IV in which cognitive interviews were conducted, findings on meaning and interpretation of key terms, understanding the intent of the question, plus issues to do with the question length and structure can be linked to the individual and organizational aspects of the socio ecological model.

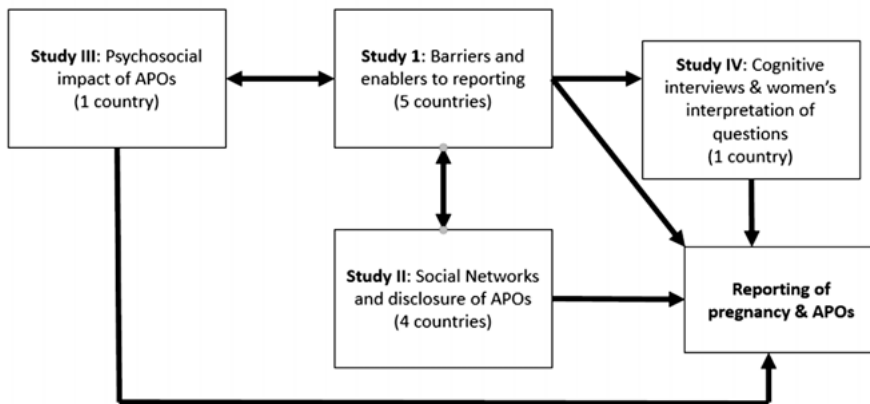Figure 6 shows the four studies, their linkages and how they build on each other.

Figure 6: Relationships between the four studies

9. Discussion

9.1 Overview of main findings

The current study identified barriers and enablers to reporting of pregnancy and adverse pregnancy outcomes in Ghana, Uganda, Guinea Bissau, Ethiopia and Bangladesh. Remarkably, there were many similarities between the five con- texts and across the two continents. These factors highlight the common ele- ments between Africa and Asia. A summary of main findings from each paper follows:

Study I: Barriers related to survey interview tools and processes were evident. For instance, many women viewed questions about pregnancy or APOs as ir- relevant or intrusive. Social-cultural and spiritual factors were common and variation in recognition of the baby's value was a barrier. Disclosure was fa- cilitated by certain enablers like the interviewers' skills and strategies in build- ing rapport, probing and being empathetic.

Study II: Communication around APOs was taking place within social net- works, framed around the sender, the message and the receiver. News was often shared by the woman who suffered the event, her partner, or their fami- lies for various reasons like community expectations and making sense of what happened. After an APO, people responded with words of comfort to the bereaved. Besides physical and emotional proximity, convenience and exist- ing relationships, recipients were informed due to their decision-making roles and existing community hierarchies.

Study III: After an APO, people suffered various psychosocial effects, in- cluding grief, depression, blame, envy and more. These manifested regardless of type of pregnancy loss or sex of the bereaved. Interviews about APOs re- minded respondents of their loss and brought back deep sorrow. However, many also shared that at the end of the interview they felt better, especially when interviewers comforted and encouraged them. Respondents often agreed to interviews because they wanted advice on recognizing danger signs so that the next time they could rush and seek appropriate care. Most also hoped that the studies in which they participated would result in tangible benefits, for instance better health services. Therefore they participated actively and an- swered what they were asked, in the hope of positive outcomes.

Study IV: This focused on participants' comprehension of questions and their interpretation of key terms. Some questions were easily and correctly understood, especially those with less technical terms or without multiple sections. Most participants struggled with questions asking whether the woman had her living biological children residing with her or not. For question 206 on giving birth to a living baby who later died, half (10/20) of the participants in the cognitive interviews thought it was about any child who died, regardless of age. There were comprehension difficulties with long ques- tions like 210 that asks about miscarriages, newborn deaths and stillbirths together. There were also varying and incorrect definitions for miscarriages and stillbirths among some of the participants in the cognitive interviews.

Overall, the study's main findings can broadly be grouped under methodological issues, community related factors and individual attributes. Table 8 summarises these, alongside their implications for reporting, followed by further discussion of each of the three components.

Table 8: Findings and their implications for measurement of pregnancy and adverse pregnancy outcomes

Factor	Evidence from the PhD study	Implications for reporting in surveys & surveillance
Methodological		
Interviewer skills	• Probing, empathy, experience, training	• Increased reporting
Question framing	Long, double barrelled or unclear questions	• Under reporting • Misclassification
Unclear key terms	Difference between local or individual understanding and biomedical definitions	• Misclassification • Under reporting
Communities and context		
Socio-cultural factors	May encourage silence about pregnancies and APOs	• Under reporting
Less value attached to fetal deaths at earlier gestation	• Less acknowledgement of babies as humans • Over estimate of gestational age	• Under reporting • Misclassification
Social networks	• Informal reporting of APOs is happening • Lessons for community engagement and entry	• Can increase survey reporting if lessons tapped into
Community definitions of adverse pregnancy outcomes	• Negative wording used • Same word applied to mean different APOs	• Under reporting • Misclassification
Individual factors		
Negative psychosocial effects of the APO	Difficult to talk about the APOs	• Under reporting
Expectations from the interview or research team	• Want health education and to learn how to avoid pregnancy loss • Desire for tangible benefits from interview	• Increased reporting

9.2. Methodological aspects as a focal point of measurement

Methodological barriers and enablers identified include skill and strategies of the interviewers; the interview tools and clarity of questions; and interview processes.

Interviewer skills were instrumental in enabling collection of quality data on pregnancy and APOs, particularly where applied positively, for instance probing and empathy (Study I). A well trained and experienced interviewer is able to gather more accurate or quality data and a lot of this experience is field-based, rather than classroom-based. In a study in Mali, where interviewers were trained to be empathetic and understanding, they were more likely to gain the respondent's trust, leading to more truthful reporting (64). Furthermore, a household survey to determine the burden of APOs in Uganda noted that higher reporting of stillbirths could be due to women's trust in interview ers (132). However, they did not explore more about the circumstances needed for women to reveal APOs. Influence of the interviewer role has been identified elsewhere, including in reporting sexual behaviour during surveys among adolescent girls in Kenya (70) and thus critical attention should be paid not just to the process of recruitment but more importantly to training of interviewers.

Interviewers can gain knowledge and skills through interactive training sessions where those with more experience describe what they usually do to collect better data, beyond discussions about the tool only. In cases where they are paired to go to the field, it could be done intentionally so that the newer ones are attached to the more experienced from whom they can learn before starting data collection on their own. Another opportunity is through pre-testing as an opportunity for experience building. However, this should be under supervision, as indeed the entire data collection process should be as part of quality assurance.

Trust is also built by the interviewers in various ways, including how they start the interview. Since in the settings like Uganda and other similar countries fluency in the local language is required, interviewers may be from that geographical area but should not interview people whom they know, as part of guaranteeing confidentiality and trust building.

Cognitive interviews (Study IV) revealed that framing of questions sometimes presented difficulties to the respondents. For example, long questions were problematic, especially those that were double barrelled, that is asking two or

more questions within the same sentence but expecting one answer from the respondent, as indicated in the results section for questions 204 and 210. For instance, 210 is stated as: Women sometimes have a pregnancy that does not result in a live birth. For example, a pregnancy can end in a miscarriage, an abortion, or the child can be born dead. Have you ever had a pregnancy that did not end in a live birth? The instruction in the DHS VIII interviewer's manual is to ensure that the full question is read out to the respondent. The subsequent question (211) requires the interviewer to record the number of losses mentioned in 210 together, without differentiation of kind of loss. Therefore while the woman being interviewed may have responded to 210 by mentioning that she had experienced one abortion and one stillbirth, it won't be recorded that way. Rather, in 211 it will be noted as 2 pregnancy losses, without differentiating that these were of 2 different types. This results in unclear numbers for each loss. A study in India on nutrition coverage survey questions noted the challenges with long questions that had multiple concepts, with respondents missing the intention of the question (133).

Among the characteristics of a well-designed survey is questions that bring out reliable and valid responses from study participants and inconsistency of questions introduces error (134). Graesser and others highlight that question misinterpretation by a respondent means an inaccurate answer, so reducing measurement errors requires question modifications to ensure they can be correctly interpreted. They further cite Graesser et al (1996) who identified 12 frequent difficulties with questions, which are i) unfamiliar technical terms, ii) vague predicate terms, iii) ambiguous nouns, iv) complex syntax, v) those that burden the memory, vi) false or inaccurate presuppositions, vii) vague question category, viii) question that falls in more than one category, ix) unclear question purpose, x) answer options differ from what question is asking, xi) questions for which answers are difficult to recall, xii) questions for which respondents would probably not know the answer (134).

Studies have been done elsewhere to assist with formulating questions for use in surveys, acknowledging incompleteness of DHS data (135). Although not referred to as cognitive interviews, a study on women's recall of neonatal care in Malawi and Bangladesh, under Saving Newborn Lives programme conducted interviews to assess survey questions and concepts and women's understanding of them. The study findings were partially to inform development of questions in surveys on newborn care in low income settings and recommendations were made around language and instances where there was ambiguity (135). In the context of this PhD's study findings, careful attention must always be paid to question development in surveys (not only DHS) and cognitive interviews applied, more especially where the questions have not been asked before in the study area or are new to a particular population, even if the tool has been successfully applied elsewhere. It should not be assumed that

because people elsewhere interpreted the questions well, it will be the same to another setting.

The cognitive interviews (Study IV) showed instances where women misinterpreted the questions, with many confused about what a miscarriage, stillbirth or neonatal death was exactly. However, most of them still provided answers. This means that there is a risk of misclassification, with respondents likely describing another event rather than the one asked about. This potential misclassification has also been acknowledged in other studies (136).

9.3. Understanding communities and contextual factors

This thesis has pointed out community related factors that may be detrimental to or enhance reporting during surveys. The main ones discussed in this section include the socio-cultural and spiritual beliefs (Study I), social networks and community entry (Study II) and definitions of key terms (Study I and IV).

Socio-cultural influences around adverse pregnancy outcomes were extraordinarily similar across the five different settings. This was especially so for stigma, witchcraft, religion and spiritual beliefs. Studies in South Africa, Ethiopia, Gambia, Uganda and Cameroon identified similar barriers to reporting APOs, as well as grief and patriarchy (73,108,137). Consistently across all sites in our study, cultural factors played a role in encouraging silence around pregnancy and APOs. Indeed, pregnancy in Africa has been noted as a private event that is initially not revealed to the whole community (32). Women are often silent about it except to a few close people and may be unlikely to disclose early pregnancies to interviewers (72). In all sites, religion (predominantly Christianity and Islam) contributed to people hiding their pregnancies and any induced abortions. On the other hand, these religions played a positive role as a tool of offering comfort by social networks after an APO occurred. In Matlab HDSS, religion ensured that most stillbirths and newborn deaths received a close to normal burial, thus demystifying the APOs and surrounding stigma. Therefore, incorporating religious leaders as partners and agents of change could be considered, especially in sensitization about reporting, stigma reduction interventions but also for broader reproductive health issues.

Consistent with literature, Study I found fear of judgement and stigma after an APO (79,83). In a scoping review on stillbirth stigma, though most articles were from high income countries, Pollock and others identified public and self-stigma, challenges to the bereaved parents' identity and ability to make memories, especially with lack of a birth certificate, as well as a culture of silence where people avoid talking about the baby (138). In Nigeria, a social network analysis revealed self-stigma in the bereaved woman and a sense of

shame, likened at one point to being incarcerated (139). In rural Vietnam, fear of stigma was a barrier to the quality and accuracy of reporting deaths (137). On the contrary, in Afghanistan it was revealed that stillbirths were openly discussed in communities without shame and rarely stigmatised unless they had congenital abnormalities; rather, it was said that talking about a still-birth could prevent it happening again (136). The authors emphasised that this openness to disclosing and discussing stillbirths in communities meant they were less likely to be hidden, thus a reduction in under reporting in surveys.

An important and novel finding is that of a seeming gestational gradient, with more barriers to reporting APOs occurring at earlier gestations (Study I). Therefore, miscarriage is less likely to be reported than other APOs. Stillbirths are also often less likely to be reported than neonatal deaths and neonatal deaths less reported than older child deaths. This gestational gradient is partly related to the lower societal recognition in terms of mourning or recognition of loss and also the associated stigma, especially with earlier gestation losses. It is partially exhibited through the various burial and mourning practices and the perceptions of value of the different APOs. Given these findings of more stigma associated with losing a baby at a younger gestation, it is possible that whilst women might not report these events at all, when they are reported they may overestimate gestational age. Therefore during surveys, increased probing and fact checking may be needed for interviewers to ascertain the occurrence of APOs that happen earlier and ensure that if reported, the event is not misclassified.

Nevertheless, Study II showed that reporting of APOs is sometimes being done informally within social networks and it discussed the why, whom and how of this and acknowledged their importance because people exist within social networks that influence their behaviour and beliefs. This indicates that survey reporting could tap into some of the lessons that are encouraging disclosure in informal settings. For instance some people shared about loss because they wanted to know the causes and how to prevent it, in addition to receiving comfort and support from other community members (Study I and II). This is again similar to the study in Afghanistan, where people discussed causes and prevention of stillbirths with each other (136). In a study done in Nigeria on social networks of women bereaved by stillbirths, six categories of relationships were identified, many of which are reported in study II: family, neighbors, friends, aquaintances, colleagues and health workers (139). More interestingly, about half of networks identified were family networks and least represented were health workers.

Since disclosure is done in a number of cases, how can the causes and effects of APOs, together with why they should be formally reported, be communicated via social networks? Study II discussed how the diffusion of innovation

theory (117) can guide how people adopt innovations and strategies, i.e. the diffusion in a community. By looking at formal reporting of APOs as an innovation, the diffusion of innovation theory would help in community entry and engagement for example before the start of a survey, to sensitise people about the survey purpose and benefits of truthful reporting. It is also important to know the community gate keepers and work with them as an entry point for survey implementation to be easier.

On further reflection, during this PhD study various community entry strategies were used, especially for Study I and II. For instance, the HDSS teams sensitised the populations about the EN-INDEPTH study using media like telephone messages before the interviews were done. The approach of sending telephone messages about the study had shortcomings however because during the FGDs in Iganga Mayuge, some respondents indicated not receiving the message. For Studies III and IV, working with VHTs was extremely beneficial and increased people's willingness to participate in the study. Investment in sensitisation using other means was not possible due to the limited study budget but the two studies could have benefited more from that prior awareness. It was also helpful that at the time of data collection for Study III, the Iganga Mayuge HDSS team was in the field conducting a data collection round, and in that setting receiving interviewers linked to the HDSS is routine. On the other hand there was an element of surveillance fatigue in all the five HDSS study sites.

Community definitions of APOs, the negative connotations they carry and the confusion around what exactly is being referred to as shown in this study are a cause for concern with regard to reporting (Study I and IV). There were instances of mixing up miscarriages with stillbirths and neonatal deaths with stillbirths. The negative connotations of some of these deaths in the local language were detrimental to reporting as well, in addition to the same term being used to mean different APOs (Study I). In Tanzania, reproductive narratives with women who had an APO and interviews with other females in the community showed that local language definitions of different APOs overlapped in meaning and were hard to differentiate; thus, women often reported having one kind of APO while describing another (18). This could potentially result in misclassification of the event during reporting, with for instance a miscarriage reported as a stillbirth or vice versa, leading to underreporting of certain events. Where a survey involving questions on APOs is going to be done, it is important to understand local, context-specific terminologies used for key terms like stillbirths that may differ from the biomedical meanings and also do appropriate translations. Christou et al recommended collection of data on gestational age in months or weeks as part of such surveys (136), to help clarify the event referred to.

Study I highlighted gender issues in instances where the permission of men was required for women to take part in interviews and sometimes they were forbidden to do so, while in other cases men wanted to sit and listen to the interview, although others accepted without any conflict. Implications of not revealing pregnancy early, besides under reporting, could be low attendance of first antenatal care in the first trimester, which has been noted in Uganda, with as few as 29% of pregnant women going for antenatal care in the first trimester (140). This could increase the problems associated with late care seeking if the pregnancy is shrouded in secrecy.

With the focus on improving reporting of pregnancy and APOs and positive birth outcomes, it is important that although in the DHS it is women that report APOs, they may not necessarily always be the decision makers in their households. Gender power relations in communities need to be understood (141) and these should be context-specific. Integration of a gender lens in any intervention to improve reporting of pregnancy and APOs, including in surveys is important because collection of accurate data will have long term effects on planning for improved pregnancy outcomes.

9.4. Individual respondent attributes as influencers of measurement

In line with the socio-ecological theoretical framework, individual factors like education level, age, having experienced an APO and familiarity with the language of the interview may influence under reporting or influence measurement in other ways.

Studies I and III indicate how the negative psychosocial effects of the APO can lead to under reporting in surveys, for example when the respondent avoids the topic, lies that they have not experienced an APO, remains silent or breaks into tears and the interview ends. The interview may also be longer and more difficult for both the respondent and interviewer. Although psychosocial impacts of APOs have been studied, more of these are from high income settings (94,103,106,142), with much less published in low income settings (59,75,90). However, this study found similar outcomes to both those of the aforementioned, where APOs have been reported to cause extreme grief, crying, men wanting to appear strong, anxiety about the next pregnancy, envy, anger, a feeling of shame and guilt and others (89,143). More so, this thesis included men, unlike many other studies that tend to focus more on women (138), although more studies are gradually including men. We showed that men also grieve and deeply at that, including crying, depression, anxiety and experiencing physical illness. There are some variations though, with men

more prone to grief suppression so as to support the mother of the baby, as has been noted elsewhere (142,144). Additionally, men were often anxious about the financial aspect of the APO.

What is much less known and published is the link between APOs and reporting during surveys and surveillance settings. In Study I, it was revealed that psychosocial impacts increase under reporting because women do not want to relive the bad memories (145). That study involved focus group discussions with women (whether they had experienced APOs or not) and survey interviewers. This PhD specifically conducted narratives with both women and men who had APOs, seeking more in-depth information. This thesis further explored their reactions to being interviewed after an APO and indeed found that interviews resurrected memories of its occurrence, with some respondents crying and terminating that part of the interview. While conducting research on sensitive topics like pregnancy loss, it is important to understand that the respondent is grieving and this grief does not necessarily end, regardless of how far back the event happened.

Verbal and Social Autopsy (VASA) has also been associated with emotional distress on the side of both respondents and interviewers (146,147). VASA is a method employed to determine the cause of death by asking family members about the events preceding the death (148,149).

Understanding of key terms and questions and their influence on accuracy of responses was highlighted in the cognitive interviews in study IV. This understanding may be influenced by socio demographics like education and one's depth of understanding of the interview language. A rapid evaluation to assess respondents interpretation of questions in an HIV indicator survey in Tanzania reported that questions could be misunderstood for different reasons including unfamiliarity with terms or concepts particularly in English, as well as ambiguities and translation challenges (150). Study IV also described cases where women misinterpreted the questions asked but still provided answers, which also revealed confusion as to what a miscarriage, stillbirth or neonatal death means.

The current study details the fact that when people who have suffered APOs agree to participate in an interview on such a distressing topic, they also have their expectations that they hope to be fulfilled (Study III). These include their expectation of advice on recognition of danger signs, guidance on what went wrong and how to avoid another pregnancy loss, amidst hope that the interviews will result in improved service delivery at health facilities. Events surrounding pregnancy loss are complex (149) and interviewers should know how to handle bereaved respondents.

For instance elsewhere, contextually appropriate interviewer training in bereavement counselling has been recommended for verbal autopsy, to ensure interviewers can handle the distress likely to occur (151). In relation to people's expectations from interviews on pregnancy loss, it may be helpful if interviews on APOs were conducted with a component of health education, where respondents are concurrently provided with information on what causes the various kinds of pregnancy loss and how these could potentially be avoided in the future. Some respondents may need counselling services as well. It is important to provide some benefits to respondents, not just burdens (147). In Australia, interviewers in a study with people who lost children undertook a course on bereavement counselling, in addition to the researchers referring some respondents to a social worker where necessary (152). In fuure, it may also be beneficial to make a direct comparison between those who reported the occurrence of APOs and those who did not.

9.5. Future research

The following research areas are important for further understanding of improving reporting on pregnancy and APOs in low-income settings like the PhD study sites.

- Developing and testing the feasibility and effectiveness of an improved training module for survey interviewers, with prospective assessment. It would be important to study the related costs and effects on data collection
- Further research on how to improve tools for surveys on pregnancy and APOs, to ensure more accurate and consistent reporting in different cultures and languages.
- Embedding summary or brief health education and counselling into surveys on adverse pregnancy outcomes: Research on this may be helpful, alongside determining the feasibility, acceptability, cost and time implications.
- Enhanced training of health workers on providing bereavement care and its subsequent effects on psychosocial wellbeing of women and men after APOs and their attitudes to reporting in a research or other setting.
- Co-designing services with women and families/communities to assess improvements of these on psychosocial impact and reduction of stigma and the subsequent impact on reporting.

9.7. Contribution of this research study to the body of knowledge

This study was conducted in a multi-country setting, encompassing east and west Africa and southern Asia. It is therefore among the first multi-county LMIC focused studies conducting primary research on under reporting of pregnancy and APOs during surveys and surveillance settings. More uniquely, it makes a novel contribution with regard to linking these to under reporting of pregnancy and APOs.

It thus builds up the body of literature, providing further cross-cultural perspectives and experiences from five low-income countries. It shows that the barriers and enablers to reporting pregnancy and APOs are generally similar across the countries, enhancing transferability, although context-specific improvements may be needed.

It also provides perspectives of field interviewers, who have previously not been interviewed much with regard to reporting of pregnancy and APOs. For Uganda in particular, little is published about the psychosocial impact of APOs and bereavement care and this study went in depth to understand this, including narratives with men. Furthermore, the study shares new perspectives on why people agree to distressing interviews and the fact that a well conducted interview can be beneficial. These insights are valuable to work around improving measurement, including attainment of ENAP and SDG targets and to researchers working in the broader field of maternal and newborn health.

This PhD study provides holistic insights to improving survey processes, including data collection, interviewer training, question structure, the interview process, as well as understanding the individual and community.

A qualitative approach was used to complement quantitative results, providing explanations that back up survey and other quantitative findings on the subject area. More so, the study ably utilised theory, that is, the socio-ecological model, demonstrating its applicability from study conception to data collection, examining various levels of the model and highlighting the interactions among them. In this way, the study makes a contribution to theoretical literature.

This study shows that miscarriages, abortions, still births and neonatal deaths, which may not be considered important at times are actually so, not only to national and international planning, government and research communities but also to the individual who directly experiences the loss and their family. By improving understanding of this topic, the study will help policy makers and add to data relevant to working towards the achievement of SDGS.

The study also demonstrates the use of cognitive interviews in the maternal and child health field in an LMIC setting, which is a different approach to querying participants' interpretations of survey questions.

Finally, the study calls attention to the very important potentially therapeutic role of the interviewers in helping women and men who experience pregnancy or neonatal loss to begin to cope with their losses and to connect them to urgently needed resources.

10. Methodological considerations

10.1. Strengths of the study

This study had a large, multi-country collection of comprehensive qualitative data from both Africa and Asia, with major efforts made for similar data collection and analyses to allow comparisons between sites and also between differing APOs. The same methods and tools were used across the different sites, both of which encouraged comparability of results.

This study was nested within the EN-INDEPTH survey, a quantitative randomized comparison of two household survey modules for measuring stillbirths and neonatal deaths, conducted within the same five HDSS sites as this study. The survey focused on various aspects of improving measurement from the quantitative aspect and this PhD study provided complementary and additional data.

The inclusion of adolescents, women who had suffered APOs and men whose spouses or partners had an APO in low-income settings allowed for a more diverse picture than previous studies. This study as well held FGDs with data collectors or interviewers, whose input is often excluded and yet they are central to the interview process. These were a rich source of information regarding methodological aspects of survey completion, but also in terms of their interaction with respondents, their understanding of local cultures and different field experiences and enablers that are often undocumented. Overall, the FGDs gave insights into the community level practices, which can be a resource during health planning.

10.2. Limitations

Although the first two studies were done in five and four HDSS sites respectively, study III and IV were only conducted in Iganga Mayuge HDSS. Therefore, it cannot be assumed that the findings of the cognitive interviews are applicable in the other four sites. However, it was necessary to have this indepth approach for a more complete picture on barriers and enablers to reporting and findings from the narratives and cognitive interviews complement the multi-country results. More so, the findings from the indepth studies still fit in

with the overall PhD focus on reporting, and some overlap with the multi-country findigs, giving more diverse but balanced conclusions.

Overall, this was a qualitative study whose findings are not expected to be generalized to wider populations. Nevertheless, doing it in five countries and finding multiple similarities points to the fact that in similar settings, the reasons for reporting pregnancy and APOs may be comparable, thus it still provided a good learning platform. Additionally, the EN-INDEPTH survey was focused on the quantitative aspects of improving reporting, with this PhD focused on understanding the "why" and "how".

For the cognitive interviews, only one round of questions was held with participants unlike some other studies that do repeat rounds, improving the tool with the respondents' feedback until there is a level of satisfaction with it. I believe that this did not affect the conclusions drawn in this study. However, it would have been good to conduct cognitive interviews in the local language and possibly in other countries.

Study II was not designed with the intention of doing a full social network study. This is a limitation duly noted, that could possibly have provided stronger information on social networks.

Additionally, relevant literature from the study countries across the various topics discussed especially in the literature review section was not always available. Therefore, where possible literature from other low and middle income settings was used, alongside relevant literature from high income settings.

10.3. Using a qualitative research approach

Overall, the study's epistemology took an interpretative approach, focused on understanding the meaning of phenomena. This study used qualitative methodology, which was appropriate to the overall study goal on understanding barriers and enablers to reporting of pregnancy and APOs. The intention was to understand the phenomena therein and why and how they occur, unlike a quantitative approach that would have focused on measurement and quantification (121).

The thematic approach as defined by Braun and Clarke (129,153) was chosen for three of the studies over other qualitative data analysis methods like content analysis, grounded theory or discourse analysis. This was because it was deemed more appropriate with regard to the researcher identifying themes using a mostly unstructured and deeply interpretative process. More so, the study employed an existing theory and did not aim to generate a new one. Although

for Study I an a priori codebook was developed, this was mostly to provide guidance to a big research team. However, each country was able to identify themes from their data. More so, it was useful to apply for the fairly large sample that was aimed at heterogeneity, multiple data collection methods and understanding individual experiences within broader contexts (129).

10.3.1. Trustworthiness of study findings

Similar to quantitative research where reliability and validity of findings must be demonstrated, methodological rigour is required in qualitative research and the researchers must show what they did to achieve this (154–156). It is often described as trustworthiness, demonstrated through the concepts of credibil- ity, transferability, dependability and confirmability, further explained in table 9.

Table 9: Definition of trustworthiness criteria in qualitative research

Criteria	Definition	Some approaches to demonstra- tion
Credibility	How well the researchers represent the respondents views Linoln and Guba as cited by Nowell et al (156) Whether the respondents find the results believable (154)	• Triangulation of data collection • Researcher triangulation • Peer debriefing • Member checking • Referential adequacy
Transferabil- ity	How generalizable the in- quiry is but on a case-to- case basis (155)	• Purposive sampling • Thick description (ade- quate contextual infor- mation)
Dependability	The process of research is documented, traceable and rational (155)	• Reflexivity • Audit trail
Confirmabil- ity	Findings are from the data and not just imagined by the researcher (155)	• Triangulation • Reflexivity • Confirmability audit

This PhD study ensured trustworthiness of findings in the following ways:

Credibility

As part of credibility, triangulation of data collection was done. Triangulation in qualitative research has been recommended as one of the ways in which study rigour is improved. It explores complementarity, convergence and dis-

sonance and can assist researchers to study their topic of interest from various dimensions (157).

Farmer et al (157) further describe the different types of triangulation. These include methodological (using two or more research methods), data (collecting data from multiple sources), investigator (two or more people analyse the data) and theoretical (use of multiple theories). The current study employed methodological, data, investigator and theoretical triangulation. For methodological triangulation, multiple research methods applied were focus group discussions, narratives and cognitive interviews. A variety of respondents provided data, that is, women interviewed in the EN-INDEPTH survey, interviewers who collected data in the same survey, women and men specifically selected because they experienced APOs and women participants for cognitive interviews, thus data triangulation. Investigator triangulation was adhered to through having more than one member of the research team involved in analysis for each of the studies. More so, for the multi-country studies (I and II), the analysis team included analysts from each country.

This helped to identify the areas of convergence across the different studies. For instance, the role of stigma around adverse pregnancy outcomes was a finding in both Study I and III, while broader socio-cultural issues were evident in Studies I-III. Individual level attributes and their influence on under reporting, for instance understanding of questions and language were visible in Studies I and IV, as was the clarity and relevance of questions.

Farmer et al developed a triangulation protocol outlining six steps that they recommend for adoption in qualitative studies: i) sorting, ii) convergence coding, iii) convergence assessment, iv) completeness assessment, v) researcher comparison and vi) feedback (154). However, this PhD study did not apply these steps systematically as suggested in this framework, which may perhaps be noted as one of the study limitations.

Transferability
Detailed or thick descriptions of how the studies were conducted have been provided in this thesis, so that if other people seek to apply the findings to their contexts they can make an informed judgement. While qualitative studies are not set up to generalize findings to larger populations, this study demonstrated applicability of results to other contexts to some extent, by virtue of the fact that many of the results were similar in different countries, cultures and contexts.

Dependability
Methods used in the study are well documented, as are records of transcripts. The indication of rationality is partly the fact that the methods used were rep-

licated across different countries and applied with limited hindrances faced by the country teams. A reflexivity section is also included in this thesis, highlighting the researcher's analysis of self.

Confirmability
Study findings are derived from the data and indeed if a confirmability audit were to be done, the results could be verified. One of the steps taken to ensure confirmability is data collection and researcher triangulation. Reflexivity is also highlighted in the subsequent section.

10.3.2. Reflexivity

As the author of this PhD thesis and lead author of the four studies, I need to reflect on my role in generation and analysis of the data because there are different attributes of mine that unavoidably influence the study findings and write up. My professional background is two-fold, as a social worker and trained health services researcher, working in the public health field. By the time of submitting this thesis, I had worked in the field of maternal and newborn health research for 12 years, mostly in the qualitative research space, in both rural and urban parts of Uganda.

I am therefore aware of the local socio-cultural and other contexts of pregnancy and pregnancy loss and knowledgeable about sexual and reproductive health broadly and more specifically the maternal and newborn health field. Both the knowledge and expertise helped me to shape the study better, refining it from being an objective in the EN-INDEPTH study to a complete PhD study, with assistance from other EN-INDEPTH team members and my PhD supervisors. The development of tools, conducting various analyses and writing the book have all been influenced by my rooting in qualitative work and in the social sciences. However, I can say that I did not know the depth of some of the issues, especially from the perspective of women residing in rural areas.

Additionally, while I have experience with development of study tools, I have not myself been an interviewer in a DHS survey or HDSS surveillance process. I thus learned a lot from the interviewers in the FGDs (across all countries), who shared practical field experiences that helped to improve this study and the analysis process, especially the recommendations around methodological aspects. I supplemented this with knowledge and experience from taking part in training the quantitative data collectors in Iganga Mayuge for the EN-INDEPTH survey, which used the DHS tool (VII). The lessons from the data collectors, plus the learnings from Study I and II were instrumental in refining development of Study IV that used cognitive interviews. Therefore gradually,

building up from Study I to IV, I have increased my knowledge and familiarity with various content and skills needed for the study.

As a female, when we were conducting data collection in the field for the first two studies, respondents appeared comfortable with my presence in the FGDs in Iganga Mayuge HDSS. In cases where we went into the rural communities, I was conscious of the need to fit in, knowing the local contexts and thus endeavoured to dress up and behave appropriately. Although I was not present in data collection in the sites outside Uganda, the qualitative teams, including the moderators and note takers were all residents of those countries, with cultural and contextual understanding.

However, for study III on psycho-social effects of pregnancy loss, I only attended a few of the narratives, mostly to ensure that the research assistants were able to direct the interview well since most of them were used to in-depth and key informant interviews. Although I was in the field, I intentionally did not attend most of the narratives because I was very visibly pregnant. From a perspective of empathy and knowledge of the effects of pregnancy loss, I did not think it fair to be in front of someone being interviewed about pregnancy loss and likely still suffering the effects. I further acknowledge that my previous experiences with my own pregnancies, as well as witnessing cases of pregnancy loss from close family in a low income setting influenced the lens with which I approached this research.

For other aspects of data collection, in all the study sites, the interview teams were led by researchers with either Master's or PhD degrees, who jointly formed a collaborative, consistent, multi-country qualitative working group. The FGDs were organised by the HDSS teams, which are known within the local communities.

11. Conclusion and Recommendations

11.1. Conclusion

Many stillbirths and newborn deaths can actually be prevented. Nonetheless, they must be accurately counted in order to know the scale of the problem and to design appropriate interventions and services. Surveys like the DHS and surveillance studies are a globally trusted source of data for planning, programming and research. They are critical for statistics on mortality and morbidity, in this case related to pregnancy and adverse pregnancy outcomes. However, the current study demonstrates that surveys and surveillance systems have weaknesses and gaps, resulting in inaccurate data.

Deliberate interventions to improve survey and surveillance data collection processes and outcomes are required. Otherwise, planning for interventions around pregnancy and adverse pregnancy outcomes shall continue to be based on unreliable data, undermining visibility and prioritization of these events, particularly stillbirths and newborn deaths. Consequently, adverse pregnancy outcomes shall remain a burden to the mental health of those who experience them.

11.2. Recommendations

These recommendations are not only for the DHS but also for any other study using a survey approach to collect data on pregnancies and adverse pregnancy outcomes or to gather similarly sensitive information from vulnerable populations, for instance studies on sexual and gender based violence. Recommendations are also relevant to the health and demographic surveillance system sites plus policy makers. Table 10 provides a summary, followed by a narrative that further outlines the recommendations.

Table 10: Summary of study recommendations

Recommendation	Details

Improved survey design and implementation	• Conduct cognitive interviews to improve tools especially in new populations where they haven't been used or with new questions
	• Accurate translations, especially of key terms
	• Precise, simple and non-technical questions
	• Strengthened, interactive interviewer training
	    ○ Training in soft skills and ethics
	    ○ Training in dealing with grieving respondents

Improving psychosocial wellbeing & knowledge of people who experience APOs	• Interviews with embedded counselling • Interviews with a brief component of health education • Undertake research on costs & feasibility of these approaches
Refining the interview process	• Clear consent at the start to avoid unrealistic expectations • Key technical terms should first be described by the interviewer
Community engagement and stigma reduction around APOs	• Sensitize people on benefits of reporting pregnancy and APOs • Reduce stigma & shame around APOs • Continuous engagement of the HDSS communities on benefits of studies

Recommendations are further elucidated in this section. I have divided them into four broad categories.

A. Improved survey design & implementation

While surveys are under conceptualization and implementation, the following should be paid attention to in relation to the overall approach to be used:

1. **Testing tools using cognitive interviews**: Although many researchers briefly conduct pre-testing of study tools, the importance of using the cognitive interview approach should be emphasized. Through cognitive interviews, researchers take more time to ensure that the questions are clear and easily understood by potential respondents. Interviewers can also play a role if for instance they are engaged in a discussion on how well the respondents understand the tool after the cognitive interviews. However, this recommendation is to other studies on pregnancy and pregnancy loss, especially if using new tools, introducing new questions or modules, or adapting those used in other contexts. It may not apply in the regular DHS where it may not be feasible to conduct cognitive interviews in all countries.

2. As this study has emphasised, tools are central to eliciting accurate and quality responses. **Translation of tools using accurate and culturally recognized definitions of the different APOs**, particularly miscarriage and stillbirths is necessary. Where these definitions are not known in advance, researchers should work with the local population ahead of time to confirm the local terminologies. Having precise, simple and non-technical questions is critical.

3. **Strengthened, interactive interviewer training** to ensure in-depth understanding of the study and ability to explain its purpose to others.

    a. They must be able to explain for instance the different kinds of APOs and the importance of the information that respondents share. It would be good for each interviewer to have a written manual as a field guide.

    b. Training interviewers on **soft skills** needed for successful interviewing e.g. building rapport, probing and empathy, which are more commonly paid attention to in qualitative studies. These may not be usually be deeply taught and explained in the context of survey training, with a lot more focus on the tool and ensuring interviewers understand it. This can be

through **interactive and reciprocal training** that involves the experienced interviewers sharing their strategies to make respondents more comfortable and open up. It is important to discuss and tap into interviewers' practical field experience as part of the training, especially those that have been involved in household surveys before. **Ethics sessions** for interviewers on handling such interviews, for instance empathetically but without telling lies that one experienced an APO are necessary.

c. Interviewers need training in **dealing with grieving respondents**, including empathy, allowing the respondent to calm down before proceeding, amongst other approaches. Interviewer training should include a component on handling grief, for instance the reactions to expect and recognizing them.

B. *Improving psychosocial wellbeing & knowledge of people who experience APOs*

1. Conducting interviews with **counselling embedded in the study or referral for counselling**, considering the cost and time implications. This could be through interviewers sharing the relevant contact information, or study organisers embedding counselling into their research, with a trained counsellor accompanying the interviewers and providing counselling after the interview. Alternatively, grieving parties could be linked to counselling services where available.

2. Interviews on APOs in LICs could be conducted with a **brief component of health education embedded**, where respondents are concurrently provided with information on what causes the various kinds of pregnancy loss and how these could potentially be avoided by the mother in the future. This is particularly for settings with sub-optimal provision of information on causes of pregnancy loss in the health facilities, or where investigation of causes of APOs is not thoroughly done or well communicated. This could be done through distribution of simple fact sheets with infographics explaining causes of APOs, danger signs, prevention, etc.

I recommend that the counselling and health education are made compulsory for things like verbal and social autopsy around APOs. Research and Ethics Committees can recommend this. It is important that researchers should aim to provide benefits rather than simply extracting information

C. *Refining the interview process*

In spite of adequate preparation with the study design, tools and interviewer preparation, the data collection process itself must be well handled to ensure quality data, including:

1. Conducting a **detailed and comprehensive consent** at the start, so that the respondent knows what to expect from the study and what is feasible in terms of benefits they shall receive. This will avoid raising unrealistic expectations.

2. **Key technical terms** should first be described by the interviewer before (s)he goes ahead to ask questions about them, to ensure that the interviewer and respondent are speaking about the same thing.

D. *Community engagement and stigma reduction around APOs*

1. **Sensitisation of citizens on reporting pregnancy and associated mortality**: The Government and other stakeholders must continually sensitize citizens on the importance of truthfully reporting their pregnancies and pregnancy outcomes, whether positive or negative. Until people understand the link between their pregnancies and planning and delivery of social services by the Government and other partners, they may not take surveys or other research on this seriously, as well as non-survey elements like compulsory birth and death registration. Periodic mass media campaigns can be done to this end, as well as placing information in strategic places like health facilities and places of worship. Otherwise, survey tools and processes shall be improved in vain.

2. It is critical to **reduce stigma and shame** around adverse pregnancy outcomes. This can be done through sensitization, but also increased advocacy around APOs like stillbirths nationally and globally, normalising discussions around such outcomes and increasing their visibility and subsequent reporting.

3. **Continuous engagement of the HDSS communities** on the purpose and benefits of the HDSS and other studies it incorporates, to avoid respondent fatigue. Additionally, regular dissemination of findings from the studies conducted as part of surveillance should be done.

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