Towards Improved Data and Understanding of Stillbirth Determinants in Low- and Middle-Income Countries: Insights from Afghanistan

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This thesis is submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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DECLARATION

This thesis is to the the best of my knowledge and belief, original and my own, except where acknowledgement has been made to the work of others. I have not submitted this thesis, either in full or in part, for a degree to this or any other university or institution. All assistance received in preparing this thesis, and all material included from published sources has been acknowledged and referenced.

Aliki Christou 30 November 2018

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STATEMENT OF CANDIDATE'S CONTRIBUTION

The work presented in this thesis was completed while enrolled in the School of Public Health at the University of Sydney under the supervision of Associate Professor Camille Raynes-Greenow, Professor Michael Dibley and Dr Ashraful Alam. For all four manuscripts included in this thesis, the candidate developed the research question, study design and methodology, performed the data analysis, interpreted the data, prepared the first draft of the manuscript, and revised and finalised the manuscripts for submission for publication. For the work completed in Chapter One and Chapter Two, the candidate gained access to publicly available data online. For Chapters Three and Four, the candidate prepared the research protocols, data collection instruments, obtained ethical approval from relevant committees, trained field staff, and coordinated and participated in the data collection. The candidate is the primary author on all publications. The candidate wrote the introduction and conclusion, performed the literature review and compiled the thesis. The contribution of all co-authors involved in this work and for each manuscript are detailed in signed statements of contribution in Appendix I.

ETHICS APPROVAL

Ethics approval for the work presented in Chapter One and Chapter Two was not required as these studies were based on publicly available secondary data sources where ethical clearances had already been obtained. The research conducted for Chapter Three and Chapter Four was approved by the human research ethics committees of the Afghanistan National Public Health Institute in Kabul, Afghanistan and the University of Sydney in Sydney, Australia. The signed ethics approval letters from each committee can be found in Appendix II.

ABBREVIATIONS

| aRR | adjusted Risk Ratio/Relative Risk |
|----------|---|
| ARR | Annual Rate of Reduction |
| AMS | Afghanistan Mortality Survey |
| AMANHI | Alliance for Maternal and Newborn Health Improvement |
| ANC | Antenatal Care |
| ANPHI | Afghanistan National Public Health Institute |
| AUC | Area Under the Receiver Operator Curve |
| внс | Basic Health Centre |
| BPHS | Basic Package of Health Services |
| CDC | Centres for Disease Control |
| СНС | Comprehensive Health Centre |
| CHERG | Child Health Epidemiology Reference Group |
| СНЖ | Community Health Worker |
| CI | Confidence interval |
| CRVS | Civil Registration and Vital Statistics |
| CSO | Central Statistics Organisation |
| DHS | Demographic and Health Surveys |
| EPHS | Essential Package of Health Services |
| EmOC | Emergency Obstetric Care |
| END | Early neonatal/newborn death |
| ENAP | Every Newborn Action Plan |
| GA | Gestational Age |
| GBD | Global Burden of Disease |
| GBS | Group B Streptococcus |
| GNI | Gross National Income |
| HDSS | Health and Demographic Surveillance Sites |
| HIC | High-income country |
| HIV/AIDS | Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome |
| HSC | Health Sub-Centre |
| HMIS | Health Management Information System |
| ICD-10 | International Statistical Classification of Diseases and related Health Problems, 10 th Revision |
| ICD-MM | International Classification of Diseases Maternal Mortality |
| ICD-PM | International Classification of Diseases Perinatal Mortality |
| IHME | Institute for Health Metrics and Evaluation |
| INDEPTH | International Network for the Demographic Evaluation of Populations and Their Health |
| IPI | Inter-pregnancy Interval |
| LB | Live birth |
| | |

| LMIC | Low- and middle-income countries |
|---------|--|
| MDG | Millennium Development Goal |
| MHT | Mobile Health Team |
| MICS | Multiple Indicator Cluster Survey |
| MMR | Maternal mortality ratio |
| MNCH | Maternal, newborn and child health |
| MoPH | Ministry of Public Health |
| MSH | Management Sciences for Health |
| NMR | Neonatal mortality rate |
| NATO | North Atlantic Treaty Organisation |
| NGO | Non-Government Organisation |
| OR | Odds Ratio |
| РРН | Post-partum haemorrhage |
| RAMOS | Reproductive Age Mortality Study |
| RMNACH | Reproductive, maternal, newborn, adolescent and child health |
| RR | Risk ratio or relative risk |
| RHS | Reproductive Health Survey |
| SDG | Sustainable Development Goals |
| SB | Stillbirth |
| SBA | Skilled Birth Attendant |
| SBR | Stillbirth rate |
| ТВА | Traditional birth attendant |
| TFR | Total fertility rate |
| UK | United Kingdom |
| UN | United Nations |
| UNHCR | United Nations High Commissioner for Refugees |
| UNICEF | United Nations Children's Fund |
| US | United States |
| USD | United States Dollar |
| USAID | United States Agency for International Development |
| VA | Verbal Autopsy |
| WHO | World Health Organisation |
| WHO-MCS | World Health Organisation Multi-Country Survey |

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ABSTRACT

The limited availability and low-quality of national-level data to understand stillbirth determinants in low- and middle-income countries is a major barrier to stillbirth prevention efforts globally. Data for producing stillbirth estimates in these settings generally come from national household surveys due to the high proportion of women that give birth at home, and because of inadequate or absent civil and vital registration systems. There are several quality concerns with stillbirth data from household surveys, particularly around under-reporting and misclassification, which affect the reliability of estimates. What also remains underexplored in low- and middle-income countries, is to what extent social, cultural, and other factors affect the disclosure and reporting of stillbirth, as this has important implications for stillbirth data quality. Context is also critical to consider when understanding the underlying contributing factors that increase women's risk to stillbirth, as access and uptake of interventions to reduce stillbirth are dependent on a range of factors that affect decision-making around care-seeking and quality of care.

This thesis sought to explore and review the availability of country-level data on stillbirth risk factors for low- and middle-income countries to outline the limitations with this data and how it can be improved. Using a national survey from Afghanistan, a high-burden country, this thesis aimed to demonstrate how better data could be generated to understand the determinants of stillbirth in a context where there is little evidence to guide efforts for stillbirth reduction. This thesis also endeavoured to identify and understand the contextual factors that influence stillbirth data quality and explore the underlying pathways and contributing factors leading to stillbirth.

Chapter One of this thesis was a systematic assessment of stillbirth data availability from nationallyrepresentative household surveys (the Demographic and Health Surveys or DHS) completed between 2000 and 2015 in low- and middle-income countries. The aim of this assessment was to outline what data exists and the limitations and challenges with using this data to understand the determinants and causes of stillbirths, highlighting how this data can be improved. Chapter Two uses data from one of these surveys – the 2010 Afghanistan Mortality Survey - which captured more comprehensive data for stillbirths, to perform a multivariable regression analysis to describe the key risk factors for stillbirth and intrapartum stillbirth for Afghanistan. The findings from Chapter Two are used to demonstrate how more and better data for stillbirth risk factors could be rapidly generated for other low- and middle-income countries. Chapters Three and Four present findings from a qualitative study undertaken in Kabul province, Afghanistan between October-November 2017 using semi-structured, in-depth interviews with mothers and fathers that experienced a stillbirth, female community elders, various healthcare providers, and health officials. Chapter Three explores community and healthcare provider experiences, perceptions, and practices around stillbirth in Afghanistan to understand how these contextual factors might impact on the reporting, disclosure, and data collection on stillbirth. In Chapter Four, analysis of the qualitative narratives is used to understand the contribution of contextual, individual, household-level and health system factors to stillbirth, and develop a conceptual pathways map describing the possible pathways leading to stillbirth.

The assessment of 117 household surveys from 70 low- and middle-income countries in Chapter One identifies substantial variation across DHS surveys in the measurement of stillbirths, with limited scope to examine risk factors or causes. The method used to count stillbirths varied; most surveys (84.2%) used a live birth history with a reproductive calendar, while only 16 (14.0%) surveys from 12 countries (17.1%) did a full pregnancy history to capture detailed information on stillbirth. Antenatal and delivery care data for stillbirths was available in only 15 surveys (13.2%) from 12 countries; the remainder recorded this only for live births. On further exploration, only two of these six surveys had complete maternity care data for stillbirths. Data on maternal conditions were captured in 17 surveys (16.0%), but only in six could these be linked to stillbirths. Only three surveys included verbal autopsies on stillbirth for establishing cause of death. Chapter Two demonstrates the potential of household surveys to provide country-level data on stillbirth risk factors for low- and middle-income countries where data is lacking. The findings in Chapter Two show that in Afghanistan, the risk of stillbirth was three times higher among women residing in the Central Highlands (aRR: 3.01, 95% CI: 1.35, 6.70) and over nine times higher among women of Nuristani ethnicity (aRR: 9.15, 95% CI: 2.95, 28.74). Women who did not receive antenatal care had over three times increased risk of stillbirth (aRR: 3.03, 95% CI: 1.73, 5.30), while receiving high-quality antenatal care was important for reducing the risk of intrapartum stillbirth. Women experiencing antenatal complications including antepartum bleeding, infections, headaches, and reduced fetal movements were also at increased risk of stillbirth. Reduced fetal movements in the delivery period increased stillbirth risk by almost seven times (aRR: 6.82, 95% CI: 4.20, 11.10). Facility births had a higher risk of stillbirth overall (aRR: 1.55, 95% CI: 1.12, 2.16), but not for intrapartum stillbirths.

The qualitative findings from Chapter Three identify several factors that potentially impact the reporting and disclosure of stillbirth. At the community level, variation in the local terminology and interpretation of stillbirth and specific birth attendant practices could lead to under-reporting and misclassification of stillbirth. While differential customs, rituals, and burial practices dependent on presence or absence of signs of life after birth, the perceived value and social recognition of a

stillborn, and openness of families to disclose and discuss stillbirths, had the potential to minimise under-reporting. At the health facility, healthcare provider's practices driven by institutional culture and demands, family pressure, and socio-cultural influences appeared to exacerbate underreporting or misreporting of stillbirths.

Parents' and healthcare providers' stories of their stillbirth experiences in Chapter Four shed light on some of the key pathways leading to stillbirth. Low levels of healthcare utilisation was a critical factor contributing to stillbirth and underscored by women's lack of decision-making power, sociocultural barriers to access, lack of perceived need and benefit of care during pregnancy and childbirth, and low general knowledge of self-care during pregnancy. Perceptions about quality of care including the behaviour of healthcare providers, and economic and physical barriers, also affected access to health services and were indirect pathways to stillbirth. Quality of care was also a recurring factor underlying stillbirth, while several health system challenges led to delays in receiving care due to inappropriate referrals, inadequately equipped facilities, and harmful or inadequate provider practices. The armed conflict had direct adverse effects on the fetus due to exposure to harmful and toxic substances. This was perceived to be responsible for congenital anomalies and adverse pregnancy outcomes including stillbirth.

The findings of this thesis have several important implications for improving stillbirth data in lowand middle-income countries. It identifies gaps and inconsistencies in existing national household surveys and makes recommendations for modifications to these to facilitate globally comparative assessments across countries, and over time. This can assist with moving forward efforts towards generating better data for stillbirths in future DHS surveys and supports the calls made over the years regarding improvements required in stillbirth data for low- and middle-income countries. This thesis also provides the first population-based assessment of stillbirth risk factors for Afghanistan, a conflict-affected nation where stillbirth rates continue to be some of the highest in the world. Findings on the key risk factors associated with stillbirth in Afghanistan add to the evidence-base needed to inform and prioritise stillbirth prevention measures on the national maternal and newborn health agenda. The qualitative findings support and add to the evidence on how community and healthcare provider experiences, perceptions, and practices can influence underreporting of stillbirths, and how these may be overcome. It also identifies where interventions and efforts could begin to focus to facilitate stillbirth reduction in Afghanistan

INTRODUCTION

OVERVIEW OF INTRODUCTION

The introduction is divided into three parts. Part I describes the rationale for this thesis, outlines the research aims and objectives, provides an overview of the methods, and the organisation of the thesis. Part II is a review of the literature which covers the global burden, epidemiology and definitions of stillbirth, stillbirth data sources, and selected risk factors and causes for stillbirth in low- and middle-income countries. Part II also presents the evidence to date on stillbirth data availability and quality, focusing on the data gaps relating to the availability of risk factor data. Part III describes the setting and context of Afghanistan, the country from which where secondary data was sourced and where primary data collection was conducted. Part III also provides a brief overview of the Afghan health system, the current situation of maternal and child health, and reviews the current evidence on stillbirth in Afghanistan including gaps and need for knowledge.

RATIONALE

Stillbirths have long been overlooked on the global public health agenda and at the national level in most countries, but especially in low- and middle-income countries¹ (Lawn et al., 2011). Each year, there are 2.6 million stillbirths, 98% of which occur in low- and middle-income countries (Blencowe et al., 2016). These deaths, of babies born without any signs of life from anywhere between 16 to 28 weeks or more gestation depending on the definition adopted, remained uncounted and under-investigated for decades, leaving parents and families to suffer in silence without recognition of their loss. Not counting these deaths meant that for a long time the global and national burden of stillbirth was largely unknown, and this was a key reason stillbirth prevention did not receive any attention both globally and nationally.

It was not until the mid-1990s that the first global estimates for stillbirth were produced by the World Health Organisation (WHO) which provided the first evidence which revealed the enormous extent of this neglected burden (WHO, 1996). This was followed by several more estimates in subsequent years which showed little decline in stillbirths compared with child and maternal deaths and began to direct attention towards reducing stillbirths (Cousens et al., 2011; Stanton et al., 2006; WHO, 2007a). The increasing recognition and evidence around the long-term social, psychological, economic, and health impacts on women and families, and acknowledgement that for parents, these deaths were equally as devastating as the loss of any child, also provided a further imperative to investigate stillbirth (Heazell et al., 2016). This growing attention to stillbirths also quickly uncovered some significant information gaps that made efforts to reduce these deaths challenging – namely, the absence and low-quality of data available on stillbirths (Lawn et al., 2010).

Data are fundamental to inform decision-making in public health. Without data, there is no evidence for countries and governments to prioritise and allocate funding, direct programmatic and policy efforts, and make commitments to reduce and prevent stillbirths. Thus, data are imperative to ensure accountability. The first country-level estimates for stillbirth were published in 2006 which, despite poor quality data from many low- and middle-income countries, provided some evidence on

¹ Low-and middle-income countries in this thesis generally refers to those countries classified by the World Bank in 2018-19 as lowincome (Gross National Income (GNI) per capita of US\$995 or less in 2017)) or lower-middle income (GNI per capita of US\$996 to \$3895 in 2017) (World Bank, 2018b)

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the burden (WHO, 2007a). Global, regional, and national stillbirth estimates continue to be updated and published approximately every five years, each year with increasing data using more robust modelling methods to predict the burden (Blencowe et al., 2016; Cousens et al., 2011). However, knowledge of key risk factors and causes are also essential to select and prioritise preventative strategies and interventions to reduce stillbirths, yet there is a scarcity of evidence on these for most low- and middle-income countries (Aminu et al., 2014; Lawn et al., 2016). Although quality evidence exists for some known risk factors from studies in high-income nations, country-specific evidence of the contributing factors to stillbirth are crucial for national-level priority setting and selection and implementation of interventions, as many known, cost-effective interventions to prevent stillbirth exist (Bhutta et al., 2014). Most studies from low- and middle-income countries that investigate stillbirth are facility-based and given that a large proportion of women in these countries give birth at home, this limits the use of this data. Prospective, population-based studies are increasing in number but are not adequate to inform national-level decision making. Different countries and contexts vary considerably in their demographics, fertility, disease burden, health service availability and utilisation, and socio-cultural context, all of which affect the risk of stillbirth. This absence of country-specific data on risk factors was a crucial gap in the literature for understanding stillbirth in low- and middle-income countries and formed the underlying basis of the research questions this thesis endeavoured to explore, with the aim to investigate and identify how this data could be improved.

In addition to the problem of data availability, another challenge and limitation with stillbirth data is quality, or more specifically, the accuracy of the data. There are several difficulties with capturing stillbirth outcomes accurately, as vital signs at birth need to be confirmed to distinguish stillbirths from early newborn deaths and can lead to misclassification (Lawn et al., 2009; Liu et al., 2016). This results in under-reporting of stillbirth and thus affects the accuracy of stillbirth estimates and is a major barrier to quantifying the real burden. In low- and middle-income countries, most data on stillbirth is obtained from household surveys carried out with women and so are based on their recollection of what they were told about their baby by the birth attendant. Quality data are imperative not just for capturing outcomes precisely, but also for evaluating the impact of interventions. There are also numerous other reasons stillbirths may be under-reported which are underscored by the socio-cultural and community context (Frøen et al., 2011).

Context is a critical factor when examining stillbirth – the social, cultural, political, and economic environment all have a bearing on stillbirth risk either directly or indirectly, and can affect our ability to capture accurate data on these deaths (Frøen et al., 2009). Stillbirth can be very much influenced

by individual or community perceptions around pregnancy and pregnancy loss which can affect the disclosure and reporting of stillbirths (Haws et al., 2010). In some settings, stigmatisation and blame directed at women who experience a pregnancy loss can preclude disclosure of any death (Kiguli et al., 2015). In countries where induced abortion is socially stigmatised or illegal, it is possible that a stillbirth may be concealed, so it is not mistaken for an abortion (Erviti et al., 2004; Haws et al., 2010). The influence of context has not been adequately considered when understanding how to capture stillbirth data more accurately and is an under-explored area that this thesis also aimed to address.

RESEARCH AIMS & OBJECTIVES

The overarching aims of this thesis were to examine the current status and limitations with nationallevel stillbirth data from low- and middle-income countries that are impeding stillbirth prevention efforts and identify how improvements can be made to increase the availability of risk factor data. Secondly, was to understand how (the socio-cultural) context and individual and community perceptions influence the accuracy of stillbirth data and can further inform our understanding of contributing factors and future prevention of stillbirth. The specific objectives of this thesis were:

- To explore and review the availability of country-level stillbirth data and outline the limitations and challenges with using the data for understanding the determinants and causes of stillbirths, and for cross-country comparisons.
- ii. To demonstrate how to facilitate improvements in stillbirth data availability and quality to improve understanding of stillbirth risk factors for low- and middle-income countries, using the case of Afghanistan as an example.
- iii. To examine how community and healthcare provider experiences, perceptions, and practices influence stillbirth data collection and data quality, and how this could inform future stillbirth data collection methodologies.
- iv. To qualitatively explore through parents', communities', and healthcare providers' stillbirth experiences, the underlying pathways and contributing factors leading to stillbirth.

This thesis argues that the current status of stillbirth data for low- and middle-income countries globally is inadequate, but there are opportunities to improve the availability of data on stillbirth risk factors relatively rapidly with sufficient commitment. It also contends that stillbirth data quality cannot be adequately improved without consideration of the contextual factors within each country setting that influence data collection. Further, context also needs to be examined when trying to

understand risk factors, as implementation, access to, and uptake of interventions to reduce stillbirth are dependent on a range of contextual factors that affect decision-making around careseeking, and quality of care.

METHODS AND CONCEPTUAL APPROACH

In this thesis I applied both quantitative and qualitative methodologies to explore data availability to understand stillbirth determinants and demonstrate how better data could be obtained, and to investigate how context influences both stillbirth data quality and stillbirth risk, in the context of Afghanistan. A detailed description of the methods used are provided within each chapter. The first two chapters of this thesis are based on quantitative methods using secondary data sources, while the final two chapters are based on primary data collected from a qualitative research study undertaken in Kabul province in Afghanistan. Several conceptual and theoretical models are drawn upon or developed as part of the findings of the thesis to examine the determinants of or pathways to stillbirth and the factors that influence stillbirth data reporting.

Central to this thesis are the concepts of data availability and data quality to understand the burden and determinants of stillbirth for low- and middle-income countries. Stillbirth data availability is examined in detail in Chapter One. Data quality is a multi-dimensional concept with many definitions. In this thesis, I considered several core attributes or dimensions that define data quality to guide the approach, particularly in Chapters One and Three. There are various definitions and frameworks in the literature on how to assess data quality, which vary across public health and other sectors in terms of attributes or characteristics measured, with up to 49 attributes identified (Chen et al., 2014; Nambiar & Nair, 2017; WHO, 2003). The most common data quality components that cut across most of these definitions and frameworks are accuracy, timeliness, completeness, comprehensiveness, accessibility and utility (Table 1).

| Data quality dimension | Definition | | | |
|------------------------|--|--|--|--|
| Accuracy & validity | The data measures what they intend to measure. Accurate data minimises errors. | | | |
| Reliability | Data are measured and collected consistently. | | | |
| Completeness | All required data is present. | | | |
| Timely | Data is current and up to date. | | | |
| Comprehensiveness | Data has all the detail needed. | | | |
| Utility | Data produced is useful and pertinent. | | | |
| Accessibility | Data is available and accessible to the individuals that need to use the data (when and where needed). | | | |

Table 1: Dimensions of data quality and definitions for selected components of data quality

This thesis did not aim to validate all aspects or components of data quality directly, but instead used these core attributes as a guide, to inform the assessment of the limitations in stillbirth data and how contextual factors can affect the quality of this data. Chapter One in this thesis focusses on data availability for risk factors and causes of stillbirth across household surveys and examines the consistency in stillbirth capture across data collection methodologies used. Chapter One also reviews the completeness of data across countries and the timeliness and the accessibility of data for policy and program makers. It also explores whether the data captured is comprehensive and incorporates sufficient detail for potential risk factor analysis. Chapter Two uses data from a national-level household survey to identify factors associated with stillbirths and to investigate how to improve data availability on stillbirth risk factors for low- and middle-income countries. Chapter Three examines the impact that contextual factors can have on data quality but reflecting predominantly on data accuracy, reliability, and completeness of stillbirth data.

The methodological approach of the qualitative study is outlined in Chapters Three and Four. Briefly, this qualitative study was undertaken in one urban and two rural districts of Kabul province between October and November 2017. Data collection consisted of a total of 55 in-depth, semi-structured interviews with women and men that had a recently experienced stillbirth, female community elders, community health workers (CHW), and other key informants including different levels of healthcare providers and government health officials. Participants were recruited using purposive and snowball sampling primarily from three maternity hospitals in urban Kabul, and two lower-level facilities and CHWs in two rural districts of Kabul province. We limited data collection methods to indepth interviews based on the advice of Afghan study investigators and as recommended by the local research and ethics committee. We decided against including focus group discussions given that the sensitivity around the topic was largely unknown at the time.

The overall approach behind the qualitative work of this thesis was to explore the underlying processes and pathways that lead to stillbirth to better understand how and why stillbirths occur, and how, why, and what factors impact on stillbirth data quality and data collection on stillbirth. A qualitative study was chosen because it is the most useful method to explore and understand the why and how to obtain rich, in-depth descriptions of individual or collective behaviours and experiences in their social contexts (Malterud, 2001; Pope & Mays, 1995). In this thesis, the qualitative data assisted with both complementing and triangulating the findings from the quantitative analyses. Thematic analysis was used to analyse the data where patterns in the data were categorised into themes that emerged as being important to the research question (Braun & Clarke, 2006). I used both deductive and inductive approaches for the analysis, classifying patterns

according to pre-determined themes, but also allowing new themes to emerge from the data (Fereday & Muir-Cochrane, 2006).

ORGANISATION OF THE THESIS

This main body of this thesis includes four chapters each of which contains a separate manuscript based on the research findings (summarised in Box 1). At the time of submission, the first paper has been published, the second has been accepted, and the third and fourth papers have been submitted to peer-reviewed journals for consideration. Within each chapter, the supplementary online material for each manuscript is included after the manuscript.

Box 1: Overview of manuscripts included in thesis

CHAPTER ONE: CURRENT STATUS OF STILLBIRTH DATA AVAILABILITY IN LOW- AND MIDDLE-INCOME COUNTRIES

Paper I: Aliki Christou, Michael J. Dibley, and Camille Raynes-Greenow. 2017. Beyond counting stillbirths to understanding their determinants in low-and middle-income countries: a systematic assessment of stillbirth data availability in household surveys. *Tropical Medicine & International Health* 22 (3):294-311. (Published)

CHAPTER TWO: OPPORTUNITIES TO INCREASE DATA & EVIDENCE ON STILLBIRTH DETERMINANTS IN LOW- AND MIDDLE-INCOME COUNTRIES

Paper II: Aliki Christou, Michael J. Dibley, Mohammad Hafiz Rasooly, Adela Mubasher, Sayed Murtaza Sadat Hofiani, Mohammad Khakerah Rashidi, Patrick J. Kelly, Camille Raynes-Greenow. **Understanding country-specific determinants of stillbirth using household surveys – the case of Afghanistan.** Paediatric and Perinatal Epidemiology (In-press. Accepted 21 November 2018)

CHAPTER THREE: CONTEXTUAL FACTORS INFLUENCING STILLBIRTH DATA QUALITY

Paper III: Aliki Christou, Ashraful Alam, Sayed Murtaza Sadat Hofiani, Mohammad Hafiz Rasooly, Adela Mubasher, Mohammad Khakerah Rashidi, Michael J. Dibley, Camille Raynes-Greenow. **How community and healthcare provider perceptions and practices influence reporting and disclosure and data collection on stillbirth: findings of a qualitative study in Afghanistan**. (submitted to journal)

CHAPTER FOUR: UNDERSTANDING PATHWAYS LEADING TO STILLBIRTH: INSIGHTS FROM AFGHANISTAN

Paper IV: Aliki Christou, Ashraful Alam, Sayed Murtaza Sadat Hofiani, Mohammad Hafiz Rasooly, Adela Mubasher, Mohammad Khakerah Rashidi, Michael J Dibley, Camille Raynes-Greenow. Pathways leading to stillbirth: the role of care-seeking and care during pregnancy in Afghanistan. (submitted to journal) Chapter One in this thesis entails an assessment of globally available, country-level stillbirth data by systematically mapping data availability for stillbirth from nationally-representative household surveys (the Demographic and Health Surveys or DHS surveys) completed between 2000 and 2015 for 70 low- and middle-income countries. The objective was to outline what data exists, and what the limitations and challenges are with using the data for understanding the determinants and causes of stillbirths. I examined data sources from the DHS program website, including published reports and their associated questionnaires by extracting data into a pre-structured form. This appraisal paid particular attention to not only data availability, but also the consistencies in methodologies and wording of questions used to capture data for stillbirth.

In Chapter Two, I used a dataset from one of the surveys identified in Chapter One – the 2010 Afghanistan Mortality Survey – which was a modified, special DHS survey identified as having captured more comprehensive data for stillbirths. This data was used to undertake a multivariable regression analysis to describe the key risk factors for stillbirth and intrapartum stillbirth in this setting, and to demonstrate how more and better data for understanding stillbirth determinants could be rapidly generated for other low- and middle-income countries if their surveys could be similarly adapted. It also provides insights into the risk factors for stillbirth in Afghanistan where no data was previously available. This dataset included verbal autopsy data on stillbirth, which allowed the inclusion of several other variables not usually captured for stillbirth in household surveys and also correct for any misclassification between pregnancy outcomes. This chapter argues that it is possible to rapidly generate more and better quality data on stillbirth determinants for low- and middle-income countries by making modifications to surveys already being implemented in these settings.

Chapters Three and Four were part of a qualitative study I undertook in Kabul province in Afghanistan to explore the experience, perceptions and practices around stillbirth among parents, and healthcare providers in the facility and community setting. In these chapters, I wanted to gain an in-depth understanding of the contextual factors that affect stillbirth data reporting but also the contributing factors to stillbirth. In regard to context, I refer to the socio-cultural environment, namely, the factors that shape individual and community perceptions and practices when a stillbirth occurs – both at the household level and at the facility level. In these chapters, I argue that context has a fundamental impact on our understanding of stillbirth – on both the burden and accuracy of estimates, and on efforts to address and reduce risk factors for stillbirth.

In Chapter Three, I investigate how community and healthcare provider experiences, perceptions and practices can impact on stillbirth data quality at both the household level and facility-level.

Specifically, this research examined how contextual factors can influence the reporting, disclosure, and data collection for stillbirth. Here I highlight how specific practices and perceptions potentially impact on two key elements that affect stillbirth data quality – under-reporting and misclassification. Based on this analysis, I develop two conceptual frameworks around these themes, to illustrate the process through which these perceptions and practices affect stillbirth data. In this Chapter, I endeavour to provide evidence on key influences of the accuracy and reliability of stillbirth data.

In Chapter Four, I use the qualitative interviews to examine how parent's and healthcare providers' experiences of stillbirth could provide insight into contributing factors leading to these deaths. This was done by analysing individual's accounts of their stillbirth experiences and the sequence of events that occurred leading up to these deaths from both parents, community, and healthcare provider perspectives. Based on this analysis, I thematically categorised underlying contributing elements, and present the various pathways in a conceptual pathways map. This part of the thesis was done to assist with explaining and placing into context some of the findings in Chapter Two on risk factors for stillbirth. I focus on how context influences these pathways, especially in relation to care-seeking and understanding some of the barriers to the implementation, access, uptake of interventions that have the potential to prevent or reduce the risk of stillbirth.

This thesis ends with a conclusion where I review the significance of the main findings of the research that constitute this thesis, including the implications for policy and research. Here, I identify areas for future research for improving data availability and quality of stillbirth data and discuss the implications of the findings for future stillbirth research in Afghanistan.

GLOBAL STILLBIRTH BURDEN AND EPIDEMIOLOGY

MAGNITUDE OF STILLBIRTH GLOBALLY

The most recent global stillbirth estimates from 2015 suggest there are 2.6 million (range: 2.4-3.0 million) late trimester stillbirths annually, giving a worldwide stillbirth rate of 18.4 per 1000 births (Blencowe et al., 2016). Most stillbirths (98%) occur in low- and middle-income countries with sub-Saharan Africa and South Asia accounting for 77% of the global burden with two-thirds of stillbirths taking place in just ten countries (Lawn et al., 2016) (Table 2). In addition, some of the highest stillbirth rates are found in countries affected by conflict and political instability (Table 2). For the first time in 2015, the Global Burden of Disease (GBD) study also included stillbirths and estimated that globally there were 2.1 million stillbirths (range: 1.8-2.5 million) slightly less than that reported by Blencowe et al. (2016) owing to the use of different modelling methods (Wang et al.). The worldwide stillbirth rate reported by the GBD study was 14.9 stillbirths per 1000 live births; however, the use of different denominator definitions (total births vs live births in GBD estimates) prevents direct comparisons of these rates.

These global estimates have a wide range of uncertainty around them and are likely to be conservative due to the low-quality and accuracy of stillbirth data available used to model these estimates primarily from low- and middle-income countries (Lawn et al., 2011). Moreover, if stillbirths of earlier gestation (prior to 28 completed weeks) were to be included, then the burden would be far greater (Smith et al., 2018). In high-income countries, over half of stillbirths occur between 22 and 28 completed weeks of gestation but these are not included in the global estimates (Flenady et al., 2011b). In low- and middle-income countries, data is not routinely collected or reported for fetal deaths before 28 weeks (Lawn et al., 2009).

The number of stillbirths that occur worldwide every year is almost equivalent to the number of early neonatal deaths (Lawn et al., 2011), yet international attention and resources directed to stillbirth prevention has not been commensurate with this burden (Lawn et al., 2009). Consequently, stillbirths were neglected for many decades and the decline in global stillbirth rates over the past 15 years has been slower than those of neonatal, child, and maternal mortality. In addition, prior to 2006, there were no country-level stillbirth estimates available,

further contributing to the invisibility of stillbirths on both national and global health agendas. The lack of data to quantify not only the burden, but also trends, risk factors, and causes, has been a significant barrier to the prioritisation of stillbirth prevention efforts globally.

| Co | untries with highest <u>stil</u> | lbirth rates | | Countries with hig | ghest absolute <u>st</u> | illbirth numbers | <u>i</u> |
|------|-----------------------------------|---|------|--|--------------------------|--|------------------------------------|
| Rank | Country | Stillbirth rate (per 1000 total births) | Rank | Country | Number of stillbirths | Cumulative total number of stillbirths | Cumulative % of stillbirths~ |
| 1 | Pakistan | 43.1 | 1 | India | 592 086 | 592 086 | 22.6 |
| 2 | Nigeria | 42.9 | 2 | Nigeria | 313 706 | 905 792 | 34.6 |
| 3 | Chad^ | 39.9 | 3 | Pakistan | 242 556 | 1 148 348 | 43.8 |
| 4 | Guinea Bissau^ | 36.7 | 4 | China | 122 341 | 1 270 689 | 48.5 |
| 5 | Niger | 36.7 | 5 | Ethiopia | 96 531 | 1 367 220 | 52.2 |
| 6 | Somalia^ | 35.5 | 6 | Democratic Republic of Congo [^] | 87 780 | 1 455 000 | 55.5 |
| 7 | Djibouti^ | 34.6 | 7 | Bangladesh | 83 060 | 1 538 060 | 58.7 |
| 8 | Central African Republic^ | 34.4 | 8 | Indonesia | 73 435 | 1 611 495 | 61.5 |
| 9 | Togo^ | 34.2 | 9 | Tanzania | 47 060 | 1 658 555 | 63.3 |
| 10 | Mali^ | 32.5 | 10 | Niger | 36 216 | 1 694 771 | 64.7 |
| 11 | Comoros^ | 30.5 | 11 | Kenya | 34 985 | 1 729 756 | 66.0 |
| 12 | Benin | 30.3 | 12 | Egypt | 34 656 | 1 764 412 | 67.4 |
| 13 | Ethiopia | 29.7 | 13 | Uganda | 34 151 | 1 798 563 | 68.7 |
| 14 | Yemen^ | 29.0 | 14 | Sudan^ | 32 338 | 1 830 901 | 69.9 |
| 16 | Democratic Republic of Congo*^ | 27.3 | 15 | Angola | 30 655 | 1 861 556 | 71.1 |
| | Angola* | 27.3 | 16 | Afghanistan^ | 28 056 | 1 889 612 | 72.1 |
| 17 | Mauritania* | 27.1 | 17 | Brazil | 27 808 | 1 917 420 | 73.2 |
| | Afghanistan*^ | 26.7 | 18 | Philippines | 25 811 | 1 943 231 | 74.2 |
| 18 | Côte d'Ivoire | 26.7 | 19 | Chad^ | 25 170 | 1 968 401 | 75.1 |
| 19 | Burundi^ | 26.6 | 20 | Yemen^ | 24 646 | 1 993 047 | 76.1 |
| 20 | Bangladesh | 25.4 | | | | | |

Table 2: Top 20 countries with the highest stillbirth rates and absolute number of stillbirths in 2015

Source: Table adapted from Lawn et al. (2016) with additional data extracted from Appendix of Blencowe et al. (2016)

*Equal ranking

^Classified as fragile and conflict affected countries by the World Bank (2015)

~Out of a total of 2.62 million stillbirths

REGIONAL AND WITHIN COUNTRY VARIATION IN STILLBIRTH RATES

The overall global stillbirth rate of 18.4 per 1000 total births does not reveal the variation that exists regionally and between countries. In low- and middle-income countries, stillbirths continue to occur at rates more than ten-fold greater than high-income countries; stillbirth rates in sub-Saharan Africa and Southern Asia are over 25 per 1000 births, while in developed regions the overall stillbirth rate is three per 1000 births (Lawn et al., 2016). Among high-income countries, Finland, Iceland, and Denmark have some of the lowest reported stillbirth

rates worldwide with less than two stillbirths per 1000 births, while among low-income countries, Nigeria and Pakistan have some of the highest rates with over 40 stillbirths per 1000 births every year (Blencowe et al., 2016). Among the regions of South-East Asia and Oceania, and Northern Africa and Western Asia, stillbirth rates range from 12-15 per 1000 births, while in Latin America the overall stillbirth rate is around 8 per 1000 births (Lawn et al., 2016). There are also disparities within regions; for example, in Latin America, the stillbirth rate in Haiti was 24.9 per 1000 births in 2015, whereas in the neighbouring Dominican Republic it was 11.1 per 1000 births (Lawn et al., 2016; Pingray et al., 2018).

Stark inequalities exist in stillbirth rates within countries as well with exceptionally high regional and ethnic disparities. These regional disparities may be related to socio-economic inequalities and inequities in access to and the availability of quality of care (Lawn et al., 2016). India, for example, displays wide regional disparities; analyses using data from the 2010-2013 Annual Health Survey covering nine Indian states found Uttar Pradesh in Northern India had the highest stillbirth rate at 14.8 per 1000 births while Madhya Pradesh in Central India had the lowest at 4.2 per 1000 births (Altijani et al., 2018). This study found that increasing stillbirth rates were strongly associated with increasing socio-economic deprivation and lower use of health services. In Brazil, the prevalence of stillbirth ranges from 26 per 1000 births in the North-east to a low of 5.2 per 1000 births in the Centre-west, but these regional disparities could not be explained by variation in socio-economic status and were more likely to be related to access to care (Carvalho et al., 2018).

Urban and rural differences in the stillbirth burden also persist, varying between low- and middle-income countries and high-income countries. In low-and middle-income countries, two-thirds of stillbirths occur in rural areas mostly likely because rural populations are more socio-economically disadvantaged and have lower levels of access to maternity and emergency obstetric care and caesarean sections (Lawn et al., 2016). Whereas in high-income countries, most stillbirths occur in urban areas as this where the majority of the population reside.

TRENDS IN STILLBIRTH RATES

The first global data on stillbirth was for the year 1995 published by the WHO which estimated a stillbirth rate of 29 per 1000 births or a total of 4.3 million stillbirths globally (WHO, 1996). These estimates did not report stillbirth rates at the national or regional level which were not

available until 2006 (WHO, 2007a). The most recent stillbirth estimates cannot be compared directly with these figures due to updates to modelling methods and input data; therefore, global trends can be examined from the year 2000. Between 2000 and 2015, global third-trimester stillbirth rates declined by 26% from 24.7 per 1000 births to 18.4 per 1000 births (total numbers declined from 3.25 million to 2.62 million) or an annual rate of reduction (ARR) of 1.9% (Blencowe et al., 2016). This rate of decline remains slower than the global reductions observed for under-five child mortality (ARR 4.0%) and maternal mortality (ARR 3.0%) (WHO et al., 2015; You et al., 2015).

These reductions in stillbirths have also not been uniform across regions. High-income countries experienced a ten-fold reduction in stillbirth rates over the past century which fell from over 50 per 1000 births in the 1930s to less than five per 1000 births in 2015 (Goldenberg et al., 2009; Lawn et al., 2016). The introduction of antenatal care (ANC), an increase in facility births, and the availability of caesarean sections between 1935-1940 are thought to be responsible for these reductions (Goldenberg et al., 2016). The most notable declines in stillbirth rates occurred between the years 1950-1975 and were attributed to the prevention of infections, and improved coverage of skilled birth attendance and obstetric care (Woods, 2008). Most of the decline in stillbirths was primarily a result of reductions in intrapartum stillbirths, which now only account for a small proportion of stillbirths in high-income settings. However, antepartum stillbirths continue to occur with minimal declines observed since the 1980s (Goldenberg et al., 2011).

Although stillbirth rates in high-income countries are currently much lower than low- and middle-income countries, in some countries the rates have slowed or stopped declining altogether for many decades (Flenady et al., 2011b). The ARR in the stillbirth rate between 2000 and 2015 was only 1.8% among high-income countries (Blencowe et al., 2016). Disparities also exist between high-income countries; the overall stillbirth rate for high-income countries is 3.8 per 1000 births but in Bulgaria for example, the stillbirth rate is almost double at 5.8 per 1000 births and Denmark's is less than half with only 1.7 stillbirths per 1000 births (Flenady et al., 2011b). This also indicates that further reductions in stillbirth in high-income settings are possible.

Trends in stillbirth rates from low- and middle-income countries can only be examined for the past 15-20 years when data become available. Despite an overall reduction, the pace of decline

in the stillbirth rates across low- and middle-income countries varies considerably. Between 2000 and 2015 the slowest reductions have been in sub-Saharan Africa where stillbirth rates fell by only 1.4%, while South Asia also experienced minimal declines with an ARR of 2.2% (Blencowe et al., 2016). Individual countries within these regions have, however, done exceptionally well including Bangladesh which experienced an ARR of 3.4%, thought to be a result of dramatic declines in fertility and improvements in coverage of care and access to caesarean sections (Lawn et al., 2016). Across all regions, the Eastern Asian region demonstrated the fastest decline with an overall ARR of 4.5% in the same time period (Lawn et al., 2016). This drop is largely attributed to the declines in stillbirths in China where the ARR in the stillbirth rate was 4.6%. Across Latin American countries the overall ARR was 2.1%; however, this rate masks the much higher rates of reduction in some countries such as Cuba (ARR 3.8%) (Lawn et al., 2016). Although there is currently limited evidence available on the drivers behind these declines, an ecological study of Latin American countries suggests stillbirth rates are correlated with both socio-economic and healthcare access factors including women's education, gross domestic product per capita, fertility rates, and facility births (Pingray et al., 2018).

GLOBAL RECOGNITION OF STILLBIRTH

Stillbirths have often been referred to as the 'invisible loss' resulting from decades of not being counted and the lack attention received globally and nationally on public health agendas (Frøen et al., 2009; Lawn et al., 2011; Lawn et al., 2009). International efforts were focused on reducing maternal, child, and neonatal mortality as a result of their prioritisation through the United Nations (UN) Millennium Development Goals (MDG) where stillbirths were not included. Stillbirths were also not routinely collected by the WHO for many years, nor were incorporated in the Global Burden of Disease metrics until 2015. The low political and policy prioritisation of stillbirth continues today with their exclusion from the recent Sustainable Development Goals (SDG), despite efforts and advocacy for their inclusion (Qureshi et al., 2015). Allocation of donor funding to stillbirths has also been insufficient and disproportionate to the burden (Frøen et al., 2016). A recent analysis of antenatal and neonatal health funding by Pitt and colleagues (2017) found that over a ten-year period only two projects mentioned the word stillbirth - another factor hampering efforts to reduce stillbirths.

Another important reason behind the invisibility of stillbirth has been the numerous and inconsistent definitions used globally and the absence of systematic data on the numbers, rates, and specific causes (Lawn et al., 2011). Accurate data to understand the burden and background characteristics and contextual factors behind these deaths is imperative to reduce stillbirths. There are also more complex social factors contributing to the absence of attention, recognition, and reporting of stillbirth. This includes social taboos, stigmatisation, and blame directed towards women who experience a pregnancy loss, and misconceptions that exist, including fatalistic attitudes, and lack of perceived importance of stillbirth even by healthcare providers (Frøen et al., 2011).

Publication of the first peer-reviewed, systematic national stillbirth estimates in 2006 helped to raise attention of the stillbirth burden (Stanton et al., 2006), and a subsequent BMC series in 2009 – Stillbirths: The Global Picture and Evidence-based Solutions - published evidence of available interventions to reduce stillbirth and also pointed to concerns with data quality and needs (Bhutta et al., 2009; Darmstadt et al., 2009; Haws et al., 2009; Lawn et al., 2009; Menezes et al., 2009; Yakoob et al., 2009). However, global attention towards stillbirth reduction gained momentum with the first stillbirth Lancet series in 2011 that published global and national stillbirth estimates with trends since 1995 (Cousens et al., 2011). This highlighted the extent of the burden and inadequate reduction in stillbirths and advocated for increasing recognition of these deaths (Cousens et al., 2011; Frøen et al., 2011; Goldenberg et al., 2011). Importantly, this series brought attention to the lack of data on stillbirths, the conflicting and numerous definitions and cause of death classification systems, which made it a challenge to generate comparable data across countries (Lawn et al., 2011). As part of this series, as well as subsequent publications, there were several calls to action for data improvements and accountability, with some success transpiring through the commitment of global agencies to start tracking and monitoring stillbirths at a national level (Moxon et al., 2015).

Notable advances were made in 2014 for the increased recognition of stillbirths through the landmark Every Newborn Action Plan (ENAP) launched at the World Health Assembly (by the WHO and United Nations Children's Fund (UNICEF) which set targets for countries to achieve stillbirth rates of 12 or less per 1000 births by 2035 and was endorsed by 190 countries (WHO, 2014). In 2015, as part of this action plan, the UN Inter-agency Group for Child Mortality Estimation was tasked with overseeing the regular estimates of national stillbirth rates and integrating these metrics within the UN system. A five-year roadmap for improving measurements and testing indicators was also developed (Moxon et al., 2015; WHO, 2015). One of the recommendations of the ENAP was to improve the recording of every birth, neonatal death, stillbirth, and to reduce equity gaps (WHO, 2014).

STILLBIRTH DEFINITIONS

A stillbirth or fetal death is a baby born without any signs of life after a given threshold of gestational age, birthweight, or body length. The 10^{th} revision of the International Classification of Diseases (ICD-10) refers to fetal deaths (not stillbirth) which it defines as, '...death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.' (WHO, 2011). The WHO defines stillbirth according to the ICD-10 definition as the '...death of a fetus that has reached a birthweight of 500g or more, or gestational age of 22 or more completed weeks, or has a body length of more than or equal to 25 cm.' Within this definition, stillbirths are further classified as late fetal deaths (\geq 1000 g or 28 weeks or more) or early fetal deaths (500-1000 grams or between 22-28 weeks gestation).

For international comparisons, the WHO recommends reporting of stillbirth as a late fetal death with a birthweight of 1000g or more, or gestational age of 28 weeks or more (if birthweight is unavailable), or length of 35cm or more. However, it also recommends the recording of outcomes at lower thresholds (WHO, 2007a). The reasoning behind the selection of 28 weeks or higher gestational age was because very few births prior to this can survive in countries where neonatal intensive care is not widely available (Lawn et al., 2011). The definitions for stillbirth and other pregnancy outcomes for international comparisons are illustrated in Figure 1.

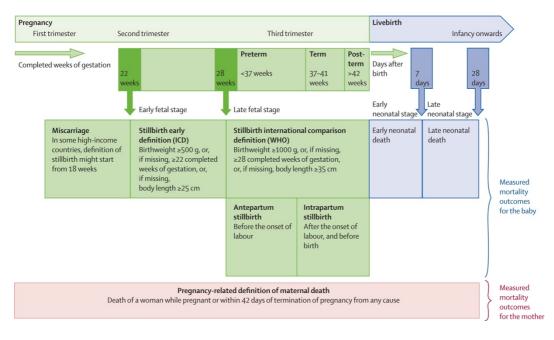


Figure 1: Definition of stillbirth and other pregnancy outcomes as outlined in the International Classification of Diseases, 10th Revision

Source: Figure from Lawn et al. (2011) used with permission from publisher.

The definition of stillbirth adopted by individual countries varies and is based on different parameters with variations in the minimum gestational age threshold which can be anywhere between 16-28 weeks (Fretts, 2011). Many high-income countries use a lower cut-off ranging between 20-24 weeks; Australia uses 20 weeks or 400g (although this varies between the datasets), while the United Kingdom (UK) uses 24 weeks, and the Netherlands uses 16 weeks. Some countries apply different definitions across states such as the United States (US) where nine different definitions exist (Frøen et al., 2009). In low- and middle-income countries where weight at birth is rarely measured, an estimate of gestational age is the most frequently used criteria and is generally based on a woman's last menstrual period or occasionally fundal height measures.

Birthweight and gestational age do not yield comparable stillbirth estimates, and a higher stillbirth rate is obtained if gestational age threshold is used (Blencowe et al., 2016). Data on estimated gestational age is more available than birthweight particularly in settings where babies are not frequently weighed due to high prevalence of home births. Estimated gestational age is also preferred in low- and middle-income countries as it is a better predictor of maturity and therefore, viability (Mohangoo et al., 2013). The lack of a consistent definitions in use across countries has made internationally comparable data challenging to obtain. It has also added to the confusion and uncertainty of the stillbirth burden which has been a major barrier to their recognition. Most published global stillbirth estimates have been based on the WHO's definition for international comparison of 28 weeks or more gestational age. However, there are concerns that large proportion of stillbirths that occur prior to 28 weeks, especially from high-income nations, are not included in global estimates which therefore further under-estimates the burden (Smith et al., 2018).

TIMING OF STILLBIRTH

Stillbirths are categorised according to the time of death as either antepartum, occurring prior to the onset of labour, or intrapartum, after the onset of labour but before birth (Figure 1) (Lawn et al., 2010). Globally, around half of stillbirths (1.3 million) are intrapartum, but variation exists across countries; in low- and middle-income countries intrapartum stillbirths constitute around 60% of stillbirths - the highest being in South Asia; while in high-income countries intrapartum stillbirths account for only 10% of stillbirths (Lawn et al., 2016).

Stillbirths that occur around labour have different risk factors and causes to those that occur earlier in pregnancy; therefore, distinguishing between them has important implications for prioritising and targeting programmatic interventions. In low-income settings, where fetal heart rate monitoring and use of ultrasound are not widespread, assessment of skin appearance is frequently used as a surrogate measure to assess the timing of death (Lawn et al., 2016). Intrapartum or "fresh" stillbirths generally have normal skin appearance, while antepartum stillbirths show signs of skin maceration which usually begins 6-12 hours after fetal death (Genest & Singer, 1992). However, it has been suggested that this marker may underestimate intrapartum stillbirths when fetal death during labour takes place at home and there are delays in accessing care (Gold et al., 2014; Lawn et al., 2016).

The intrapartum stillbirth rate is considered an indicator of the quality of care received during childbirth (Fauveau, 2007). Intrapartum stillbirths are directly associated with coverage of timely, and good quality care at birth (Goldenberg et al., 2007), while antepartum stillbirths are linked to sub-optimal antenatal care and underlying maternal health conditions. Important to note, is that data on timing of stillbirths is rarely collected in low- and middle-income countries, making it difficult to prioritise programs (Lawn et al., 2016).

STILLBIRTH DATA SOURCES AND LIMITATIONS

OVERVIEW OF DATA SOURCES

The importance and necessity for complete and quality data for stillbirths is considered critical in efforts to reduce deaths. The absence of national-level data especially from countries which constitute over 90% of stillbirths worldwide, continues to be one of the major barriers to stillbirth prevention efforts (Frøen et al., 2009; Lawn et al., 2011). Because of this, and the biases in the limited data that are available, national stillbirth rates for the majority of countries are generated using complex modelling methods to develop prediction models based on data from vital registration, surveillance systems, household surveys, facility data and extensive literature searches (Lawn et al., 2009). The global and national estimates for stillbirths published in 2006, 2011, and 2016, were all based on such models (Blencowe et al., 2016; Cousens et al., 2011; Stanton et al., 2006), and it is likely the next estimates will also be without substantial improvements in the quality and quantity of data from low- and middle-income countries. Authors of the global stillbirth rates since the previous estimates in 2011 suggesting encouraging progress is being made to increase stillbirth data; however, 38 countries still did not have any data, and the quality of data remained low (Blencowe et al., 2016).

Globally, stillbirth data is obtained from several different data sources. Stillbirth data from highincome countries comes primarily from routine data including vital registration systems and perinatal mortality reporting systems. Vital registration systems can achieve high coverage but have been found to underestimate stillbirths by around 19-30% and are not considered the gold standard (Cousens et al., 2011; Stanton et al., 2006), and worldwide, only 2% of third-trimester stillbirths are captured through vital registration (Lawn et al., 2010). Health facility data is an important source of nationally-representative data in countries with high rates of institutional births and where there is incomplete vital registration of stillbirths.

The majority of resource-constrained settings either lack or have unreliable civil registration and vital statistics systems (CRVS) for counting births and deaths (Mikkelsen et al., 2015), and also tend to have the most limited data collection systems for documenting stillbirths (Frøen et al., 2009). In many of these low- and middle-income countries a large proportion of women give birth at home and may not have contact with the health system or with any health professional

during pregnancy or childbirth, and so there is no recording or registration of these births. Even if women do give birth in a health facility, death certificates for stillbirths (and often neonatal deaths) are rarely issued (Lawn et al., 2014). Facility-based data including that from Health Management Information Systems (HMIS) are not representative and subject to bias, overestimating stillbirth rates and other outcomes due to selective referral of women with severe complications.

Reliable, nationally-representative stillbirth data from low- and middle-income countries is scarce. The only source of nationally-representative mortality data including for stillbirths for many countries is from national household surveys such as the DHS surveys (ICF International, 2018). Other population-based data sources include those from health and demographic surveillance sites such as the INDEPTH (International Network for the Demographic Evaluation of Populations and Their Health) network and community-based, prospective, multi-country studies such as the Global Network study and Alliance for Maternal and Newborn Health Improvement (AMANHI) study (AMANHI study group, 2016; Bose et al., 2015). Described next are the nationally-representative household surveys and the INDEPTH network.

Nationally-representative household surveys: Demographic and Health Surveys, Reproductive and Health Surveys (RHS) and Multiple Indicator Cluster Surveys (MICS)

The USAID-supported DHS surveys are large, nationally-representative household surveys done in over 80 low- and middle-income countries on a regular basis (approximately every five years) by the DHS program since 1984 and coordinated by ICF International (ICF International, 2018). They are based on large samples ranging from 5000-30 000 households. Many countries which participate in the DHS program do not have adequate routine data collection or reporting systems or universal use of health facilities making DHS data the only reliable source of health information. In these settings, they are an invaluable resource of data on the population health and nutrition situation and have been used to track progress over time informing programs and policy-making on public health issues. They have been essential for providing data to track achievements in maternal, child and neonatal mortality, providing data for the MDGs, Countdown initiatives, and the Commission on Information and Accountability for Women's and Children's Health, and will be central for tracking the SDGs (Boerma et al., 2018; Hancioglu & Arnold, 2013; Schweitzer, 2015). They are also increasingly used to examine trends and predictors of maternal and child health and mortality, coverage of care, and health service utilisation (Footman et al., 2015; Hancioglu & Arnold, 2013). The DHS program developed standard model questionnaires from which countries can adapt for their local context and also offer several optional modules. These surveys are the primary data source of stillbirth numbers nationally for many low- and middle-income countries. These are usually captured from the women's questionnaire using a contraceptive calendar, or more rarely, a full pregnancy history. Data collection and limitations to the use of this data are reviewed in detail in Paper I of Chapter One of this thesis.

The RHS surveys conducted by the Centres for Disease Control and Prevention (CDC) division of reproductive health began in the 1970s when they were known as Contraceptive Prevalence Surveys later renamed the Maternal and Child Health/Family Planning Surveys. RHS have predominantly been implemented in Latin American and Eastern European countries, and since the 1980s these surveys have been comparable to DHS (IHME, 2018). Similar to DHS, these surveys cover topics including infant and child mortality, fertility, family planning, maternal and child health, immunisation, breastfeeding, HIV/AIDS and sexual health. In these surveys, stillbirth is recorded in a similar way to the DHS. Data from RHS are also integrated into the statistical datasets in *STAT compiler* (online statistical software) of the DHS program website (ICF International, 2015).

The MICS surveys overseen by UNICEF are another national household survey program that collects information on mortality, health, nutrition, education among other indicators (UNICEF, 2018) and are a key source of data for tracking global indicators particularly for the MDGs and SDGs. MICS surveys began in 1995 and have been carried out every three or five years in over 100 countries since. Both the DHS and MICS programs collaborate to ensure their indicators are comparable (Hancioglu & Arnold, 2013). Presently, the core MICS survey questionnaires do not record stillbirths or any non-live births; however, some countries have adapted their surveys to include some questions on stillbirth (i.e. 2010 South Sudan Household Survey). It is not clear if these surveys will begin to capture stillbirth data routinely in the future, but it has been advocated and encouraged by researchers working in stillbirth metrics (Frøen et al., 2009; Lawn et al., 2011).

International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) Health and Demographic Surveillance Sites (HDSS)

The INDEPTH network is a global network of research centres that conduct longitudinal health and demographic surveillance of populations in low- and middle-income countries. The network was established in 1998 in response to the lack of reliable population data and brought together existing HDSS sites (including the longest running site in Bangladesh - the Matlab Demographic and Health Surveillance Sites in Bangladesh that was first established in 1963) and continues to include other sites. HDSS systems are implemented in selected regions within countries and use routine surveillance at regular intervals to ensure coverage of every household in the entire population of a specific geographic area over time. They capture data on vital events including births, deaths, migration, and causes of deaths, in addition to socio-demographic information (Sankoh & Byass, 2012) and monitor disease prevalence over time. There are currently 48 HDSS sites across 19 countries participating (INDEPTH Network, 2018).

Although HDSS data is epidemiologically more robust than cross-sectional data, it is limited in that it is not representative of the wider population. They generally sample a population ranging from 10 000 -100 000 individuals. Moreover, not all HDSSs collect data on pregnancy losses, and data on maternal conditions and healthcare use during pregnancy are not always available. A further complication is that different sites collect pregnancy outcomes using different methodologies and data collection occurs at varying intervals due to variation in surveillance rounds (Akuze et al., 2017). Despite these limitations, they do provide important and often more reliable population-based data on stillbirths, which is often used to make comparisons and undertake validation studies with national household survey data (Espeut & Becker, 2015; Helleringer et al., 2015).

DATA LIMITATIONS AND DATA QUALITY

Stillbirths are under-reported to a much larger extent than live births or neonatal deaths and the earlier in pregnancy the death occurs, the greater the likelihood of under-reporting (WHO, 2007a). It is estimated that the extent of under-reporting of stillbirths in vital registration systems and population-based surveys ranges from 20-40% (WHO, 2007a). Vital registration frequently relies on families to register the stillbirth themselves and in some contexts, stillbirth is associated with maternal blame or can lead to other severe consequences which can affect the reporting of such deaths (Frøen et al., 2009). Moreover, if there are any costs associated with registration, this can also deter families from registering (Qureshi et al., 2015).

Household surveys are the largest source of data on stillbirths from low- and middle-income countries, but there are several limitations to the data from these surveys given the methodological challenges associated with the accurate measurement of stillbirth at the community level. Under-reporting and misclassification are the two key concerns. DHS predominantly uses a complete live birth history of all women of reproductive age, and in most surveys stillbirths are captured using a reproductive calendar that records women's contraceptive use and pregnancy outcomes in the preceding five years. This source is perceived to be unreliable and underestimates stillbirths by about 36% when compared to facility-based data (Cousens et al., 2011). In 2015, DHS updated their model questionnaires surveys (DHS-7) and included a retrospective, truncated pregnancy loss history to capture pregnancy losses in the preceding five years in addition to the prospective live birth history (DHS Program, 2015). However, selected DHSs include a full pregnancy history rather than a live birth history which record more detailed information on stillbirths and miscarriages and produces more reliable stillbirth estimates (Bradley et al., 2015); but as yet, these have not been widely implemented by the DHS program despite the requests from stillbirth researchers over the years (Lawn et al., 2011). RHS surveys on the other hand, use a full pregnancy history approach (IHME, 2018).

The ratio of stillbirth to early neonatal deaths is often used to assess the quality of survey-based estimates for stillbirth and provides an indication of the extent of under-reporting. The number of stillbirths should be equal to or slightly exceed early neonatal deaths. Based data from a historical review of vital registration data studies, the WHO proposed a factor of 1.2 as the expected ratio of stillbirths to early neonatal deaths for countries with high early neonatal morality rates of 20 or more per 1000 live births (WHO, 2007a). Surveys with values of less than 1.2 suggest under-recording of stillbirths, while values around the expected ratio indicate better capture of stillbirths.

The 2015 global stillbirth estimates used DHS and RHS data to model stillbirth rates for many low- and middle-income countries and reported a median stillbirth to neonatal death ratio of 0.6, suggesting substantial under-ascertainment of stillbirths. Of the 163 surveys screened, 33 were excluded due to ratios of less than 0.33 (Blencowe et al., 2016). This is quite a substantial

proportion of surveys and supports the findings above that the current methodology used by most DHS surveys to collect stillbirth data needs improvement.

Validity studies comparing the capture of stillbirth in DHS surveys to prospectively collected HDSS data have quantified the extent of misclassification in DHS surveys. In Bangladesh, DHS data shows good sensitivity (91%) with only 3% of stillbirths misclassified as live births, and 9% misclassified as abortions (Espeut & Becker, 2015). A more recent study in Uganda compared a pregnancy history survey capture of stillbirth compared to HDSS data and found that the pregnancy history, in some years, captured more pregnancy outcomes than regular surveillance (Kadobera et al., 2017). However, this may have been affected by the methods used for the surveillance which involved interviewing other household members about a woman's pregnancy if the woman was not at home during the surveillance.

As with all retrospective surveys, recall bias is a limitation and completeness and accuracy of recall reduces over time. This may potentially contribute to under-reporting as well; however, studies of maternal recall of perinatal events in both low- and high-income countries generally report good maternal recall (Mung'ala-Odera & Newton, 2001; Rao et al., 2003).

Misclassification between stillbirths and early neonatal deaths is also an issue affecting the reliability of household level data. The ability of birth attendants to identify a stillborn is challenging in low-resource settings especially if the birth took place at home; there may be inadequate assessment of vital signs, or failed resuscitation of a newborn death that may result in misclassification (Lawn et al., 2009). Misclassification may be both unintentional or intentional to avoid blame, or hospital audit reviews of the death or other reasons that may benefit either families or health providers (Frøen et al., 2009; Lawn et al., 2009; Spector & Daga, 2008; Stanton et al., 2006). An investigation by Liu and colleagues (2016) into misclassification in Malawi compared the capture of stillbirths and early newborn deaths using a full birth history compared with verbal/social autopsy and found that one-fifth of neonatal deaths were misclassified as stillbirths. Lower odds of misclassification were observed if there were signs of baby movements in the days prior to the birth, while a significantly higher odds of misclassification when there were signs of birth injury, supporting some of the reasons driving misclassification (Liu et al., 2016). Further similar studies are needed in other settings which also include an assessment of misclassification in the other direction as well (stillbirths misclassified as neonatal deaths).

In addition to the limitations in the mechanism of data capture, there are other contextual and socio-cultural factors that may affect under-reporting or misclassification of stillbirth that are less well understood. In many low- and middle-income settings, pregnancy is perceived to be a vulnerable time for women and early pregnancy is often concealed. Pregnancy losses may also be hidden to avoid social ramifications including shame, stigma and blame towards the mother (Cecil, 1996; Frøen et al., 2009; Haws et al., 2010). In order to improve data capture across all sources, an understanding of those underlying social processes is essential to inform better design of surveys and other data capture methods.

CURRENT STATUS AND PROGRESS IN DATA IMPROVEMENTS

In 2011, the first *Lancet* stillbirth series identified how stillbirth data needs to be improved for all countries, not only for counting stillbirths but on data related to the timing of the death, maternal conditions and coverage of care for all pregnancies inclusive of those that end in a stillbirth (Lawn et al., 2011). For low- and middle-income countries, the fastest means to improve data meant increasing the quality and reliability of data collected through household surveys such as DHS and MICS. In the second *Lancet* stillbirth series in 2016, it was again highlighted that there was a lack of investment in improving stillbirth data from household surveys (Lawn et al., 2016). Reliable national-level data from low- and middle-income countries were still lacking, and no data were available to understand the determinants and risk factors for stillbirth at a country-level. Data on causes was virtually non-existent. The absence of progress in improving stillbirth data from household surveys was one of the motivating factors behind the work presented in Chapter One of this thesis – to understand what data is captured and how, identify where the gaps and problems are, and how this data could be improved.

There is encouraging progress on improving stillbirth data in countries through efforts to strengthen national health information systems as well as civil registration and vital statistics. The launch of the WHO's guide and initiative in 2016 - *Make Every Baby Count: audit and review of stillbirths and early neonatal deaths* - as part of efforts under the ENAP provides guidance and data collection tools for countries to improve data systems for reporting of deaths to ensure every death is counted, that minimum information around these deaths is recorded, and cause of death is assigned (Kerber et al., 2015; WHO, 2016a). This will not only improve data, but also the quality of care as more information is gained surrounding cause of stillbirths. The

commitment by the UN to integrate stillbirth rates into their system will also assist with generating more data and holding countries accountable.

Chapters One, Two, and Four of this thesis are centred around stillbirth data availability and understanding of stillbirth risk factors. The next section gives a brief overview of the evidence on causes of stillbirth and a more in-depth discussion on the current knowledge on known stillbirth risk factors, focusing on those relevant for low- and middle-income country settings.

CAUSES AND RISK FACTORS FOR STILLBIRTH

Understanding the causes and risk factors for stillbirth is critically important for making progress in implementing prevention strategies. For a factor to be classified as a cause of stillbirth, it needs to be clear that the outcome would not have happened without that factor being present and there should be a plausible mechanism leading to fetal death. Risk factors for stillbirth are those characteristics that consistently show an association with the condition and the incidence of stillbirth, for example, maternal age, but are not clearly or necessarily on the causal pathway (McClure et al., 2009). A summary of established risk factors and causes for stillbirth are presented in <u>Table 3</u>. These can be broadly grouped under socio-demographic factors, maternal factors, fetal factors, healthcare access factors, maternal medical conditions, and fetal conditions. As several risk factors can also be causal, these are grouped separately. It is important to note that for many stillbirths the underlying risk factors and causes are unknown. For low- to middle-income and high-income countries the causes and risk factors show both variations and similarities. A review of the current evidence on these is presented in later sections.

| RISK FACTOR | RISK FACTOR & CAUSAL FACTOR |
|---|---|
| SOCIO-DEMOGRAPHIC FACTORS | MATERNAL MEDICAL CONDITIONS |
| Low socio-economic status Low education or literacy | Hypertensive diseases (pre-eclampsia, eclampsia/chronic hypertension, untreated thyroid) |
| | Diabetes (pre-existing or gestational) |
| MATERNAL FACTORS | Maternal trauma |
| Obstetric factors/history | Rhesus incompatibility |
| Maternal age (<16 or ≥35 years) Nulliparity Short inter-pregnancy interval | Other medical conditions (renal disease, systemic lupus erythematosus, sickle cell disease, cholestasis, thrombophilia) |
| Previous pregnancy loss | Placenta and cord |
| Delivery at ≥41 weeks gestation (post-term) | Placental abruption |
| Assisted reproductive technology | o Placenta previa |
| • Nutritional | Placental malfunction (necrosis/thrombosis) |
| Maternal anaemia | Labour complications |
| Short maternal stature | Prolonged/obstructed labour |
| Very low body mass index or obesity/overweight | Ruptured uterus |
| Behavioural/lifestyle/environmental | Cord accident |
| Alcohol, tobacco, or other drug use | Aggressive labour stimulation |
| Indoor air pollution | Maternal infections |
| Violence against women | o Malaria |
| Indoor air pollution | o Syphilis |
| Violence against women | Other maternal bacterial and viral infections (HIV, Influenza, Parvovirus, Toxoplasmosis, Rubella, Varicella CMV, TB, Hepatitis Rubella, Varicella) |
| FETAL FACTORS | FETAL CONDITIONS |
| • Male sex | Fetal growth restriction |
| HEALTHCARE ACCESS/UTILISATION | De novo fetal distress |
| Lack of access to or inadequate ANC | Congenital anomaly |
| Lack of access to or inadequate hospital care | Malpresentation |

Table 3: Established risk factors and causes of stillbirth

Source: Content is based on Goldenberg et al. (2016), Lawn et al. (2016), Aminu et al. (2014), and Lawn et al. (2011) Abbreviations: CMV- cytomegalovirus, HIV- Human Immunodeficiency Virus, TB - tuberculosis

The conceptual framework in Figure 2 from Blencowe et al. (2017) illustrates the relationship between currently known risk factors and how they interact leading to stillbirth.

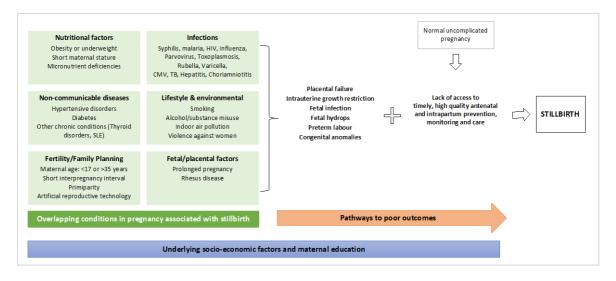


Figure 2: Conceptual framework illustrating known pathways to stillbirth *Source: Figure reproduced from Blencowe et al. (2017). Permission to use based on open-access policy of journal.*

CLASSIFICATION AND CAUSES OF STILLBIRTH

Identification of causes of stillbirths can be challenging and globally there is very little quality data available to understand causes (Flenady et al., 2017; Reinebrant et al., 2018). As a result, there are no global or national cause of death estimates for stillbirth similar to what exists for neonatal deaths (Lawn et al., 2011). Even in high-income countries where placental pathology and autopsies are more available, variation in classification and insufficient investigation results in a substantial proportion of stillbirths without an identifiable cause (Flenady et al., 2011b). For the majority of stillbirths in low- and middle-income settings, no cause of death is recorded or not recorded adequately (Edmond et al., 2008; Goldenberg et al., 2011).

Classification of causes facilitates a better understanding of why stillbirths occur and what interventions or action needs to be taken to prevent these deaths and enables comparisons between and within countries. There is currently no systematic global reporting or internationally accepted classification system of the causes of stillbirth. This has been a key concern raised over the years and has hampered stillbirth prevention efforts (Goldenberg et al., 2011; Lawn et al., 2011). A recent systematic review identified 81 different classification systems that have been used between the years 2009 and 2014 (Leisher et al., 2016b). None of these systems met all the characteristics identified by experts as necessary for a global classification system; many could not link associated maternal conditions with the perinatal death and only 20% distinguished stillbirths according to timing as antepartum or intrapartum stillbirth (Leisher et al., 2016a). The array of classification systems that exist and the lack of compatibility between them, as well as the absence of a global universally agreed upon system, prevents the accurate identification of causes of stillbirths and prohibits comparisons across different countries and regions.

Few studies that have assessed cause of death for stillbirth in low- and middle-income countries and those have also used various classification systems or only report on timing of death as either antepartum or intrapartum (Aminu et al., 2014). Most classification systems have not been designed for use in low-resource countries as the majority require access to diagnostics such as placental histological examinations, bacterial culture, and post-mortem examination which are often not available in these settings (Flenady et al., 2017; Goldenberg et al., 2018). As an alternative, verbal autopsy is commonly used to identify a cause of death in low-income settings where there are absent or weak death certification systems and where deaths frequently occur outside of the formal health system (Nichols et al., 2018). Verbal autopsy is an indirect method for identifying a cause of death and involves interviewing care-givers or other family members about the events and illness symptoms leading up to the death to determine a probable cause of death (WHO, 2016b). Some limitations to verbal autopsies have been noted, including concerns about reliability, variability in assignment of cause of death classification, and diagnostic accuracy (Edmond et al., 2008; Flenady et al., 2017).

To overcome some of the challenges with identifying stillbirth causes, improve reporting of perinatal deaths and facilitate consistent capture of causes of death, in 2016 the WHO developed the first global classification systems for perinatal deaths – the WHO Application of ICD-10 to Perinatal Deaths or WHO ICD-PM (WHO, 2016c). This system was designed for use across low-, middle- and high-income country settings. A key feature of the ICD-PM was its focus on the mother-baby dyad and consideration of the importance of maternal conditions on perinatal deaths (Vogel et al., 2014). This classification system follows the coding rules of ICD-10 and is modelled on the WHO application of ICD-10 to deaths during pregnancy, childbirth and the puerperium: ICD-maternal mortality (ICD-MM). ICD-PM has three important features – it identifies the timing of the death as either antepartum, intrapartum, or neonatal; it identifies the cause of perinatal death using ICD-10 coding grouped into clinically relevant and user-friendly categories; and identifies the main maternal condition linked with the perinatal death (Allanson et al., 2016b). To date, there has been limited implementation and evaluation of ICD-PM, but pilot-testing through retrospective application to datasets from South Africa and the UK demonstrate its value and utility (Allanson et al., 2016a).

Current evidence on causes of stillbirth

A recent systematic review by Reinebrant and colleagues (2018) provides a comprehensive collation of studies on the globally reported causes of stillbirth for low-, middle-, and high-income countries including pooled estimates of these causes (Table 4). Across all country groupings, unexplained stillbirth was the largest category. In low-income countries, infections (15.8%), hypoxic peripartum deaths (11.6%), and antepartum haemorrhage (9.3%) were among the top five causes of stillbirths. In middle-income countries, placental conditions (13.7%), specific fetal/pregnancy pathology (11.0%), and antepartum haemorrhage (9.1%) were the leading causes, and in high-income countries the main causes were placental conditions (14.4%), congenital anomalies (14.0%) and antepartum haemorrhage (8.4%).

Another systematic review of studies conducted between 2000 and 2013 reporting causes of stillbirth specifically for low- and middle- income countries found that almost 60% (range: 3.8%-57.4%) of stillbirths remained unclassified (Aminu et al., 2014). In this review, the most commonly reported cause of stillbirth were maternal conditions (range: 8.0-50.0%) including diabetes and infections such as syphilis, HIV, and malaria. This was followed by placental causes (7.5-42.0%), congenital anomalies (2.1-33.3%), intrapartum causes including asphyxia and birth trauma (3.1-25.0%), and umbilical causes (2.9-12.0%).

| LOW-INCOME COUNTRIES | | | | | | | |
|----------------------|--------------------------------------|------------------------|--------------|--|--|--|--|
| Ranking | Cause of stillbirth | Pooled estimate (%) | 95% CI | | | | |
| 1 | Unexplained | 41.0 | (20.6, 63.3) | | | | |
| 2 | Infection | 15.8 | (9.7, 23.0) | | | | |
| 3 | Other unspecified condition | 13.8 | (0.1, 61.0) | | | | |
| 4 | Hypoxic peripartum death | 11.6 | (0.8, 31.5) | | | | |
| 5 | Placental condition | 9.6 | (0.5, 26.6) | | | | |
| 6 | Antepartum haemorrhage | 9.3 | (4.9, 14.8) | | | | |
| 7 | Hypertension | 7.0 | (0.4, 10.6) | | | | |
| 8 | Umbilical cord condition | 8.2 | (2.3, 17.1) | | | | |
| 9 | Spontaneous preterm | 4.8 | (2.4, 8.1) | | | | |
| 10 | Specific fetal/pregnancy pathologies | 4.2 | (0.1, 13.6) | | | | |
| 11 | Maternal conditions | 3.8 | (1.7, 6.5) | | | | |
| 12 | Congenital anomalies | 3.3 | (1.3, 5.9) | | | | |
| 13 | Fetal growth restriction | - | - | | | | |
| 14 | Terminations (unspecified) | - | - | | | | |

Table 4: Pooled estimates of global causes of stillbirths for low-, middle-, and high-income countries based on a systematic review of 33 country-representative reports, 2009-2014

| MIDDLE- | | | | | | |
|----------|--------------------------------------|------------------------------------|--------------------------|--|--|--|
| Ranking | Cause of stillbirth | Pooled estimate (%) | 95% CI | | | |
| 1 | Unexplained | 43.7 | (24.1, 64.2) | | | |
| 2 | Other unspecified condition | 18.7 | (0.9, 51.5) | | | |
| 3 | Placental condition | (7.8, 21.0) | | | | |
| 4 | Specific fetal/pregnancy pathologies | 11.0 | (3.7, 21.4) | | | |
| 5 | Antepartum haemorrhage | Antepartum haemorrhage 9.1 (3.4, 1 | | | | |
| 6 | Umbilical cord condition | 7.1 | (2.7, 13.2) | | | |
| 7 | Hypertension | 6.5 | (0.4, 19.5) | | | |
| 8 | Congenital anomalies | 5.8 | (4.7, 7.1) | | | |
| 9 | Maternal conditions 5.6 (2.0, 10 | | | | | |
| 10 | Terminations (unspecified) | 5.5 | (0.1, 34.5) | | | |
| 11 | Hypoxic peripartum death | 5.2 | (1.6, 10.5) | | | |
| 12 | Spontaneous preterm | 3.5 | (0.5, 8.9) | | | |
| 13 | Fetal growth restriction | 2.0 | (1.0, 3.3) | | | |
| 14 | Infection | 0.6 | (0.1, 1.5) | | | |
| HIGH-IN | COME COUNTRIES | | | | | |
| Ranking | Cause of stillbirth | Pooled estimate (%) | 95% CI | | | |
| 1 | Unexplained | 31.2 | (17.5, 47.6) | | | |
| 2 | Placental condition | 14.4 | (2.7, 33.2) | | | |
| 3 | Congenital anomalies | 14.0 | (9.9, 18.7) | | | |
| 4 | Antepartum haemorrhage | 8.4 | (6.2, 10.8) | | | |
| 5 | Other unspecified condition | 9.3 | (1.8, 21.6) | | | |
| 6 | Infections | 6.1 | (2.6, 11.0) | | | |
| 7 | Umbilical cord condition | 5.7 | (3.7, 8.0) | | | |
| 8 | Terminations (unspecified) | 6.9 | (0.7, 18.5) | | | |
| 9 | Maternal conditions | 4.2 | (2.0, 7.2) | | | |
| | Estal and the sector istication | 3.8 | (0.6, 9.6) | | | |
| 10 | Fetal growth restriction | | | | | |
| 10 11 | Hypoxic peripartum death | 3.6 | (1.3, 6.8) | | | |
| | | 3.6 2.9 | (1.3, 6.8) (1.9, 4.1) | | | |
| 11 | Hypoxic peripartum death | | | | | |

Data source: Reinebrant et al. (2018) Abbreviations: CI – confidence interval

More recent data from prospective, population-based studies from low- and middle-income countries provide further insights into the causes of stillbirth. The Global Network study group (McClure et al., 2015a) recently reported on causes of stillbirths from population-based registries in six low- and middle-income countries using a prospectively defined classification system (McClure et al., 2018). Overall, asphyxia was the leading cause of death accounting for

almost half of stillbirths (46.6%), followed by infections (21.3%), unknown causes (17.1%), congenital anomalies (8.4%) and prematurity (6.6%). It was noted that regional differences existed across countries with infections being the leading cause among sub-Saharan African sites. This study also determined causes separately for macerated (antepartum) vs non-macerated (intrapartum) stillbirths. For macerated stillbirths, the cause of death was either infection (32.3%), asphyxia (28.1%), or was unknown (30.1%), while 10.8% were due to congenital anomalies. Over half of non-macerated stillbirths were caused by asphyxia (55.4%), followed by infection (16.1%), unknown causes (11.8%), prematurity (9.7%), and congenital anomaly (7.2%) (McClure et al., 2018).

Also recently, the AMANHI study group published population-based estimates of causes of stillbirths for 11 community-based settings in eight countries of South Asia and Sub-Saharan Africa as part of a prospective cohort study (Ahmed et al., 2018). Cause of death was established for 71% of antepartum and 81% of intrapartum stillbirths using verbal autopsy. Complications in labour and delivery, hypertensive disorders, infections, and placental complications leading to antepartum haemorrhage accounted for 80% of intrapartum deaths. For antepartum stillbirths hypertensive disorders, infections, and placental conditions were the identified cause of three-quarters of deaths (Ahmed et al., 2018). There were marked differences according to region in this study as well with infections accounting for half (50%) of antepartum stillbirths in sub-Saharan African sites compared with only 18% across South Asian sites (Table 5). Hypertensive disorders were the cause of substantially more intrapartum and antepartum stillbirths in South Asia compared to Sub-Saharan Africa (20% vs 4% for intrapartum stillbirth and 47% vs 21% for antepartum).

| | Region | | | | | |
|---|-------------------------|-------------------|---------------------|---------|--|--|
| | South Asia [*] | | Sub-Saharan Africa# | | | |
| | % | 95% CI | % | 95% CI | | |
| CAUSE OF INTRAPARTUM STILLBIRTH | N=1 | .830 [~] | N=491~ | | | |
| Complications of labour and delivery | 57 | (55-59) | 69 | (64-73) | | |
| Complications of placenta: antepartum haemorrhage | 10 | (9-11) | 12 | (9-15) | | |
| Maternal medical conditions | | | | | | |
| Hypertensive disorder of pregnancy | 20 | (18-21) | 4 | (3-6) | | |
| Infections | 6 | (5-7) | 11 | (8-13) | | |
| Other medical conditions | 1 | (1-2) | <1 | - | | |
| Accident/injury | <1 | <1 | 0 | - | | |
| Congenital malformations | 2 | (2-3) | 1 | (0-2) | | |
| Other specific fetal cause | 3 | (2-4) | 3 | (2-5) | | |
| CAUSE OF ANTEPARTUM STILLBIRTH | N=1879 ⁺ | | N= | N=658+ | | |
| Maternal medical conditions | | | | | | |
| Hypertensive disorder of pregnancy | 47 | (45-49) | 21 | (18-24) | | |
| Infections | 18 | (17-20) | 50 | (46-53) | | |
| Other medical conditions | 2 | (2-3) | 4 | (3-6) | | |
| Accident/injury | 2 | (1-2) | <1 | (0-0.5) | | |
| Complications of placenta: antepartum haemorrhage | 21 | (19-23) | 15 | (13-18) | | |
| Complications of labour and delivery | 3 | (2-4) | 5 | (3-7) | | |
| Congenital malformations | 4 | (3-5) | 3 | (2-4) | | |
| Other specific fetal cause | 3 | (2-4) | 2 | (1-3) | | |

Table 5: Major causes of intrapartum and antepartum stillbirths based on a prospective cohort study of 11 community-based sites in South Asia and sub-Saharan Africa

Source: Data sourced from Ahmed et al. (2018)

*South Asian countries included Bangladesh (Sylhet), India (Haryana & Uttar Pradesh), and Pakistan (Karachi & Matiari)

"Sub-Saharan African sites included Democratic Republic of Congo (North & South Upangi), Ghana (Brong Ahafo), Kenya (Western Province), Tanzania (Ifkara, Pemba) and Zambia (Southern Province).

[~]Represents intrapartum stillbirths with an identifiable cause of death. In South Asian sites, 20.0% (455/2285) and in sub-Saharan African sites 17.6% (105/596) of intrapartum stillbirth had no identifiable cause.

⁺ Represents antepartum stillbirths with an identifiable cause of death. In South Asian sites, 25.0% (626/2505) and in sub-Saharan Africa sites 39.7% (434/1092) of antepartum stillbirth had no identifiable cause of death

RISK FACTORS ASSOCIATED WITH STILLBIRTH

Most of the existing evidence on risk factors for stillbirth is primarily from rigorous studies in high-income settings. In low- and middle-income countries, risk factor studies are mostly from small population-based, prospective or facility-based studies, and two systematic reviews. Because of the absence of large, nationally-representative studies it is difficult to generalise findings at a country-level. Lawn and colleagues (2016) published a global comparative risk factor analysis to provide guidance for countries on what to focus on presenting modelled population attributable risks for 12 modifiable risk factors associated with stillbirth by different regions. These are summarised in <u>Table 6</u>. Infections, including malaria and syphilis, and preexisting maternal conditions such as diabetes and hypertension disproportionately affect lowand middle-income countries in Southern Asia and Sub-Saharan Africa. Post-term pregnancies and maternal age over 35 years were also important demographic factors across all regions. Overweight and obesity, and tobacco use were factors contributing to a substantial proportion of stillbirths in middle- to high-income countries.

| | REGION* | | | | | | | | |
|---------------------------------------|-----------|-------------------------------|------------------|---------------------------|---|-----------------------------------|-----------------|---------------------------------|-----------|
| | Global | Sub- Sahar an Africa | Southern Asia | South- eastern Asia | Northern Africa & Western Asia | Caucasu s & Central Asia | Eastern Asia | Latin America & Caribbean | Developed |
| Risk factor | PAF % | | | | | | | | |
| DEMOGRAPHIC AND FERTILITY | | | | | | | | | |
| Maternal age (>35 years) | 6.7 | 8.3 | 4.7 | 8.7 | 8.8 | 4.9 | 3.3 | 6.7 | 8.5 |
| INFECTIONS | | | | | | | 1 | | |
| Syphilis | 7.7 | 11.2 | 6.1 | 10.5 | 1.3 | 1.5 | 1 | 3.7 | 0.9 |
| ніх | 0.3 | 0.7 | 0 | 0.1 | 0 | 0 | 0 | 0.1 | 0 |
| Malaria | 8.0 | 19.7 | - | - | - | - | - | - | 0 |
| NON-COMMUNICABLE DISEASE | & OBESITY | | | | | | | | |
| Overweight & obesity | 10.0 | 10.0 | 8.0 | 8.0 | 22.0 | 17.0 | 7.0 | 19.0 | 18.1 |
| Maternal pre-existing diabetes | 7.6 | 8.7 | 7.0 | 6.3 | 11.5 | 4.5 | 4.8 | 4.6 | 2.8 |
| Maternal pre-existing hypertension | 10.4 | 11.7 | 10.2 | 9.0 | 10.7 | 10.1 | 7.0 | 8.0 | 7.0 |
| Pre-eclampsia | 2.6 | 3.1 | 2.3 | 2.7 | 1.1 | 3.1 | 2.3 | 1.8 | 2.7 |
| Eclampsia | 2.1 | 3.3 | 1.6 | 0.9 | 2.2 | 0.1 | 0.2 | 0.8 | 0.1 |
| FETAL FACTORS | | | | | | | | | |
| Post-term pregnancy (≥42 weeks) | 14.0 | 14.9 | 14.9 | 14.9 | 14.9 | 8.0 | 8.0 | 8.0 | 4.2 |
| Rhesus disease | 0.7 | 0.7 | 0.8 | 0.1 | 0.9 | 1.2 | 0.1 | 0.8 | 0.6 |
| LIFESTYLE & ENVIRONMENTAL I | ACTORS | | | | | | | | |
| Tobacco | 1.6 | 1.0 | 1.5 | 2.8 | 2.8 | 1.0 | 1.0 | 4.7 | 6.4 |

Table 6: Population attributable risk of factors associated with stillbirth globally and by region

Source: Data sourced from Lawn et al. (2016)

Abbreviations: HIV- Human Immunodeficiency virus, PAF – Population Attributable Fraction

The next section outlines in detail the evidence on some of the major risk factors associated with stillbirth mentioned above, focusing on those that are most relevant for low- and middleincome country settings. These have been broadly grouped into the following six categories, I) Maternal factors - maternal age, parity, interpregnancy interval, previous adverse pregnancy outcome, II) Maternal conditions - hypertensive diseases, diabetes, infections, and malnutrition III) Fetal factors - male sex, IV) Socio-demographic factors - socio-economic status and maternal education, V) Access to healthcare - antenatal care and skilled birth attendance, VI) Fetal wellbeing - reduced fetal movement.

MATERNAL FACTORS

Maternal age

Both advanced maternal age (defined as aged 35 years and older) and very young age at childbirth are associated with increased odds of stillbirth across all settings (Gordon et al., 2013; Huang et al., 2008; Lean et al., 2017a; Waldenstrom et al., 2015). In many countries, there is a U-shaped relationship between maternal age and stillbirth (Spong, 2011). Lawn et al. (2016) estimated that almost 7% of stillbirths globally can be attributed to older maternal age (>35 years). An independent association between older maternal age and stillbirth has been consistently documented in several large-scale studies controlling for other factors that have a higher incidence in older women (including gestational diabetes, obesity, hypertension, and multiple gestation) (Flenady et al., 2011a). However, an independent relationship between young maternal age and increased risk of stillbirth has not been clearly established. Different studies use different categorisations and lower cut-offs for young age ranging from below 16 years to below 20 years. Population-based studies from high-income countries find that the impact of young maternal age on stillbirth risk is usually reduced or disappears once other factors related to social disadvantage including education, socio-economic status, and smoking are taken into account (Canterino et al., 2004). Findings from studies in low-resource settings are more variable, again complicated by varying age cut-offs (Althabe et al., 2015; Ganchimeg et al., 2013).

High-quality data from studies in low-and middle-income countries are scarce, but generally, both advanced and young maternal age has been found to increase the odds of stillbirth (Aminu et al., 2014; Saleem et al., 2018). A multi-country, prospective, population-based study of five low-income countries in Africa, South Asia, and Latin America identified both young maternal age (which was defined as <20 years) and advanced maternal age of over 35 years as risk factors for stillbirth (Saleem et al., 2018). A ten-year review of hospital records in India reported 2.3 times increased odds of stillbirth in women aged 35 years or more, and over six times among women below 20 years (Bhattacharyya & Pal, 2012). Similarly, in a case-control study in urban Dhaka, Bangladesh, women aged 35 years or more had 2.6 times the odds of stillbirth (Nahar et al., 2013). In Eastern Uganda, women aged 30 years or more had four times increased risk to stillbirth compared to women aged 20-30 years, while women below 20 years had over three times the risk of stillbirth (Nankabirwa et al., 2011). A study of four million health facility births in China found very high odds of stillbirth in women younger than 15 years (OR: 4.3; 95% CI: 3.5, 5.3) while the odds of stillbirth among women over the age of 30 years increased incrementally from 1.3 for women aged 35 to 39 years, to 2.0 for women aged 45-49 years (Zhu et al., 2016).

The underlying mechanisms behind the increased risk in women of young maternal age below 16 years, is most likely a result of physical immaturity, pelvic size, and complications during labour. The mechanism behind the increased risk of older women is less clear. Pregnancy complications/conditions such as hypertension and diabetes are more common in older women, but studies indicate that even when these are adjusted for, maternal age still remains an independent risk factor (Fretts et al., 1995). A more direct effect of maternal age due to placental insufficiency or dysfunction has been pinpointed as a potential mechanism for increased susceptibility of women to stillbirth as well as fetal growth restriction (Jolly et al., 2000; Lean et al., 2017b; Naeye, 1983). Recently, research into the impact of paternal age has also demonstrated an increased risk of adverse outcomes including stillbirth and miscarriage (Nybo Andersen & Urhoj, 2017).

PREGNANCY AND OBSTETRIC HISTORY

Parity

Parity is also commonly reported to be associated with an increased risk of stillbirth in low- and middle-income settings. Both primiparity and grand multiparity (parity equal to or greater than five pregnancies) show an increased risk of stillbirth in several studies from low- and middle-income countries (Aminu et al., 2014). A prospective cohort study from Eastern Uganda found that nulliparous women had over seven times the odds of stillbirth (OR: 7.2; 96% CI: 2.0, 25.5) (Nankabirwa et al., 2011; Ronsmans et al., 2008). In rural Ghana, primiparity increased the odds of antepartum stillbirths by nearly three times (OR: 2.84, 95%CI: 2.24, 3.61) and intrapartum stillbirths by almost two times (OR: 1.91, 95% CI: 1.45, 2.51) compared to women with two children (Ha et al., 2012).

Although not as much of a concern in high-income settings, the prevalence of high fertility and therefore, high parity, is common in many low- and middle-income countries, and some but not all studies have found an association with stillbirth. There are, however, variations in the

categorisation of parity or gravidity which make it difficult to make comparisons. In a recent prospective study in five low-income countries, Saleem et al. (2018) reported risks ranging from 1.3-1.4 times greater in women with three or more children compared to women with a parity of between one to two. A large prospective study using data from a perinatal database of 19 Latin American countries found that women with four or more children had a relative risk of stillbirth of 1.52 (95% CI: 1.39, 1.67) (Conde-Agudelo et al., 2000).

Grand multiparity is closely related to other factors that are associated with stillbirth including maternal age and lower socio-economic status. Examination of the interaction between parity and advanced maternal age has not been assessed adequately in low- and middle-income settings. Research from high-income countries demonstrates that stillbirth risk is raised in primiparous women aged 35 years or more compared with primiparous women below 35 years (Waldenstrom et al., 2015). A population-based study from a demographic surveillance site in Uganda found that nulliparity and grand multiparity alone were not associated with stillbirth, but that women aged over 35 years and with grand multiparity had increased odds of stillbirth (OR: 1.97, 95% CI: 1.32, 2.89) (Kujala et al., 2017).

Interpregnancy interval

Interpregnancy interval (IPI) is the length of time between the date of the previous birth to the next conception. Both very short (<12 months) and very long intervals (≥59 months) have been associated with adverse pregnancy outcomes including stillbirth (Conde-Agudelo et al., 2005; Hegelund et al., 2018). However, the outcome of the preceding pregnancy impacts on the risk associated with the subsequent interpregnancy interval. A recent systematic review and meta-analysis found that an IPI of less than six months after a miscarriage did not increase the risk of stillbirth in the subsequent pregnancy (Kangatharan et al., 2017). The suggested mechanism underlying short intervals and stillbirth risk is related to the biological effects of maternal nutritional depletion and nutritional deficiency particularly of folate and iron stores (King, 2003; Smits & Essed, 2001). Confounding by prematurity has also been proposed as another explanation for the effect of short birth interval suggesting short gestation is responsible (Stanton, 1996). The associated with advanced maternal age, or multi-gravidity.

In 2005, the WHO recommended a birth space of at least 24 months (equal to a pregnancy interval of 33 months) following the birth of a live born infant, and a minimum of six months

following a miscarriage (WHO, 2007b). However, studies since have contradicted these recommendations; DaVanzo et al. (2012) in their cohort study in Bangladesh found that IPI of less than or equal to three months after a miscarriage were more likely to result in a live birth compared to an interval of 6-12 months. A large Danish registry study also found that the risk of miscarriage was reduced with IPIs of less than six months (Hegelund et al., 2018).

Several studies from low-income countries have found increased risk or odds of stillbirth with shorter intervals; however, there are variations in the measurement and categorisation of pregnancy intervals across studies. In Uganda, women with IPI of less than 33 months had 1.5 (95% CI: 1.09, 1.98) times higher odds of stillbirth (Kujala et al., 2017). Williams et. al. (2008) in their study of 80 000 births between 1992-2002 to women in rural North India found three times increased odds of stillbirth (OR: 3.18, 95% CI: 2.69, 3.57) among births with intervals below 18 months.

Previous stillbirth or other adverse pregnancy outcome

There is strong evidence of an association between previous stillbirth and increased risk of stillbirth in the subsequent pregnancy from several studies across all settings (Aminu et al., 2014; Flenady et al., 2011a). The magnitude of the risk depends on the cause of death in the preceding pregnancy with an increased likelihood of recurrence when the cause is related to placental abruption, hypertensive diseases, or other genetic causes (Reddy, 2007); while for unexplained stillbirths and other causes the evidence is conflicting. Previous adverse pregnancy outcomes such as small for gestational age and preterm birth are also important risk factors for a subsequent stillbirth (Smith et al., 2007; Surkan et al., 2004). Unfortunately, data on causes of previous stillbirths or even the outcome of previous births are often not readily available for low- and middle-income countries.

A systematic review and meta-analysis on the risk of recurrent stillbirth found almost five times higher risk of stillbirth in second pregnancies if the first pregnancy was a stillbirth (OR: 4.77, 95% CI: 3.77, 6.18) in studies from high-income countries (Lamont et al., 2015). Most studies from low- and middle-income countries vary in their assessment of whether a woman had a previous stillbirth or if they had any previous pregnancy loss which includes miscarriages and abortion, but consistently show an increased likelihood of stillbirth with any previous pregnancy loss. Ouyang (2013) in their examination of outcomes of women's second pregnancies using survey data from 23 developing countries found that those who had a stillbirth in their first pregnancy had a 2.35 times higher odds of stillbirth (95% CI: 1.65, 3.37) in their second pregnancy, and also had increased risk of giving birth to a low birthweight baby. McClure et al. (2015b) in their prospective, population-based study of around 270 000 births from seven sites across six lowand middle-income countries found that a prior pregnancy loss increased the relative risk to stillbirth in the subsequent pregnancy by 2.4 times (95% CI: 2.2, 2.7) compared to women with no prior loss. Smaller studies have found much higher risks; a population-based study of over 34 000 birth outcomes between 1984 and 2011 in Eastern Uganda found that women with any previous adverse outcome had over six times the odds of stillbirth (OR: 6.16, 95% CI: 4.26, 8.88) (Kujala et al., 2017). In a large population-based cohort study including over 80 000 babies in rural Ghana, women had around ten times increased odds of having an intrapartum stillbirth (OR: 14.12, 95% CI: 8.44, 11.77) and antepartum stillbirth (OR: 14.12, 95% CI: 12.27, 16.24; if she had experienced one or more previous stillbirths (Ha et al., 2012). A prospective cohort study with 1688 women in Tanzania reported over seven times (OR: 7.50, 95% CI: 3.23, 24.3) increased risk of stillbirth among women with a previous stillbirth (Watson-Jones et al., 2007).

MATERNAL CONDITIONS

Hypertensive disease, diabetes, and infections

It is critically important to understand maternal conditions associated with stillbirth given that maternal and fetal outcomes are so closely related, yet there is a dearth of data from low- and middle-income countries (Lawn et al., 2011). Several maternal conditions are associated with stillbirth. Hypertension and diabetes occur in women from all countries with about 10% of all stillbirths attributed to these two conditions; while pre-eclampsia and eclampsia account for 4.7% of stillbirths (Lawn et al., 2016). Pre-eclampsia and eclampsia occur in an estimated 6% of pregnancies and results in reduced blood flow that can lead to poor fetal growth, hypoxia and subsequently stillbirth (McClure et al., 2006). Unmanaged diabetes can lead to macrosomia and raise the risk of obstructed labour, while poorly controlled diabetes can increase the risk of congenital anomalies. Few studies have examined the prevalence of gestational diabetes among pregnant women in low- and middle- income countries. The evidence suggests that in sub-Saharan Africa the prevalence of gestational diabetes ranges from 2-14%, while in South Asia it is up to 18% (Utz & De Brouwere, 2016). The WHO Multi-Country Survey (WHO-MCS) which included 308 392 women with singleton pregnancies from 29 countries, found that hypertensive disorders were the most common maternal morbidities and reported in 2.7% of women (Vogel et al., 2014). In this study, women with pre-eclampsia and eclampsia had

significantly increased risk of both late macerated fetal death and fresh late fetal deaths (Vogel et al., 2014). A registry-based study in Tanzania found pre-eclampsia and placental abruption as the strongest maternal risk factors for stillbirth (Chuwa et al., 2017). These conditions are all manageable with timely screening and treatment in settings where blood pressure and urine protein screening is routine, and where induction of labour and caesarean section is available (McClure et al., 2006).

Infections are an important factor contributing to stillbirths in low- and middle-income countries. It is estimated that up to 50% of stillbirths could be attributed to infections (Goldenberg et al., 2010). However, there are very few studies from low- and middle-income countries that have examined the association between infection and stillbirth. Global analyses based on modelling suggest that malaria contributes to about 20% of stillbirths in sub-Saharan Africa, while syphilis accounts for 11% (Lawn et al., 2016; Moore et al., 2017). Women infected for the first time with malaria are at an increased risk of stillbirth, while recurrent infections are not usually associated with elevated risk (Shulman et al., 2001). Other infections associated with increased risk of stillbirth in low- and middle-income countries include HIV and toxoplasmosis (Aminu et al., 2014). Data is limited, but estimates suggest that 0.7% of stillbirths are attributed to HIV/AIDS in sub-Saharan Africa (Lawn et al., 2016).

Infections can lead to stillbirth via several mechanisms; either directly, through placental damage, or by causing illness in the mother. Direct infection can occur through the placenta or membranes and damage vital organs including the lungs and heart (Goldenberg & McClure, 2011). Group B streptococcus (GBS) infection can lead to stillbirth in the same way. In the case of malaria and syphilis, direct infection of the placenta results in reduced blood flow to the fetus without directly interacting with the baby. Infections may harm the fetus indirectly by causing severe illness in the mother resulting in fever or other reactions that can lead to stillbirth without directly infecting the fetus (i.e. maternal influenza and polio). Infection can also occur early in pregnancy and cause congenital anomaly that leads to fetal death which may occur later in pregnancy (Goldenberg et al., 2010).

Due to the absence of widespread availability of diagnostic tests in many low- and middleincome countries there are few studies available which have examined the magnitude of the risk of different infections with stillbirth. A cross-sectional study with 785 women in two health facilities in Ghana found that women with malaria had almost twice the risk of stillbirth (OR: 1.9, 95% CI: 1.2, 9.3) compared with those with no malaria diagnosis (Yatich et al., 2010). A hospitalbased case-control study in Sudan found that a history of malaria during the pregnancy increased the risk of stillbirth by three times (OR: 3.0, 95% CI: 1.0, 8.9) (Bader et al., 2010). Studies in sub-Saharan Africa found about three times increased risk of stillbirth in women with confirmed syphilis infection (Aminu 2014). Data on other infectious causes of stillbirth in lowand middle-income countries is limited. GBS is known to be associated with increased risk of stillbirth. However, the magnitude of this risk in low- and middle-income countries is unknown primarily due to lack of data available and challenges in capturing this data (Lawn et al., 2017). Stillbirth associated with GBS is likely to occur via ascending infection in-utero from the mother's genitourinary tract (Seale et al., 2017b). In 2015, it was estimated that there were at a minimum 57 000 fetal infections and stillbirth resulting from GBS globally, the majority (42 000) of which were in Africa (42 000) and 13 000 in Asia (Seale et al., 2017a). The proportion of stillbirths associated with GBS infection was estimated to be about 1% in high-income countries and about 4% in sub-Saharan Africa. At this time, data is not available for other low- and middle-income settings (Seale et al., 2017b).

Maternal malnutrition

Maternal malnutrition is a key contributor to fetal growth restriction and low birthweight and is significantly associated with an increased risk of stillbirth (Di Mario et al., 2007; Imdad & Bhutta, 2012). Undernutrition, anaemia, and short maternal stature have demonstrated associations with stillbirth in low and middle-income countries. The evidence on maternal anaemia and stillbirth has been variable, especially from high-income country studies. However, a recent large retrospective cohort study in England including over 14 000 women confirmed the association of maternal haemoglobin with stillbirth, adjusting for several confounders (Nair et al., 2017). The authors found that the risk of stillbirth reduced linearly for every one unit increase in haemoglobin at the first antenatal care visit (OR: 0.70, 95% CI: 0.58, 0.85) and that stillbirth risk increased by almost five times (OR: 4.97, 95% CI: 2.09, 11.79) in women with moderate to severe anaemia compared with women with normal haemoglobin levels (Nair et al., 2017).

In low- and middle-income countries, over 40% of pregnant women are anaemic (McLean et al., 2009; Rahman et al., 2016). Most studies examining the relationship between anaemia and stillbirth risk in these settings although smaller scale, show an association with moderate to severe anaemia which increases the risk of stillbirth by 3-4 times. A cross-sectional study of two hospitals in Ghana found a strong increased risk (OR: 4.3, 95% CI: 2.8, 41.8) of stillbirth among

women with severe anaemia (haemoglobin level <8 g/dL) and low serum folate (serum folate concentration <6.8 nmol/L) (OR: 3.5, 95% CI: 1.9, 17.1) (Yatich et al., 2010). A retrospective cohort study examining hospital records of 1007 pregnant women in Assam, India, found an increased risk of perinatal death (OR: 16.42, 95% CI: 4.38, 61.55) among women with severe anaemia (haemoglobin level of <7g/dL), although no separate reporting of stillbirth risk was available (Nair et al., 2016). In a prospective cohort study in Tanzania among 1688 women who received antenatal care, there was an independent association between stillbirth and anaemia (OR: 3.74, 95% CI: 1.1, 12.8) and short maternal stature (<156 cm) (OR: 2.64, 95% CI: 1.1, 6.3) (Watson-Jones et al., 2007).

FETAL FACTORS

Male sex

Male babies have approximately 10% increased risk of stillbirth compared to females (Mondal et al., 2014). Most routine statistics do not report the sex of stillborn babies and this characteristic is also not regularly captured in studies from low- and middle-income countries. A population-based study of ~34 000 births in from Eastern Uganda found that male babies had a 40% increased odds of stillbirth (OR: 1.41; 95% CI: 1.11-1.80) compared to females (Kujala et al., 2017). The importance of recording the sex of stillborn babies is to establish what the practices are that lead to a sex ratio imbalance that could be the result of intentional sex-selective practices. The mechanism behind this raised risk is hypothesised to be related to x-linked congenital conditions, poor fetal growth, and increased risk of preterm birth for male babies (Lawn et al., 2016).

SOCIO-DEMOGRAPHIC FACTORS

Socio-economic status

Low socio-economic status has been consistently associated with stillbirth between and within countries and may account for over half of stillbirths (Aminu et al., 2014; Di Mario et al., 2007). Varying definitions or indicators of socio-economic levels are used across studies to represent socio-economic disadvantage including wealth, income, maternal education or literacy, paternal education, employment status, ethnicity and urban/rural residence. The mechanism underlying the relationship is not straightforward as socio-economic disadvantage influences risk behaviours, health-seeking behaviours, exposure to other risks (household air pollution, arsenic etc.) and access to healthcare. Many studies that examine the effect of socio-economic status on stillbirth risk find that after adjusting for other factors (i.e. smoking), the effect of the relationship is reduced. A study using national data from Ghana found that increased stillbirth risk among women of low educational levels might be mediated through exposure to biomass fuels and unsafe water (Amegah et al., 2017).

Socio-economic inequalities in stillbirth risk have been established in many middle- and highincome settings (Almasi-Hashiani et al., 2017; Zeitlin et al., 2016). A recent systematic review identified that lower socio-economic status increases the risk of stillbirth by 20% and accounts for 9% of stillbirths in high-income settings (Flenady et al., 2011a; Zeitlin et al., 2016). Similar quantification of risk for low-income contexts is currently not available due to lack of data (Lawn et al., 2016). Despite a clear link between poverty and increased stillbirth risk, research studies from low- and middle-income settings show variable results. Population-based studies in rural Uganda and rural Ghana did not find any association between stillbirth and wealth or maternal education after accounting for other factors (Engmann et al., 2012; Kujala et al., 2017) and several other studies have also not observed an association (Afulani, 2016; Lee et al., 2011). A case-control study of 234 women in urban Dhaka slums reported a significant association of stillbirth with monthly household income (OR: 2.0, 95% CI: 1.0, 3.4) and maternal literacy (OR: 1.7, 95% CI: 1.2, 2.5) (Nahar et al., 2013). A recent study in South Korea examined the effect of socio-economic status on pregnancy outcomes in a setting where all women have access to antenatal care through government financing. This study found that women of lower socioeconomic status received poorer quality antenatal care, were at greater risk of obstetric complications, and were more likely to have abortions (Kim et al., 2018). A multi-site, prospective observational study in urban settings from eight countries (that included low, middle, and high-income countries) found low socio-economic status to be a significant predictor of antepartum stillbirth (Hazard ratio: 1.6, 95% CI: 1.2-2.1) among women with good access to antenatal care (Hirst et al., 2018).

Maternal education

Maternal education is frequently used as a proxy indicator of socio-economic status. Findings on the relationship between stillbirth and maternal education can vary. Saleem et al.'s (2018) multi-country study found that low levels of education were associated with increased risk of stillbirth among women in Pakistan and Guatemala, but not in India or Africa. A study in rural Ghana found a dose-response relationship between increasing socio-economic deprivation and risk of intrapartum stillbirth but not for antepartum stillbirth, and this was not affected by healthcare utilisation suggesting other factors were at play (Ha et al., 2012). Similarly, a hospital study in Nepal found that intrapartum stillbirths were significantly associated with both household wealth and maternal education (Ashish et al., 2016). The relationship between maternal education and stillbirth is not straightforward as even educated women in low-income countries face other barriers to accessing care that might increase their risk to stillbirth.

ACCESS TO CARE

Antenatal care and skilled birth attendance

Lack of or inadequate access to antenatal and obstetric care is a major risk factor for stillbirth in low- and middle-income countries. In low- and middle-income countries around 46% of women give birth outside of a health facility without the presence of a skilled birth attendant; among women in the poorest wealth quintiles, this proportion increases to about 70% (Montagu et al., 2017). Skilled birth attendance is strongly associated with lower levels of intrapartum stillbirth. Low-quality intrapartum care and lack of timely referral are also key determinants of stillbirth (Goldenberg et al., 2007; Yakoob et al., 2011).

Lack of or inadequate use of antenatal care has been found to increase the risk of stillbirth by three to four times in low- and middle-income countries (Aminu et al., 2014; Romero-Gutierrez et al., 2005). A study across seven low- and middle-income countries found that women who did not receive any antenatal care had a significantly higher risk of stillbirth, ranging from 1.5 times higher in Pakistan to over four times higher in the two sites in Africa (Kenya and Zambia) (Saleem et al., 2018). The association between stillbirth and place of childbirth varied; in some cases, there was a statistically significant increase in risk when women gave birth in a health facility, while in other locations risk was reduced. Several reasons may explain these findings, including poor quality of care and lack of timely access to caesarean sections, referral bias, and delays in care-seeking (Neogi et al., 2018) which can all result in more stillbirths occurring at the facility-level (Bailey et al., 2017; Maaløe et al., 2016). An analysis of data from 51 countries by Goldenberg et al. (2007) found that for each 1% increase in women with at least four or more antenatal care visits there was a reduction of 0.16 intrapartum stillbirths per 1000 births. This study also showed that as caesarean section rates increased up to 8%, intrapartum stillbirth rates also declined (Goldenberg et al., 2007).

The relationship between the quality of antenatal care and stillbirth has been examined to a lesser extent in low- and middle-income countries as limited data exists and there are currently no standard indicators for quality of care. Evidence suggests that content and quality of care may be low even when there is high coverage (Benova et al., 2018). There is also no evidence to indicate which specific components of antenatal care are the most important for reducing risk. Afulani et al. (2016) identified that quality of antenatal care was a strong predictor of stillbirth in Ghana and that higher quality antenatal care reduced the odds of stillbirth by about half. To date, this is the only study from a low- and middle-income country that has quantified the association between antenatal care quality and stillbirth.

Numerous factors influence access to care that need to be taken into consideration including socio-economic status, distance to care, and in many low-income countries, women's autonomy and decision-making ability (Ahmed et al., 2010; Osamor & Grady, 2016). Women without an income or access to resources must rely on and request permission from their husband or other family members to seek care (Ganle et al., 2015; Treacy et al., 2018). So even among educated women, there are other factors at play that create barriers to accessing care.

FETAL WELL-BEING

Reduced fetal movements

Maternal perception of fetal movement has long been used as a marker of fetal wellbeing (Heazell & Frøen, 2008). Studies from high-income settings suggest that between 4-16% of women will report reduced fetal movement at some point during their pregnancy (Frøen, 2004). Multiple studies have shown a relationship between reduced fetal movement and stillbirth as well as other adverse pregnancy outcomes including fetal growth restriction and preterm birth (Heazell et al., 2017; Holm Tveit et al., 2009; Sinha et al., 2007; Stacey et al., 2011). The largest case-control study to date undertaken across 41 maternity units in the UK by Heazell et al.(2018) examined fetal movement in relation to stillbirth found that women with decreased movements had over 4 times the odds of stillbirth compared with women whose movements were unchanged (OR 4.51, 95% CI: 2.38, 8.55). The relationship between reduced fetal movements and stillbirth is thought to be the result of placental dysfunction and that reduced movements are a symptom of placental insufficiency that leads to either acute or chronic fetal hypoxia (Warrander et al., 2012; Winje et al., 2012). Currently, there is very little evidence around the association between reduced fetal movements and stillbirth from low- and middle-

income country settings as this information is rarely collected from mothers who have had a stillbirth. One case-control study from urban Dhaka slums in Bangladesh assessed fetal movement and found that decreased fetal movement had 3.2 times (95% CI: 1.7, 6.2) increased risk of stillbirth (Nahar et al., 2013)

PART III: STUDY CONTEXT

The central theme of this thesis is to explore stillbirth data availability and quality, and stillbirth risk factors; however, apart from Chapter One, the remainder of this thesis draws on secondary and primary data collected from Afghanistan. This data is used to demonstrate how stillbirth data from low- and middle-income countries can potentially be improved, and to investigate how the context in which stillbirths occurs and from where stillbirth data are collected, can influence these. The demographic, socio-cultural, economic, political, and health system context all have a significant bearing on both the determinants of stillbirth but also the issues concerning stillbirth data quality. Thus, Part III provides an overview of the Afghan country context including the health system, the maternal and child health situation, what is known about stillbirth and the gaps in knowledge that this thesis aimed to address.

AFGHANISTAN COUNTRY CONTEXT

Afghanistan is a culturally-rich nation located in south-central Asia sharing borders with six different countries, the longest being with Pakistan along the east and south, Iran to the west, Tajikistan, Uzbekistan and Turkmenistan to the north, and China in the north-east (Figure 3). The country's strategic geopolitical location situates it along many trade and migration routes which have made it vulnerable to foreign conquerors from Iran and central Asia to India for decades. Afghanistan is administratively separated into eight development regions: the North-Eastern, Northern, Central Highlands, Capital, Eastern, South-Eastern, and Southern regions. These regions are further subdivided into 34 provinces that comprise a diverse range of geographic terrains, ethnicities, and languages. The landscape of the country is mostly mountainous. The Hindu Kush mountain range divides the country from the north-east to the south-west into three distinct geographic regions/zones – the mountainous central highlands, the south-west plateaus characterised by deserts, and the smaller and most fertile northern plains.

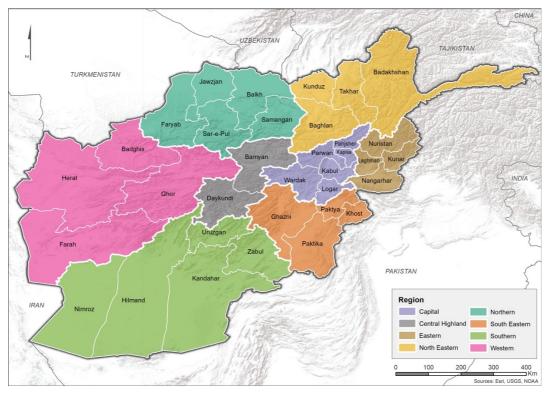


Figure 3: Map of Afghanistan showing administrative regions and provinces *Source: Map from Christou et al. (2019), and prepared by Mr Rafiqul Haider*

The distinct ethnic and tribal groups of Afghanistan are a central social feature of the population, although these are surrounded by socio-political sensitivity and actual populations numbers are a point of contention. The largest group are the Pashtuns who comprise around 40% of the population, followed by the Tajiks (30%), then the Hazaras (10%). The Uzbeks and Turkmen make up around 10% each, and the Aimaqs comprise around 5%. The number of smaller ethnic groups comprising of less than 3% of the population make up the remainder of the population and include the Nuristani, Pashai, Baloch, and several others (Barfield, 2010). Afghanistan has two official languages – Dari and Pashto. Dari language of Persian origin and considered the lingua franca, while Pashto is widely spoken in the southern regions and is the mother tongue of the Pashtuns. An additional 40 other minor languages are also spoken across the country. Afghanistan is a Muslim country; 85% of the population are Sunni while between 7-15% are Shias and Ismails. There is also a very small (<1%) non-Muslim population consisting of Sikhs and Hindus (Barfield, 2010).

POLITICAL HISTORY

Afghanistan has a long history of protracted conflict and political instability that has been ongoing for over four decades and continues to this day. In the 19th century, Afghanistan found

itself caught up in the power struggle between British India and Russia, which led to several British-Afghan wars in the late 19th and early 20th centuries referred to as the 'Great Game' in a rivalry over the control of Central Asia. The Afghans defeated the British in 1919 and Afghanistan officially gained independence. In 1926, King Amanullah declared that Afghanistan was a monarchy; he established diplomatic relations with the international community and fought for Afghanistan's first constitution which introduced several social reforms to modernise the country, including co-educational public schools and abolishing the burga. These reforms were faced with overwhelming armed opposition, and in 1929 the king was forced to abdicate from the throne and fled the country. Kabul was then seized by rebel forces who maintained power until their defeat 11 months later by King Amanullah's cousin who then took the throne until he was assassinated in 1933. King Amanullah's son, Mohammad Zahir Shah, then succeeded the throne and reigned for 40 years as the last King of Afghanistan until 1973 when he was ousted by a coup. During his reign he introduced a new constitution which turning Afghanistan into a modern democratic state with free elections, civil rights, and liberation for women. While King Shah was overseas, his cousin and former prime minister, Mohammad Daoud Khan, staged a coup and declared himself as president, establishing a republican government.

In 1978, President Khan was assassinated by the communist People's Democratic Party of Afghanistan in a violent coup known as the Saur Revolution, and Nur Mohammad Turaki became president. Opposition to reforms introduced by the party led to unrest and civil war. Eventually, Soviet forces invaded after President Turaki was assassinated to support the communist government. A Soviet-Afghan war ensued with the US supporting the Afghan Mujahadeen. The war between Afghan insurgents and Soviet occupier-backed government persisted until 1989 when the Soviet army withdrew. This was followed by two civil wars between 1992 and 1996 when the communist regime collapsed, and Afghan political parties agreed on peace and signed a power-sharing accord that led to the creation of the Islamic State of Afghanistan and appointed an interim government for a transition period. This civil war destroyed much of the social infrastructure of the country including the health system. Despite a transitional government in place, regional militias fought for power leaving the country without strong leadership allowing the Taliban to gain control in 1996. The Taliban imposed restrictive laws which limited women's movements; women were no longer allowed to work unless they were in healthcare role or leave home without being accompanied by a male relative. Female education was banned and girls could no longer attend school and the Taliban

enforced a strict code of dress where women were to be covered and wear the burqa (Barfield, 2010). There were many short- and long-term consequences to this including limitations on accessing health services and led to a generation of women today without any education.

In 2001, following the US-led invasion of Afghanistan, the Taliban were overthrown, and a new government was formed under Hamid Karzai as president and coalition NATO (North Atlantic Treaty Organisation) forces took control in 2003. Since 2002, national elections have been in place and in 2014, Ashraf Ghani became president. Since the victory over the Taliban, Afghanistan was considered a post-conflict zone but continues to face widespread insecurity and insurgency. Terrorist attacks and ongoing conflict between armed opposition groups and international forces continues and has worsened following the withdrawal of foreign troops in 2014. Since 2001, estimates indicate that over 31 000 civilians have been killed and over 40 000 have been injured (Crawford, 2016). In the first nine months of 2018 marked the highest number of civilian casualties since 2014 (UNAMA, 2018).

POPULATION DEMOGRAPHICS

The current population of Afghanistan is estimated to be around 30 million which includes a nomadic population (the *Kuchis*) of 1.5 million. An additional 2.4 million registered and up to three million undocumented Afghans reside as refugees in neighbouring Pakistan and Iran. Although urbanisation is on the rise, three quarters of the population reside in rural areas (CSO, 2017). Average population growth was 3.3% between 2004-2017 and partially a result of very high fertility rates. In 2015, women had on an average of 5.3 children– a slight increase from 2010 where the rate was 5.1 (ANPHI/MoPH et al, 2011; CSO et al., 2017). This is also a driving factor behind Afghanistan's very young population structure where 48% of the population are below 15 years of age (CSO, 2018). The average life expectancy is only 60 years – also one of the lowest in the world rankings (CSO, 2016). Large-scale immigration including an influx of Afghanist returning from living in Iran and Pakistan is also contributing to the population growth. Since 2004, there have been approximately 2.9 million documented returnees (World Bank, 2018a).

ECONOMIC SITUATION

Afghanistan is one of the least developed nations in the world, ranked 169 out of 188 countries on the human development index in 2015 (UNDP, 2016). Significant improvements in economic growth occurred from 2002 after the Taliban was removed from power as international assistance and overseas remittances flowed into the country. Most recently, however, the situation has worsened; since 2014 growth slowed to 2.7% from an average of 9% in the decade preceding as a result of the withdrawal of international security forces, a reduction in foreign aid, and worsening security situation (World Bank, 2018a). The proportion of the population living under the poverty line has increased from 37% in 2012 to 55% in 2016-2017, and food insecurity rose from 30% to 45% between 2012 to 2017 (CSO, 2018). Almost 40% of Afghanistan's labour force is either unemployed or under-employed (CSO, 2016). Adult literacy rates remain low at 35% with female literacy especially low (males 49.4%; females 19.9%) (CSO, 2018).

OVERVIEW OF AFGHANISTAN HEALTH SYSTEM

During the Taliban regime of the 1990s, the health system of Afghanistan collapsed, and most of its infrastructure was destroyed. Prior to this, health services were mostly curative 80% of which were delivered by non-government organisations (NGOs). After the fall of the Taliban, once the interim government took control in 2002, extensive efforts were made by the Afghan government with support from the international community to rebuild and strengthen the health system. The country's health indicators at this time were the worst they had ever been; the maternal mortality ratio was 1600 per 100 000 births and child mortality was at 257 per 1000 live births (Bartlett et al., 2017). Nearly one in four children were dying before the age of five. The Ministry of Public Health (MoPH) together with the support of key donors, and the international community devised a strategy to deliver a basic package of health services (BPHS) that included sustainable, cost-effective interventions to address the priority health needs of the population, particularly women and children.

The BPHS was the foundation of the primary healthcare system in rural Afghanistan, specifying a package of key services to deliver at each type of primary healthcare facility and also outlined the organisation and delivery of these services (MoPH, 2005a). The BPHS consists of seven elements: i) maternal and newborn health, ii) child health and immunisation, iii) public nutrition, iv) communicable disease treatment and control, v) mental health, vi) disability services, vii) regular supply of essential drugs. The MoPH took on a predominantly stewardship role sub-contracting health service delivery to NGOs using three different contracting mechanisms including Performance-based Partnership Agreements. NGOs deliver the BPHS in 31 of 34 of the country's provinces and the MoPH oversees the remaining three provinces using a contracting-in mechanism. In 2005, an Essential Package of Hospital Services (EPHS) was added to complement the BPHS and was designed to facilitate and promote a referral system. The EPHS established a standardised package of the services and resources that for each level of hospital services in the Afghan health system should have available including the district, provincial and regional level (MoPH, 2005b). Implementation of BPHS and EPHS is, to this day, entirely supported by external donors who provide 75% of total public health expenditure on healthcare (MoPH, 2012).

STRUCTURE OF THE HEALTHCARE SYSTEM

The health services in Afghanistan operate through a semi-hierarchical structure beginning with primary care services which are delivered through health posts and CHWs at the village or community-level, and through Health Sub-Centres (HSC), Mobile Health Teams (MHT) and Basic Health Centres (BHC). Secondary care services operate through Comprehensive Health Centres (CHC) and district hospitals in larger villages or communities of a province, and tertiary care services at the provincial and national levels are represented by provincial, regional, national and speciality hospitals. HSCs are an intermediary facility introduced to bridge the service gap between health posts and BPHS levels of service delivery, while MHTs are an extension of BHC to provide services to remote areas and geographically hard to reach areas (MOPH, 2010). Each facility type is designed to cover a certain population and delivers services as specified in the BPHS or EPHS (MoPH, 2005b, 2010). Health posts, BHCs and CHCs offer basic curative and preventative services at the community level, while district hospitals are as a link between primary care facilities and higher-level referral hospitals. Figure 4 illustrates the link between the BPHS and EPHS and Table 7 summarises the services, staff, population covered and the number of facilities available at each level of services as of 2018.

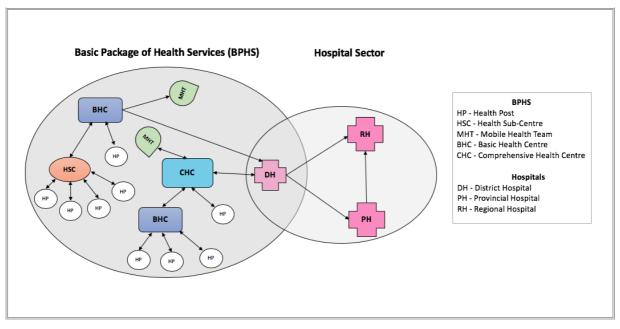


Figure 4: Link between Basic Package of Health Services (BPHS) and the hospital sector in Afghanistan's health system

Source: Adapted from MoPH (2010)

| HEALTH FACILITY TYPE | SERVICES DELIVERED AND CATCHMENT POPULATION |
|-----------------------------------|--|
| HEALTH POSTS 17 297 | Basic health services delivered by CHWs from their homes which function as health posts First point of contact for health services Staff: one female and one male CHW Catchment population: 1000-1500 people (~100-150 families) Services: Limited curative care/treatment of minor illnesses i.e. acute respiratory infections, malaria, diarrhoea. Micronutrient supplementation, distribution of condoms and contraceptives. Community DOT5, growth promotion, nutrition counselling & micronutrient supplementation, and antenatal care Female CHWs promote birth preparedness, safe home delivery with SBA, pregnancy danger signs, refer complicated cases to health centre, basic essential newborn care |
| HEALTH SUB-CENTRES 986 | Intermediate health delivery facility designed to bridge the gap between health posts and BPHS levels of service delivery Overall purpose is to increase access to health service to under-served populations Intended to serve a population between 3000-7000 Initially established in private houses Support health posts and CHWs Provides most BPHS services including health education, immunisation, family planning, TB case detection and referral and follow up of TB cases. Can treat infectious diseases including diarrhoea and pneumonia. Referral of complicated cases to higher level facilities Staff includes two technical staff - a community midwife and male nurse |
| MOBILE HEALTH TEAMS 242 | Established to ensure access to basic health services in remote areas. They are an extension of the Basic Health Centre services and services are similar to what is recommended for Basic Health Centres Staff: male health provider (doctor or nurse), female health provider (community midwife or nurse, vaccinator and driver |
| BASIC HEALTH CENTRE 873 | Small facility offering the same services as a health post but with more complex outpatient care Supervises activities of health posts in the catchment area Serves a population of 15 000-30 000 people Minimum staff: a nurse, a community midwife, and two vaccinators, community health supervisors to supervise CHWs Services: antenatal, childbirth, postpartum care and newborn care; immunisations, non-permanent family planning; integrated management of childhood diseases; treatment of malaria and tuberculosis, identification, referral, and follow-up care for patients with disabilities and mental health issues Community midwife can manage normal deliveries and refer complicated cases |

Table 7: Structure of healthcare delivery in Afghanistan

| HEALTH FACILITY TYPE | SERVICES DELIVERED AND CATCHMENT POPULATION |
|---|---|
| COMPREHENSIVE HEALTH CENTRE 432 | Provides a wider range of services than the Basic Health Centres Catchment population is 30 000-60 000 people Has limited space for inpatient care and a laboratory Staff include both male and female doctors, male and female nurses, midwives, one psychosocial counsellor, and laboratory and pharmacy technicians. Physiotherapists visit on an outreach basis from district hospitals Provides minor and essential surgery, basic emergency obstetric care and blood transfusion services should be available Handles complicated cases of malaria, and other childhood illnesses, outpatient care for patients with disabilities mental health patients |
| DISTRICT HOSPITAL 84 | At the district level handles all services specified in the BPHS including the most complicated cases Functions as a referral hospital at the district level Covers a population of 100 000 -300 000 people in one to four districts. Major surgery under general anaesthesia, comprehensive EmOC, sterilizations, X-rays, blood transfusion Comprehensive outpatient and inpatient care for patients with disabilities and mental health illness, and rehabilitation for patients requiring physiotherapy Provides a wider range of essential medicines, treatment of severe malnutrition, and laboratory services than health centres Hospital staff: doctors including female obstetricians/gynaecologists; a surgeon, anaesthetist, paediatrician; doctor serving as focal point for mental health, midwives; laboratory and X-ray technicians, pharmacist, dentist and dental technician, and 1-2 physiotherapists (male and female) |
| PROVINCIAL HOSPITAL 27 | Functions as a referral hospital for the Provincial Public Health Care System 75-250 beds Offers the same clinical services as district hospitals and sometimes a few additional specialties Staffed with surgeons, obstetricians and can manage complicated cases Usually the last referral point for patients referred from the districts. In some cases, can refer patients to higher levels of care in regional or speciality hospitals in Kabul |
| REGIONAL HOSPITAL 9 | Primarily a referral hospital with several specialities 200-400 beds Provides inpatient and emergency services at higher level than what is available in District and Provincial hospitals including specialty surgical, laboratory and imaging services |
| SPECIALITY/NATIONAL HOSPITAL 30 | Highest level of referral centres for tertiary medical care located mostly in the capital Act as referral hospitals for provincial and regional hospitals Provide education and training for healthcare workers There are two specialty women's hospitals in Afghanistan, as well as two national general hospitals with maternity wings, all located in Kabul city |

Source: Content is sourced from MoPH (2010) and (MoPH, 2005b). The number of health facilities are for 2018 and sourced from WHO (2018). Abbreviations: BHS – Basic health centre, BPHS - Basic Package of Health Services, CHW - Community Health Worker, DOTS- Directly observed treatment short-course, EmOC – Emergency Obstetric Care, SBA- Skilled birth attendant TB- Tuberculosis

OVERVIEW OF MATERNAL, CHILD AND NEONATAL HEALTH IN AFGHANISTAN

MATERNAL, NEONATAL, AND UNDER-FIVE CHILD MORTALITY

Nationally representative data on maternal, neonatal, and under-five child mortality for Afghanistan comes from several surveys completed since 2003. However, due to variation in survey methodology, representativeness, and estimation methods used, it is challenging to use these to assess the trends accurately. The first nationally-representative maternal mortality estimates were provided by the 2010 Afghanistan Mortality Survey (AMS) which reported a maternal mortality ratio of 327 deaths per 100 000. Previous to this, the only estimates available were from the 2002 the *Reproductive Age Mortality Survey* (known as RAMOS-I), a sub-national survey done in four districts of four provinces in Afghanistan which documented a maternal mortality ratio (MMR) of 1600 per 100 000 live births (Bartlett et al.). If these estimations are correct, it indicates a substantial reduction in this eight-year period, and although the RAMOS-I survey was not nationally representative, the MMR was very close to national estimates produced by WHO for the year 2000 (1900 per 100 000) using modelling methods (WHO, 2004). Serious concerns were raised following the 2010 AMS results which suggested that significant under-estimation of mortality may have resulted from non-sampling errors including under-reporting, and many researchers were sceptical about the findings labelling them as 'too good to be true' (Carvalho et al., December 2015,; Hill, 2012; Michael et al., 2013).

In 2011, a second RAMOS survey was done which showed a significant decrease in the MMR since 2002 (713 per 100 000 in Ragh and 166 per 100 000 in Kabul) (Bartlett et al., 2017). In 2017, the results of the first standard Demographic and Health Survey carried out in Afghanistan in 2015 were published and revealed that the MMR had risen sharply from the 327 in 2010 to 1291 per 100 000 live births (CSO et al., 2017). This was an alarming finding, and researchers from the RAMOS II study hypothesised that this increase was related to the increased insecurity in Afghanistan that has occurred since 2010. The MMR published by the UN Maternal Mortality Estimation group also indicated an MMR of 396 per 100 000 live births for 2015 - a 64% decline since 2000, but this used data from the 2010 AMS (WHO et al., 2015). Other modelled estimates produced by the Institute of Health, Metrics and Evaluation (IHME) estimated an MMR of 789 per 100 000 for 2015 (Kassebaum et al., 2016). These variations may be due to the different estimation methods used, as well as poor quality input data. They also highlight the difficulties with obtaining accurate mortality data in unstable conflict settings.

In 2016, a comprehensive Countdown to 2015 analysis by Akseer et al. (2016b) compiled the leading causes of maternal deaths in Afghanistan from a WHO analysis in 2003-2009 and a more recent update by the IHME in 2013. Haemorrhage, hypertensive disorders, and obstructed labour were identified as the leading causes of preventable deaths in Afghan mothers; notably, the proportion of deaths from haemorrhage appears to have reduced between these two time periods (Table 8) (Akseer et al., 2016b; GBD collaborators, 2015; Say et al., 2014).

| | Data source & year | |
|---------------------------------|--------------------|--------------|
| | WHO 2003-09 | IHME 2013 |
| | N=63 585 | N=8778 |
| | % | % |
| CAUSE OF DEATH | | |
| Haemorrhage | 46.0 | 18.6 |
| Hypertensive disorders | 15.0 | 13.5 |
| Obstructed labour | 12.0 | 9.0 |
| Sepsis/other maternal infection | 6.0 | 9.4 |
| Abortive outcome | 3.0 | 13.5 |
| Other causes | 13.0 | 21.2 |
| Other direct causes | 5.0 | 14.7 |

Table 8: Major cause of maternal deaths in Afghanistan estimated from the WHO for 2003-2009 and IHME for 2013

Source: Data from Akseer et al. (2016b)

Estimates from different sources on neonatal and under-five child mortality in Afghanistan are more consistent and show an overall steady decline. Based on estimates from the UN Interagency Group for Child Mortality Estimation, between 2003 and 2015, neonatal mortality decreased by 27% from 50 to 36 per 1000 live births, while under-five child mortality declined by 30% from 128 to 91 per 1000 live births (Akseer et al., 2016b). Recent data from the 2015 Afghanistan DHS which were published after the UN estimates indicate much lower mortality rates for 2015; this survey reported a neonatal mortality rate of 22 per 1000 live births and an under-five mortality rate of 55 per 1000 live births (CSO et al., 2017). These rates were much lower than expected, and DHS advised that they should be interpreted with caution as data quality checks pointed to very high levels of under-reporting of neonatal mortality in particular (CSO et al., 2017). In 2017, the UN Inter-agency Group published estimates for the year 2016 and reported a neonatal mortality rate of 40 per 1000 live births and under-five child mortality rate of 70 per 1000 live births for Afghanistan (UN IGME, 2017).

The leading causes of death of under-five children in Afghanistan based on data from the 2010 AMS, estimates from the UN Child Health Epidemiology Reference Group (CHERG), and the IHME for the year 2013 sources compiled by Akseer and colleagues (2016b) are presented in Table 9. Pneumonia, diarrhoea, and infections (i.e. sepsis, meningitis, tetanus) were the leading causes of under-five child deaths for 2013. Preterm birth complications and intrapartum-related death were also identified as the cause of around 10% of under-five child deaths according to CHERG estimates.

| | Data source and year | | |
|-----------------------------|---------------------------------|---|---|
| | Afghanistan Mortality Survey | Child Health Epidemiology Reference Group | Institute for Health Metrics & Evaluation |
| | 2010 | 2013 | 2013 |
| | N=1993 | N=100 106 | N=94 720 |
| | % | % | % |
| CAUSE OF DEATH | | | |
| Pneumonia | 16.5 | 20.1 | 23.9 |
| Diarrhoea | 7.7 | 13.2 | 12.6 |
| Preterm birth complications | 16.8 | 10.3 | 14.2 |
| Intrapartum related events | 16.0 | 10.5 | 4.3 |
| Measles | 1.2 | 3.9 | 1.7 |
| Injury | 5.1 | 6.5 | 6.8 |
| Malaria and HIV/AIDS | 1.0 | 0.0 | 0.5 |
| Sepsis/meningitis/tetanus | 18.5 | 11.7 | 7.5 |
| Congenital anomalies | 2.7 | 2.1 | 12.9 |
| Other child conditions | 11.5 | 19.0 | 8.7 |
| Other neonatal conditions | 3.1 | 2.5 | 7.0 |

Table 9: Major cause of death of children aged 0-59 months in Afghanistan estimated fromthe 2010 AMS, the CHERG and the IHME for 2013

Source: Data sourced from Akseer et al. (2016b)

COVERAGE OF CARE

In 2015, only 18% of women in Afghanistan received the recommended four or more antenatal care visits and 50% reported attendance of a skilled birth provider at their most recent birth (CSO et al., 2017). This is, however, a dramatic improvement from coverage levels seen in 2003-04 where only 14% of births were attended by a skilled provider (Akseer et al., 2016b). Despite these modest gains, there remains inadequate access to and utilisation of both antenatal care and quality obstetric care services (Kim et al., 2012) with stark inequities in access between urban and rural areas and across regions (Akseer et al., 2016a; Kim et al., 2016). Akseer et al. (2016b) examined correlates of coverage change in skilled birth attendance between 2003 to 2010 and identified that the key drivers were deployment of community midwives, proximity to a facility, maternal literacy, availability of nurses and quality of care. Contraceptive use in Afghanistan is also very low with only 23% of currently married women using any form of contraception and 20% using a modern method, despite over 90% of men and women having knowledge of contraceptive methods (CSO et al., 2017). Caesarean section rates in 2015 were

low with only 3% of births delivered by caesarean section - a decline from 5% reported in the 2010 AMS (ANPHI/MoPH et al, 2011; CSO et al., 2017).

There are several health system challenges that Afghanistan faces including an insufficient number of female healthcare providers and the costs of health services and treatment (Tappis et al., 2016). There are also additional contextual challenges and social and cultural norms surrounding women's low levels of autonomy and education that directly impact on care-seeking delays and child health outcomes in Afghanistan (Hirose et al., 2011; Newbrander et al., 2013).

STILLBIRTH IN AFGHANISTAN: WHAT IS KNOWN AND GAPS IN KNOWLEDGE

There is a paucity of data available on stillbirth for Afghanistan. The only national-level sources that have reported on stillbirth numbers are the two household surveys - the 2010 Afghanistan Mortality Survey which was a special (DHS) mortality survey, and the 2015 Afghanistan Demographic and Health Survey - the first standard DHS survey done in the country (ANPHI/MoPH et al, 2011; CSO et al., 2017). As discussed in previous chapters, DHS surveys underestimate the stillbirth rates considerably; therefore, modelled estimates provide the only reliable data. The most recent modelled stillbirth estimates for the year 2015 reported an estimated stillbirth rate of 26.7 per 1000 births for Afghanistan - a decline from an estimated rate of 35.7 per 1000 births in 2000, indicating an average annual rate of reduction of only 1.9% (Blencowe et al., 2016).

In the DHS surveys, stillbirths are combined with early neonatal deaths and reported under the measure of perinatal mortality, although the total number of stillbirths are available in the reports. The 2010 AMS reported a perinatal mortality rate of 42 per 1000 births and a total of 402 stillbirths among 19 489 pregnancies of seven or more months gestation in a sample of women aged 12-49 years, thus giving an overall stillbirth rate of 21 per 1000 births (ANPHI/MoPH et al, 2011). However, these figures exclude the South zone of Afghanistan (approximately one-third of the country) because of under-sampling in this area and issues with extreme under-reporting of deaths. In the 2015 Afghanistan DHS, a perinatal mortality rate of 36 per 1000 pregnancies was reported; however, this was among women aged 15-49 years. The crude stillbirth numbers reported in this period were 641 stillbirths out of 32 443 pregnancies of seven or more months giving a stillbirth rate of 19.8 per 1000 births.

household surveys are much lower than the modelled estimates described earlier confirming that under-reporting is likely to be an issue. Even with this under-reporting, what is apparent is that very little change in stillbirth rates has occurred over a five-year period.

In addition to these surveys, there have only been two published studies from Afghanistan that report on stillbirth or perinatal mortality. The most recent study by Guidotti et. al. (2009) used data from a 2006 facility-based maternal and neonatal surveillance system done in four maternity hospitals in Kabul. They reported a perinatal mortality rate of 43.5 per 1000 total births and stillbirth rate of 38.0 per 1000 total births, although they did not state how stillbirth was defined here. Of note in this study was the very high risk of intrapartum fetal deaths among babies weighing ≥2500g cases who were born by caesarean section. This was over five times (RR: 5.6; 95% CI: 4.5, 7.0) the rate observed for vaginal deliveries and was proposed by the authors to be related to inadequate monitoring of labour and quality of care at facilities (Guidotti et al., 2009). The second study by Dott et al. (2005) undertaken in one maternity hospital in Kabul city, reported an overall perinatal mortality rate of 56 per 1000 births and a stillbirth rate of 46 per 1000 births. The definition of stillbirth used in this study was fetal death at 22 weeks or more completed weeks of gestation. Over three-quarters (78%) of stillbirths in this study were antepartum stillbirths (Dott et al., 2005). The much higher rates of stillbirth observed in these facility-based studies are likely to be the result of referral bias.

Stillbirth and perinatal mortality rates were also reported as part of the WHO-MCS of maternal and newborn health done from 2010-2012 that surveyed over 300 000 women in 359 health facilities across 29 countries. This survey documented a stillbirth rate (late fetal death) of 19.9 per 1000 births for Afghanistan; however, here only 17.6% were macerated stillbirths and 82.4% were fresh or intrapartum stillbirths (Vogel et al., 2014). The considerable differences in the proportion of antepartum versus intrapartum stillbirths between this survey and the above study by Dott et al. (2005) suggest assessment of stillbirth timing is either not measured reliably or not recorded accurately.

There are even fewer studies that have examined underlying determinants of stillbirth or of perinatal mortality in Afghanistan. To date, only one published study was found using data from 2007-2008 from a maternity hospital in the province of Herat in western Afghanistan (Hirose et al., 2012). The sample in this study included near-miss women who were admitted with life-threatening conditions. The study found almost seven times increased odds of stillbirth when

care-seeking delays lasted between one and three hours compared with less than one hour (OR: 6.6, 95% CI: 1.6, 26.3). The odds of stillbirth also increased by over three times in women who lacked financial autonomy (OR: 3.1, 95% CI: 1.1, 8.4) and by 2.5 times (OR: 2.5, 95% CI: 1.0, 6.3) if the mother's residence was not in close proximity to her birth home (Hirose et al., 2012).

Other than this one study, there is very little understanding of the underlying risks or determinants for stillbirth or perinatal deaths in Afghanistan. Conclusions or generalisations cannot be made based on the findings of one small facility-based study from only one province. From the data reported in the DHS surveys, most stillbirths appear to occur in rural areas; of the 641 stillbirths reported in 2015 DHS, only 49 were in urban areas (CSO et al., 2017). With so few studies and data available to provide insight into why stillbirths occur and how they can be reduced, these deaths have gained little visibility to policy and programmers in Afghanistan. For stillbirth reduction to gain any traction and attention nationally, more research and data are needed to raise the profile of stillbirths and to identify interventions that need to be prioritised and implemented. Chapters One to Chapter Four of this thesis provide some of this evidence.

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CHAPTER ONE

THE CURRENT STATUS OF STILLBIRTH DATA AVAILABILITY IN LOW- & MIDDLE-INCOME COUNTRIES

Paper I: Beyond counting stillbirths to understanding their determinants in low-and middle-income countries: a systematic assessment of stillbirth data availability in household surveys

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Beyond counting stillbirths to understanding their determinants in low- and middle-income countries: a systematic assessment of stillbirth data availability in household surveys

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OBJECTIVE To systematically map data availability for stillbirths from all countries with Demographic and Health Surveys (DHS) surveys to outline the limitations and challenges with using the data for understanding the determinants and causes of stillbirths, and for cross-country comparisons.

METHODS We assessed data sources from the DHS programme website, including published DHS reports and their associated questionnaires for surveys completed between 2005 and 2015. RESULTS Between 2005 and 2015, the DHS programme completed 114 surveys across 70 low- and middle-income countries. Ninety-eight (86.0%) surveys from 66 countries collected stillbirth data adequately to calculate a stillbirth rate, while 16 surveys from 12 countries did not. The method used to count stillbirths varied; 96 (84.2%) surveys used a live birth history with a reproductive calendar, while 16 (14.0%) surveys from 12 countries did a full pregnancy history. Based on assessment of questionnaires, antenatal and delivery care information for stillbirths was only available in 15 surveys (13.2%) from 12 countries (17.1%). Data on maternal conditions/complications were captured in 17 surveys (16.0%), but only in six could these be linked to stillbirths. Data on other recognised risk factors were scarce, varying considerably across surveys. Upon further examination of data sets from surveys with maternity care data on non-live births, we found incomplete capture of these data; only two surveys had adequately and completely collected these for stillbirths. CONCLUSION Substantial variation exists in DHS surveys in the measurement of stillbirths, with limited scope to examine risk factors or causes. Without immediate improvements, our understanding of country-specific trends and determinants for stillbirths will remain hampered, limiting the development and prioritisation of programmatic interventions to prevent these deaths.

keywords stillbirth, foetal death, perinatal mortality, measurement, Demographic and Health Survey, low- and middle-income countries

Introduction

Abstract

Stillbirths until recently have received little attention on the global public health agenda, yet every year there are almost as many stillbirths as early newborn deaths [1]. A large proportion of stillbirths could be prevented if our understanding was improved through high-quality and complete data that accurately describe the burden, causes and risk factors. Low- and middle-income countries (LMICs) are disproportionately affected, accounting for 98% of the 2.6 million stillbirths that occurred in 2015 [2]. However, stillbirths are not routinely reported in vital statistics in LMICs, and the global and national stillbirth estimates published in 2006, 2011 and 2016 were generated using complex modelling due to the absence of quality data [1–3].

Over the past two decades, there has been little progress in reducing stillbirths, particularly in South Asia and sub-Saharan Africa, where the largest burden lies [2, 4]. The lack of country-specific data for stillbirths is a major barrier to reducing stillbirths as it prevents adequate understanding of the circumstances surrounding stillbirths, and impedes opportunities for intervention in countries with the highest burden. A systematic review of the literature examining the causes and risk factors associated with stillbirths in LMICs found only 2% of studies included were

from low-income countries and these were mostly hospital-based, highlighting the need for more populationbased studies in these settings [5]. The 2011 stillbirth *Lancet* series advocated for improved data collection in LMICs by focusing on existing, nationally representative population-based surveys including the Demographic and Health Surveys (DHS), Multiple Indicator Cluster Surveys (MICS) and demographic surveillance sites [1, 3, 4, 6]. The lack of investment in improving stillbirth data persists, and the gap was raised again in 2015 [7]; however, few changes have occurred to improve household survey data [1, 4, 7].

DHS surveys are large, nationally representative household surveys and the most widely implemented and publicly available source of population, health and nutrition information in LMICs [8]. Operating since 1984, the USAID-funded DHS programme has conducted surveys in over 80 countries [9]. DHS data are widely used to understand determinants of maternal and child health outcomes and to conduct globally comparable analyses across countries and time periods [10, 11]. They are also the main source of data for stillbirths for high-burden countries; however, these data are recognised as being inadequate, underestimating stillbirths by over a third [1] and have rarely been used to examine underlying risk factors and causes of stillbirths.

In 2014, the landmark *Every Newborn Action Plan* launched at the World Health Assembly-set targets to achieve stillbirth rates of 12 or fewer per 1000 births by 2035 and was endorsed by 190 countries [12]. To track progress towards achieving this goal and devise programmes to target the key causes and determinants of stillbirths, adequate data are imperative. Here, we methodically assess how stillbirth data are captured in the DHS, and what data are available for identifying risk factors that can inform strategies for stillbirth prevention and neonatal survival.

Methods

Study design

We reviewed data sources available through the DHS programme website, including published DHS reports and their associated questionnaires.

Sample

Data sources included all published DHS reports available on the DHS programme website and their associated questionnaires [9]. Selected Reproductive Health Surveys (RHS) reports were accessed from the Global Health Data exchange website [13] following the initial search. DHS surveys typically include three questionnaires – a household questionnaire, a women's questionnaire and in some cases, a men's questionnaire. The DHS programme also provides several optional modules or questionnaires (for malaria, HIV/AIDS, verbal autopsy questionnaire) that are incorporated by some surveys, all of which were reviewed for relevant data. The STATcompiler tool [14], an online data analysis tool on the DHS programme website, was accessed to generate stillbirth and perinatal mortality rates where possible.

Box I Key messages

- Substantial variation exists across DHS surveys in the method used to document mother's reproductive history and capture stillbirths
- There is an absence of data available on antenatal and intrapartum care for stillbirths in DHS surveys, limiting the scope to investigate stillbirths in relation to mothers' health service utilisation
- Measures of maternity care indicators particularly for components of antenatal care (ANC) show considerable variation across surveys due to country adaptations and lack of available standards to assess quality of ANC. This is important for potential examination of stillbirths, as well as other health outcomes
- Screening for maternal conditions or complications during pregnancy and delivery are not routinely assessed in DHS surveys. These measures are included in selected surveys but not part of the model DHS questionnaires, yet are important for understanding the most common conditions and complications predisposing mothers to stillbirths
- There are variations and inconsistencies in assessment of other potential modifiable risk factors for stillbirths across surveys
- There is a dearth of information collected on the causes of stillbirths with only four countries having included a verbal autopsy questionnaire on stillbirths to establish cause of death over the ten-year period examined
- There is an absence of assessment of timing of stillbirths and whether the death was antepartum or intrapartum. Timing of stillbirths is important to identify as risk factors for antepartum *vs.* intrapartum stillbirths can differ requiring different programmatic interventions
- The infrequency of DHS surveys, country-specific adaptations of questions and response options, and the absence of reporting of stillbirth rates in published reports even when data are collected are some key challenges
- The DHS surveys provide an opportunity to generate improved, globally comparative data for better understanding of the true burden, trends and risk factors for stillbirths in LMICs

Selection of surveys

We limited the search to DHS/RHS surveys completed between 2005 and 2015, and included all countries where the DHS programme conducts surveys. Over the ten-year period, countries completed multiple surveys, and rather than restrict our search to the most recent, we included all surveys due to variations in questionnaires over time. Survey types selected for inclusion included all DHS surveys (Standard DHS, Continuous DHS, Interim DHS and Special DHS) and Special surveys under the Other category (described in Box 2). The search was limited to completed surveys where full reports and associated questionnaires were available. Surveys were included only if the data were publicly available and accessible through the DHS programme. Selected RHS surveys were included in this analysis as the DHS programme integrates data from some of these surveys into its online database, and they also capture stillbirth data. We excluded surveys/reports that may be accessed or available through other websites, but not through the DHS website, as was the case for several Pacific countries (i.e. Papua New Guinea 2006-2007, Nauru 2007, Marshall Islands 2007, and Kirbati 2009, Samoa 2009, Solomon Islands 2007, Tonga 2012, Tuvulu 2007 and Vanuatu 2013) as these could not be identified in a systematic way, and data collection was not always overseen by the DHS programme.

Surveys completed prior to 2005 were excluded. Other survey types carried out by the DHS programme that do not report pregnancy outcome data were not included (i.e. AIDS Indicator Surveys, Service Provision Assessments, Malaria Indicator Surveys and Key Indicator Surveys). Ongoing surveys and completed surveys where the full reports were not yet available were excluded. We did not include MICS as they are not integrated into the DHS website and do not routinely collect stillbirth data.

Procedure

We searched for surveys on the DHS programme website [16] using the *Survey Search* function in November 2015 and applying the inclusion and exclusion criteria outlined above. The STATcompiler tool [14] was used to generate summary tables of stillbirths, early neonate deaths and perinatal mortality. Data available through STATcompiler are limited to surveys completed up to 2013, and indicators that are comparable across countries. We therefore manually collated data from published reports of surveys done after 2013 and where the method used to measure stillbirth and perinatal

Box 2 Description of different DHS and RHS survey types examined

Standard DHS surveys are nationally representative household surveys carried out approximately every five years and permit comparisons to be made over time. Sample sizes ranges from 5000 to 30 000 households. They consist of core questionnaires, which cover demographic, and health measures such as fertility, family planning, reproductive health and child health as well as optional questionnaires or modules on special topics such as maternal mortality, anaemia testing, anthropometry, domestic violence. Countries may choose to include modules as relevant for the country context

Interim DHS surveys are shorter versions of the DHS survey that focus on key performance monitoring indicators and are done between rounds of standard DHS surveys. They generally have smaller sample sizes than standard DHS surveys and often do not capture mortality indicators

Continuous DHS surveys were initially developed to replace the five-yearly surveys and arose from interest from countries to produce health information on a more regular basis. They are done at more frequent intervals (yearly or semi-annually). Currently, only Peru and Senegal conduct continuous DHS surveys and have a permanent DHS programme office located in-country [15] *Special DHS and Special Surveys* are additional surveys done in between standard DHSs that collect specialised population-level information. This includes surveys done specifically on maternal mortality, reproductive health, malaria and anaemia prevalence surveys, or may focus on specific subpopulations such as adolescent reproductive health *Reproductive Health Surveys (RHS)* undertaken in

predominantly Latin American and Eastern European countries and conducted by the Centres for Disease Control and Prevention (CDC); however, the questionnaires are based on the DHS core questionnaires and the data are comparable to DHS surveys [13]

mortality were different, and may not have generated comparable data.

Data extraction and indicator selection

We developed a customised, pre-structured spreadsheet to extract data from survey reports, questionnaires and STATcompiler-generated tables to allow for comparative assessment of data availability across countries and survey years. All DHS reports meeting the inclusion criteria were downloaded, reviewed and information abstracted into the customised database.

Survey indicators/measures assessed

Indicators were initially selected based on the DHS model questionnaires focusing on measures relevant for determining stillbirth estimates, known or potential risk factors for stillbirths, coverage of interventions known to prevent stillbirths and capture of cause-of-death data [17, 18]. We reviewed the methods/instruments used to report pregnancy outcomes to determine the proportion of surveys that recorded stillbirths, the method used to capture stillbirths, proportion of surveys with data on maternity (antenatal and delivery) care for stillbirths, maternal conditions/complications, and potential modifiable risk factors for stillbirth, and cause-of-death data. Due to the large variation in questionnaires from country adaptations and different phases of the DHS, additional indicators were added as they were identified in the surveys. We also noted whether stillbirths were reported in the narrative report for the surveys.

Stillbirth and perinatal mortality capture

We reviewed the survey methodology used to ascertain stillbirths across the various surveys. DHS surveys generally complete either a live birth history or a full pregnancy history with all women of reproductive age to measure fertility in the reproduction section of the women's questionnaire. In addition to all the mother's live births, pregnancy histories record all non-live births including stillbirths, miscarriages and abortions, whereas birth histories do not. To generate perinatal mortality rates and stillbirth rates, a birth history must be supplemented with a reproductive calendar. The reproductive calendar captures a month-by-month retrospective history of all the mothers' reproductive events in the 60-month period prior to the interview including pregnancies, live births and terminations (stillbirths, miscarriages, abortions) in addition to documenting contraceptive use. Stillbirths and perinatal mortality can be calculated directly from a full pregnancy history without the need for a calendar. Additional methods used by some surveys incorporate a live birth history form with single questions about non-live births, or a separate table for recording details of nonlive births (see Box 3 and Appendix S1a-d for examples from DHS questionnaires).

Generally, DHS surveys apply the definition of a stillbirth as a foetal death in pregnancy that occurs at seven or more months gestation [19]. This is in accordance with the WHO recommendation of reporting of stillbirths for international comparison as a late foetal death at 28 weeks or more gestation, or with a birthweight of 1000 g or more. However, in the DHS duration of pregnancy is only recorded in months, and 7 months may mean pregnancy duration is anywhere from 22 to 30 weeks of gestation. The majority of births in lowincome countries occur at home, so birthweight is often unknown, and even with facility deliveries, stillborn babies are rarely weighed, making gestational age the main criteria by which stillbirths can be based upon.

The instruments used to capture pregnancy outcomes in the DHS/RHS surveys record the duration of the mother's pregnancies in months, and in most surveys, stillbirths are determined by the analyst based on a gestational age cut-off of 7 months or more. There are some exceptions in surveys that use full pregnancy histories or where single questions are used where the mother is asked directly about the outcome of her pregnancy and whether it resulted in a live birth, stillbirth, miscarriage or abortion instead of asking about the duration of each pregnancy. It is not clear in these cases what instruction is provided to the interviewer in defining each of these outcomes to the mother. Box 3 outlines in detail how stillbirths are determined using each of the instruments.

Maternity care data

We examined the surveys to identify the proportion that collected data on maternity care received during pregnancy and delivery for stillbirths. These indicators included mother's utilisation of antenatal care (ANC) (number and timing of visits), content of ANC, details of delivery characteristics (use of skilled birth attendant, delivery location) and access to emergency obstetric care (Caesarean section, planned or emergency, other procedures).

Coverage of specific ANC components in the standard DHS model questionnaire included whether during any ANC visits mothers had their blood pressure taken, a blood or urine test, if they received antihelminths, were vaccinated against tetanus, received iron-folic acid supplements, were informed of pregnancy complications, maternal anthropometry measures assessed, and in malaria- and HIV-endemic countries, provision of antimalarial drugs and screening for HIV. Any additional ANC components identified were added to the form to highlight variations in country adaptations.

Maternal conditions or complications

We examined how many surveys captured data on antepartum conditions or complications a mother experienced during the pregnancy (severe headache, vaginal bleeding, blurred vision, seizures, fatigue, swelling of hands or feet, pale/anaemic) or during labour (i.e.

Box 3 Summary of methods used by DHS and RHS to capture mothers' reproductive history to determine stillbirths and perinatal mortality

(a) Live birth history supplemented with a reproductive calendar

- Both live birth history and reproductive calendar are needed to calculate stillbirth rates.
- The birth history asks mothers about all live births she has ever had including whether the pregnancy was single or multiple, the birth date, sex, if the baby was still alive and if not, their age at death (see Appendix S1a for example from Uganda 2011 DHS)
- The reproductive calendar records all the mothers' reproductive outcomes in the previous five years. This includes all live births and non-live births/terminations (stillbirths, abortions, miscarriages) and records the length of gestation for each pregnancy in months
- Stillbirths are determined from calendar based on the duration of the pregnancy when it ended. Any pregnancy loss that occurred during the seventh month onwards is defined as a stillbirth

(b) Pregnancy history

- The pregnancy history alone allows determination of stillbirths and perinatal mortality without the need of a reproductive calendar; however, many surveys with a pregnancy history also include the reproductive calendar and published stillbirth numbers in the reports are predominantly based on the calendar data for comparative purposes
- The pregnancy history records the result of all the mothers' pregnancies in her lifetime. Similar questions to the birth history are included, with the addition of questions about any non-live births, such as when the pregnancy ended and how many months pregnant the mother was when it ended
- Surveys vary in terms of whether the interviewer gathers the information beginning with the mother's first pregnancy or her most recent (last) pregnancy, and if the pregnancy outcome is determined by the mother by asking her whether each pregnancy resulted in a live birth, miscarriage, stillbirth or abortion (see Appendix S1b for example; used by several Central Asian and Eastern European countries, that is Armenia, Ukraine, Azerbaijan, Moldova and Kyrgyz Republic), or by the analyst based on questions on whether the baby was born alive, born dead or lost before birth, the duration of the pregnancy when it ended (see Appendix S1c for example; used by Nepal, Pakistan, Philippines, Ghana and Afghanistan). In some cases, the latter method also includes a question on whether the baby cried, moved or breathed after birth to differentiate between a stillbirth and early neonate death
- Variations exist on the information captured for non-live births; many do not ask about the gender and whether the pregnancy was a multiple or single pregnancy
- (c) Live birth history with separate section/table on non-live births
- Live birth history is done first and is followed by a separate section/table with questions for the non-live births capturing information on when the birth occurred, and how many months pregnant the mother was. It does not include whether the birth was a multiple pregnancy or the gender of the stillbirth as is done for the live birth history
- Stillbirths are determined based on the duration of the pregnancy when the pregnancy ended. Surveys that use this particular method usually also include a reproductive calendar
- This method is similar to a pregnancy history; however, as non-live births are in a separate table, they remain excluded from the maternity care section in the later part of the woman's questionnaire. This method has been adapted for the most recent Phase 7 DHS model questionnaire provided by DHS for surveys conducted from 2013 onwards and has also been used in the Albania 2008–2009 DHS and Zimbabwe 2010–2011 DHS (see Appendix S1e for example from Zimbabwe 2010–2011 DHS)
- (d) Live birth history and separate single questions for non-live births
- Includes a live birth history plus additional single questions are incorporated into the women's questionnaire to establish how many pregnancies a mother had which did not result in a live birth, including how many were stillbirths, miscarriages and abortions. Single questions may or may not include miscarriages or abortions (see Appendix S1d, for example, from Pakistan 2006–2007 DHS; used in RHS surveys including Nicaragua 2006 and Paraguay 2008)
- This may or may not include when the births occurred, or how many months pregnant the mother was. In most cases, this is not included, but could be determined from the reproductive calendar if one was included

prolonged labour, excessive bleeding, convulsions, fever with abnormal vaginal discharge, retained placenta). As these measures are not included in the DHS model surveys, we included all possible complications mentioned in any DHS survey that did include these questions. Coverage of whether care was sought for complications and type of provider were also included.

Other modifiable risk factors for stillbirths

We examined all surveys for data availability on known, modifiable risk factors for stillbirth. We did not include maternal factors and other socio-demographic risk factors known to be routinely collected in all DHS surveys or could be calculated from the data sets (such as maternal

age, parity, multiple pregnancy, pregnancy intervals, prior pregnancy termination, maternal education and socioeconomic status). Risk factors were initially chosen based on what was available in the DHS model questionnaire, and based on known risk factors in the literature, we screened DHS surveys for coverage of any additional indicators. Risk factors included women's smoking status, exposure to indoor smoke, use of biomass fuel, use of iodised salt, short maternal stature, history of diabetes, history of high blood pressure, alcohol consumption, domestic violence during pregnancy, fistula and female genital mutilation or cutting.

Verbal autopsies on stillbirths

We examined the proportion of DHS surveys that incorporated verbal autopsy tools to assess the causes of stillbirths.

Examination of data sets that capture maternity care data for stillbirths

We explored 12 of the 15 data sets from the DHS surveys identified as having collected maternity care (ANC and delivery care) data on stillbirths to identify how well these data were collected, and for how many stillbirths, data were available. Data sets for three RHS surveys were not available on the DHS website and so not included in the analysis. Data sets were downloaded from the DHS website, and using the data file from the women's questionnaire, a pregnancy outcome variable was generated using data collected from pregnancy histories to identify all live births, stillbirths, miscarriages and abortions (if the data sets had not already included such a variable) in the five years preceding the survey. For data sets where a pregnancy outcome was not already available, we defined stillbirths as a pregnancy loss (baby born dead or lost before birth) at 7 months or more gestation, with no signs of life (no movement or breathing) at birth. A miscarriage was considered a baby lost prior to 7-month gestation, while abortions were pregnany losses where something was done to intentionally end the pregnancy. DHS surveys usually collect ANC data only for the mother's most recent birth, while delivery care indicators are collected on the last two, or occasionally last three births. We restricted the analysis to the mother's most recent birth and used descriptive statistics to summarise maternity care data availability for all birth outcomes. All statistical analyses were conducted using STATA/SE version 14.2.

Results

Characteristics of surveys included

Since 1985, the DHS programme completed 373 surveys across 91 countries. We found 119 surveys across 70 countries that met our eligibility criteria. Five were subsequently excluded because they were specialised surveys focused on specific diseases (Mali 2010 Anaemia Prevalence Survey; Dominican Republic 2007 and 2013 HIV Prevalence Surveys; Rwanda 2011 Population Size Estimation Survey; Indonesia 2007 Special Young Adult Reproductive Survey). We further included six RHS surveys that provided perinatal mortality data to the DHS data repository. In total, 114 DHS and RHS surveys from 70 countries were identified and included in subsequent analysis (Figure 1). Table 1 summarises surveys by type, region, language, year and frequency. The majority (81.6%; n = 93/114) were standard DHS surveys, nine were continuous DHS (7.9%; n = 9/114), four were special surveys (3.5%; n = 4/114), and six were RHS (5.3%; n = 6/114) surveys.

Almost half (49.1%; n = 56/114) of the surveys were conducted in the sub-Saharan African region, followed by Latin America and the Caribbean (19.3%; n = 22/114); South and South-East Asia (17.5%; n = 20/114); and North Africa/West Asia/Central Asia/Europe (14.0%; n = 16/114). About half of the countries (55.7%; 39/70) had one survey over the ten-year period, while 23 (32.9%; n = 23/70) countries had two surveys each, and six countries (8.6%; n = 6/70) had completed three surveys. Peru had done seven surveys, as it has been implementing yearly continuous DHS surveys.

Stillbirth and perinatal mortality capture

Table 2 summarises the various methods used to record mother's reproductive history in the selected DHS surveys. Of the 114 surveys, 96 (84.2%) used a live birth history and 16 (14.0%) used a pregnancy history. Of the 96 that used a birth history, 89 (78.1%) were accompanied by a reproductive calendar. Most that had done a pregnancy history also included the reproductive calendar. The 16 surveys that had implemented the pregnancy history represented 13 countries predominantly in Central and West Asia and South Asia (Appendix S3). Sixteen surveys from 12 countries had used a live birth history but no reproductive calendar or any other method or questions to capture stillbirths.

Of 114 surveys, 98 (86.0%) had collected stillbirth numbers adequately to determine a stillbirth rate

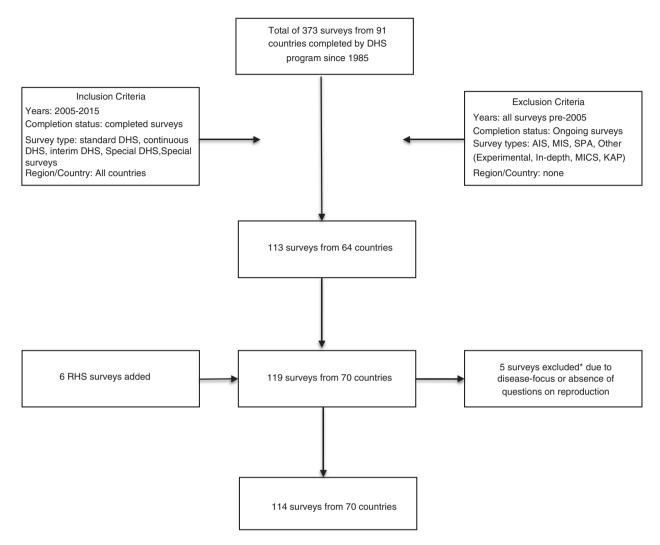


Figure 1 Flowchart summarising selection of surveys for inclusion. *Surveys excluded: Mali 2010 Anaemia Prevalence Survey; Dominican Republic 2007 and 2013 HIV Prevalence Surveys; Rwanda 2011 Population Size Estimation Survey; Indonesia 2007 Special Young Adult Reproductive Survey. AIS, AIDS indicator Survey; KAP, knowledge attitudes practices; MICS, multiple indicator cluster survey; MIS, malaria indicator surveys; RHS, Reproductive Health Surveys; SPA, Service Provision Assessment.

either using the birth history supplemented with the reproductive calendar, or a pregnancy history. The 16 surveys from 12 countries that did not collect stillbirth data adequately to calculate stillbirths or perinatal mortality are listed in Table 3. Of these, most had a single pregnancy termination question (*Have you ever had a stillbirth, miscarriage or abortion?*) but stillbirths could not be differentiated or quantified as no time period was specified through follow-up questions (i.e. *how many such pregnancies have you had in your life?*), and a reproductive calendar was not used (Appendix S3).

Availability of maternity (antenatal care and delivery care) data

Only 15 surveys (13.2%; 15/114) from 12 countries (17.1%; 12/70) captured ANC use, components of ANC received and delivery care information for stillbirths (Table 4; Appendix S4). The majority of surveys appeared to capture these data only for live births.

All surveys were reviewed for ANC component measures to identify to what extent content and quality of ANC is captured particularly in relation to important factors that may affect stillbirth risk/pregnancy outcomes. The number

| Table I Summary of DHS surveys completed between 2005 and | d |
|---|---|
| 2015 meeting inclusion and exclusion criteria | |

| | No. surveys | | |
|---|-------------|------------|--|
| Survey characteristic $N = 114$ (unless otherwise stated) | n | % | |
| Total number of surveys (2005–2015) | 114 | _ | |
| Total number of countries | 70 | - | |
| Survey type | | | |
| Standard DHS | 93 | 81.6 | |
| Continuous DHS | 9 | 7.9 | |
| Reproductive Health Surveys (RHS) | 6 | 5.3 | |
| Special* | 4 | 3.5 | |
| Interim DHS | 2 | 1.8 | |
| Region | | | |
| Sub-Saharan Africa | 56 | 49.1 | |
| Latin America and Caribbean | 22 | 19.3 | |
| South and South-East Asia | 20 | 17.5 | |
| North Africa/West Asia/Europe | 14 | 12.3 | |
| Central Asia | 2 | 1.8 | |
| Language of report | | | |
| English | 66 | 57.9 | |
| Other† | 48 | 42.1 | |
| DHS phase model questionnaire used | | | |
| V (2003–2008) | 43 | 40.6 | |
| VI (2008–2013) | 54 | 50.9 | |
| VII (2013–2018) | 4 | 3.8 | |
| NA | 5 | 4.7 | |
| Year of survey $(N = 113)$ | | | |
| 2005 | 12 | 10.6 | |
| 2005–2006 | 4 | 3.5 | |
| 2006 | 6 | 5.3 | |
| 2006–2007 | 4 | 3.5 | |
| 2007 | 9 | 8.0 | |
| 2007–2008 | 2 | 1.8 | |
| 2008 | 8 | 7.1 | |
| 2008–2009 | 6 | 5.3 | |
| 2009 | 5 | 4.4 | |
| 2009–2010 | 1 | 0.9 | |
| 2010 | 10 | 8.8 | |
| 2010–2011 | 2 | 1.8 | |
| 2011 | 8 | 7.1 | |
| 2011–2012 | 5 | 4.4 | |
| 2012 | 11 | 9.7 | |
| 2012–2013 | 3 | 2.7 | |
| 2013 | 9 3 | 8.0 2.7 | |
| 2013–2014 | 3 5 | | |
| 2014 | 5 | 4.4 | |
| Number of surveys per country in | N (no. of | | |
| time period $(N = 70)$ | countries) | | |
| 1 | 39 | 55.7 | |
| 2 | 23 | 32.9 | |
| 3 | 6 | 8.6 | |

| 2 | 23 | 32.9 |
|---------------------------|------------------------------|------|
| 3 | 6 | 8.6 |
| 4 | 1 | 1.4 |
| 5 | - | _ |
| 6 | - | - |
| 7 | 1 | 1.4 |
| *Special surveys included | the following: 2010 Afghanis | stan |

*Special surveys included the following: 2010 Afghanistan Mortality Survey 2007 Ghana Maternal Health Survey; 2012 Indonesia Adult Reproductive Survey; and 2011–2012 Laos Social Indicator Survey.

†Other languages included French, Portuguese and Spanish. DHS, Demographic Health Survey; RHS, Reproductive Health Survey. and timing of the first ANC visit was routinely assessed in all surveys with some also capturing timing of last ANC visit. There was substantial variation in the collection of coverage of key components of ANC interventions (Table 5; Appendix S4). ANC components included in the DHS model questionnaire include blood pressure screening, and blood and urine tests. Assessment of maternal anthropometry varied across different DHS phases; weight was included in the Phase 5 (2003–2008) model questionnaire only, whereas height was never in the model questionnaire, yet several surveys have chosen to include it. Coverage of other ANC components in the model questionnaire included tetanus vaccinations, consumption of iron-folate and being informed of pregnancy complications.

Almost all surveys assessed whether women had blood pressure measured (96.5%; 110/114), a urine test (96.5%; 109/113), blood test (95.6%; 109/114) and been informed about pregnancy complications (93.0%; 106/ 114). Almost three-quarters of surveys (70.2%; 80/114) asked women whether they were weighed, while 29.0% (33/114) asked whether their height was measured. Several surveys included questions on other optional ANC components such as whether the mother had an ultrasound (12.3%; 14/114), offered a syphilis test (7.1%; 8/ 113), and whether the foetal heartbeat was checked (15.0%; 17/113). Only 11 surveys (9.8%; 11/113) collected information on emergency preparedness and birth planning. Several inconsistencies were noted in the birth preparedness components, with variations in the format and response options across surveys (not shown).

Availability of data on maternal conditions or complications

Only 17 (14.9%; 17/114) surveys potentially captured data on maternal conditions or complications in the antenatal period, and of these, eight identified if subsequent care was sought (Appendix S5). Slightly more surveys included questions about delivery complications (19.3%; 22/114), most of which included details of the complications. Only four surveys determined whether care was sought for delivery complications and from which provider type or location. Of the 16 surveys that obtained information on maternal complications, only six included a pregnancy history that may allow linking of this information to stillbirths. Four surveys asked about complications without specifying if they were antepartum or intrapartum (2010 Afghanistan Mortality Survey (AMS), 2007 Ghana Maternal Health Survey (MHS) and 2011-2012 and 2005-2006 Honduras DHS). We also found large variations in how questions were phrased – a

| Method/instrument included in | No. surveys | (N = 114) | No. countries $(N = 70)$ | | |
|---|-------------|-----------|--------------------------|------|--|
| DHS survey to record mother's reproductive outcomes | n | % | n | % | |
| Reproductive calendar included | 89 | 78.1 | 56 | 80.0 | |
| Live birth history | 96 | 84.2 | 59 | 84.3 | |
| Full pregnancy history (live + non-live births) | 16 | 14.0 | 12 | 17.1 | |
| Live birth history + separate non-live birth history table | 2 | 1.8 | 2 | 2.9 | |
| Full pregnancy history + reproductive calendar included | 12 | 10.5 | 10 | 14.2 | |
| Live birth history only (no reproductive calendar) | 16 | 14.0 | 12 | 17.1 | |

Table 2 Instruments used in DHS/RHS surveys to record mother's reproductive history and capture pregnancy outcomes for calculation of stillbirths and perinatal mortality

DHS, Demographic and Health Survey; RHS, Reproductive Health Survey.

| Table 3 Countries and surveys where stillbirths could not be | 2 |
|--|---|
| quantified based on assessment of questionnaires | |

| Country | Year | Survey type |
|--------------------------|-----------|----------------------|
| Cambodia | 2005 | Standard DHS |
| Cameroon | 2011 | Standard DHS |
| Congo Brazzaville | 2011-2012 | Standard DHS |
| Congo Brazzaville | 2005 | Standard DHS |
| Congo DRC | 2011-2012 | Standard DHS |
| Congo DRC | 2007 | Standard DHS |
| Cote d'Ivorie | 2011-2012 | Standard DHS |
| Dominican Republic | 2013 | Standard DHS |
| Dominican Republic | 2007 | Standard DHS |
| Gabon | 2012 | Standard DHS |
| Guinea | 2012 | Standard DHS |
| Haiti | 2012 | Standard DHS |
| Haiti | 2005-2006 | Standard DHS |
| Laos | 2011-2012 | Special Survey (SIS) |
| Rwanda | 2007-2008 | Standard DHS |
| Togo | 2013-2014 | Standard DHS |
| 16 Surveys, 12 countries | | |

DHS, Demographic and Health Survey; DRC, Democratic Republic of Congo; SIS, Social Indicator Survey.

comparison of selected countries is provided in Appendix S6. For many, the response options did not allow the interviewer to specify the time period complications occurred. Differences in response options for questions regarding complications varied across all surveys with no two surveys being similar. The India 2005–2006 NFHS asked mothers about each symptom rather than asking an open question about what problems they experienced, thereby prompting responses.

There were also variations in whether either antepartum or delivery complications, or both were collected and this

Table 4 Countries and surveys where ANC and delivery caredata captured for all births (live births & stillbirths) based onassessment of questionnaires

| Country | Year | Survey type |
|--------------------------|-----------|----------------------|
| Afghanistan | 2010 | Special survey (AMS) |
| Armenia | 2010 | Standard DHS |
| Armenia | 2005 | Standard DHS |
| Azerbaijan | 2006 | Standard DHS |
| El Salvador | 2008 | RHS |
| Georgia | 2005 | RHS |
| Ghana | 2007 | Special survey (MHS) |
| Jamaica | 2008-2009 | RHS |
| Moldova | 2005 | Standard DHS |
| Nepal | 2011 | Standard DHS |
| Nepal | 2006 | Standard DHS |
| Pakistan | 2012-2013 | Standard DHS |
| Philippines | 2008 | Standard DHS |
| Philippines | 2013 | Standard DHS |
| Ukraine | 2007 | Standard DHS |
| 15 Surveys, 12 countries | | |

AMS, Afghanistan Mortality Survey; DHS, Demographic and Health Survey; RHS, Reproductive Health Survey; MHS, Maternal Health Survey.

varied within countries as well. The 2007 Bangladesh DHS included questions on delivery complications but not for antepartum conditions/complications, while in the 2011 survey the questions on complications were absent.

Assessment of other potential risk factors for stillbirth

The inclusion of questions about other potential risk factors for stillbirth was inconsistent across surveys. Table 6 summarises the proportion of all DHS/RHS surveys that

| | Surveys that m of indicator | easured coverage |
|---|-----------------------------|------------------|
| Received any ANC 'rovider of ANC Place of ANC Months pregnant at first ANC visit Months pregnant at last ANC visit* Fotal number of ANC visits received mponents/content of ANC Blood pressure measured† Weight measured*'† Height measured*'† Height measured*'† Irine test† ($n = 113$) Blood test† nformed of where to seek care for complications*'‡ ($n = 113$) formed of where to seek care for complications* ($n = 113$) Birth planning and birth preparedness done*'† ($n = 113$) JItrasound done* Foretal heartbeat was checked* ($n = 113$) JItrasound done* Foretal heartbeat was checked* ($n = 113$) JItrasound done* Counselled on breastfeeding*'† ($n = 113$) Offered a syphilit test* ($n = 113$) Prefere taus vaccination Received tetanus vaccination Received tetanus vaccination Received iron supplementation during last pregnancy Malaria prophylaxis Assessed for vitamin A deficiency Differed and tested for HIV/AIDS during ANC Counselled on HIV/AIDS during ANC Counselled on HIV/AIDS during ANC Divery/intrapartum care indicators killed attendance at delivery Place of delivery Referral for delivery* Jse of safe delivery kit* Caesarean section done The count of Caesarean section (planned or emergency) Reason for Caesarean section * | n | % |
| Coverage of ANC | | |
| Received any ANC | 112 | 98.2 |
| Provider of ANC | 112 | 98.2 |
| Place of ANC | 110 | 96.5 |
| Months pregnant at first ANC visit | 110 | 96.5 |
| Months pregnant at last ANC visit* | 28 | 24.6 |
| Total number of ANC visits received | 111 | 97.4 |
| Components/content of ANC | | |
| Blood pressure measured [†] | 110 | 96.5 |
| Weight measured*' [*] | 80 | 70.2 |
| Height measured*',† | 33 | 28.9 |
| Urine test† $(n = 113)$ | 109 | 96.5 |
| Blood test† | 109 | 95.6 |
| Informed signs of pregnancy complications \dagger ; $(n = 113)$ | 106 | 93.0 |
| Informed of where to seek care for complications [*] ($n = 113$) | 61 | 53.5 |
| Birth planning and birth preparedness done [*] , \dagger (<i>n</i> = 113) | 11 | 9.7 |
| Ultrasound done* | 14 | 12.3 |
| Foetal heartbeat was checked* $(n = 113)$ | 17 | 15.0 |
| Uterine height measured* | 19 | 16.7 |
| Stomach was examined* | 10 | 8.8 |
| Counselled on breastfeeding*', $(n = 113)$ | 6 | 5.3 |
| Offered a syphilis test* $(n = 113)$ | 8 | 7.1 |
| Other ANC components | | |
| Received tetanus vaccination | 107 | 93.9 |
| Received iron supplementation | 110 | 96.5 |
| Took calcium supplementation during last pregnancy | 4 | 3.5 |
| Took antihelminths during last pregnancy | 79 | 69.3 |
| Malaria prophylaxis | 60 | 52.6 |
| Assessed for vitamin A deficiency | 50 | 43.9 |
| Offered and tested for HIV/AIDS during ANC | 79 | 69.3 |
| Counselled on HIV/AIDS during ANC | 70 | 61.4 |
| Delivery/intrapartum care indicators | | |
| Skilled attendance at delivery | 112 | 98.2 |
| Place of delivery | 113 | 99.1 |
| Referral for delivery* | 5 | 4.4 |
| Use of safe delivery kit* | 6 | 5.3 |
| Caesarean section done | 112 | 98.2 |
| Timing of Caesarean section (planned or emergency) | 6 | 5.3 |
| Reason for Caesarean section* | 4 | 3.5 |
| Other procedures done during delivery (vacuum, forceps, blood transfusion)* | 5 | 4.4 |
| | 15 | 13.2 |
| Surveys with mother's AINC utilisation available for stillbirths | 13 | 13.2 |
| Surveys with delivery care data available for stillbirths | 14 | 12.3 |

| Table 5 Availability | of ANC and delivery | care coverage indicators in | DHS/RHS surveys done between | 2005 and 2015 |
|----------------------|---------------------|-----------------------------|------------------------------|---------------|
|----------------------|---------------------|-----------------------------|------------------------------|---------------|

*Indicator not included in DHS model questionnaire.

†Considered one of the eight components of WHO's focused ANC package.

‡No longer included in DHS model questionnaire as of last phase (Phase 7).

ANC, Antenatal Care; DHS, Demographic and Health Survey; RHS, Reproductive Health Survey.

include questions to capture other modifiable risk factors for stillbirth. Mothers' smoking status was captured in almost all surveys (86.8%; 99/114), while exposure to

second-hand smoke in the home was only assessed by less than half (40.4%; 46/114). The type of fuel used for cooking was examined by most (96.5%; 110/114), and

about three-quarters (74.6%; 85/114) determined exposure to smoke inside the home from cooking, and household consumption of iodised salt (69.3%; 79/114). Very few surveys assessed the prevalence of obstetric fistula (18.4%; 21/114) and female genital mutilation/cutting (27.2%; 31/114), and about half (55.3%; 63/114) had asked women whether they had ever experienced violence while pregnant. Fewer than 20% of surveys asked mothers if they had ever been diagnosed with high blood pressure, diabetes or anaemia (Table 6).

Verbal autopsies on stillbirths

Only six of 114 surveys incorporated a verbal autopsy questionnaire, and of those, four had a separate verbal autopsy module for stillbirths (Afghanistan 2010 AMS, Ghana 2008 DHS, Nepal 2006 DHS, and Pakistan 2006–2007 DHS). Two of these (Nepal 2006 DHS and

Table 6 Availability of data on potential modifiable risk factorsand preventive interventions for stillbirths in DHS/RHS surveysconducted between 2005 and 2015

| | DHS surveys with data available | | | |
|--|---------------------------------------|------|--|--|
| Potential modifiable risk factor for stillbirth $(N = 114 \text{ unless otherwise specified})$ | п | % | | |
| Mother's smoking status | 99 | 86.8 | | |
| Mother's consumption of alcohol/drugs | 15 | 13.2 | | |
| Type of fuel used for cooking | 110 | 96.5 | | |
| Exposure to indoor smoke from cooking | 85 | 74.6 | | |
| Exposure to second-hand smoke from other members in the household smoking | 46 | 40.4 | | |
| Consumption of iodised salt* | 79 | 69.3 | | |
| Female genital mutilation/circumcision [†] | 31 | 27.2 | | |
| Ever had fistula† | 21 | 18.4 | | |
| Domestic violence during pregnancy† | 63 | 55.3 | | |
| Ever been diagnosed with diabetes [†] $(n = 113)$ | 19‡ | 16.7 | | |
| Ever been diagnosed with high BP or hypertension \dagger ($n = 113$) | 23§ | 20.2 | | |
| Ever been diagnosed with anaemia [†] $(n = 113)$ | 5 | 4.4 | | |
| Household possession of mosquito nets (n = 113) | 69 | 60.5 | | |
| Households use of insecticide treated mosquito nets [†] $(n = 113)$ | 59 | 51.8 | | |

*Assessed by testing of salt at time of survey.

†These are optional modules in DHS and not included in DHS model questionnaire.

‡Four surveys that collect this only for women aged over

35 years or over 40 years of age.

§Three surveys that collect this only for women aged over 35 years or over 40 years of age.

Pakistan 2006–2007 DHS) reported the timing (antepartum or intrapartum) of stillbirth in the report's narrative, and one (Pakistan 2006–2007 DHS) reported the cause of death, despite all four having collected this information. The Swaziland 2006–2007 DHS survey had included a question about the timing of stillbirths in the main part of the women's questionnaire – 'Was this last stillbirth macerated or fresh? By macerated I mean the body may have started to decompose'; the results of these were not reported in the narrative DHS report.

Absence of reporting of stillbirth estimates in DHS narrative reports

Although the majority of countries had collected data on stillbirths according to their questionnaires, several had not reported results in the narrative DHS report. Of the 98 surveys that collected quantifiable stillbirth data, 12 surveys (11.0%) from 10 countries (14.0%) had not reported these in their reports (Table 7).

Examination of selected DHS data sets for maternity care data on stillbirths

Upon examination of data sets from DHS surveys that potentially collected antenatal and delivery care received for non-live births in addition to live births, we found that the data were not completely collected for all cases of stillbirths that they should have been. Table 8 summarises the findings from five of the data sets. In only two surveys (Ghana 2007 MHS and Afghanistan 2010 AMS) were the data available for all stillbirths if a mother's most recent pregnancy resulted in a stillbirth.

Table 7 Countries/surveys that collected stillbirth data* but did not publish results in the DHS narrative report

| Country | Year | Survey type |
|----------------------|-----------|--------------|
| Benin | 2011-2012 | Standard DHS |
| Benin | 2006 | Standard DHS |
| Burkina Faso | 2010 | Standard DHS |
| Cambodia | 2010 | Standard DHS |
| Comoros | 2012 | Standard DHS |
| Jamaica | 2008-2009 | RHS |
| Madagascar | 2008-2009 | Standard DHS |
| Mali | 2012-2013 | Standard DHS |
| Mali | 2006 | Standard DHS |
| Niger | 2006 | Standard DHS |
| Paraguay | 2008 | RHS |
| Rwanda | 2010 | Standard DHS |
| 12 Surveys, 10 count | tries | |

*According to questionnaire included in Appendix (Supporting information) of published DHS narrative report.

| Table 8 Completeness of maternity care data availability for stillbirths in five selected DHS surveys |
|--|
|--|

| | Pakistan 2012–2013 DHS | Nepal 2006 DHS | Azerbaijan 2006 DHS | Ghana 2007 MHS | Afghanistan 2010 AMS* |
|---|------------------------------|----------------------|------------------------|----------------------|--------------------------|
| Number of stillbirths in the last 5 years captured by DHS survey | | | | | |
| Unweighted counts | 363 | 144 | 29 | 141 | 387 |
| Weighted counts | 424 | 134 | 35 | 143 | 405 |
| Number of stillbirths that were a mothers' most recent pregnancy (and should have been included | 155 | 75 | 14 | 81 | 208 |
| in maternity care section) | | | | | |
| Number of stillbirths in survey with maternity care data | 74 | 29 | 5 | 81 | 208 |
| Percentage of stillbirths in survey with maternity care data (%) | 47.7 | 38.7 | 35.7 | 100.0 | 100.0 |

AMS, Afghanistan Mortality Survey; DHS, Demographic and Health Survey; MHS, Maternal Health Survey. *Excludes the South Zone of Afghanistan.

Discussion

This study systematically assessed data availability for stillbirths in nationally representative household surveys from LMICs over the last ten years highlighting variations in stillbirth capture and the limited data available to assess risk factors and causes of death for stillbirths both intracountry over time, or for cross-country comparison. DHS surveys are an invaluable, and often, the only source of high-quality population health data for many LMICs countries where routine data collection and reporting systems are inadequate or non-existent, and where utilisation of health facilities is low. In these contexts, DHS surveys have been a key data source to track global health indicators including the Millenium Development Goals (MDGs) [8] and will be important for the Sustainable Development Goals (SDGs). The global target set in 2014 to reduce stillbirths to 12 per 1000 births by 2030 [12] will require reliable data for monitoring progress and understanding risk factors to facilitate selection and prioritisation of interventions to reduce stillbirths. The DHS surveys provide an immediate opportunity to do so if they can provide quality and comparable data.

Our analysis has identified variations in the method used to ascertain whether a mother had a stillbirth. To record a mother's reproductive history, the majority of surveys use a live birth history supplemented with a reproductive calendar, while full pregnancy histories have been carried out in less than 20% of surveys over the last ten years. A limitation to using live birth histories is that foetal deaths (including stillbirths) are excluded in later parts of the DHS questionnaire that record mother's health service utilisation (ANC and delivery care) during her last pregnancy. Given the importance of ANC and emergency obstetric care in reducing stillbirth risk, this is a critical oversight in the data collection that should be addressed, and importantly, can lead to an underestimation of the importance of these interventions on pregnancy outcomes. The variation in use of birth history *vs*. pregnancy histories has previously been highlighted as problematic, with a preference for pregnancy histories because they provide a more comprehensive description of all pregnancy outcomes and the option to link maternal conditions with those outcomes.

Pregnancy histories are used less frequently by the DHS, but evidence suggests they produce better quality stillbirth estimates. An analysis of 168 DHSs and RHSs compared the different instruments used to measure perinatal mortality and assessed the quality of stillbirth estimates using stillbirth to early neonatal death (SB: END) ratio. In low-income countries, the number of stillbirths should be almost equal to or slightly higher than the number of early neonate deaths with expected ratios being around 1:2 [20]. Pregnancy histories were superior in identifying more stillbirths, producing ratios closer to 1:2, although both methods underestimated stillbirths [21]. A validity study comparing birth histories to pregnancy histories in Bangladesh in relation to completeness of reporting of infant deaths also found that pregnancy histories were far better for estimating infant mortality [22]. These results support the use of pregnancy history over birth history to improve the quality of stillbirth data, confirming previous research that stillbirths are underestimated using the reproductive calendar [3].

The 2006 and 2011 Nepal DHSs, 2006 Pakistan DHS, and 2008 and 2013 Philippines DHSs incorporated pregnancy histories, as did several central and West Asian countries including Ukraine, Kyrgyzstan and Kyrgyz Republic. The 2010 AMS also provides an alternative format. With several examples available, whether

pregnancy histories could be implemented more widely should be explored and has been advocated by maternal and newborn health researchers [2, 6]. Some possible disadvantages of using a pregnancy history over live birth history to note is that interview time would be increased and there would be fewer live births with antenatal, delivery and post-natal care data, which may require a slight increase in the overall sample size for DHS surveys which would have cost implications. Given the absence of adequate data for stillbirths, the potential disadvantages should be weighed against the benefits of capturing much needed data for preventing these deaths.

Inclusion of a reproductive calendar is necessary for determining stillbirth and perinatal mortality rates in surveys that use a live birth history. Where reproductive calendars were not included, some countries incorporated single questions on how many stillbirths a mother had in the previous five years allowing the calculation of stillbirth rates. However, 16 surveys from 12 countries used only a birth history, and no stillbirth data were available due to problematic the wording of the questions; some ask mothers whether they have ever had a stillbirth, miscarriage or abortion but did collect how many of each, or specify a time period, reducing the usefulness of the data. These discrepancies could be easily addressed to ensure these countries, some of which are known to be high-burden countries [2], have adequate and comparable stillbirth data. Inconsistencies between surveys for the same country also exist; for example, the 2011 Cameroon DHS did not include a reproductive calendar, yet in 2004 it did, so no stillbirth data are available in the most recent survey. Calendar estimates are not ideal, but until all surveys collect women's reproductive histories in the same manner, they will continue to be the main but low-quality source of stillbirth data. The recent update to the DHS model women's questionnaire (Phase 7) incorporated a short non-live birth history table that follows the birth history to document pregnancy losses, capturing when the loss occurred and how many months pregnant the mother was - similar to what the reproductive calendar records. The reason for its introduction may be a step towards moving away from the use of the calendar, yet it still excludes stillbirths and other non-live births from being included in later parts of the women's survey where mothers are asked about health service utilisation during their pregnancy.

The availability of data in relation to access to and quality of antenatal and intrapartum care for stillbirths was almost absent. Even in those surveys with pregnancy histories where these data should have been available, they were incomplete and not all stillbirths were included when they should have been, suggesting that more clarity on which births should be included in the maternity care section is required. If full pregnancy histories were implemented and all births (instead of only live births) were included in the maternity care section of the women's questionnaire, it would be possible to capture this information, allowing for a greater understanding of the country-specific patterns and impact of these interventions. ANC visits provide an opportunity to target mothers with key interventions including blood pressure monitoring, iron supplementation, tetanus vaccination, and education on complications in pregnancy, and to identify women with complications or conditions that might adversely affect the pregnancy. The variability in content and components of ANC captured across DHS surveys makes assessment of this challenging.

There is the potential for differential bias in the responses to the maternity care questions for live births vs. stillbirths, and more efforts will be needed to minimise this through adequate interviewer training. In many LMICs, stigmatisation, abuse and rejection are frequently experienced consequences for mothers with stillborn babies [23-25], which may discourage disclosure and reporting of stillbirths and may also influence responses provided for births that did not result in a live birth. Haws et al. [26] explored the potential effect of stigma associated with stillbirths on stillbirth mortality measures in Tanzania emphasising the importance of considering local concepts, meaning and consequences of perinatal loss during survey instrument design. The extent of under-reporting or misreporting as a result of this is not known and the variations across different cultures have not been explored in depth.

Globally, recommended interventions for ANC visits based on the WHO's focused ANC model (includes measurement of weight, height, BP, urine and blood tests, counselling breastfeeding, danger signs and birth planning) are not comprehensively and routinely included in DHS surveys, which are generally limited to blood pressure measurement, blood and urine testing, and informing mothers of pregnancy complications. Assessment of anthropometry measures varied considerably, yet data on these will be important to avoid adverse pregnancy outcomes, given that maternal under nutrition and short maternal stature are important risk factors for stillbirths [27]. Birth and emergency preparedness is part of the WHO's recommended focused ANC model and demonstrated to be effective for reducing neonatal and maternal mortality through its effect on improving skilled birth attendance and facility deliveries [28, 29], yet DHS coverage of birth planning interventions was low, and components of birth planning assessed also varied. Birth planning was one of eight interventions with high-quality evidence supporting its effectiveness in prevention of

stillbirths [30]; therefore, ensuring is implementation as part of ANC packages will be important to monitor. Although not part of routine ANC in LMICs, coverage of ultrasound or fundal height measurement was also rarely collected. Selected surveys included other indicators, but the reason for their inclusion and whether they generated any useful data is not clear. Improved standardisation of key components to assess coverage of ANC components is needed to ensure that essential data are collected across all countries and surveys and to avoid collecting unnecessary information.

Ensuring quality ANC is critical for preventing antepartum stillbirths. ANC attendance rates are high in some contexts where neonatal mortality remains high, pointing to the need to assess the content, quality and timing of visits, not only the number. Assessment of coverage of core components of ANC can provide a proxy for quality of ANC; however, no standard index exists for determining what quality ANC entails in low-income settings, with various studies generating their own measures that incorporate not only assessment of service provision, but also patients satisfaction with care received [31-34]. Marchant et al. [35] considered having received all eight components of ANC based on WHO's focused ANC model as a measure of 'high quality' in their study in Africa and India and found that the highest proportion of high-quality ANC contacts was only 11% in Nigeria, suggesting that quality of ANC requires better monitoring.

Identification and screening for complications/conditions during the antepartum period or during childbirth are critical for reducing the risk of stillbirth [36], yet these questions are not included in the model DHS questionnaires. As questions are not standardised, several inconsistencies were found in capturing data on maternal conditions including not specifying whether complications were ante- or intrapartum, or measuring only one or the other. Response options also varied, with most responses based on mother's recall while in other surveys prompting was used, thus limiting cross-survey comparisons. DHS surveys are based on a standardised model questionnaire, and countries may modify questions and include additional modules relevant to the country context. Although beneficial, this creates challenges for comparability across indicators, countries and over time as this study has demonstrated. Several studies have examined DHS surveys for data availability related to specific indicators, availability of disaggregated data or for subgroups such as adolescents, and identified that adaptation of response options and other inconsistencies have made international comparisons challenging [37-40]. To enable improved understanding of maternal conditions associated with stillbirths, ensuring and standardising their measurement in

DHS surveys could assist with prioritising preventive interventions to detect and manage these conditions.

The need for verbal autopsies to establish cause of death is critical, as up to 70% of stillbirths in LMICs remain unexplained [41]. We found only four surveys completing verbal autopsy for stillbirths over the ten-year period examined, and none in the last five years, despite recommendations for increasing their frequency [4, 42]. Given that results from the verbal autopsies were not published in the narrative DHS reports raises questions about the utility of the data generated.

Understanding the timing of stillbirths is important for identifying where the major burden lies, and which interventions would be most effective. Intrapartum stillbirths are linked to quality of obstetric care, while antepartum stillbirths are related to maternity care received during pregnancy; therefore, differentiating between them is important to provide useful programmatic information to inform interventions, but DHS surveys currently do not include the timing in the model questionnaires. The verbal autopsy questionnaires assess the baby's skin condition at birth to determine when the stillbirth occurred, so this question could potentially be incorporated in the women's questionnaire, although the reliability of this method has been questioned [43]. Further testing and validation of questions that would yield the most reliable results are needed.

Standard DHS surveys are designed to be carried out every five years, but only 30 of the 70 countries examined were at least two surveys done in the ten-year period. The infrequency of surveys is a major limitation to their usefulness, and ensuring greater regularity will be particularly important for countries where maternal and newborn health outcomes are poor. Implementation of DHS surveys is dependent on USAID funding, and each country's willingness to conduct them. It may be worthwhile assessing where bottlenecks for implementation exist for more regular and frequent implementation. Peru and Senegal have successfully done continuous DHS surveys every year; however, some difficulties with analysing the data have been raised [10]. A key aim of DHS surveys is to generate quality data to inform policy and programme planning and for monitoring and evaluation purposes. They are a primary source of reproductive and maternal and child health data accessible to policymakers, yet several surveys that collected stillbirth data did not include the results in the report's narrative.

Third-trimester foetal deaths are frequently combined with early neonatal deaths in the measure of perinatal mortality, which is reported by the majority of surveys (in LMICs) due to difficulties in distinguishing between the two outcomes [44]. Misclassification between stillbirths and early neonatal deaths can be a challenge in

low-income settings where deliveries are often conducted in the home by untrained traditional birth attendants due to lack of knowledge, socio-cultural reasons or other perceived benefits or disadvantages associated with not disclosing a stillbirth [3, 6].

The DHS programme clearly acknowledges the problem surrounding underreporting, omission and misclassification of stillbirths and early neonate deaths, and consequently reports the perinatal mortality. However, the importance of reporting these two outcomes independently is critical for drawing attention to stillbirths, as well as understanding the burden and targeting of public health interventions. The inclusion of the confirmatory question on whether there were any signs of life and whether the baby moved, cried or breathed after birth in the pregnancy history module certainly helps with distinguishing between stillbirths and early neonate deaths and may explain why data from these pregnancy histories may have better reporting of stillbirths compared to the calendar data.

DHS survey data are increasingly utilised to understand risk factors for maternal, child and neonatal mortality with results disseminated through peer-reviewed publications which ensures greater access to information for policv and programme decision makers [10]; however, we identified only one publication using DHS data that examined perinatal mortality [45] as an outcome, and one with stillbirth as an outcome [46] - most likely due to the limitations associated with the data outlined in this paper. Two other publications were also identified - one using the 2011 Ethiopia DHS data [47] and another using the 2013 Nigeria DHS data [48] to examine determinants and risk factors for stillbirths, which included healthcare utilisation variables for stillbirths. Given our study findings, these data are not available in these two data sets as these surveys only included a live birth history and so only live births could have been included in the maternity care section of the survey. This further supports our argument for better and clearer data availability for stillbirths in household surveys such as the DHS.

This objective and systematic assessment of data availability for stillbirths in DHS surveys over the last decade is a key strength of this paper. Importantly, it outlines limitations restricting the utility of DHS data for understanding stillbirths. A key limitation is that we only included surveys available on the DHS programme website. Several surveys for countries in the Asia-Pacific region were identified through Internet searches and were available through national government websites but not on the DHS programme website. These varied in the technical assistance received from DHS – some were carried out without DHS involvement at all, or the DHS programme did not have rights to distribute the data (personal communication, DHS programme, 25 February 2016). It is unlikely that their inclusion would have changed our study findings.

Conclusion

This study has provided evidence on the limitations on the use of DHS data for understanding stillbirths, with key recommendations for practical changes that can be incorporated to improve the data outlined in Box 4. Stillbirth data in household surveys has shown little improvement over the last decade despite several global calls to action [7]. A large proportion of stillbirths are preventable with known interventions and preventive measures identified [17]. If the circumstances around these deaths can be better understood within each country context, it would allow for the prioritisation and

Box 4 Recommendations for changes to DHS surveys to improve data availability for stillbirths

- 1 Replace live birth histories with full pregnancy histories across all DHS surveys for ascertaining mother's reproductive history to improve quality of stillbirth data
- If single stillbirth questions are to be used for counting stillbirths ensure time period is specified (i.e. last 5 years)
- Include reproductive calendars for countries where stillbirth estimates are absent and only live birth histories are done
- 2 Include all non-live births especially stillbirths in the antenatal, delivery and post-natal care (maternity care) section of the model DHS women's questionnaire to allow comprehensive understanding of the impact of quality of care on pregnancy outcomes
- 3 Standardise measurement of coverage of ANC and intrapartum care components and identify a minimum set of indices to determine quality of ANC and intrapartum care
- 4 Standardise capture of maternal conditions and complications during pregnancy and labour and pre-existing conditions that increase stillbirth risk for inclusion in DHS model questionnaire
- 5 Include capture of the timing of stillbirths to better quantify the burden of antepartum and intrapartum stillbirths at a national level to inform prioritisation of programmatic interventions
- 6 Improve measurement of coverage of evidence-based effective interventions known to prevent stillbirths
- 7 Improve reporting of stillbirths in narrative DHS reports ensures countries that collect stillbirth rates report results in the narrative and executive summaries of published DHS reports to ensure visibility to key policy and programme decision makers

translation of key interventions into healthcare delivery systems to prevent these deaths from occurring. Stillbirths are closely correlated with neonatal and maternal mortality [49], and so addressing stillbirths would also contribute to improved maternal and newborn survival.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. (a) Live birth history example from Uganda 2011 DHS survey questionnaire. (b) Pregnancy history example from women's questionnaire in Kyrgyz Republic 2012 DHS. (c) Pregnancy history example from women's questionnaire in Nepal 2011 DHS. (d) Separate non-live birth history table example from women's questionnaire in Zimbabwe 2010–2011 DHS. (e) Separate single questions for non-live births from women's questionnaire in the Pakistan 2006–2007 DHS.

Appendix S2. Survey characteristics of DHS/RHS surveys included.

Appendix S3. Summary of stillbirth and perinatal mortality data in DHS, instruments used to capture stillbirth data, and availability of data in narrative DHS reports, 2005–2015.

Appendix S4. Variation in measurement of coverage of antenatal care components in DHS and RHS surveys and availability of data for stillbirths based on review of questionnaires, 2005–2015.

Appendix S5. Data availability in DHS/RHS surveys completed between 2005 and 2015 on maternal antepartum and delivery complications based on review of questionnaires.

Appendix S6. Variation in response options for questions on conditions or complications experienced during pregnancy in DHS survey questionnaires.

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Additional Supporting Information

Appendix S1a. Live birth history example from women's questionnaire in Uganda 2011 DHS survey

| 211 Now I would like to record the names of all your births, whether still alive or not, starting with the first one you had. RECORD NAMES OF ALL THE BIRTHS IN 212. RECORD TWINS AND TRIPLETS ON SEPARATE ROWS. (IF THERE ARE MORE THAN 12 BIRTHS, USE AN ADDITIONAL QUESTIONNAIRE, STARTING WITH THE SECOND ROW). | | | | | | | | | |
|---|--|--|---|--|--|--|--|--|--|
| 212 What name was given to your (first/next) baby? RECORD NAME. BIRTH HISTORY NUMBER | 213 Is (NAME) a boy or a girl? | 214 Were any of these births twins? | 215 In what month and year was (NAME) born? PROBE: When is his/her birthday? | 216 Is (NAME) still alive? | 217 IF ALIVE: How old was (NAME) at his/her last birthday? RECORD AGE IN COM- PLETED YEARS. | 218 IF ALIVE: Is (NAME) living with you? | 219 IF ALIVE: RECORD HOUSE- HOLD LINE NUMBER OF CHILD (RECORD '00' IF CHILD NOT LISTED IN HOUSE- HOLD). | 220 IF DEAD: How old was (NAME) when he/she died? IF '1 YR, PROBE: How many months old was (NAME)? RECORD DAYS IF LESS THAN 1 MONTH; MONTHS IF LESS THAN 1WO YEARS; OR YEARS. | 221 Were there any other live births between (NAME OF PREVIOUS BIRTH) and (NAME), including any children who died after birth? |
| 01 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ 220 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER | DAYS 1 MONTHS 2 YEARS 3 | |
| 02 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ Z20 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD ◀ BIRTH NO 2 NEXT ◀ BIRTH |
| 03 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ Z20 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 221) | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD ◀ BIRTH NO 2 NEXT ◀ BIRTH |
| 04 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ Z20 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 221) | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD↓ BIRTH NO 2 NEXT↓ BIRTH |
| 05 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ Z20 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD UNE NUMBER | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD↓ BIRTH NO 2 NEXT↓ BIRTH |
| 06 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 ↓ Z20 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 221) | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD J BIRTH NO 2 NEXT J BIRTH |
| 07 | BOY 1 GIRL 2 | SING 1 MULT 2 | YEAR | YES1 NO 2 | AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 221) | DAYS 1 MONTHS 2 YEARS 3 | YES 1 ADD 4 BIRTH NO 2 NEXT 4 BIRTH |

| 211 PREGNANCY HISTOF Starting with your first pregn RECORD ALL PREGANCIE | ancy, please | e tell me the following | information: | | | | | | | | | |
|--|--|--|---|--|---|---------------------------------------|----------------------------------|--|--|---|---|--|
| 212 Did your (first/next) pregnancy end in a live birth, a stillbirth , a miscarriage, or an abortion? | 213 Was this a single or a multiple birth? | 214 In what month and year (was this child born / did this pregnancy end?) | 215 Were there any other pregnancies between this and the pregnancy we were just talking about? IF YES, ADD IT TO TABLE | 215A CHECK 212: RECORD SAME RESPONSE | 216 What name was given to this child? WRITE 'BABY 1' BABY 2', ETC. IF NO NAME WAS GIVEN TO A CHILD | 217 Is (NAME) a boy or girl? | 218 Is (NAME) still alive? | 219 IF ALIVE: How old was (NAME) on his/her last birthday? RECORD AGE IN COMPLETE YEARS | 220 IF ALIVE: Is (NAME) Iiving with you? | 221 IF ALIVE: RECORD HOUSEHOLD LINE NO. OF CHILD. RECORD '00' IF CHILD NOT LISTED IN HOUSEHOLD | 222 IF DIED: How old was (NAME) when he/she died? IF '1 YR', PROBE: How many months old was (NAME)? RECORD DAYS IF LESS THAN 1 MONTH; MONTHS IF LESS THAN 1 YEARS; OR YEARS. | 222A IF DIED: Does (NAME) have a death certificate? IF NO, PROBE: Has (NAME)'s death eve been registered in ZAGS 1 = HAS CERTIFICATE 2 = REGISTERED 3 = NEITHER 8 = DON'T KNOW |
| 01 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 214 | SING 1 MULT 2 | | | LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 NEXT PREGNANCY | NAME: | BOY 1 GIRL 2 | YES 1 NO 2 ↓ 222 | AGE IN YEARS | YES 1 NO 2 | LINE NO.: | DAYS 1 MONTHS 2 YEARS 3 | NEXT PREGNACY |
| 02 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 214 | SING 1 MULT 2 | | YES 1 ADD 4 ^J PREGN NO 2 | LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 NEXT PREGNANCY | NAME: | BOY 1 GIRL 2 | YES 1 NO 2 ↓ 222 | AGE IN YEARS | YES 1 NO 2 | LINE NO.: | DAYS 1 MONTHS 2 YEARS 3 | NEXT PREGNACY |
| 03 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 214 | SING 1 MULT 2 | | YES 1 ADD 4 ^J PREGN NO 2 | LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 NEXT PREGNANCY | NAME: | BOY 1 GIRL 2 | YES 1 NO 2 ↓ 222 | AGE IN YEARS | YES 1 NO 2 | LINE NO.: NEXT PREGNANCY | DAYS 1 MONTHS 2 YEARS 3 | |
| 04 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 214 | SING 1 MULT 2 | | YES 1 ADD 4 ^J PREGN NO 2 | LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 NEXT PREGNANCY | NAME: | BOY 1 GIRL 2 | YES 1 NO 2 ↓ 222 | AGE IN YEARS | YES 1 NO 2 | LINE NO.: | DAYS 1 MONTHS 2 YEARS 3 | |
| 05 LIVE BIRTH 1 STILL BIRTH 2 MISCARRIAGE 3 ABORTION 4 GOTO 214 | SING 1 MULT 2 | | YES 1 ADD 4 ^J PREGN NO 2 | LIVE BIRTH 1 STILL BIRTH2 MISCARRIAGE3 ABORTION4 NEXT PREGNANCY | NAME: | BOY 1 GIRL 2 | YES 1 NO 2 ↓ 222 | AGE IN YEARS | YES 1 NO 2 | LINE NO.: | DAYS 1 MONTHS 2 YEARS 3 | |

Appendix S1b. Pregnancy history example from women's questionnaire in Kyrgyz Republic 2012 DHS survey

| 213 | RECORD ALL THE | ecord all your pregnancies, PREGNANCIES IN 215. RE THAN 12 PREGNANCIE | RECORD TWI | NS AND TRIPLET | S ON SEPARATE | LINES. | |
|---|---|---|--|--|--|--|----------------------------------|
| 214 PREGN ANCY HISTORY NUMBER | 215 Think back to your first pregnancy. Was that a single or multiple pregnancy? | 216 Was the baby born alive, born dead, or lost before birth? | 217 Did that baby cry, move, or breathe when it was bom? | 218 What name was given to the child? | 219 Is (NAME) a boy or a girl? | 220 In what month and year was (NAME) born? PROBE: When is his/her birthday? | 221 Is (NAME) still alive? |
| 01 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) - J BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 226) - J | YES 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO |
| 02 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) - J BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 226) J | YES 1 NO 2 ↓ 225 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO |
| 03 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) — J BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 225) — J | YE\$ 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO 22 |
| 04 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218)+ JORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 226) | YES 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO 22 |
| 05 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) – J BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 226) – J | YES 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO 22 |
| 06 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) - J BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 226) J | YES 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO |
| 07 | SING 1 MULT 2 | BORN ALIVE 1 (SKIP TO 218) BORN DEAD 2 LOST BEFORE FULL TERM 3 (SKIP TO 225) | YES 1 NO 2 ↓ 226 | NAME | BOY 1 GIRL 2 | MONTH YEAR | YES NO |

Appendix S1c. Pregnancy history example from women's questionnaire in Nepal 2011 DHS survey

| 222 IF BORN ALIVE / How old was (NAME) at his/her last birthday? RECORD | 223 AND STILL LI Is (NAME) Iiving with you? | 224 VING: RECORD HOUSE- HOLD LINE NUMBER OF CHILD (RECORD 100' | 225 IF DEAD: How old was (NAME) when he/she died? IF '1 YR', PROBE: How many months old was (NAME)? | 226 IF BORN DEAD OR In what month and year did this pregnancy end? | 227 LOST BEFORE E How many months did this pregnancy last? RECORD | 228 IRTH: Did you or someone else do something to end this pregnancy? | 229 Were there any other pregnancies between the previous pregnancy |
|---|---|---|---|--|---|--|---|
| AGE IN COM- PLETED YEARS. | | IF CHILD NOT LISTED IN HOUSE- HOLD). | RECORD DAYS IF LESS THAN 1 MONTH; MONTHS IF LESS THAN TWO YEARS; OR YEARS. | | IN COM- PLETED MONTHS. | | and this pregnancy? |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER | DAYS 1 MONTHS 2 YEARS 3 (NEXT PREGNANCY) | | MONTHS | YES 1 NO 2 | |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD ↓ PREGNANCY NO 2 NEXT↓ PREGNANCY |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD 4 PREGNANCY NO 2 NEXT 4 PREGNANCY |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | MONTH YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD 4 PREGNANCY NO 2 NEXT 4 PREGNANCY |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD↓ PREGNANCY NO 2 NEXT↓ PREGNANCY |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD ↓ PREGNANCY NO 2 NEXT ↓ PREGNANCY |
| AGE IN YEARS | YES 1 NO 2 | HOUSEHOLD LINE NUMBER (GO TO 229) | DAYS 1 MONTHS 2 YEARS 3 (GO TO 229) | MONTH YEAR | MONTHS | YES 1 NO 2 | YES 1 ADD 4 PREGNANCY NO 2 NEXT 4 PREGNANCY |

| 230 | Have you ever had a pregnancy that r ended in a stillbirth? | niscarried, was aborted, or | YES 1 NO 2 | → 238 |
|------|---|--|--|--------|
| 231 | When did the last such pregnancy en | 1? | MONTH | |
| 232 | CHECK 231: LAST PREGNANCY ENDED IN JAN. 2005 OR LATER | LAST PREGNANCY ENDED BEFORE JAN. 2005 | | → 238 |
| 232A | 232B In what month and year did that pregnancy end? MONTH YEAR | 233 How many months pregnant were you when that pregnancy ended? MONTHS | 234 Since January 2005, have you had any other pregnancies that did not result in a live birth? | |
| 01 | | | YES 1 NO 2 | → 235 |
| 02 | | | YES 1 NO 2 | → 235 |
| 03 | | | YES 1 NO 2 | → 235 |
| 04 | | | YES 1 NO 2 | → 235 |
| | RE ARE MORE THAN FOUR PREGNAN A NEW QUESTIONNAIRE. | CIES SINCE JANUARY 200 | 05 THAT DID NOT RESULT IN A LIVE BIRTH, GO TO 23 | 2A ROW |
| 235 | ENTER 'T' IN THE CALEN | | N A LIVE BIRTH IN JANUARY 2005 OR LATER, T THE PREGNANCY TERMINATED AND 'P' FOR HS OF PREGNANCY. | |

Appendix S1d. Separate non-live birth history table example from women's questionnaire in Zimbabwe 2010-11 DHS survey

| 229 | Have you ever had a pregnancy that miscarried, was aborted, or ended in a stillbirth? | YES 1 NO 2 → 23 | 34 |
|-----|---|------------------------|----|
| 230 | When did the last such pregnancy end? PROBE TO ASK BETWEEN WHICH BIRTHS, ETC. | MONTH | |
| 231 | CHECK 230: LAST PREGNANCY ENDED IN JAN. 2001 OR LATER JAN. 2001 | 7 → 23 | 34 |
| 232 | How many months pregnant were you when the <u>last</u> such pregnancy ended? | MONTHS | |
| 233 | Since January 2001, how many pregnancies have you had that did not result in a live birth. How many of these pregnancies were miscarried, aborted or ended in a still birth? | NUMBER OF MISCARRIAGES | |
| | IF 7 OR MORE, RECORD '7'. | | |
| | | | |

Appendix S1e. Separate single questions for non-live births from women's questionnaire in the Pakistan 2006-07 DHS survey

| | | SURVE | Y CHARACTERIS | STICS | ELIGIBLE WOMEN | SAMPLED |
|-----------------------------|--------|----------------|--|---|------------------|--------------------------|
| Country and survey year | Region | Survey type | Language report and/or survey | DHS phase model questionnaire used | Women sampled | Age range of women |
| SUB-SAHARAN AFRICA | | | | | | |
| Benin 2011-12 | SSA | Standard DHS | French | IV | all women | 15-49 |
| Benin 2006 | SSA | Standard DHS | French | V | all women | 15-49 |
| Burkina Faso 2010 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Burundi 2010 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Cameroon 2011 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Cape Verde 2005 | SSA | Standard DHS | Portuguese | IV | all women | 15-49 |
| Comoros 2012 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Congo (Brazzaville) 2011-12 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Congo (Brazzaville) 2005 | SSA | Standard DHS | French | V | all women | 15-49 |
| Congo DRC 2013-14 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Congo DRC 2007 | SSA | Standard DHS | French | V | all women | 15-49 |
| Cote d'Ivoire 2011-12 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Equatorial Guinea 2011 | SSA | Standard DHS | Spanish | VI | all women | 15-49 |
| Ethiopia 2011 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Ethiopia 2005 | SSA | Standard DHS | English | IV | all women | 15-49 |
| Gabon 2012 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Gambia 2013 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Ghana 2014 | SSA | Standard DHS | English | VII | all women | 15-49 |
| Ghana 2008 | SSA | Standard DHS | English | V | all women | 15-49 |
| Guinea 2012 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Guinea 2005 | SSA | Standard DHS | French | V | all women | 15-49 |
| Kenya 2008-09 | SSA | Standard DHS | English | V | all women | 15-49 |
| Lesotho 2009 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Liberia 2013 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Liberia 2007 | SSA | Standard DHS | English | V | all women | 15-49 |
| Madagascar 2008-09 | SSA | Standard DHS | French | V | all women | 15-49 |
| Malawi 2010 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Mali 2012-13 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Mali 2006 | SSA | Standard DHS | French | V | all women | 15-49 |
| Mozambique 2011 | SSA | Standard DHS | Portuguese | VI | all women | 15-49 |
| Namibia 2013 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Namibia 2006-07 | SSA | Standard DHS | English | V | all women | 15-49 |
| Niger 2012 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Niger 2006 | SSA | Standard DHS | French | V | all women | 15-49 |
| Nigeria 2013 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Nigeria 2008 | SSA | Standard DHS | English | V | all women | 15-49 |
| Rwanda 2010 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Rwanda 2007-08 | SSA | Interim DHS | English | V | all women | 15-49 |
| Rwanda 2005 | SSA | Standard DHS | English | V | all women | 15-49 |
| Sao Tome and Principe 2008 | SSA | Standard DHS | Portuguese | V | all women | 15-49 |
| Senegal 2014 | SSA | Continuous DHS | French | VII | all women | 15-49 |
| Senegal 2012-13 | SSA | Continuous DHS | French | VI | all women | 15-49 |
| Senegal 2010-11 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Senegal 2005 | SSA | Standard DHS | French | IV | all women | 15-49 |
| Sierra Leone 2013 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Sierra Leone 2008 | SSA | Standard DHS | English | V | all women | 15-49 |
| Swaziland 2006-07 | SSA | Standard DHS | English | V | all women | 15-49 |

Appendix S2. Survey characteristics of DHS/RHS surveys included

| | | SURVEY | STICS | ELIGIBLE WOMEN | SAMPLED | |
|---------------------------------|---------|-----------------------------|--|---|------------------|--------------------------|
| Country and survey year | Region | Survey type | Language report and/or survey | DHS phase model questionnaire used | Women sampled | Age range of women |
| Tanzania 2010 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Togo 2013-14 | SSA | Standard DHS | French | VI | all women | 15-49 |
| Uganda 2011 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Uganda 2006 | SSA | Standard DHS | English | V | all women | 15-49 |
| Zambia 2013-14 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Zambia 2007 | SSA | Standard DHS | English | V | all women | 15-49 |
| Zimbabwe 2010-11 | SSA | Standard DHS | English | VI | all women | 15-49 |
| Zimbabwe 2005-06 | SSA | Standard DHS | English | V | all women | 15-49 |
| N. AFRICA/EUROPE/W. ASIA | 00/1 | | 28 | | | 10 10 |
| Albania 2008-09 | NAWAE | Standard DHS | English | v | all women | 15-49 |
| Armenia 2010 | NAWAE | Standard DHS | English | VI | all women | 15-49 |
| Armenia 2005 | NAWAE | Standard DHS | English | V | all women | 15-49 |
| Azerbaijan 2006 | NAWAE | Standard DHS | English | V | all women | 15-49 |
| Egypt 2014 | NAWAL | Standard DHS | English | VI | ever-married | 15-49 |
| Egypt 2008 | NAWAE | Standard DHS | English | V | ever-married | 15-49 |
| Egypt 2005 | NAWAE | Standard DHS | English | IV | ever-married | 15-49 |
| Georgia 2005 | NAWAL | RHS | English | NA | all women | 15-49 |
| Jordan 2012 | NAWAL | Standard DHS | English | VI | ever-married | 15-49 |
| Jordan 2009 | NAWAE | | - | VI | | 15-49 |
| Jordan 2009 | NAWAE | Interim DHS Standard DHS | English | V | ever-married | 15-49 |
| Moldova 2005 | NAWAE | Standard DHS | English | IV | ever-married | 15-49 |
| | | | English | V | all women | |
| Ukraine 2007 | NAWAE | Standard DHS | English | | all women | 15-49 |
| Yemen 2013 | NAWAE | Standard DHS | English | VI | ever-married | 15-49 |
| CENTRAL ASIA | <u></u> | Characterist DUC | E l'ala | | | 45.40 |
| Kyrgyz Republic 2012 | CA | Standard DHS | English | VI | all women | 15-49 |
| Tajikistan 2012 | CA | Standard DHS | English | VI | all women | 15-49 |
| SOUTH & SOUTH-EAST ASIA | 6654 | Characteriat DUC | E a all'ala | | | 12.10 |
| Bangladesh 2011 | SSEA | Standard DHS | English | VI | ever-married | 12-49 |
| Bangladesh 2007 | SSEA | Standard DHS | English | V | ever-married | 10-49 |
| Cambodia 2014 | SSEA | Standard DHS | English | VII | all women | 15-49 |
| Cambodia 2010 | SSEA | Standard DHS | English | VI | all women | 15-49 |
| Cambodia 2005 | SSEA | Standard DHS | English | V | all women | 15-49 |
| India 2005-06 | SSEA | Standard DHS | English | V | all women | 15-49 |
| Indonesia 2012 | SSEA | Standard DHS | English | VI | all women | 15-49 |
| Indonesia 2007 | SSEA | Standard DHS | English | V | ever-married | 15-49 |
| Maldives 2009 | SSEA | Standard DHS | English | V | ever-married | 15-49 |
| Nepal 2011 | SSEA | Standard DHS | English | VI | all women | 15-49 |
| Nepal 2006 | SSEA | Standard DHS | English | V | all women | 15-49 |
| Pakistan 2012-13 | SSEA | Standard DHS | English | VI | ever-married | 15-49 |
| Pakistan 2006-07 | SSEA | Standard DHS | English | V | ever-married | 12-49 |
| Sri Lanka 2006-07 | SSEA | Standard DHS | English | IV | ever-married | 15-49 |
| Philippines 2013 | SSEA | Standard DHS | English | VI | all women | 15-49 |
| Philippines 2008-09 | SSEA | Standard DHS | English | V | all women | 15-49 |
| Timor-Leste 2009-10 | SSEA | Standard DHS | English | VI | all women | 15-49 |
| LATIN AMERICA AND THE CARIBBEAN | | | | | | |
| Bolivia 2008 | LAC | Standard DHS | Spanish | V | all women | 15-49 |
| Colombia 2010 | LAC | Standard DHS | Spanish | VI | all women | 13-49 |
| Colombia 2005 | LAC | Standard DHS | Spanish | V | all women | 13-49 |
| Dominican Republic 2013 | LAC | Standard DHS | Spanish | VI | all women | 15-49 |

| | | SURVE | CHARACTERIS | STICS | ELIGIBLE WOMEN | N SAMPLED |
|-------------------------|--------|----------------|--|---|------------------|--------------------------|
| Country and survey year | Region | Survey type | Language report and/or survey | DHS phase model questionnaire used | Women sampled | Age range of women |
| Dominican Republic 2007 | LAC | Standard DHS | Spanish | v | all women | 15-49 |
| El Salvador 2008 | LAC | RHS | Spanish | NA | all women | 15-49 |
| Guatemala 2008-09 | LAC | RHS | Spanish | NA | all women | 15-49 |
| Guyana 2009 | LAC | Standard DHS | English | V | all women | 15-49 |
| Haiti 2012 | LAC | Standard DHS | French | VI | all women | 15-49 |
| Haiti 2005-06 | LAC | Standard DHS | French | V | all women | 15-49 |
| Honduras 2011-12 | LAC | Standard DHS | Spanish | VI | all women | 15-49 |
| Honduras 2005-06 | LAC | Standard DHS | Spanish | V | all women | 15-49 |
| Jamaica 2008-09 | LAC | RHS | English | NA | all women | 15-49 |
| Nicaragua 2006-07 | LAC | RHS | Spanish | NA | all women | 15-49 |
| Paraguay 2008 | LAC | RHS | Spanish | NA | all women | 15-44 |
| Peru 2014 | LAC | Continuous DHS | Spanish | VII | all women | 15-49 |
| Peru 2013 | LAC | Continuous DHS | Spanish | VI | all women | 15-49 |
| Peru 2012 | LAC | Continuous DHS | Spanish | VI | all women | 15-49 |
| Peru 2011 | LAC | Continuous DHS | Spanish | VI | all women | 15-49 |
| Peru 2010 | LAC | Continuous DHS | Spanish | VI | all women | 15-49 |
| Peru 2009 | LAC | Continuous DHS | Spanish | V | all women | 15-49 |
| Peru 2007-08 | LAC | Continuous DHS | Spanish | V | all women | 15-49 |
| SPECIAL SURVEYS | | | | | | |
| Afghanistan 2010 AMS | SSEA | Special | English | VI | ever-married | 12-49 |
| Ghana 2007 MHS | SSA | Special | English | V | all women | 15-49 |
| Indonesia 2012 ARH | SSEA | Special | English | VI | never married | 15-24 |
| Lao DRC 2011-12 SIS | SSEA | Special | English | VI | all women | 15-49 |

AMS - Afghanistan Mortality Survey; ARH - Adolescent Reproductive Health; MHS- Maternal Health Survey; SIS - Social Indicator Survey; CA- Central Asia; LAC- Latin America and the Caribbean; NAWAE- North Africa/West Asia/Europe; SSA- Sub-Saharan Africa; SSEA- South and South-East Asia

Appendix S3. Summary of stillbirth and perinatal mortality data in DHS, instruments used to capture stillbirth data, and availability of data in narrative DHS reports, 2005-2015

| | | DATA SOURCE | STILL | BIRTH AN | D PERIN DATA | | | | INSTRUMENTS FOR STILLBIRTH DATA CAPTURE | | | | | STILLBIRTH DATA IN REPORT | | |
|---------------------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|---|---|---|-----------------------------------|---|-----------------------------------|--|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported | |
| SUB-SAHARAN AFRICA | | | | | | | | | | | | | | | | |
| Benin | 2011-12 DHS | STATcompiler | 80 | 232 | 24 | 13,215 | 6 | 0.34 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO | |
| Benin | 2006 DHS | STATcompiler | 210 | 394 | 37 | 16,139 | 13 | 0.53 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO | |
| Burkina Faso | 2010 DHS | STATcompiler | 173 | 299 | 30 | 15,548 | 11 | 0.58 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO | |
| Burundi | 2010 DHS | STATcompiler | 159 | 175 | 41 | 8,139 | 20 | 0.91 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | NO | |
| Cameroon | 2011 DHS | | | | | | | | | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Cape Verde | 2005 DHS | DHS report | 21 | 28 | 22 | 2232 | 9 | 0.75 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | NO | |
| Comoros | 2012 DHS | STATcompiler | 12 | 64 | 23 | 3,248 | 4 | 0.19 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO | |
| Congo (Brazzaville) | 2011-12 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Congo (Brazzaville) | 2005 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Congo Democratic Republic | 2013-14 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Congo Democratic Republic | 2007 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Cote d'Ivoire | 2011-12 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Equatorial Guinea | 2011 DHS | DHS report | 22 | 79 | 37 | 2709 | 8 | 0.28 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |

| | | DATA SOURCE | STILLE | BIRTH AN | D PERIN DATA | | | | INSTRUMENTS FOR STILLBIRTH DATA CAPTURE | | | | | STILLBIRTH DATA IN REPORT | | |
|--------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|---|---|---|-----------------------------------|---|-----------------------------------|--|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported | |
| Ethiopia | 2011 DHS | STATcompiler | 204 | 347 | 46 | 12,076 | 17 | 0.59 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Ethiopia | 2005 DHS | STATcompiler | 117 | 303 | 37 | 11,280 | 10 | 0.39 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Gabon | 2012 DHS | · · | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Gambia | 2013 DHS | STATcompiler | 89 | 151 | 30 | 7,995 | 11 | 0.59 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Ghana | 2014 DHS | DHS report | 81 | 140 | 38 | 5,776 | 14 | 0.58 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Ghana | 2008 DHS | STATcompiler | 40 | 75 | 39 | 2,949 | 14 | 0.53 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Guinea | 2012 DHS | | 10 | ,,, | 55 | 2,313 | | 0.00 | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Guinea | 2005 DHS | STATcompiler | 98 | 189 | 44 | 6,467 | 15 | 0.52 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Kenya | 2008-09 DHS | STATcompiler | 68 | 149 | 37 | 5,920 | 11 | 0.46 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Lesotho | 2009 DHS | STATcompiler | 63 | 145 | 54 | 3,795 | 17 | 0.45 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Liberia | 2013 DHS | STATcompiler | 70 | 129 | 30 | 6,572 | 11 | 0.54 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| | 2007 DHS | · | 81 | 125 | 38 | 5675 | 14 | 0.60 | | LIVE BIRTH HISTORY | YES | NO | YES | NO | YES | |
| Liberia | 2007 DHS 2008-09 DHS | DHS report | 175 | | | | | 0.80 | Single questions | | | | | NO | NO | |
| Madagascar | | STATcompiler | | 242 | 32 | 12,861 | 14 | | Calendar | | YES | YES | NO | | | |
| Malawi | 2010 DHS | STATcompiler | 316 | 477 | 40 | 20,013 | 16 | 0.66 | Calendar | | YES | YES | YES | NO | YES | |
| Mali | 2012-13 DHS | STATcompiler | 64 | 292 | 34 | 10,465 | 6 | 0.22 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO | |

| | | DATA SOURCE | STILL | BIRTH AN | D PERIN DATA | | | | INSTRUME | NTS FOR STILLBIRTH DATA (| CAPTURE | | STILLBIRTH DATA IN REPORT | | |
|-----------------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|-----------------------------------|---|---|-----------------------------------|---|-----------------------------------|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported |
| Mali | 2006 DHS | STATcompiler | 194 | 493 | 47 | 14,614 | 13 | 0.39 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Mozambique | 2011 DHS | STATcompiler | 127 | 320 | 38 | 11,831 | 11 | 0.40 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Namibia | 2013 DHS | STATcompiler | 39 | 77 | 24 | 4,843 | 8 | 0.51 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Namibia | 2006-07 DHS | STATcompiler | 46 | 101 | 29 | 5,046 | 9 | 0.46 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Niger | 2012 DHS | STATcompiler | 225 | 229 | 33 | 13,571 | 17 | 0.98 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Niger | 2006 DHS | STATcompiler | 123 | 212 | 33 | 10,077 | 12 | 0.58 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Nigeria | 2013 DHS | STATcompiler | 396 | 925 | 41 | 32,224 | 12 | 0.43 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Nigeria | 2008 DHS | STATcompiler | 228 | 870 | 39 | 28,328 | 8 | 0.26 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Rwanda | 2010 DHS | STATcompiler | 154 | 167 | 35 | 9,291 | 17 | 0.92 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Rwanda | 2007-08 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| Rwanda | 2005 DHS | STATcompiler | 160 | 227 | 44 | 8,872 | 18 | 0.70 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | NO |
| Sao Tome and Principe | 2008-09 DHS | | 100 | | | 0,072 | 10 | 0.70 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Senegal | 2014 DHS | | • | | | · · | | • | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Senegal | 2012-14 DHS | · · · | • | | · · | | | • | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Senegal | 2010-11 DHS | STATcompiler | 192 | 250 | 38 | 11,645 | 16 | 0.77 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |

| | | DATA SOURCE | STILL | BIRTH AN | D PERIN DATA | | | | INSTRUMENTS FOR STILLBIRTH DATA CAPTURE | | | | | STILLBIRTH DATA IN REPORT | | |
|--|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|--|---|---|-----------------------------------|---|-----------------------------------|--|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported | |
| Senegal | 2005 DHS | STATcompiler | 215 | 265 | 45 | 10,745 | 20 | 0.81 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Sierra Leone | 2013 DHS | STATcompiler | 100 | 377 | 39 | 12,298 | 8 | 0.27 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Sierra Leone | 2008 DHS | STATcompiler | 49 | 147 | 34 | 5,860 | 8 | 0.33 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Swaziland | 2006-07 DHS | STATcompiler | 35 | 49 | 29 | 2,864 | 12 | 0.71 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Tanzania | 2010 DHS | STATcompiler | 143 | 156 | 36 | 8,319 | 17 | 0.92 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Тодо | 2013-14 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA | |
| Uganda | 2011 DHS | STATcompiler | 165 | 164 | 40 | 8,240 | 20 | 1.01 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Uganda | 2006 DHS | STATcompiler | 142 | 169 | 36 | 8,564 | 17 | 0.84 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Zambia | 2013-14 DHS | DHS report | 180 | 247 | 31 | 13563 | 13 | 0.73 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Zambia | 2007 DHS | STATcompiler | 91 | 156 | 38 | 6,526 | 14 | 0.58 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Zimbabwe | 2010-11 DHS | STATcompiler | 85 | 137 | 39 | 5,676 | 15 | 0.62 | Calendar and separate table for non-live births | BIRTH HISTORY + NON- LIVE BIRTH HISTORY TABLE | YES | YES | YES | NO | YES | |
| Zimbabwe NORTH AFRICA, EUROPE, WEST ASIA | 2005-06 DHS | STATcompiler | 40 | 89 | 25 | 5,271 | 8 | 0.45 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Albania | 2008-09 DHS | STATcompiler | 6 | 12 | 11 | 1,583 | 4 | 0.50 | Calendar and separate table for non-live births | BIRTH HISTORY + NON- LIVE BIRTH HISTORY TABLE | YES | YES | YES | NO | YES | |

| | | DATA SOURCE | STILL | BIRTH AN | D PERIN DATA | ATAL MOR | | | INSTRUMENTS FOR STILLBIRTH DATA CAPTURE | | | | | STILLBIRTH DATA IN REPORT | | |
|--------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|--|---|---|-----------------------------------|---|-----------------------------------|--|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported | |
| Armenia | 2010 DHS | STATcompiler | 8 | 7 | 11 | 1,457 | 5 | 1.14 | Calendar and pregnancy history table | PREGNANCY HISTORY | YES | YES | YES | NO | YES | |
| Armenia | 2005 DHS | STATcompiler | 12 | 16 | 19 | 1,524 | 8 | 0.75 | Calendar and pregnancy history table | PREGNANCY HISTORY | YES | YES | YES | NO | YES | |
| Azerbaijan | 2006 DHS | STATcompiler | 37 | 53 | 39 | 2,326 | 16 | 0.70 | Calendar | PREGNANCY HISTORY | YES | YES | YES | NO | YES | |
| Egypt | 2014 DHS | DHS report | 104 | 135 | 15 | 15,772 | 7 | 0.77 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Egypt | 2008 DHS | STATcompiler | 87 | 118 | 19 | 10,677 | 8 | 0.74 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Egypt | 2005 DHS | STATcompiler | 129 | 186 | 23 | 13,729 | 9 | 0.69 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Georgia | 2005 RHS | STATcompiler | 35 | 32 | 30 | 2,200 | 16 | 1.09 | Calendar | PREGNANCY HISTORY | YES | YES | NO | YES | NO | |
| Jordan | 2012 DHS | STATcompiler | 51 | 119 | 17 | 9,885 | 5 | 0.43 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Jordan | 2009 DHS | STATcompiler | 81 | 91 | 19 | 9,254 | 9 | 0.89 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Jordan | 2007 DHS | STATcompiler | 58 | 90 | 15 | 9,922 | 6 | 0.64 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| Moldova | 2005 DHS | STATcompiler | 23 | 7 | 19 | 1,605 | 14 | 3.29 | Calendar and pregnancy history table Calendar and | PREGNANCY HISTORY | YES | YES | YES | NO | YES | |
| Ukraine | 2007 DHS | STATcompiler | 4 | 7 | 10 | 1,181 | 3 | 0.57 | pregnancy history table | PREGNANCY HISTORY | YES | YES | YES | NO | YES | |
| Yemen | 2013 DHS | DHS Report | 253 | 320 | 36 | 16,133 | 16 | 0.79 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES | |
| CENTRAL ASIA | | | | | | | | | | | | | | | | |

| | | DATA SOURCE | STILL | BIRTH AN | D PERIN DATA | ATAL MORT | | | INSTRUME | NTS FOR STILLBIRTH DATA | CAPTURE | | STILLI | BIRTH DA | |
|-------------------------------|-----------------------------------|------------------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|---|---|---|-----------------------------------|---|-----------------------------------|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported |
| Kurre Denuklia | | CTATes mailes | 10 | 50 | 10 | 4 000 | | 0.27 | Calendar and pregnancy | | | VEC | VEC | NO | VEC |
| Kyrgyz Republic Tajikistan | 2012 DHS 2012 DHS | STATcompiler STATcompiler | 16 45 | 59 80 | 18 24 | 4,098 | 4 | 0.27 | history table Calendar and pregnancy history table | PREGNANCY HISTORY PREGNANCY HISTORY | YES | YES | YES YES | NO | YES |
| SOUTH & SOUTH-EAST ASIA | | | | | | | | | | | | | | | |
| Bangladesh | 2011 DHS | STATcompiler | 232 | 220 | 50 | 9,021 | 26 | 1.05 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Bangladesh | 2007 DHS | STATcompiler | 175 | 169 | 55 | 6,232 | 28 | 1.04 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Cambodia | 2014 DHS | DHS report | 42 | 100 | 20 | 7295 | 6 | 0.42 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Cambodia | 2010 DHS | STATcompiler | 72 | 177 | 30 | 8,273 | 9 | 0.41 | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Cambodia | 2005 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| India | 2005-06 DHS | STATcompiler | 1,105 | 1,686 | 49 | 57,543 | 19 | 0.66 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Indonesia | 2012 DHS | STATcompiler | 181 | 268 | 26 | 17,129 | 11 | 0.68 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Indonesia | 2007 DHS | STATcompiler | 174 | 241 | 25 | 16,678 | 10 | 0.72 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Maldives | 2009 DHS | STATcompiler | 34 | 35 | 18 | 3,770 | 9 | 0.97 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Nepal | 2011 DHS | STATcompiler | 53 | 149 | 37 | 5,444 | 10 | 0.36 | Calendar | PREGNANCY HISTORY | YES | YES | YES | NO | YES |
| Nepal | 2006 DHS | STATcompiler | 126 | 129 | 45 | 5,671 | 22 | 0.98 | Calendar | PREGNANCY HISTORY | YES | YES | YES | YES | YES |
| Pakistan | 2012-13 DHS | STATcompiler | 412 | 522 | 75 | 12,389 | 33 | 0.79 | Calendar | PREGNANCY HISTORY | YES | YES | YES | YES | YES |

| | | DATA SOURCE | STILLI | BIRTH AN | D PERIN DATA | | | | INSTRUME | NTS FOR STILLBIRTH DATA | CAPTURE | | | BIRTH DA REPORT | |
|---------------------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|-----------------------------------|---|---|-----------------------------------|---|-----------------------------------|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported |
| Pakistan | 2006-07 DHS | DHS report | 1,296 | 362 | 73* | 10,444 | 124 | 3.58 | Single questions | LIVE BIRTH HISTORY | YES | NO | YES | YES | YES |
| Sri Lanka | 2006-07 DHS | DHS report | 62 | 57 | 17 | 7,051 | 9 | 1.09 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Philippines | 2013 DHS | DHS report | 83 | 71 | 22 | 7,065 | 12 | 1.17 | Pregnancy history table | PREGNANCY HISTORY | YES | NO | YES | NO | YES |
| Philippines | 2008 DHS | DHS report | 93 | 85 | 28 | 6452 | 14 | 1.09 | Pregnancy history table | PREGNANCY HISTORY | YES | NO | YES | NO | YES |
| Timor-Leste | 2009-10 DHS | STATcompiler | 22 | 158 | 18 | 9,850 | 2 | 0.14 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| LATIN AMERICA & CARIBBEAN | | | | | | | | | | | | | | | |
| Bolivia | 2008 DHS | STATcompiler | 98 | 158 | 29 | 8,825 | 11 | 0.62 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Colombia | 2010 DHS | STATcompiler | 86 | 130 | 14 | 15,930 | 5 | 0.66 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Colombia | 2005 DHS | STATcompiler | 91 | 139 | 17 | 13,870 | 7 | 0.65 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Dominican Republic | 2013 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| Dominican Republic | 2007 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| El Salvador | 2008 RHS | STATcompiler | 77 | 43 | 19 | 6,457 | 12 | 1.79 | Single questions | LIVE BIRTH HISTORY | YES | NO | YES | YES | YES |
| Guatemala | 2008-09 RHS | STATcompiler | 183 | 110 | 31 | 9,441 | 19 | 1.66 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Guyana | 2009 DHS | STATcompiler | 28 | 38 | 34 | 1,908 | 15 | 0.74 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Haiti | 2012 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |

| | | DATA SOURCE | STILLE | BIRTH AN | D PERIN DATA | ATAL MOR | | | INSTRUME | NTS FOR STILLBIRTH DATA | CAPTURE | | STILLE | BIRTH DA REPORT | |
|-----------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|--|---|---|-----------------------------------|---|-----------------------------------|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported |
| Haiti | 2005-06 DHS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| Honduras | 2011-12 DHS | STATcompiler | 102 | 124 | 22 | 10,276 | 10 | 0.82 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Honduras | 2005-06 DHS | STATcompiler | 124 | 108 | 23 | 10,289 | 12 | 1.15 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Jamaica | 2008-09 RHS | STATcompiler | 53 | 49 | 23 | 4,438 | 12 | 1.08 | Calendar & pregnancy history table | PREGNANCY HISTORY | YES | YES | NO | NO | NO |
| Nicaragua | 2006-07 RHS | STATcompiler | 89 | 94 | 20 | 8,945 | 10 | 0.95 | Single questions | LIVE BIRTH HISTORY | YES | NO | YES | NO | YES |
| Paraguay | 2008 RHS | STATcompiler | 62 | 43 | 28 | 3,718 | 17 | 1.44 | Single questions | LIVE BIRTH HISTORY | YES | NO | NO | NO | NO |
| Peru | 2014 DHS | DHS report | 131 | 132 | 15 | 17,290 | 8 | 0.99 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2013 DHS | DHS report | 149 | 144 | 17 | 17,131 | 9 | 1.03 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2012 DHS | STATcompiler | 71 | 79 | 17 | 8,874 | 8 | 0.90 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2011 DHS | STATcompiler | 69 | 53 | 14 | 8,495 | 8 | 1.30 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2010 DHS | STATcompiler | 52 | 62 | 13 | 8,535 | 6 | 0.84 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2009 DHS | STATcompiler | 80 | 74 | 16 | 9,385 | 9 | 1.08 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| Peru | 2007-08 DHS | STATcompiler | 104 | 60 | 19 | 8,602 | 12 | 1.73 | Calendar | LIVE BIRTH HISTORY | YES | YES | YES | NO | YES |
| SPECIAL SURVEYS | 2007 00 013 | | 104 | 00 | 15 | 0,002 | 12 | 1.75 | Calcillat | | 125 | 123 | 123 | 110 | |
| Afghanistan | 2010 AMS | DHS Report | 402 | 409 | 42 | 19489 | 21 | 0.98 | Pregnancy history table | PREGNANCY HISTORY | YES | NO | YES | NO | YES |

| | | DATA SOURCE | STILL | BIRTH ANI | D PERIN DATA | ATAL MORT | | | INSTRUME | NTS FOR STILLBIRTH DATA | CAPTURE | | | BIRTH DA | TA IN |
|--------------|-----------------------------------|---------------------|-----------------------|------------------------------------|---------------------|--|---|--------------|-----------------------------------|---|---|-----------------------------------|---|-----------------------------------|--|
| Country Name | Year of survey and survey type | Data extracted from | Number of stillbirths | Number of early neonatal deaths | Perinatal mortality | Number of pregnancies of 7+ months duration | SBR (no stillbirths per 1000 pregnancies of 7+ months) | SB:END Ratio | Source of stillbirth estimates | Instrument used to record mother's reproductive history | Stillbirths captured in quantifiable way | Reproductive calendar included | Perinatal mortality/stillbirth table | Stillbirth rate (SBR) reported | Perinatal mortality rate (PMR) reported |
| Ghana | 2007 MHS | DHS Report | 146 | 165 | 45 | 6960 | 21 | 0.88 | Pregnancy history table | PREGNANCY HISTORY | YES | NO | YES | NO | YES |
| Indonesia | 2012 ARH | | | | | | | | Calendar | LIVE BIRTH HISTORY | YES | YES | NO | NO | NO |
| Lao DRC | 2011-12 SIS | | | | | | | | NA | LIVE BIRTH HISTORY | NO | NO | NA | NA | NA |
| | | | | | | | | | No. of s | urveys with data available | 98 | 89 | 81 | 5 | 78 |
| | | | | | | | | | N | o. of surveys without data | 16 | 25 | 17 | 93 | 20 |
| | | | | | | | | | No. Sur | veys where not applicable | 0 | 0 | 16 | 16 | 16 |
| | | | | | | | | | | Total | 114 | 114 | 114 | 114 | 114 |

. No data available

YES - data on this indicator is collected in this survey; NO - data on this indicator is not collected in this survey; NA - not applicable as previous column was negative

AMS - Afghanistan Mortality Survey; ARH - Adolescent Reproductive Health; MHS- Maternal Health Survey; SIS - Social Indicator Survey; SB:END – stillbirth to early neonate death ratio

Appendix S4. Variation in measurement of coverage of antenatal care components in DHS and RHS surveys and availability of data for stillbirths based on review of questionnaires, 2005-2015

| | | | | | AN | C CHARA | CTERIST | cs | | | | | | | Α | NC CON | IPONEN | тs | | | | | |
|----------------------|-----------------------------------|--|--|--------------------------------------|-----------------|--------------|------------------------------|----------------------|-----------------------------|----------|-----------------|-----------------|------------|------------|------------|------------------|-------------------------|--------------------------|--|-----------------------------|---|---|----|
| Country DHS MODEL | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | |
| QUESTIONNAIRES | | | | | | | | | | | | | | | | | | | | | | | |
| DHS PHASE 5 | 2003-2008 | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| DHS PHASE 6 | 2008-2013 | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| DHS PHASE 7 | 2013-18 | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO | NO | NO |
| SUB-SAHARAN AFRICA | | | | | | | | | | | | | | | | | | | | | | | |
| Benin | 2011-12 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | YES | NO | NO |
| Benin | 2006 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | YES | YES | NO |
| Burkina Faso | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Burundi | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Cameroon | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Cape Verde | 2005 DHS | | | YES | YES | | | | | YES | YES | YES | YES | NO | NO | NO | YES | | | | | | |
| Comoros | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Congo (Brazzaville) | 2011-12 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | NO | NO |
| Congo (Brazzaville) | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |

| | | | | | AN | C CHARA | CTERIST | ICS | | | | | | | A | NC CON | IPONEN | TS | | | | | |
|------------------------------|-----------------------------------|--|--|--------------------------------------|-----------------|--------------|------------------------------|----------------------|-----------------------------|----------|-----------------|-----------------|------------|------------|------------|------------------|-------------------------|--------------------------|--|-----------------------------|---|---|----|
| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Ē |
| Congo Democratic Republic | 2013-14 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Congo Democratic Republic | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Cote d'Ivoire | 2011-12 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Equatorial Guinea | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |
| Ethiopia | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Ethiopia | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Gabon | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Gambia | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Ghana | 2014 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Ghana | 2008 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Guinea | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Guinea | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Kenya | 2008-09 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | YES | YES | YES | NO |
| Lesotho | 2009 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | NO | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Liberia | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |

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|------------|-----------------------------------|--|--|--------------------------------------|-----------------|--------------|------------------------------|----------------------|-----------------------------|----------|-----------------|-----------------|------------|------------|------------|------------------|-------------------------|--------------------------|--|-----------------------------|---|---|-----------------------------|
| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Birth planning/preparedness |
| Liberia | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Madagascar | 2008-09 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Malawi | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | YES | NO | NO | YES | NO | NO |
| Mali | 2012-13 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Mali | 2006 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Mozambique | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Namibia | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Namibia | 2006-07 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Niger | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Niger | 2006 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Nigeria | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Nigeria | 2008 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Rwanda | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Rwanda | 2007-08 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Rwanda | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |

| | | | | | AN | C CHARA | CTERIST | ICS | | | | | | | Α | NC CON | IPONEN | TS | | | | | |
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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Birth planning/preparedness |
| Sao Tome and Principe | 2008-09 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES^ | NO | NO | NO | NO |
| Senegal | 2014 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Senegal | 2012-14 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Senegal | 2010-11 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Senegal | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Sierra Leone | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Sierra Leone | 2008 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Swaziland | 2006-07 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | YES | NO | NO | NO | NO | YES | YES | NO |
| Tanzania | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Тодо | 2013-14 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Uganda | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Uganda | 2006 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Zambia | 2013-14 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | YES |
| Zambia | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | YES |
| Zimbabwe | 2010-11 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |

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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Birth planning/preparedness |
| Zimbabwe | 2005-06 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| N. AFRICA/EUROPE/W.ASI A | 2003 00 0113 | | | | | | | | | 123 | 113 | | | | | | | | | | | | |
| Albania | 2008-09 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | YES | YES | YES | NO |
| Armenia | 2010 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Armenia | 2005 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Azerbaijan | 2006 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Egypt | 2014 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Egypt | 2008 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | YES | YES | NO | NO |
| Egypt | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Georgia | 2005 RHS | ALL BIRTHS | YES | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | YES | YES | NO | NO |
| Jordan | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Jordan | 2009 DHS | LAST LIVE BIRTH | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO |
| Jordan | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Moldova | 2005 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | YES | YES | YES | NO |

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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Ē |
| Ukraine | 2007 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Yemen | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Kyrgyz Republic | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Tajikistan SOUTH & SOUTH-EAST | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| ASIA Bangladesh | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | NO | YES | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO |
| Bangladesh | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | NO | YES | YES | NO |
| Cambodia | 2014 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Cambodia | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| Cambodia | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | NO | NO |
| India | 2005-06 DHS | LAST LIVE BIRTH | NO | YES | YES | NO | YES | YES | NO | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | YES | YES | NO |
| Indonesia | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | NO | NO | NO | NO | YES | YES | YES |
| Indonesia | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | NO | NO | NO | NO | YES | YES | YES |
| Maldives | 2009 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | NO | YES | YES | NO |

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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Ē |
| Nepal | 2011 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | YES |
| Nepal | 2006 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | YES |
| Pakistan | 2012-13 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | NO | YES | NO | NO |
| Pakistan | 2006-07 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | YES | NO | NO | NO | NO | NO | YES | YES | YES |
| Sri Lanka | 2006-07 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | NO | NO | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Philippines | 2013 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | YES |
| Philippines | 2008 DHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | YES |
| Timor-Leste | 2009-10 DHS | LAST LIVE BIRTH | NO | NO | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| LATIN AMERICA & CARIBBEAN | | | | | 125 | 125 | 125 | 125 | 125 | 125 | 125 | | 125 | 123 | | | | | | | 123 | 123 | |
| Bolivia | 2008 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | NO | NO | YES | YES | NO |
| Colombia | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |
| Colombia | 2005 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | NO | NO | NO | YES | YES | NO |
| Dominican Republic | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | YES | NO | YES | YES | NO | YES | NO | NO |
| Dominican Republic | 2007 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |
| El Salvador | 2008 RHS | LAST BIRTH# | YES | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO |

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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | Informed where to go for pregnancy complications | Birth planning/preparedness |
| Guatemala | 2008-09 RHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | NO | NO | NO | YES | YES | YES | NO | NO | NO | YES | NO | NO | NO | NO |
| Guyana | 2009 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Haiti | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | YES | NO | NO | NO | YES | YES | NO |
| Haiti | 2005-06 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Honduras | 2011-12 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | YES | YES | NO | YES | YES | NO | NO |
| Honduras | 2005-06 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |
| Jamaica | 2008-09 RHS | LAST BIRTH | YES | YES | NO | YES | YES | YES | NO | YES | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO | NO |
| Nicaragua | 2006-07 RHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | YES | NO | YES | NO | NO | NO | YES | NO | YES |
| Paraguay | 2008 RHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | NO | YES | NO | NO | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO |
| Peru | 2014 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | YES | NO | YES | YES | NO |
| Peru | 2013 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | YES | NO | YES | YES | NO |
| Peru | 2012 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | YES | NO | YES | YES | NO |
| Peru | 2011 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | YES | NO | YES | YES | NO |
| Peru | 2010 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | NO | YES | YES | NO | YES | YES | NO |
| Peru | 2009 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |

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| Country | Year of survey and survey type | Birth antenatal care information available for | Antenatal care data for stillbirth potentially available ¹ | Any ANC received during pregnancy | Provider of ANC | Place of ANC | Months pregnant at first ANC | Number of ANC visits | Months pregnant at last ANC | BP taken | Weight measured | Height measured | Urine test | Blood test | Ultrasound | Stomach examined | Uterine height measured | Foetal heartbeat checked | Offered a Syphilis test as part of prenatal care | Counselled on breastfeeding | Informed signs of pregnancy complications during ANC | ed whei ncy con | Birth planning/preparedness |
| Peru | 2007-08 DHS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | NO | YES | YES | NO | NO | YES | YES | NO |
| SPECIAL SURVEYS | | | | | . 20 | . 20 | . 20 | . 20 | | . 20 | . 10 | | . 10 | | | | . 10 | | | | . 20 | . 20 | |
| Afghanistan | 2010 AMS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Ghana | 2007 MHS | LAST BIRTH | YES | YES | YES | YES | YES | YES | NO | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | YES | YES | NO |
| Indonesia | 2012 ARS | LAST LIVE BIRTH | NO | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | YES | NO | YES | NO | NO | NO | NO | YES | YES | YES |
| Lao DRC | 2011-12 SIS | LAST LIVE BIRTH | NO | YES | YES | NO | YES | YES | NO | YES | NO | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO | NO | NO |
| Total no. surveys that co | llected data on indic | ator | 98 | 112 | 112 | 110 | 110 | 111 | 28 | 110 | 80 | 33 | 109 | 109 | 14 | 10 | 19 | 17 | 8 | 6 | 106 | 61 | 11 |
| Total no. surveys that di | d not collect data on | indicator | 15 | 2 | 2 | З | 3 | 2 | 85 | 4 | 34 | 81 | 4 | 5 | 100 | 104 | 95 | 96 | 105 | 107 | 7 | 52 | 102 |
| Total number of surveys | | | 113 | 114 | 114 | 113 | 113 | 113 | 113 | 114 | 114 | 114 | 113 | 114 | 114 | 114 | 114 | 113 | 113 | 113 | 113 | 113 | 113 |

¹ If the last recorded birth was a stillbirth

Refers to all live births in last 5 years and stillbirths in last 3 years (since 2005)

^Question asked was: what kind of blood test did you have done? Answer options: haemoglobin; Syphilis; HIV/AIDS; Other

Abbreviations: ANC – Antenatal Care; ARS - Adolescent Reproductive Survey; AMS- Afghanistan Mortality Survey; DHS – Demographic and Health Survey; MHS - Maternal Health Survey; RHS – Reproductive Health Survey; SIS- Social Indicator Survey

| | MATERNAL CONDITIONS/COMPLICATIONS | | | | | | | | | | | |
|-----------------------------|--|--|--|--------------------------------------|-----------------------------------|--------------------------------------|-----------------------------|---------------------------|--------------------------|---------------------------|--|--|
| | complie | tepartum cations & seeking | | compl | very ication | | Care-se | eking fo | or delive | ry comp | lications | |
| Country & Survey year | Any maternal conditions or complications during pregnancy | Details of antepartum complications | Care-seeking for antepartum complications | Any complications during delivery | Details of delivery complications | Sought care for delivery problems | Reason for not seeking care | Provider care sought from | Place care received from | Condition improved or not | Referred or advised to seek treatment for condition | Care-seeking delay for complication |
| DHS Model Questionnaires | | | | | | | | | | | | |
| DHS Phase 5 (2003-2008) | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| DHS Phase 6 (2008-2013) | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| DHS Phase 7 (2013-1018) | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| SUB-SAHARAN AFRICA | | | | | | | | | | | | |
| Benin 2011-12 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Benin 2006 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Burkina Faso 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Burundi 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Cameroon 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Cape Verde 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Comoros 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Congo (Brazzaville) 2011-12 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Congo (Brazzaville) 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Congo DRC 2013-14 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Congo DRC 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Cote d'Ivoire 2011-12 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Equatorial Guinea 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Ethiopia 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Ethiopia 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Gabon 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Gambia 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Ghana 2014 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Ghana 2008 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Guinea 2012 | NO | NA | NA | YES | YES | YES | NO | YES | NO | NO | NO | NO |
| Guinea 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Kenya 2008-09 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Lesotho 2009 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Liberia 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Liberia 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Madagascar 2008-09 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |

Appendix S5. Data availability in DHS/RHS surveys completed between 2005 and 2015 on maternal antepartum and delivery complications based on review of questionnaires

| | | | | MATER | | DITION | s/com | PLICATIC | DNS | | | |
|----------------------------|--|--|--|--------------------------------------|-----------------------------------|--------------------------------------|-----------------------------|---------------------------|--------------------------|---------------------------|--|--|
| | complic | tepartum ations & seeking | | compli | very ication | | Care-se | eking fo | or delive | ry comp | lications | |
| Country & Survey year | Any maternal conditions or complications during pregnancy | Details of antepartum complications | Care-seeking for antepartum complications | Any complications during delivery | Details of delivery complications | Sought care for delivery problems | Reason for not seeking care | Provider care sought from | Place care received from | Condition improved or not | Referred or advised to seek treatment for condition | Care-seeking delay for complication |
| Malawi 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Mali 2012-13 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Mali 2006 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Mozambique 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Namibia 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Namibia 2006-07 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Niger 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Niger 2006 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Nigeria 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Nigeria 2008 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Rwanda 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Rwanda 2007-08 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Rwanda 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Sao Tome and Principe 2008 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Senegal 2014 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Senegal 2012-13 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Senegal 2010-11 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Senegal 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Sierra Leone 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Sierra Leone 2008 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Swaziland 2006-07 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Tanzania 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Togo 2013-14 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Uganda 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Uganda 2006 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Zambia 2013-14 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Zambia 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Zimbabwe 2010-11 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Zimbabwe 2005-06 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| N. AFRICA/EUROPE/W. ASIA | | | | | | | | | | | | |
| Albania 2008-09 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Armenia 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Armenia 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |

| | MATERNAL CONDITIONS/COMPLICATIONS | | | | | | | | | | | |
|-------------------------|--|--|--|--------------------------------------|-----------------------------------|--------------------------------------|-----------------------------|---------------------------|--------------------------|---------------------------|--|--|
| | complie | tepartum cations & seeking | | compl | very ication s | | Care-se | eking fo | or delive | ry comp | lications | |
| Country & Survey year | Any maternal conditions or complications during pregnancy | Details of antepartum complications | Care-seeking for antepartum complications | Any complications during delivery | Details of delivery complications | Sought care for delivery problems | Reason for not seeking care | Provider care sought from | Place care received from | Condition improved or not | Referred or advised to seek treatment for condition | Care-seeking delay for complication |
| Azerbaijan 2006 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Egypt 2014 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Egypt 2008 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Egypt 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Georgia 2005 | YES | YES | NO | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Jordan 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Jordan 2009 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Jordan 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Moldova 2005 | YES | YES | YES | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Ukraine 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Yemen 2013 | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| CENTRAL ASIA | | | | | | | | | | | | |
| Kyrgyz Republic 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NO | NO | NO |
| Tajikistan 2012 | YES | YES | NO | NO | NA | NA | NA | NA | NA | NO | NO | NO |
| SOUTH & SOUTH-EAST ASIA | | | | | | | | | | | | |
| Bangladesh 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Bangladesh 2007 | NO | NA | NA | YES | YES | YES | YES | YES | YES | NO | NO | NO |
| Cambodia 2014 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Cambodia 2010 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Cambodia 2005 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| India 2005-06 | YES | YES | NO | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Indonesia 2012 | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Indonesia 2007 | YES | YES | YES | YES | YES | NO | NA | NO | NO | NO | NO | NO |
| Maldives 2009 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Nepal 2011 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Nepal 2006 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Pakistan 2012-13 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Pakistan 2006-07 | YES | YES | YES | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Sri Lanka 2006-07 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Philippines 2013 | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Philippines 2008-09 | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Timor-Leste 2009-10 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |

| | | | | MATER | NAL COM | DITION | S/COMI | PLICATIC | ONS | | | |
|---------------------------------------|--|--|--|--------------------------------------|-----------------------------------|--------------------------------------|-----------------------------|---------------------------|--------------------------|---------------------------|--|--|
| | complic | tepartum ations & o seeking | | Deli compli | ication | | Care-se | eking fo | or delive | ry comp | lications | |
| Country & Survey year | Any maternal conditions or complications during pregnancy | Details of antepartum complications | Care-seeking for antepartum complications | Any complications during delivery | Details of delivery complications | Sought care for delivery problems | Reason for not seeking care | Provider care sought from | Place care received from | Condition improved or not | Referred or advised to seek treatment for condition | Care-seeking delay for complication |
| LATIN AMERICA & CARIBBEAN | | | | | | | | | | | | |
| Bolivia 2008 | YES | YES | YES | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Colombia 2010 | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Colombia 2005 | YES | YES | NO | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Dominican Republic 2013 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Dominican Republic 2007 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| El Salvador 2008 | YES | NO | NO | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Guatemala 2008-09 | YES | YES | YES | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Guyana 2009 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Haiti 2012 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Haiti 2005-06 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Honduras 2011-12 | YES* | YES* | NO | YES* | YES* | NO | NO | NO | NO | NO | NO | NO |
| Honduras 2005-06 | YES* | YES* | NO | YES* | YES* | NO | NO | NO | NO | NO | NO | NO |
| Jamaica 2008-09 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Nicaragua 2006-07 | YES | NO | YES | YES | NO | YES | NO | YES | NO | NO | NO | NO |
| Paraguay 2008 | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Peru 2014 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2013 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2012 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2011 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2010 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2009 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| Peru 2007-08 | NO | NA | NA | YES | YES | NO | NO | NO | NO | NO | NO | NO |
| SPECIAL SURVEYS | | | | | | | | | | | | |
| Afghanistan 2010 AMS | YES* | YES* | YES * | YES* | YES* | YES* | YES* | YES* | YES* | YES* | YES* | YES* |
| Ghana 2007 MHS | YES* | YES* | YES * | YES* | YES* | YES* | YES* | YES* | YES* | YES* | YES* | NO |
| Indonesia 2012 ARS | YES | YES | YES | YES | YES | NA | NA | NA | NA | NA | NA | NA |
| Lao DRC 2011-12 SIS | NO | NA | NA | NO | NA | NA | NA | NA | NA | NA | NA | NA |
| Total no. surveys with data available | 17 | 15 | 8 | 22 | 21 | 5 | 3 | 5 | 3 | 2 | 2 | 1 |
| % surveys with data available | 15% | 13% | 7% | 19% | 18% | 4% | 3% | 4% | 3% | 2% | 2% | 1% |

*Survey doesn't differentiate between antepartum and intrapartum complications YES - data on this indicator is collected in this survey; NO - data on this indicator is not collected in this survey; NA - not applicable as previous question was negative

Abbreviations: ANC – Antenatal Care; ARS - Adolescent Reproductive Survey; AMS- Afghanistan Mortality Survey; DHS – Demographic and Health Survey; MHS - Maternal Health Survey; RHS – Reproductive Health Survey; SIS- Social Indicator Survey

Appendix S6. Variation in response options for questions on conditions or complications experienced during pregnancy in DHS survey questionnaires

| | Pregnancy complications | /conditions | | | |
|-----------------|---|----------------------------|---|---|---|
| Question No. | Question | Response Options | | | |
| Pakistan 200 | 6-07 DHS | | | | |
| 435 | When you were pregnant with (NAME), did you have any of the following problems?: | | Y | N | |
| | Severe headaches? | Severe headache? | | | |
| | Blurred vision? Swelling of your hands? | Blurred vision? | | | |
| | Swelling of your face? Vaginal bleeding /spotting | Swelling of your hands | | | |
| | Fits or convulsions? | Swelling of your face? | | | |
| | Epigastric pains? | Vaginal bleeding/spotting? | | | |
| | | Fits or convulsions? | | | |
| | | Epigastric pains | | | |
| Philippines 2 | 013 DHS | -h.Qh | | 1 | |
| 419 | What symptoms or conditions did you experience | Vaginal bleeding | А | | |
| | during your pregnancy with (NAME), if any? Anything else? | Headache | В | | |
| | | Dizziness | С | | |
| | | Blurred vision | А | | |
| | | Swollen face | В | | |
| | | Swollen hands/feet | С | | |
| | | Pale or anemic | А | | |
| | | Other (specify) | х | | |
| | | None | Y | | |
| Indonesia 20 | 12 DHS | | | | |
| 414c | Did you have any complications during this pregnancy (NAME)? | | Y | N | |
| 414d | What are they? | Labour before 9 months | А | | |
| | | Vaginal bleeding | В | | |
| | | Fever | с | | |
| | | Convulsions and fainting | D | | |
| | | Other (specify) | х | | |
| Columbia 2010 [| DHS | | | | |
| 440 | During pregnancy with (Name) were you hospitalised? | | | | |
| | When were you begritelized? | Infection | A | | - |
| | Why were you hospitalised? | Bleeding | В | | _ |
| | (Mark all that are mentioned) | Hypertension | с | | |
| | | Seizures or convulsions | D | | |
| | | Threatened abortion | E | | |
| | | Rupture of membranes | F | | |
| | | Domestic violence | G | | |

| | Pregnancy complications | | <u> </u> | 1 | |
|-----------------|---|----------------------------------|----------|---|----------|
| Question No. | Question | Response Options | | | <u> </u> |
| | | Other (specify) | Н | | |
| Afghanistan 201 | | 1 | | | |
| 427 | At any time before, during or after delivery did you have any of the following problems? If Yes, what | Headache | А | | |
| | problems did you have? (Circle all mentioned) | Blurry Vision | В | | |
| | | Swollen face/hands/feet | с | | |
| | | High fever | D | | |
| | | Excessive bleeding | Е | | |
| | | Foul-smelling discharge | F | | |
| | | Lower abdominal pain | G | | |
| | | Shaking/fits | н | | |
| | | Fainted/unconscious | I | | |
| | | Too long/prolonged labour | J | | |
| | | Water broke too early | к | | |
| | | Baby wouldn't come out | L | | |
| | | Baby not moving/not moving much | м | | |
| | | Baby's hands/feet came out first | N | | |
| | | Whole body pain | 0 | | |
| | | | Р | | |
| | | Tearing/torn pelvic area | | | |
| | | CIRCLE BELOW ONLY IF WOMAN | Q | | |
| | | USES EXACT TERM | | | |
| | | Edema | R | | |
| | | Pre-eclampsia | S | | |
| | | Convulsions | Т | | |
| | | Eclampsia | U | | |
| | | Tetanus | v | | |
| | | Did not have any problems | Y | | |
| | | Other (specify) | х | | |
| ndia 2005-06 | 5 NFHS 3 | | | | |
| | | | Y | N | DK |
| 427 | During this pregnancy, did you have convulsions not from fever | | | | |
| 428 | During this pregnancy, did you have swelling of the | | | | + |
| 429 | legs, body or face? During this pregnancy, did you feel excessive fatigue? | | - | | <u> </u> |
| 423 | | | | | |
| 430 | During this pregnancy, did you have any vaginal bleeding? | | | | |
| Tajikistan 20 | 12 DHS | | | | |
| 414C | In total, how many times have you been hospitalised during this pregnancy, including day-bed occupancy? | | | | |
| 414D | Please, list the reasons for all hospitalizations. Anything else? (Record all mentioned) | Blood pressure | А | | |
| | | | | | |

| | Pregnancy comp | plications/conditions | | |
|--------------|----------------|--------------------------|---|--|
| Question No. | Question | Response Options | | |
| | | Seizures | с | |
| | | Bleeding | D | |
| | | Miscarriage threat | E | |
| | | Preterm labour threat | F | |
| | | Labour overdue | G | |
| | | Fetal/placental problems | н | |
| | | Diabetes | 1 | |
| | | Anemia | J | |
| | | STD | к | |
| | | Other infection | L | |
| | | Test/diagnostics | М | |
| | | Accident/Injury | N | |
| | | Other (specify) | x | |
| | | Don't know | Y | |

OPPORTUNITIES TO INCREASE DATA & EVIDENCE ON STILLBIRTH RISK FACTORS IN LOW- AND MIDDLE-INCOME COUNTRIES

Paper II: Understanding country-specific determinants of stillbirth using household surveys – the case of Afghanistan

Understanding country-specific determinants of stillbirth using household surveys: The case of Afghanistan

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Abstract

Background: Stillbirth rates in Afghanistan have declined little in the past decade with no data available on key risk factors. Healthcare utilisation and maternal complications are important factors influencing pregnancy outcomes but rarely captured for stillbirth in national surveys from low- and middle-income countries. The 2010 Afghanistan Mortality Survey (AMS) is one of few surveys with this information.

Methods: We used data from the 2010 AMS that included a full pregnancy history and verbal autopsy. Our sample included the most recent live birth or stillbirth of 13 834 women aged 12-49 years in the three years preceding the survey. Multivariable Poisson regression was used to identify socio-demographic, maternal, and healthcare utilisation risk factors for stillbirth.

Results: The risk of stillbirth was increased among women in the Central Highlands (aRR:3.01, 95% CI:1.35, 6.70) and of Nuristani ethnicity (aRR:9.15, 95% CI: 2.95, 28.74). Women that didn't receive antenatal care had three times increased risk of stillbirth (aRR:3.03, 95% CI:1.73, 5.30), while high-quality antenatal care was important for reducing the risk of intrapartum stillbirth. Bleeding, infection, headache, and reduced fetal movements were antenatal complications strongly associated with stillbirth. Reduced fetal movements in the delivery period increased stillbirth risk by almost seven (aRR:6.82, 95% CI:4.20, 11.10). Facility births had a higher risk of stillbirths overall (aRR:1.55, 95% CI:1.12, 2.16), but not for intrapartum stillbirths.

Conclusions: Targeted interventions are needed to improve access and utilisation of services for high-risk groups. Early detection of complications through improved quality of antenatal and obstetric care is imperative. We demonstrate the potential of household surveys to provide country-specific evidence on stillbirth risk factors for LMICs where data is lacking.

Key words: stillbirth, fetal death, perinatal death, Afghanistan, low- and middle-income country, risk factor, household surveys, Demographic and Health Survey

Introduction

A major challenge for stillbirth prevention in low- and middle-income countries (LMIC), where the largest burden lies, is the lack of adequate data to identify and quantify major risk factors at the national level.¹ Existing studies have been predominantly with women who have had contact with the formal health care system ², and while prospective, population-based studies such as those from demographic surveillance sites in LMICs are increasing,^{3, 4} there are no national-level data for many countries ¹. This lack of data on country-specific risk factors makes it challenging to direct attention to stillbirth at a national level and for countries to prioritise programmatic and policy areas for action to reduce stillbirths.

In 2009, Afghanistan was among the top ten nations accounting for almost two-thirds of the global stillbirth burden, and by 2015 little improvement was observed.^{5, 6} The annual reduction in stillbirths between 2000 and 2015 in Afghanistan was only 1.9%.⁶ The stillbirth rate remains high at 27 per 1000 births – six times that of high-income settings, yet there are no published studies to understand stillbirths in this context. Stillbirths have not been a public health priority in Afghanistan partly because of the absence of evidence on the major factors contributing to these deaths. The UN's 2016 Global Strategy for Women's, Children's and Adolescent Health now includes reduction in the stillbirth rate as a core indicator, and the 2014 Every Newborn Action Plan set the first-ever targets to reduce stillbirths to 12 per 1000 births by 2030 which was endorsed by 190 countries, including Afghanistan.⁷ It is therefore, both timely and crucial to investigate stillbirths in this high-burden country.

The 2010 Afghanistan Mortality Survey (AMS) was a modified, special Demographic and Health Survey (DHS) and one of a few nationally-representative surveys conducted in a LMIC in the last ten years that collected health service utilisation data for stillbirths and also included a verbal autopsy.⁸ The country's unique and diverse socio-cultural, linguistic, and geographic characteristics in addition to the current complex humanitarian situation, makes the need for context-specific data imperative (Box 1). The objective of this study was to identify key maternal, obstetric and healthcare utilisation factors associated with stillbirth in Afghanistan, and to demonstrate the potential of a modified DHS survey to provide country-specific evidence on risk factors for stillbirth if applied in other LMICs.

Box 1: Afghanistan country context and health situation

Afghanistan is a culturally rich nation located in south-central Asia sharing borders with six different countries, the longest being with Pakistan. The country's 34 provinces comprise a diverse range of ethnicities, languages, and geographic terrains. It is mostly a mountainous landscape with the Hindu Kush mountain range dividing the country from the northeast to the southwest into three distinct regions – the mountainous central highlands, the south-west plateaus characterised by deserts, and the smaller and most fertile northern plains. The current population is estimated to be approximately 30 million. The country is one of the least developed nations in the world, ranked 169 out of 188 nations on the human development index in 2015. About one third (37%) of the population lives below the poverty line and this has remained unchanged since 2007-08. Afghanistan has a very young population structure with 48% aged under 15 years, and average life expectancy of only 60 years. Fertility rates are high with an average of 5.3 children in 2015 – a slight increase from 5.1 in 2010.^{9, 10} Adult literacy rates remain low at 31%, particularly among females (males 45%; females 17%).

Afghanistan has faced over four decades of ongoing conflict, unstable governance and population displacement which continues. In 2016, the conflict led to the displacement of over half a million people, more than half of whom were children, and an unexpected influx of over one million Afghan refugees and returnees from Pakistan. It is estimated that over nine million people have limited or no access to essential health services, straining an already weak and recovering health system. The impact of the conflict on access to health services and health education for women and their families is, therefore, particularly challenging.

Since its release from Taliban rule in 2002, the Afghan government and international community made immense efforts to repair and strengthen the health system. Although rates of maternal and child deaths continue to be some of the highest in the world, there have been some encouraging improvements; maternal mortality has declined from 1600 deaths per 100 000 in 2002 to 327 per 100 000 in in 2010, however, a 2013 analysis suggests these rates may be inaccurate and could be around 885 per 100 000 live births. Recent estimates for under five child mortality suggest around 70 deaths per 1000 live births and a neonatal mortality rate of 40 per 1000 live births. In 2015, 18% of women received the recommended four or more ANC visits and 50% reported attendance of a skilled birth attendant at their most recent birth, an increase from 34% in 2010.¹⁰ Despite these improvements, there remains inadequate access to, and utilisation of, ANC and quality obstetric care services,¹¹ with stark inequities in access between urban and rural areas and across regions.¹² Health system challenges exist around sufficient numbers of female health care providers and the costs of health services and treatment. There are also additional contextual challenges and social and cultural norms surrounding women's low levels of autonomy and education that directly impact on care-seeking delays and child health outcomes.¹³

Methods

Data sources

Data for this analysis are from the 2010 Afghanistan Mortality Survey.¹⁰ This was the country's first nationally representative household survey and is currently the only national, population-based survey that has collected data on women's health service utilisation for stillbirth. The survey adopted a two-stage sampling design based on the 2011 Population and Housing Census preparatory frame from the Central Statistics Organisation. The design produced a sample representative at the country level for rural and urban areas, and for the North, Central and South geographical domains that are regroupings of eight geographical regions (Figure 1). The rural areas of Kandahar, Helmand, and Zabul provinces in the South were not surveyed for security reasons. Overall, the survey covered 87% of the population; the 13% not surveyed belonged mostly to the South zone.¹⁰

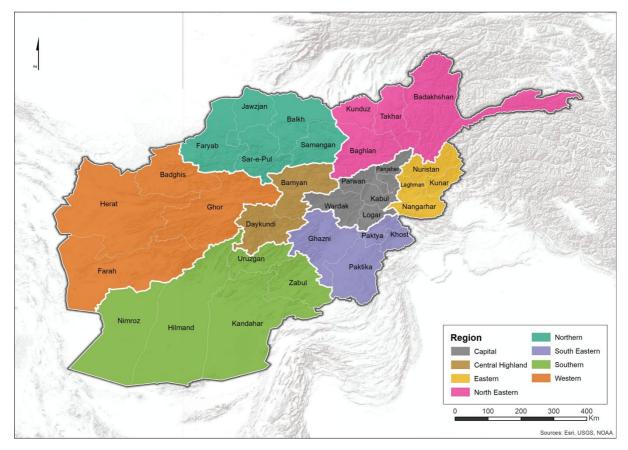


Figure 1. Map of Afghanistan showing geographic regions and provinces

We used data from three questionnaires in the AMS survey; the household, women's, and verbal autopsy (VA) questionnaire, based on the DHS model questionnaires developed by the DHS

program and adapted for Afghanistan. The women's questionnaire collected information from evermarried women aged 12-49 years including background characteristics and a complete pregnancy history which captured all pregnancies and their outcomes in a woman's lifetime. Among women that gave birth in the preceding five years, the women's questionnaires captured maternal health care utilisation including antenatal, delivery and post-natal care for the mother's last live birth or stillbirth. The VA questionnaire was completed for each death that occurred in the preceding three years.

In total, 22 351 households were interviewed, which included 47 848 women aged 12-49 years, yielding a response of 98%. We limited our analysis to all women's births within the last three years, giving a base of 17 215 births. We merged data from the VA with the women's and household data so that selected variables not available in the pregnancy histories for stillbirths could be included (fetal sex, multiple pregnancy, and timing of the stillbirth). We further restricted our sample to mothers' most recent birth, giving a sample of 13 844 women/births (13 528 live births and 316 stillbirths) then corrected any misclassification between miscarriages, stillbirths or early neonatal deaths using the VA data. This gave a final sample of 13 834 births (13 523 live births and 311 stillbirths). Details on this procedure is available in the <u>Appendix</u>.

Study variables

Dependent variable: pregnancy outcome

Our main outcome variable was pregnancy outcome for the mothers' most recent pregnancy and was coded as stillbirth or live birth (see <u>Appendix</u> for detail). We used the definition of stillbirth to be a late fetal death at ≥28 weeks' gestation as recommended by WHO for international comparisons. The 2010 AMS recorded gestational age in months so we used seven months or more as our cut off. We defined intrapartum stillbirths as those stillbirths where the mother reported no signs of skin maceration based on the VA data.

Independent variables and analytical framework

We included individual, household, and community-level explanatory variables based on those identified in the literature as having an important effect on stillbirth, and availability in the 2010 AMS dataset^{1, 14} (see <u>Appendix</u>). To guide the analysis, we developed an analytical framework by adapting existing frameworks.^{15, 16} This framework mapped explanatory variables according to proximity to the outcome as distal, intermediate and proximal determinants (<u>Figure A2</u>) and represented three defined time periods - preconception, pregnancy, and childbirth.

Statistical analysis

All analyses were performed using STATA/SE version 14.2. For the binary outcome, stillbirth, we used Poisson regression models with a log link function to estimate relative risks. All models were weighted using sample weights to account for the complex survey design and adjusted standard errors were used to obtain Wald test p-values and 95% confidence intervals.

We fitted univariable models and built three multivariable regression models to examine the association between stillbirth and the explanatory variables. We applied a sequential approach¹⁷ based on the three stages of pregnancy (Figure A2): model 1 included variables from the preconception period (community level, socio-economic, environmental & maternal factors); model 2 included factors related to the pregnancy period (antenatal care and pregnancy complications), having adjusted for the variables from stage 1; and model 3 included factors related to the delivery period (complications during the delivery period and delivery care), having adjusted for the variables from the first two stages. In the first model, no p-value criterion was used for including variables, but for subsequent models (model 2 and model 3) only variables with $p\leq0.20$ from the previous model were included into the next stage. Wealth, maternal age and education, fetal sex, and multiple gestation were considered important factors and were retained in the models regardless of their pvalues. All other variables were removed one at time, starting with the highest p-value, until only those that had $p\leq0.05$ remained. Multi-collinearity was checked using variance inflation factors. Area under the curve (AUC) and calibration plots were used to assess model performance. We used the same model building approach for identifying independent risk factors for intrapartum stillbirth.

Results

We included 13 834 births, of which 311 were stillbirths and 13 523 were live births (23 stillbirths per 1000 total births) (Table A2). Most women resided in rural areas (80.9%), were married (99.5%), and had no formal education (89.4%). First-time mothers comprised 16% of the sample, however, fertility was high with over 40% of women having at least five children prior to the index pregnancy. Approximately 5% had experienced a previous pregnancy loss. Over one-third (36.0%) of women had not received antenatal care (ANC) for their last birth, while 16% had the recommended four or more visits. Quality of ANC was generally low, with most women receiving less than five of the nine recommended services. Only one-third of births took place at a health facility with a skilled birth attendant, and less than 2% of births were caesarean sections. Almost two-thirds (60.6%) of stillbirths occurred during the intrapartum period; although the timing was unknown for nearly 20%.

The most frequent maternal conditions during pregnancy were headaches, possible hypertension or infection, and bleeding. Common complications in the delivery period were headaches, blurry vision, possible hypertension or infection, excessive bleeding, prolonged labour/malpresentation. About 1% of women in the pregnancy and delivery periods reported reduced fetal movements (<u>Table A2</u>).

Disparities in stillbirth rates across the eight geographical regions were high, ranging from 13 per 1000 births in the Northern regions to over 40 per 1000 births in the Central Highlands (Table 1). In the univariate analysis, region of residence, ethnicity and maternal age were strongly associated with stillbirth, but wealth quintile and education were not. First and higher order pregnancies, multiple gestation, previous pregnancy loss, and not receiving ANC, were all associated with stillbirth (Table 1).

| | | oirths (%) | All bi N | rths (%) | Stillbirth rate per 1000 total births | Unadjusted RR (95% CI) |
|--|----------|-----------------|--------------|-----------------|--|---------------------------------------|
| Total pregnancy outcomes (weighted) | 311 | (2.2) | 13 834ª | <u> </u> | 22.5 | |
| COMMUNITY LEVEL | | | | | | |
| Residence | | | | | | |
| Urban | 49 | (15.7) | 2636 | (19.1) | 18.5 | 1.00 (Reference) |
| Rural | 262 | (84.3) | 11198 | (80.9) | 23.4 | 1.26 (0.90, 1.77) |
| Region | | | | | | |
| North-Eastern | 34 | (10.9) | 2081 | (15.0) | 16.3 | 1.00 (Reference) |
| Northern | | (9.0) | 2145 | (15.5) | 13.0 | 0.80 (0.45, 1.42) |
| Western | | (12.0) | 1841 | (13.3) | 20.3 | 1.25 (0.72, 2.16) |
| Central Highland | 20 | (6.4) | 430 | (3.1) | 46.6 | 2.86 (1.34, 6.12) |
| Capital | 58 | (18.6) | 2635 | (19.1) | 21.9 | 1.35 (0.82, 2.21) |
| Eastern | 79 | (26.5) | 2472 | (17.8) | 32.1 | 1.97 (0.94, 4.16) |
| Southern | 16 | (5.2) | 906 | (6.6) | 17.8 | 1.09 (0.62, 1.92) |
| South eastern | 39 | (12.5) | 1324 | (9.6) | 29.3 | 1.80 (1.12, 2.88) |
| Ethnicity ¹ | | | | | | |
| Tajik | 76 | (24.3) | 4386 | (31.7) | 17.2 | 1.00 (Reference) |
| Pashtun | | (40.9) | 5992 | (43.4) | 21.2 | 1.23 (0.90, 1.69) |
| Hazara | 30 | (9.5) | 1125 | (8.1) | 26.3 | 1.53 (0.90, 2.60) |
| Uzbek | | (7.6) | 1218 | (8.8) | 19.4 | 1.13 (0.66, 1.94) |
| Nuristan | | (11.3) | 189 | (1.4) | 186.0 | 10.80 (3.67, 31.77 |
| Pashai | | (3.1) | 318 | (2.3) | 30.2 | 1.75 (0.86, 3.57) |
| Baloch/Turkmen/Other | 10 | (3.3) | 595 | (4.3) | 16.8 | 1.00 (0.43, 2.32) |
| SOCIO-ECONOMIC & ENVIRONMENTAL | | | | | | |
| Wealth quintile | | | | | | |
| Lowest | | (18.5) | | (20.4) | 20.4 | 1.07 (0.70, 1.762) |
| Second | | (24.5) | | (20.4) | 27.0 | 1.41 (0.99, 2.03) |
| Middle | | (24.0) | | (19.9) | 27.1 | 1.47 (1.01, 2.12) |
| Fourth | | (16.4) | | (19.8) | 18.7 | 0.98 (0.66, 1.45) |
| Highest | 52 | (16.6) | 2696 | (19.5) | 19.1 | 1.00 (Reference) |
| Marital status | | | | | | |
| Currently married | | (100.0) | | (99.5) | - | - |
| Previously married | 0 | (0.7) | 65.4 | (0.5) | - | - |
| Maternal education | | (00.4) | 40070 | (00.4) | 22.4 | 4 50 (0 00 0 55) |
| No education or Madrassa | | (93.1) | | (89.4) | 23.4 | 1.59 (0.99, 2.55) |
| Any education ^b | 22 | (6.9) | 1463 | (10.6) | 14.8 | 1.00 (Reference) |
| Source of drinking water ² | 150 | (40.2) | 7650 | | 10.0 | 1.00 (Deferrere) |
| Improved water source | | (48.3) | | (55.4) | 19.6 | 1.00 (Reference) |
| Unimproved water source | 161 | (51.7) | 6158 | (44.6) | 26.1 | 1.33 (0.95, 1.86) |
| Sanitation facility ³ | | | | | | |
| Improved sanitation facility | | (37.5) | | (36.5) | 23.1 | 1.00 (Reference) |
| Unimproved sanitation facility/other | 194 | (62.5) | 8781 | (63.5) | 22.1 | 0.96 (0.59, 1.56) |
| Fuel used for cooking ^₄ | | | | | | |
| Clean fuel/no food cooked in house | | (15.8) | | (20.2) | 17.7 | 1.00 (Reference) |
| Solid fuel/other | 262 | (84.2) | 11024 | (79.8) | 7.6 | 1.34 (0.94, 1.91) |
| MATERNAL & FETAL CHARACTERISTICS | | | | | | |
| Sex of baby⁵ | 424 | (42.0) | 6200 | (45.4) | 10.0 | 1.00 (D. (|
| Female | 124 | (42.0) | 6280 | (45.4) | 19.8 | 1.00 (Reference) |
| Male Broggeneratives | 172 | (58.0) | 7538 | (54.6) | 22.8 | 1.15 (0.88,1.51) |
| Pregnancy type ⁶ | 205 | (06.9) | 12601 | (00.0) | 20.0 | 1 00 (Poforonco) |
| Singleton Multiple | 285 9 | (96.8) (3.2) | 13684 133 | (99.0) (1.0) | 20.9 70.2 | 1.00 (Reference) 3.37 (1.62, 6.98) |
| Maternal age (years) | 9 | (3.2) | 122 | (1.0) | 70.2 | 3.37 (1.02, 0.98) |
| 12-18 | 22 | (7.1) | 1209 | (8.7) | 18.3 | 0.99 (0.53,1.87) |
| 19-24 | 92 | (29.6) | 5013 | (36.2) | 18.3 | 1.00 (Reference) |
| 25-34 | 134 | (43.0) | 5666 | (41.0) | 23.6 | 1.28 (0.88, 1.87) |
| ≥35 | 63 | (43.0) | 1947 | (41.0) (14.1) | 32.3 | 1.76 (1.26, 2.45) |
| Pregnancy order | 03 | (20.2) | 1)4/ | (17.1) | 52.5 | 1.70 (1.20, 2.43) |
| First pregnancy | 58 | (18.5) | 2165 | (15.7) | 26.6 | 1.64 (1.10, 2.45) |
| 2 nd -4 th pregnancy | 98 | (31.5) | 6046 | (43.7) | 16.2 | 1.00 (Reference) |
| ≥5th pregnancy | 156 | (50.0) | 5623 | (40.6) | 27.7 | 1.71 (1.30, 2.24) |
| Pregnancy interval ^c | 100 | (30.0) | 5025 | (40.0) | 27.7 | 1.7 1 (1.30, 2.24) |
| First pregnancy | 58 | (18.5) | 2165 | (15.7) | 26.6 | 1.35 (0.89, 2.04) |
| <18 months | 42 | (13.5) | 1664 | (12.0) | 25.2 | 1.28 (0.81, 2.05) |
| 18-58 months | 181 | (58.0) | 9174 | (66.3) | 19.7 | 1.00 (Reference) |

Table 1. Univariable results of factors associated with stillbirth for women's most recent birth in the preceding three years, Afghanistan 2010

| | | oirths | All bi | | Stillbirth rate | Unadjusted | |
|---|-------|------------------|---------------|------------------|-----------------------|---------------------------------------|--|
| | | (%) | 12.0243 | | per 1000 total births | RR (95% CI) | |
| Total pregnancy outcomes (weighted) | 311 | (2.2) | 13 834ª | <u> </u> | 22.5 | 1 00 /1 25 2 27 | |
| ≥59 months Provious programsy loss | 31 | (10.0) | 831 | (6.0) | 37.3 | 1.90 (1.25, 2.87) | |
| Previous pregnancy loss No ^d | 270 | (86.8) | 13080 | (94.6) | 20.6 | 1.00 (Reference) | |
| Yes | 41 | (13.2) | 754 | (5.5) | 54.4 | 2.63 (1.87, 3.71) | |
| ANTENATAL CARE | 41 | (13.2) | 7.54 | (5.5) | 54.4 | 2.03 (1.87, 3.71) | |
| Number of ANC visits ^{c, 7} | | | | | | | |
| None | 145 | (47.3) | 4969 | (36.2) | 29.1 | 1.58 (0.98, 2.55) | |
| 1 | 43 | (14.2) | 1912 | (13.9) | 22.7 | 1.23 (0.74, 2.04) | |
| 2-3 | 76 | (24.9) | 4575 | (33.3) | 16.7 | 0.90 (0.60, 1.36) | |
| 4 or more | 42 | (13.7) | | (16.6) | 18.4 | 1.00 (Reference) | |
| Timing of first ANC visit ^{c,8} | | (1017) | | (2010) | 2011 | 2.00 (| |
| First trimester | 47 | (15.4) | 2569 | (18.7) | 18.5 | 1.00 (Reference) | |
| Second trimester | 61 | (19.9) | 3721 | (27.1) | 16.5 | 0.89 (0.60, 1.34) | |
| Third trimester | 55 | (17.8) | 2459 | (17.9) | 22.3 | 1.21 (0.77, 1.89) | |
| No ANC | 145 | (46.9) | 4969 | (36.2) | 29.1 | 1.58 (0.99, 2.52) | |
| ANC provider ^{c, 9} | | . , | | , , | | , | |
| Trained provider ^e | 160 | (51.5) | 8413 | (60.9) | 19.0 | 1.00 (Reference) | |
| Untrained provider ^f | 6 | (2.0) | 432 | (3.1) | 14.1 | 0.74 (0.29, 1.89) | |
| No ANC | 145 | (46.5) | 4969 | (36.0) | 29.1 | 1.53 (1.07, 2.18) | |
| Place of ANC ^c | | . , | | . , | | | |
| Health facility/clinic | 142 | (45.5) | 7694 | (55.6) | 18.4 | 1.00 (Reference) | |
| Home/multiple providers/other | 25 | (7.9) | 1171 | (8.5) | 21.1 | 1.14 (0.63, 2.07) | |
| No ANC | 145 | (46.5) | 4969 | (35.9) | 29.1 | 1.58 (1.11,2.26) | |
| ANC components ^{c, g} | | | | | | , | |
| Weighed ¹⁰ | 51 | (16.4) | 3481 | (25.3) | 14.6 | 0.58 (0.42, 0.80) | |
| Blood pressure taken ¹¹ | 151 | (48.6) | 7932 | (57.5) | 19.0 | 0.70 (0.50, 0.98) | |
| Urine sample taken ¹² | 66 | (21.2) | 2920 | (21.2) | 22.5 | 1.00 (0.74, 1.36) | |
| Blood sample taken ¹³ | 72 | (23.1) | 2742 | (19.9) | 26.2 | 1.21 (0.90, 1.63) | |
| Given/bought iron tablets ¹⁴ | 103 | (33.1) | 5290 | (38.3) | 19.4 | 0.80 (0.56, 1.13) | |
| Took intestinal parasite drugs ¹⁵ | 11 | (3.7) | 580 | (4.2) | 19.7 | 0.87 (0.41, 1.85) | |
| Told signs of pregnancy complications ¹⁶ | 56 | (18.1) | 2888 | (20.9) | 19.2 | 0.83 (0.59, 1.17) | |
| Told where to go for complications ¹⁷ | 47 | (15.2) | 2416 | (17.5) | 19.6 | 0.85 (0.58, 1.24) | |
| Received 2+ tetanus injections ¹⁸ | 113 | (36.4) | 6868 | (49.8) | 16.4 | 0.58 (0.42, 0.80) | |
| ANC quality score ^h | | | | | | | |
| Low (0-5) | 139 | (45.3) | 7115 | (51.9) | 19.5 | 1.40 (0.86, 2.29) | |
| High (6-9) | 23 | (7.4) | 1636 | (11.9) | 13.9 | 1.00 (Reference) | |
| No ANC | 145 | (47.3) | 4969 | (36.2) | 29.1 | 2.10 (1.34, 3.29) | |
| PREGNANCY COMPLICATIONS | | | | | | | |
| Headache | | (22.2) | | () | | | |
| No | | (83.0) | 12102 | . , | 21.3 | 1.00 (Reference) | |
| Yes | 53 | (17.0) | 1733 | (12.5) | 30.6 | 1.45 (1.00, 2.09) | |
| Blurry vision | | (00 -) | 40000 | (02.5) | 24.6 | 1 00 /2 5 | |
| No | | (89.7) | 12891 | | 21.6 | 1.00 (Reference) | |
| Yes | 32 | (10.3) | 943 | (6.8) | 34.1 | 1.58 (1.05, 2.38) | |
| Bleeding or spotting | 205 | (01 7) | 12200 | (06.4) | 24.4 | 1.00 (Deferrer) | |
| No | | (91.7) | 13300 | (96.1) | 21.4 | 1.00 (Reference) | |
| Yes Brabable hypertensioni | 26 | (8.3) | 534 | (3.9) | 48.4 | 2.26 (1.41, 3.60) | |
| Probable hypertension ⁱ | 270 | (00 5) | 12027 | (02.7) | 71 7 | 1 00 /Dofarras) | |
| No Yes | | (89.5) | 12827 | (92.7) (7.2) | 21.7 | 1.00 (Reference) | |
| Yes Probable infection ^j | 33 | (10.5) | 1007 | (7.5) | 32.5 | 1.50 (0.97, 2.32) | |
| | 270 | (89.7) | 13079 | (01 E) | 21.2 | 1.00 (Reference) | |
| No Yes | | | | (94.5) (5.5) | 21.3 42.6 | 2.00 (1.35, 2.96) | |
| Yes Anaemia or thin/weak blood | 32 | (10.3) | 755 | (5.5) | 42.0 | 2.00 (1.35, 2.96) | |
| No | 201 | (93.7) | 12150 | (1 0) | 22.2 | 1.00 (Reference) | |
| | | | 13152 | (4.9) (4.9) | | | |
| Yes Reduced or no fotal movement | 20 | (6.3) | 082 | (4.9) | 28.8 | 1.30(0.83, 2.03) | |
| Reduced or no fetal movement | 200 | (96.1) | 12601 | (98.9) | 71 0 | 1.00 (Reference) | |
| No | | . , | 13684 150 | | 21.8 81 5 | | |
| Yes Too oorly contractions | 12 | (3.9) | 150 | (1.1) | 81.5 | 3.73 (1.99, 7.94) | |
| Too early contractions | 204.0 | (04.9) | 12424 | (07.0) | 22.0 | 1 00 (Potorona) | |
| No | | (94.8) (5.2) | 13424 | (97.0) (2.0) | 22.0 | 1.00 (Reference) | |
| Voc | 10.3 | (5.2) | 410 | (3.0) | 39.8 | 1.81 (0.83, 3.95) | |
| Yes Abdominal nain | | | | | | | |
| Abdominal pain | | (00 C) | 17775 | (00 7) | <u>ээ г</u> | 1 00 /Doforces) | |
| | 276 | (88.6) (11.4) | 12275 1559 | (88.7) (11.3) | 22.5 22.7 | 1.00 (Reference) 1.01 (0.64, 1.59) | |

| | | oirths | All bi | | Stillbirth rate | Unadjusted |
|---|-----|------------------|--------------|-----------------|-----------------------|--|
| | | (%) | | (%) | per 1000 total births | RR (95% CI) |
| Total pregnancy outcomes (weighted) | 311 | (2.2) | 13 834ª | | 22.5 | 1.00/0.() |
| No | | (97.8) | 13595 | (98.3) | 22.4 | 1.00 (Reference) |
| Yes | / | (2.2) | 240 | (1.7) | 28.0 | 1.25 (0.59, 2.66) |
| DELIVERY CARE | | | | | | |
| Birth attendant ¹⁹ | 112 | (2.2) | 1005 | (26.4) | 22.5 | 1.00 (D. (|
| Skilled provider ^e | | (2.2) | 4965 | (36.1) | 22.5 | 1.00 (Reference) |
| Unskilled provider ^f | | (60.9) | 8488 | (61.7) | 22.3 | 1.01 (0.70, 1.45) |
| No one | 10 | (3.2) | 306 | (2.2) | 32.6 | 1.47 (0.71, 3.04) |
| Delivered in health facility ²⁰ No | 201 | (61 0) | 0100 | (66.0) | 22.0 | 1 00 (Deference) |
| Yes | | (64.8) (35.2) | 9108 | (66.0) | | 1.00 (Reference) |
| | 109 | (35.2) | 4702 | (34.0) | 23.1 | 1.05 (0.73, 1.51) |
| Mode of delivery ^{c, 21} | 262 | (86.0) | 12067 | (01 2) | 20.5 | 1 00 (Potoronce) |
| Vaginal | | (86.0) | 12867 238 | (94.2) (1.7) | | 1.00 (Reference) |
| Caesarean section Instrumental (forceps or vacuum) | | (6.3) (7.8) | 238 560 | (1.7) (4.1) | 80.6 42.5 | 3.95 (2.02, 7.69) 2.12 (1.33, 3.37) |
| | 24 | (7.0) | 500 | (4.1) | 42.5 | 2.12 (1.55, 5.57) |
| Headache | | | | | | |
| No | 102 | (61.7) | 9023 | (65.2) | 21.3 | 1.00 (Reference) |
| Yes | | (38.3) | | (34.8) | 24.8 | 1.16 (0.82, 1.66) |
| Blurry vision | 119 | (38.3) | 4011 | (34.8) | 24.0 | 1.10 (0.82, 1.00) |
| No | 220 | (76.6) | 11390 | (82.3) | 20.9 | 1.00 (Reference) |
| Yes | | (23.4) | 2444 | (17.7) | 29.8 | 1.42 (1.01, 1.99) |
| Excessive bleeding | 75 | (23.4) | 2444 | (17.7) | 25.0 | 1.42 (1.01, 1.55) |
| No | 217 | (69.7) | 11907 | (86.1) | 18.2 | 1.00 (Reference) |
| Yes | | (30.3) | 1927 | (13.9) | 48.9 | 2.69 (2.07, 3.50) |
| Probable hypertension | 51 | (30.5) | 1527 | (10.0) | 10.5 | 2.03 (2.07, 5.50) |
| No | 240 | (77.2) | 11594 | (83.8) | 20.7 | 1.00 (Reference) |
| Yes | | (22.8) | 2240 | (16.2) | 31.6 | 1.53 (1.05, 2.22) |
| Probable infection | /1 | (22.0) | 2210 | (10.2) | 51.0 | 1.55 (1.65, 2.22) |
| No | 237 | (76.1) | 12039 | (87.0) | 19.7 | 1.00 (Reference) |
| Yes | | (23.9) | 1796 | (13.0) | 41.5 | 2.11(1.59, 2.81) |
| Prolonged/obstructed labour/malpresentation | | ,, | 2,00 | () | | (|
| No | 271 | (87.1) | 12844 | (92.8) | 21.1 | 1.00 (Reference) |
| Yes | | (12.9) | 990 | (7.2) | 40.5 | 1.96 (1.33, 2.89) |
| Water broke too early | | / | | . / | | - (,, |
| No | 280 | (90.2) | 13005 | (94.0) | 21.6 | 1.00 (Reference) |
| Yes | | (9.8) | 829 | (6.0) | 36.9 | 1.71 (1.03, 2.85) |
| Reduced or no fetal movement | | | | . , | | . ,, |
| No | 283 | (91.1) | 13678 | (98.9) | 20.7 | 1.00 (Reference) |
| Yes | | (8.9) | 157 | (1.1) | 177.2 | 8.56 (5.51, 13.3) |
| Lower abdominal pain | | | | . , | | . , -, |
| No | 182 | (58.5) | 9568 | (69.2) | 19.0 | 1.00 (Reference) |
| Yes | | (41.5) | 4267 | (30.8) | 30.3 | 1.59 (1.24, 2.04) |
| Fainting/unconsciousness | | . , | | . / | | |
| No | 289 | (93.0) | 13202 | (95.4) | 21.9 | 1.00 (Reference) |
| Yes | | (7.0) | 632 | (4.6) | 34.7 | 1.58 (0.97, 2.58) |

Abbreviation: ANC- antenatal care; RR- risk ratio

Footnotes

^aN= 13 834 unless otherwise indicated ^b Any education refers to any primary, secondary or higher level of education

^c These variables were not included in the multivariable analyses. ANC variables not included due to multi-collinearity with quality of ANC. Delivery assistant was not included due to collinearity with place of delivery. Mode of delivery not included as these are procedures might have occurred after the outcome. Severe bleeding during labour was not ^d Includes first pregnancies

^e Skilled/trained provider refers to doctor, nurse or midwife

¹ Unskilled Junite provider refers to traditional birth attendant (TBA), Community health worker (CHW), relative or friend ⁸ Reference category are those that did not receive the intervention

^h ANC quality score calculated by number of components received out of a total of 9 components (1- weight taken, 2- blood pressure taken, 3- blood sample taken, 4- urine sample taken, 5- informed signs of pregnancy complications, 6- informed where to seek care for complications, 7- received 2+ tetanus injections, 8- received iron/folic acid, and 9- received anti-helminths)

ⁱ Probable hypertension was based on mother's report of convulsions/fits/shaking/eclampsia/pre-eclampsia and/or swelling/oedema

Probable inpertension was used on mother's report of high fever and/or foul-smelling vaginal discharge Missing values (unweighted observations): ¹ n=11; ² n=24 ³ n=9, ⁴ n=23, ⁵ n=16, ⁶n=49, ⁷ n=122, ⁸ n=118, ⁹ n=22, ¹⁰ n=58, ¹¹ n=48 ¹² n=65, ¹³ n=69, ¹⁴ n=20, ¹⁵ n=133, ¹⁶ n=49, ¹⁷ n=10, ¹⁸ n=133, ¹⁹ n=78, ²⁰ n=29, ²¹ n=230

Table 2 shows the multivariable results of factors associated with stillbirth. Factors associated with stillbirth in the pre-pregnancy period (model 1) were region of residence, ethnicity, previous pregnancy loss, and nulliparity. In particular, women in the Central Highlands and South-Eastern regions had twice the risk of stillbirth and women of Nuristani ethnicity were ten times more likely to experience stillbirth. Once pregnant, taking into account utilisation of ANC and pregnancy complications, region of residence was no longer associated with stillbirth, but ethnicity remained, with Nuristani women having over nine times increased risk of stillbirth (model 2). Not receiving any ANC during pregnancy increased the likelihood of stillbirth by almost three times, while women that experienced possible infection, bleeding, and headache during their pregnancy had approximately twice the risk of stillbirth, and women experiencing reduced fetal movements were almost four times more likely to have a stillbirth. Factors independently associated with stillbirth in the delivery period (model 3) were, again, region of residence, ethnicity, previous pregnancy loss, first and multiple pregnancies, not receiving ANC, and giving birth in a health facility. The same pregnancy complications increased the risk of stillbirth, except that the effect of reduced or no fetal movement as a pregnancy complication was reduced. This is likely due to the inclusion of reduced or no fetal movement as a delivery complication in the final model, which was now the factor with the highest relative risk, increasing stillbirth risk by nearly seven times. Across all models Nuristani women consistently had a higher risk of stillbirth with at least nine times higher risk of stillbirth than the Tajik population. There was no difference in stillbirth across wealth quintiles or levels of maternal education or age after accounting for all other factors. Models were well calibrated (Figures A5) and discrimination improved from model 1 to model 3 (see AUC in Table 2).

| | Model 1: PRE-PREGNANCY | Model 2: PREGNANCY | Model 3: DELIVERY TIME |
|--|---|--|---|
| N=13 683ª | Community+ socio-economic + maternal factors | Community + socioeconomic + maternal + pregnancy complications + ANC + biological | Community + socioeconomic + maternal + pregnancy complications + ANC + delivery car + delivery complications + biological |
| Independent variables | aRR (95%CI) | aRR (95%CI) | aRR (95%CI) |
| Region | | | |
| North-Eastern | 1.00 (Reference) | | 1.00 (Reference) |
| Northern | 0.70 (0.38, 1.26)(| | 0.68 (0.38, 1.24) |
| Western | 1.52 (0.84, 2.75) | | 1.20 (0.66, 2.20) |
| Central Highlands | 2.72 (1.16, 6.36) | | 3.01 (1.35, 6.70) |
| Capital | 1.27 (0.71, 2.27) | | 1.14 (0.59, 2.29) |
| Eastern | 1.31 (0.69, 2.49) | | 1.16 (0.51, 2.02) |
| Southern | 1.20 (0.62, 2.34) | | 1.01 (0.45,1.91) |
| South-Eastern | 1.97 (1.10, 3.53) | | 1.59 (0.87, 2.89) |
| Ethnicity | 1.57 (1.10, 5.55) | | 1.55 (0.07, 2.05) |
| Tajik | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Pashtun | 1.00 (Reference) 1.07 (0.71, 1.60) | 1.22 (0.86, 1.74) | 1.07 (0.72, 1.60) |
| Hazara | 1.13 (0.63, 2.03) | 1.49 (0.88, 2.55) | 1.03 (0.61, 1.75) |
| Uzbek | 1.62 (0.85, 3.09) | 1.49 (0.88, 2.55) | 1.63 (0.86, 3.11) |
| Nuristani | | | |
| | 10.39 (3.39, 31.86) | 9.22 (3.49, 24.34) | 9.15 (2.95, 28.74) |
| Pashai Balach (Turluman (Othan | 1.65 (0.79, 3.45) | 1.95 (0.94, 4.07) | 1.78 (0.72, 4.37) |
| Baloch/Turkmen/Other | 1.04 (0.50, 2.16) | 0.92 (0.37, 2.27) | 1.02 (0.48, 2.15) |
| Wealth Index | | | |
| Poorest | 1.05 (0.65, 1.67) | 0.96 (0.61, 1.49) | 1.08 (0.64, 1.80) |
| Poorer | 1.13 (0.74, 1.74) | 1.08 (0.71, 1.64) | 1.26 (0.77, 2.07) |
| Middle | 1.10 (0.74, 1.62) | 1.02 (0.69, 1.60) | 1.16 (0.77, 1.75) |
| Richer | 0.87 (0.58, 1.31) | 0.87 (0.58, 1.30) | 0.94 (0.62, 1.41) |
| Richest | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Maternal education | / | | |
| No education/Madrassa | 1.59 (0.93, 273) | 1.41 (0.83, 2.40) | 1.50 (0.87, 2.58) |
| Any education | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Previous pregnancy loss | | | |
| Yes ^b | 2.61 (1.74, 3.91) | 2.57 (1.77, 3.75) | 2.43 (1.65, 3.59) |
| Maternal age (years) | | | |
| 12-18 | 0.79 (0.40, 1.56) | 0.80 (0.41, 1.59) | 0.82 (0.42, 1.60) |
| 19-24 | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| 25-34 | 1.33 (0.90, 1.96) | 1.32 (0.86, 2.01) | 1.36 (0.89, 2.08) |
| ≥35 | 1.65 (1.02, 2.66) | 1.58 (0.96, 2.62) | 1.62 (0.99, 2.64) |
| Pregnancy order | | | |
| 1st pregnancy | 2.18 (1.46, 325) | 2.33 (1.56, 3.47) | 2.27 (1.52, 3.38) |
| 2 nd -4 th pregnancy | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| ≥5 th pregnancy | 1.32 (0.92, 1.89) | 1.35 (0.93, 1.96) | 1.37 (0.95, 1.97) |
| ANC Quality Index | | | |
| High (6-9) | | 1.00 (Reference) | 1.00 (Reference) |
| Low (0-5) | | 1.50 (0.94, 2.41) | 1.56 (0.96, 2.53) |
| No ANC | | 2.77 (1.67, 4.61) | 3.03 (1.73, 5.30) |
| Antepartum complication: Probable | | | |
| infection ^c | | | |
| Yes ^b | | 2.25 (1.36, 3.09) | 1.94 (1.29, 2.92) |
| Antepartum complication: Bleeding or | | | |
| spotting | | | |
| Yes ^b | | 2.25 (1.45, 3.49) | 1.90 (1.19, 3.04) |
| Antepartum complication: Reduced or no | | | |
| fetal movement | | | |
| Yes | | 3.71 (1.94, 7.12) | 2.06 (1.06, 3.97) |
| Antepartum complication: Headache | | | |
| Yes ^b | | 1.70 (1.23, 2.35) | 1.67 (1.20, 2.33) |
| Delivery complication: | | 2.70 (1.23, 2.33) | (1.1.0, 1.00) |
| Reduced or no fetal movement | | | |
| Yes ^b | | | 6.82 (4.20, 11.10) |
| 103 | | | 0.02 (7.20, 11.10) |

Table 2. Multivariable results of factors associated with stillbirth for women's most recent birth in thepreceding three years, Afghanistan 2010

| | Model 1: PRE-PREGNANCY | Model 2: PREGNANCY | Model 3: DELIVERY TIME |
|----------------------------|---|--|--|
| N=13 683ª | Community+ socio-economic + maternal factors | Community + socioeconomic + maternal + pregnancy complications + ANC + biological | Community + socioeconomic + maternal + pregnancy complications + ANC + delivery care + delivery complications + biological |
| Yes ^b | | | 1.55 (1.12, 2.16) |
| Sex of baby | | | |
| Female | | 1.00 (Reference) | 1.00 (Reference) |
| Male | | 1.17 (0.89, 1.54) | 1.16 (0.88, 1.52) |
| Multiple pregnancy | | | |
| Yes ^b | | 3.01 (1.60, 75.67) | 3.19 (1.75, 5.80) |
| Area under the Curve (AUC) | 0.66 | 0.69 | 0.73 |

Footnotes:

^a N presented is the weighted population and includes all cases with complete data (13 393 live births & 290 stillbirths).

^b Reference category for variables with yes/no responses is the "No" category

^c Probable infection: if mother reported having symptoms of high fever and/or foul-smelling vaginal discharge

The subgroup analysis on intrapartum stillbirth showed that being of Nuristani or Pashai ethnicity, nulliparous women, multiple pregnancies, receiving no or low-quality ANC, or experiencing possible infection or headache during pregnancy increased the risk of stillbirth. Reduced or no fetal movement during the delivery period was also a strong predictor, whereas reduced or no fetal movement as a pregnancy complication and giving birth in health facility were no longer associated with intrapartum stillbirth once other factors were taken into account (Table 3, <u>Figure A6</u>).

Table 3. Multivariable results of factors associated with intrapartum stillbirths for women's most recent birth in the preceding three years, Afghanistan 2010

| N=13 577ª | Model 1: PRE-PREGNANCY Community + socio-economic + environmental + maternal | Model 2: PREGNANCY Community + socioeconomic + maternal + pregnancy complications + ANC + biological | Model 3: DELIVERY TIME Community + socioeconomic + maternal + pregnancy complications + ANC + delivery care + delivery complications + biological |
|--|--|--|--|
| Independent variables | aRR (95% CI) | aRR (95% CI) | aRR (95% CI) |
| Ethnicity | · · · | | · · · |
| Tajik | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Pashtun | 1.25 (0.82, 1.90) | 1.21 (0.80 ,1.84) | 1.17 (0.77, 1.78) |
| Hazara | 1.21 (0.62, 2.38) | 1.19 (0.61, 2.35) | 1.17 (0.61, 2.27) |
| Uzbek | 1.48 (0.83, 2.66) | 1.59 (0.89, 2.86) | 1.52 (0.82, 2.87) |
| Nuristani | 12.55 (4.08, 38.66) | 11.32 (3.71, 34.52) | 11.13 (3.56, 34.80) |
| Pashai | 2.81 (1.42, 5.56) | 3.11 (1.50, 6.47) | 2.92 (1.28, 6.64) |
| Baloch/Turkmen/Other | 0.55 (0.20, 1.50) | 0.57 (0.21, 1.57) | 0.57 (0.21, 1.59) |
| Wealth index | | | |
| Poorest | 0.99 (0.57, 1.70) | 0.90 (0.53,1.55) | 0.89 (0.51, 1.53) |
| Poorer | 1.08 (0.65, 1.79) | 1.06 (0.64, 1.78) | 1.04 (0.62, 1.77) |
| Middle | 1.22 (0.72, 2.06) | 1.19 (0.71, 1.98) | 1.22 (0.73, 2.05) |
| Richer | 0.84 (0.50, 1.42) | 0.84 (0.52, 1.39) | 0.85 (0.51, 1.53) |
| Richest | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Maternal education | | | |
| No education/madrassa | 1.89 (0.98, 3.66) | 1.67 (0.86, 3.24) | 1.70 (0.87, 3.32) |
| Any education | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| Maternal age (years) | | | |
| 12-18 | 0.80 (0.31, 2.06) | 0.80 (0.31, 2.03) | 0.83 (0.33, 2.12) |
| 19-24 | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| 25-34 | 1.37 (0.86, 2.22) | 1.34 (0.84, 2.15) | 1.37 (0.86, 2.18) |
| ≥35 | 1.65 (0.94, 2.92) | 1.56 (0.87, 2.80) | 1.61 (0.91, 2.87) |
| Pregnancy order | | | |
| 1st pregnancy | 2.10 (1.20, 3.70) | 2.19 (1.25, 3.86) | 2.19 (1.24, 3.88) |
| 2 nd -4 th pregnancy | 1.00 (Reference) | 1.00 (Reference) | 1.00 (Reference) |
| ≥5 th pregnancy | 1.29 (0.84, 1.99) | 1.33 (0.86, 206) | 1.34 (0.86, 2.07) |
| Previous pregnancy loss | | | |
| Yes ^b | 2.91 (1.79, 4.72) | 2.98 (1.87, 4.75) | 2.91 (1.82, 4.65) |
| Quality of ANC | | | |
| High (6-9) | | 1.00 (Reference) | 1.00 (Reference) |
| Low (0-5) | | 2.18 (1.04, 4.60) | 2.17 (1.03, 4.57) |
| No ANC | | 3.55 (1.60, 7.88) | 3.33 (1.56, 7.32) |
| Antepartum complication: Probable infection ^c | | | |
| Yes ^b | | 2.02 (1.13, 3.62) | 1.96 (1.09, 352) |
| Antepartum complication: Bleeding or spotting | | | |
| Yes | | 2.04 (1.06, 3.92) | |
| Antepartum complication: Headache | | | |
| Yes ^b | | 1.63 (1.05, 2.52) | 1.63 (1.05, 2.52) |
| Delivery complication: Reduced or no fetal | | | |
| movement | | | |
| Yes ^b | | | 8.15 (4.68, 14.18) |
| Sex of baby | | | |
| Female | | 1.00 (Reference) | 1.00 (Reference) |
| Male | | 1.50 (1.02, 2.22) | 1.51 (1.02, 2.22) |
| Multiple pregnancy | | | |
| Yes ^b | | 4.89 (2.12, 11.30) | 4.96 (2.19, 1124) |
| Area under the curve (AUC) | 0.65 | 0.70 | 0.72 |

Abbreviations: ANC – antenatal care, aRR – adjusted risk ratio, CI – confidence interval.

Abbreviations: Anc – antenational care, ann – aujusted his ratio, or –

We examined health care access disaggregated by ethnicity and region of residence to understand the disparities in stillbirth observed in access between different ethnic groups and geographic regions (Table A3, Figures A3-A4) and found that Nuristani women had the largest proportion of women that did not receive any ANC (89%) and the lowest levels of skilled birth attendance (2.5%) for their last pregnancy. The highest proportion of women receiving low-quality ANC were residents of the Capital and Northern region (Figure A3). The South-Eastern, Western and Central Highlands regions had the most women who did not receive any ANC. Skilled birth attendance was highest in the capital and lowest in the Central Highlands, North-Eastern and Western regions (Figure A4).

Comment

Principal findings

Our analysis of the 2010 Afghanistan Mortality Survey has highlighted several socio-demographic, health service utilisation, and maternal conditions that increase stillbirth in Afghan women, some of which are modifiable and can inform programmatic focus for future stillbirth prevention in the country. Determinants of stillbirth in Afghanistan included residing in the Central Highlands, being of Nuristan ethnicity, not receiving ANC, and experiencing bleeding, possible infection or headache during pregnancy. Reduced or no fetal movements during the delivery period and giving birth in a health facility were also strongly associated with stillbirth. Factors associated with intrapartum stillbirths differed slightly and included being of Nuristan or Pashai ethnicity, utilisation and quality of ANC, possible infection or headache during pregnancy. Women with first or multiple pregnancies, and previous pregnancy loss also had increased risk of intrapartum stillbirth. These findings offer an evidence-base to integrate efforts into health service delivery programmes focused on maternal, perinatal and newborn survival, as well as future national health policies where until now, no such information was available. We also demonstrate how DHS surveys can be adapted to generate more data to understand the underlying factors driving stillbirths in other LMIC settings.

The overall stillbirth rate of 22.5 per 1000 total births is lower than adjusted rates reported for Afghanistan in 2009 (29.3 per 1000) and in 2015 (26.7 per 1000) from the Lancet series which accounted for under-reporting.¹ Intrapartum stillbirths constituted almost two-thirds of stillbirths in our study and is consistent with findings from other LMICs.³ Within-country variations in stillbirth risk have been observed in many countries, as have ethnic differences,^{18, 19} Nuristani people are a

minority group that reside predominantly in the Eastern part of Afghanistan (Nuristan province) and the low levels of healthcare utilisation may explain the extremely high rates of stillbirth. The 2015 Afghanistan DHS also found only 1% of births in Nuristan province were in a health facility, and this province had the lowest levels of ANC utilisation across the country (11%). Exacerbating the situation is that the East is a high-intensity conflict zone and one of the poorest regions in the country. For intrapartum stillbirths, both Nuristani and Pashai women had higher risk of stillbirth. Pashai women also reside in the East, where high levels of conflict could have compromised access and quality of health services. The 2010 AMS did not report mortality rates according to province or ethnicity; however, the 2015 DHS reported provincial level mortality rates which showed that Nuristan province had the highest infant and under-five child mortality rates nation-wide (123 and 170 per 1000 live births respectively, compared to 45 and 55 per 1000 live births nationally).⁹ The high stillbirth rates in this group appears to reflect the pattern in regional disparities in other mortality rates.

Geographic disparities underlie maternal and child mortality, morbidity, and healthcare seeking in Afghanistan.¹² The high rates of stillbirth among women in the Central Highlands are likely due to lack of access and availability of health services, as these areas are characterised by mountainous terrain often isolated by snow. This region experiences scarcities in medical supplies due to poor transport infrastructure and security concerns, and a shortage of medical doctors willing to work there. Women from the South-Eastern region had higher risk of stillbirth in the initial multivariable model until adjustment with antenatal and delivery care variables, indicating the importance of health service utilisation in this area. High levels of conflict would likely limit access and availability of services in this area.

The diverse geographical terrain with concentrated ethnic groups in specific regions, combined with insecurity will require tailored approaches to reach these hard-to-reach, high-risk women. Tappis et. al.²⁰ in their study examining coverage of intrapartum care in selected areas of Afghanistan also identified the importance of context-specific service delivery models to ensure women in high conflict areas can access services. A major barrier to ensuring facility deliveries in some parts of the country was the inability to travel at night along major roads because of insecurity. Delivering health services to remote and mountainous areas is challenging especially in the context of insecurity, but strategies which strengthen the role of local community health workers and task shifting can be effective. A revised primary health care service delivery model, currently under development by the Ministry of Public Health may provide an opportunity to integrate alternative approaches to facilitate reductions in stillbirth.

Mothers who did not receive ANC were three times more likely to experience stillbirth and while quality did not appear to make a difference for all stillbirths, it did matter for intrapartum stillbirths. This suggests having any ANC is important for preventing stillbirths, but that quality and content of care may be critical for identifying and managing maternal conditions early that could lead to childbirth complications and intrapartum stillbirth. Overall, ANC utilisation was very low, and we measured quality according to whether the mother received any of the nine checks, not necessarily, the adequacy of the service or the initiation of treatment. Our measurement method may partly explain the absence of an overall effect of quality of ANC for stillbirths. These downstream factors are important to consider when assessing the effectiveness of ANC on stillbirth.²¹ Further investigation is needed to examine the quality of care provided and adherence to recommended advice among women. Our analysis showed that areas that achieved higher coverage of ANC (i.e. the Capital and Northern regions) actually had a higher proportion of women receiving lower quality of ANC. Ensuring adequate and high-quality ANC is one of the simplest and most costeffective recommended interventions to reduce stillbirths.²² Efforts to strengthen ANC are in progress where the Afghan government is administering a maternal and child health handbook that contains information on safe pregnancy, childbirth, and childcare to each pregnant woman and documents details of visits. It will be important to record the services received, pregnancy progress, and results from any screening tests in this handbook.

We identified several pregnancy conditions that were associated with stillbirth and are preventable. Signs of infection and antepartum bleeding were important determinants in our study and are well-established risks. Effective interventions exist for treating malaria and syphilis to reduce stillbirth,²³ and while malaria is endemic in some of the semi-arid eastern and northern provinces in Afghanistan, syphilis and HIV prevalence in Afghanistan is generally very low and limited to high risk groups such as injecting drug users and sex workers.^{24, 25} Further research is needed to identify common infections contributing to stillbirth in this setting. Hirose et al.²⁶ identified that care-seeking delays in Afghanistan were higher among women experiencing severe infections compared to other complications with more concerning symptoms, so it would be important to ensure early detection and management of both bleeding and infections by educating women and family members on the urgency of care-seeking for symptoms. Headaches during pregnancy were also a strong risk factor of both stillbirth and intrapartum stillbirth and likely a sign of pre-eclampsia or pregnancy-induced hypertension, which are known risk factors for stillbirth. Ensuring that ANC includes blood pressure checks and appropriate management will be critical for reducing complications that lead to stillbirth. Reduced fetal movements have rarely been examined in low-income countries but is a known risk factor for stillbirth.²⁷ Of all delivery complications, reduced fetal movements was one of the

strongest determinants for both stillbirth and intrapartum stillbirth in our study. It would be important to ensure women understand the need to act upon any perceived reduction or change in fetal movements, and that during the intrapartum period movements are closely monitored.

Variations exist on the effect of delivery location on stillbirth with some studies showing an increase in risk²⁸ while others indicate a protective effect.³ We found facility births had increased odds of stillbirth overall, but for intrapartum stillbirth place of birth had no effect. Referral bias, delays in care-seeking, or quality of care may account for these findings. The absence of an association with intrapartum stillbirths is likely related to the quality of care or care-seeking delays. A study examining delays in care-seeking in Afghanistan showed substantial departure and decision making delays among pregnant women with life-threatening conditions.¹³ Concerns regarding quality of intrapartum care in maternity hospitals in Afghanistan have also been documented.¹¹ Ballard et al.²⁹ in their Ethiopian study also found that women with an intrapartum emergency were twice as likely to give birth in a health facility and that facility births did not reduce stillbirth risk, suggesting the three delays was at play here.³⁰

We could not include mode of delivery in our multivariable analysis, but caesarean births showed a high positive association with stillbirth in the univariate results. A study of over 50 000 births in Kabul hospitals identified high rates of stillbirth in caesareans done for obstructed labour, malpresentation and uterine rupture, which are preventable with timely intervention.³¹ We did not have data on indication for caesarean but an assessment of 78 first line referral facilities in Afghanistan found 88% of caesarean births were emergencies,³² so it is likely most were unplanned. The ideal caesarean rate to observe reductions in intrapartum stillbirth is between 5-10%,³³ but here we found it was under 2% and more recent national data reports a rate of only 3%,⁹ therefore, improving access to caesarean would be important to prevent stillbirths in Afghanistan.

Male babies have an increased risk of stillbirth;³⁴ however, we only found a slightly increased risk among intrapartum stillbirths but not in the analysis of the full sample of stillbirths. This may have been affected by the skewed sex ratio among stillbirths in our sample which had almost 20% more male babies to female. This is higher than the usual 10% elevated risk of stillbirth in male babies.³⁴ The 2010 AMS¹⁰ and 2015 Afghanistan DHS⁹ both identified under-reporting of neonatal and under-five child female deaths, as have other household surveys from Afghanistan.³⁵ This might suggest that underreporting could also be a problem with female stillborn deaths and partly contributing to the overall underestimate of the true stillbirth burden. Under-reporting of stillbirths can occur due to social, cultural or other factors including stigma or blame towards the mother or

other consequences that might preclude disclosure.³⁶ Further investigation into these issues is needed for Afghanistan.

Strengths of the study

A key strength of this study is the use of a large nation-wide population sample to identify risk factors for stillbirth. In addition, this survey collected a comprehensive range of socio-demographic, maternal and fetal characteristics, maternal complications and health care utilisation factors for stillbirths which are not usually available in similar household surveys in LMICs.

Limitations of the data

There are several limitations to this study that should be considered. Although the 2010 AMS was a national survey, there was an underrepresentation of the South because of highly insecure areas that were not surveyed. Concerns about the accuracy of maternal and child mortality measures from this survey have been noted³⁷ and highlight the challenges with collecting reliable data in conflict zones. While we acknowledge this limitation, this is currently the only data source in the country with information to enable understanding of key determinants of stillbirth. Although an updated DHS survey was subsequently conducted, it did not capture health service utilisation, maternal or fetal factors for stillbirth, which precludes the kind of analysis reported in this paper.

Collecting information on pregnancy histories is challenging in low-income settings, and stillbirths are known to be underestimated by about 30% when collected through household surveys.⁵ The overall stillbirth rate of 22.5 per 1000 births in our study is low given the high levels of neonatal and maternal mortality in the country. It is possible these estimates have been affected by under-reporting and the data quality concerns raised with the 2010 AMS survey. The exclusion of some rural areas of the South zone of Afghanistan during sampling because of security reasons also meant that the survey covered only 66% of the South (94% of urban and 63% of rural areas were sampled) and so many stillbirths from rural areas would not have been included. The lower stillbirth rates observed in the Southern region (17.8 per 1000 births) is likely to have been affected by undersampling of rural areas of the south. Medical terminations are illegal in Afghanistan, so women may report these as stillbirths or omit them entirely which might affect the total number of pregnancies and stillbirths reported. Misclassification of stillbirths and early neonatal deaths is an issue with household surveys, but we have minimised this by using data from the VA. The reliability of using skin appearance to determine the timing of stillbirth may lead to an overestimate of intrapartum stillbirth.³⁸ Due to the small number of antepartum stillbirths we were not able to model antepartum stillbirth risk factors separately to compare with the intrapartum stillbirth risk factors.

Several known risk factors were not captured, and we could not adjust for them (i.e. consanguinity, maternal nutrition, distance to health facility, and care-seeking delays). Exposures related to the armed conflict including chemicals and radiation, are known to increase the risk of stillbirth,³⁹ but we had no measurement of these exposures. Finally, it is possible there was under-reporting of the self-reported maternal complications due to recall bias.

Interpretation

We provide for the first-time the major risk factors associated with stillbirth in Afghanistan, where there was previously a complete absence of evidence to inform future interventions and prevention efforts. Evidence-based interventions to prevent stillbirth exist²² and their implementation should be a priority for Afghanistan. We outline some recommendations in Box 2. This study also demonstrates it is feasible to rapidly produce a comprehensive analysis of stillbirth determinants for other LMICs if appropriate DHS data was available. To achieve this outcome would require some modification to the standard DHS questionnaire format to include a full pregnancy history as opposed to a live birth history,⁸ as well as the inclusion of stillbirth when collecting information on women's health care utilisation and maternal complications during pregnancy and childbirth. The 2010 AMS provides a model from which future household surveys can be adapted to collect better data for stillbirth.

Conclusions

Countries affected by conflict and instability account for the largest burden of stillbirths,⁴⁰ but strategies to improve reproductive outcomes in these areas have not received sufficient global attention and is urgently needed. Development assistance and international focus on Afghanistan has declined recently as the security situation has worsened, and gains in maternal and child health are at risk of deteriorating. To accelerate reductions in stillbirth, concerted efforts and commitment by the government and international donors are needed to invest in prioritising implementation of interventions to reduce stillbirth. Evaluating different approaches to overcome challenges in the access and utilisation of care during pregnancy and childbirth to ensure services can reach the most hard-to-reach women where the majority of stillbirths occur, will be imperative for future stillbirth reduction in Afghanistan.

Box 2: Recommendations for the prevention and reduction of stillbirth in Afghanistan

Health systems strengthening and health service delivery

- Improved coverage and monitoring of content of ANC for the early identification and management of high-risk pregnancies and early referral.
- The high number of intrapartum stillbirths indicates a need for improved quality and timely management of childbirth complications. Ensuring birth attendants at all levels of the health system are adequately trained and have the skills and resources available to manage complications will be essential.
- Increasing the availability and access to timely caesarean sections for high-risk pregnancies and minimising delays at the facility level.
- The highest burden of stillbirth in the country falls in the Central Highlands and among minority ethnolinguistic groups which will require specialised attention and targeted strategies.

Community-based education and mobilisation

- Improve community awareness and education on key danger signs during pregnancy and childbirth that need immediate action.
- Sensitisation of community specifically about stillbirths and their prevention will also be important but will require additional strategies to overcome barriers and delays in care-seeking.

Further research

- Identification of the leading infections that may be contributing to stillbirth in Afghanistan require further research and understanding.
- Improved understanding of bottlenecks and barriers at the health facility level in regard to the prevention of stillbirth.
- Assessment of the quality of antenatal and intrapartum care provided at the various levels of health facilities.
- Development of strategies to strengthen referral linkages and facilitate referral and reduce careseeking delays at the community level.

Commitment to stillbirth targets in national health strategies and policies & continued data collection on stillbirth

- Afghanistan's current National Health Policy for 2015-2020 and Reproductive, Maternal, Newborn Child and Adolescent Health (RMNCAH) Strategy for 2017-2021 do not include targets for stillbirth reduction. National commitment in future policies and strategies to the recommended targets agreed upon as part of the 2014 Every Newborn Action Plan and endorsed at the World Health Assembly will direct national attention, prioritisation and funding towards reducing stillbirths.
- Future national population-based surveys should include a full pregnancy history similar to the 2010 Afghanistan Mortality Survey to ensure ongoing data availability on the key risk factors for stillbirths. This survey data will assist with tracking progress towards meeting the global target of 12 stillbirths per 1000 births by 2030 and identifying key areas of need for interventions.

Declaration of interests

The authors declare no competing interests.

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Supplementary Appendix

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Appendix 1: Methodological detail

1.1 Construction of the main outcome variable and derivation final sample

We constructed the outcome variable based on two questions asked of the mother in the pregnancy history included in the women's questionnaire of the 2010 Afghanistan Mortality Survey (AMS) - whether her baby was born alive or born dead, and how many months pregnant she was when the pregnancy ended. All births where the baby was born dead and the death occurred at 7 months or later were coded as stillbirth, while those born dead and pregnancy length was less than 7 months, were coded as miscarriages.

Determination of the final sample is detailed in Figure A1. We created a pregnancy file including all births to women within the preceding three years of the survey which gave a total of 17 215 births. After limiting this file to women's most recent birth, this brought the sample to 13 953 births. We then excluded miscarriages and births where the baby was born dead but gestational age was missing. This reduced our sample to 13 844 births (13 528 live births; 316 stillbirths). We then used data from the verbal autopsy questionnaire to identify any misclassification between stillbirths, miscarriages and early neonatal deaths. The verbal autopsy (VA) questionnaire collected more detailed information from the mother about her pregnancy losses including whether the baby cried, moved or breathed after birth, to confirm the stillbirth, so we also constructed a pregnancy outcome variable using information from this dataset and compared these outcomes with those generated from the pregnancy history using a cross-tabulation. We considered the outcome from the VA as the reference standard. Based on the mother's most recent pregnancy of pregnancies in the last three years, the pregnancy history misclassified seven stillbirths as early newborn deaths, and seven early newborn deaths as stillbirths. A further ten miscarriages were misclassified as stillbirths (n=5) and early newborn deaths (n=5) (Table A1). We corrected these misclassifications which gave us our final sample of 13 834 births (13 523 live births; 311 stillbirths).

| | Pregnancy outcome (Pregnancy history) | | |
|------------------------------------|---------------------------------------|------------|--------|
| | Live birth | Stillbirth | Total |
| Pregnancy outcome (Verbal Autopsy) | | | |
| Live birth/early neonate death | 315 | 7 | 322 |
| Stillbirth | 7 | 289 | 296 |
| Miscarriage | 5 | 5 | 10 |
| Missing | 13 201 [*] | 15 | 13 217 |
| Total | 13 528 | 316 | 13 844 |

Table A1. Comparison of pregnancy outcomes according to the pregnancy history and verbal autopsy questionnaires for women's most recent pregnancy in the preceding three years in the 2010 Afghanistan Mortality Survey (weighted counts presented)

* VA not done on live births

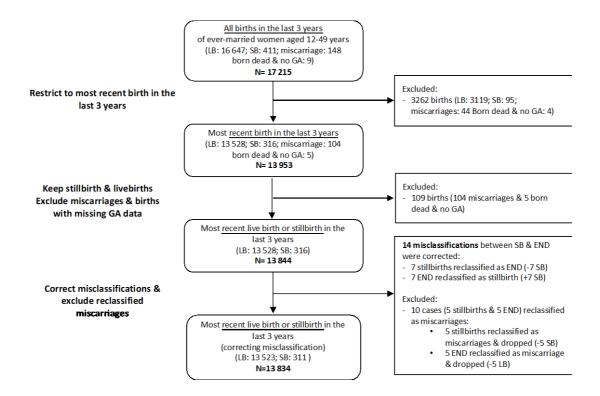


Figure A1. Flow diagram showing derivation of the final sample

(Abbreviations: END - early newborn death, GA - gestational age, LB - live births, SB - stillbirth)

1.2 Independent variables and analytical framework

Independent variables considered for this analysis are described below. The analytical framework (Figure A2) illustrates the model building steps and variables included in the multivariable models.

Community level factors

Community level variables included area of residence (urban and rural), region of residence (North, North-Eastern, Western, Central Highlands, Capital, Eastern, Southern and South-Eastern) and ethnicity (Tajik, Pashtun, Hazara, Uzbek, Nuristan, Pashai and Other (included Baloch, Turkmen and other categories)). We kept the categories as created in the original dataset as the country has distinct geographical terrain in its eight regions with a range of disparities in terms of healthcare access and security risks. Afghanistan also has very diverse and distinct ethnic groups some of who are severely marginalised or disadvantaged. Given the extent of internal migration in the country due to political instability and for economic reasons we kept all categories of ethnicities unless they constituted less than 1% of the population or had less than ten cases in the analysis sample, in which case were combined into the 'Other' category.

Socio-economic and environmental factors

These variables included wealth index (quintiles), marital status (married or not married), maternal education, source of drinking water, type of sanitation facility, and cooking fuel. Household wealth index consisted of five levels and used as reported in the 2010 AMS. This was constructed using household asset data, including ownership items ranging from a television to a bicycle or car, as well as dwelling characteristics, such as source of drinking water, sanitation facilities, and type of material used for flooring. We recoded maternal education into two categories - combining no education with Madrassa, and any education which included any education from primary, secondary or higher as the proportion of educated women in the sample was very small. Environmental variables were recoded into two categories as improved and unimproved based on the classifications guidelines of the Joint Water Supply and Sanitation Monitoring Program variables (WHO & UNICEF, 2013). Improved toilet facilities comprised flush toilets, pit latrines with ventilation or slabs if these were not shared with other households. Unimproved toilet facilities comprised any shared facilities, in addition to all other types. Improved water sources were piped water, public taps or standpipes, tube wells or boreholes, protected dug wells, protected springs and rainwater collection. Unimproved water sources included all other types. Clean fuel referred to any fuel from electricity, LPG/natural gas/biogas, while solid fuel/other included coal/ligante, charcoal, wood/straw/shrubs/grass, agricultural crops, animal dung and kerosene.

Maternal factors

This group of variables included maternal age, previous pregnancy loss (defined as any stillbirth or miscarriage prior to the index pregnancy), pregnancy order (First, $2^{nd}-4^{th}$ and 5^{th} or higher pregnancy) and pregnancy interval (<18 months, 18-58 months, or \geq 59 months).

Pregnancy-related conditions and antenatal care

Variables in this group included complications during the index pregnancy (headache, blurry vision, bleeding/spotting, possible hypertension, anaemia, reduced fetal movements, early contractions, abdominal pain, fainting/unconsciousness and possible infection). Possible infection referred to any woman who reported high fever and/or foul-smelling discharge, and probable hypertension was

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defined as any symptom that included shaking/fits/pre-eclampsia/eclampsia with or without swelling/oedema. Fetal factors included sex of the baby and whether the pregnancy was single or multiple. Antenatal care variables included number of ANC visits (None, 1, 2-3, or 4 or more), timing of first ANC visit (1st trimester, 2nd trimester, 3rd trimester), ANC provider (trained provider vs untrained provider), components of ANC received, and quality of ANC received (categorised as low if 0 to 5 components received, and high if five or more components received). The quality of antenatal care variable was constructed as an additive index based on whether or not a mother received one of the following nine services during her antenatal care visits: (1) Blood pressure check, (2) weight measured (3) urine sample test (4) blood sample test (5) information regarding pregnancy complications (6) information on where to go for pregnancy complications (7) received two or more tetanus vaccinations (8) bought or were given iron folic acid (9) received anti-helminths We coded each response as 1 if it was received and 0 if not and added these up for each women to generate a score between 0 and 9. For analysis, we categorised this variable to low quality if the number of components receive was less than five, and high quality care if five or more components were received.

Intrapartum conditions and delivery care

These variables included any complications experienced during the delivery period (reported signs of headache, blurry vision, lower abdominal pain, fainted/unconsciousness, excessive bleeding, prolonged labour or malpresentation, early labour, reduced fetal movement, possible infection, possible hypertension). We also examined place of delivery (health facility or home), delivery attendant (skilled provider vs unskilled provider) and mode of delivery (whether the birth was vaginal, caesarean section or instrumental (use of forceps or vacuum extractor).

Fetal biological factors

Fetal factors included the sex of the baby and whether the pregnancy was single or multiple gestation.

References

WHO, & UNICEF. (2013). Joint Water Supply & Sanitation Monitoring Program 2013.

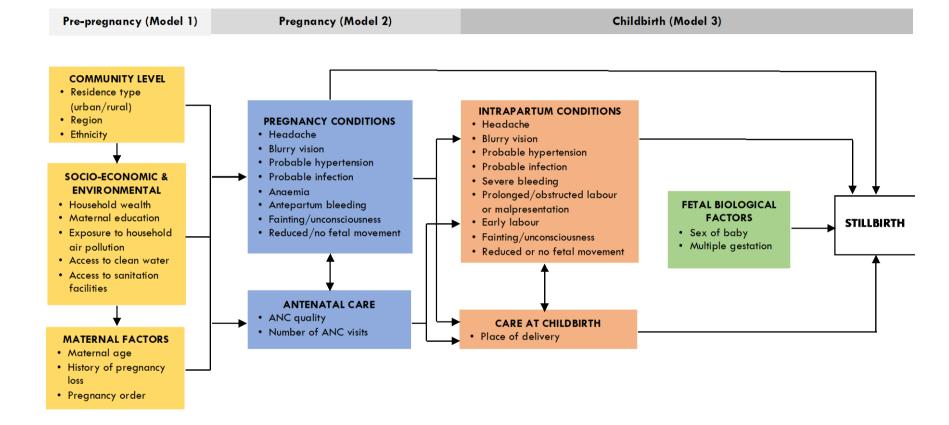


Figure A2. Analytical framework for the analysis of determinants of stillbirth in the 2010 Afghanistan Mortality Survey

Appendix 2: Results

Table A2 presents the weighted and unweighted characteristics of the sample. There was an underrepresentation of the Western, Central highlands, Eastern regions, and the Capital, while women from urban areas and the highest wealth quintiles were over-represented. We present weighted results for the remaining analyses.

2.1 Socio-demographic, maternal, fetal and health care utilisation characteristics of sample

Table A2. Weighted and unweighted distribution of socio-demographic, maternal, fetal and health care utilization characteristics of women's most recent pregnancy (live birth or stillbirth) in the preceding <u>three years</u>, Afghanistan 2010

| | Unweigh (N=14 1 | Weighted (N=13 834) | | |
|---|--------------------|------------------------|-------|----------|
| Variables | N | | Ň | % |
| Pregnancy outcome | | | | |
| Live birth | 13818 | 97.9 | 13523 | 97.8 |
| Stillbirth | 298 | 2.1 | 311 | 2.2 |
| COMMUNITY-LEVEL CHARACTERISTICS | | | | |
| Residence | | | | |
| Urban | 4172 | 29.6 | 2636 | 19. |
| Rural | 9944 | 70.4 | 11198 | 80. |
| Region | | | | |
| North-Eastern | 2322 | 16.5 | 2081 | 15. |
| Northern | 2198 | 15.6 | 2145 | 15. |
| Western | 1541 | 10.9 | 1841 | 13. |
| Central Highland | 256 | 1.8 | 430 | 3. |
| Capital | 2431 | 17.2 | 2635 | 19. |
| Eastern | 2400 | 17.0 | 2472 | 17. |
| Southern | 1398 | 9.9 | 906 | 6. |
| South-Eastern | 1550 | 11.1 | 1324 | 9. |
| Ethnicity | 1370 | 11.1 | 1021 | 5. |
| Pashtun | 4668 | 33.1 | 4386 | 31. |
| Tajik | 6389 | 45.3 | 5992 | 43. |
| Hazara | 1012 | 7.2 | 1125 | -3. |
| Uzbek | 1012 | 7.2 | 1218 | 8. |
| Turkmen | 238 | 1.7 | 264 | 1. |
| Nuristan | 163 | 1.7 | 190 | 1. |
| Pashai | 202 | 1.4 | 318 | 2. |
| Other (Baloch/others) | 317 | 2.3 | 331 | 2. |
| Missing | 11 | 0.1 | 11 | 2. 0. |
| SOCIOECONOMIC & ENVIRONMENTAL | 11 | 0.1 | 11 | 0. |
| Wealth guintile | | | | |
| Lowest | 2342 | 16.6 | 2828 | 20. |
| Second | 2342 | 17.2 | 2828 | 20. |
| | | | | |
| Middle | 2582 | 18.3 | 2757 | 19. |
| Fourth | 2973 | 21.1 | 2736 | 19. |
| Highest | 3795 | 26.9 | 2696 | 19. |
| Marital status | 4 4052 | 00 C | 42760 | 00 |
| Currently married | 14053 | 99.6 | 13769 | 99. |
| Not currently married ^a | 63 | 0.5 | 65 | 0. |
| Women's education | 40050 | 07.5 | 10070 | ~~~ |
| No education/madrassa | 12352 | 87.5 | 12372 | 89. |
| Primary | 955 | 6.8 | 821 | 5. |
| Secondary | 645 | 4.6 | 524 | 3. |
| Higher | 164 | 1.2 | 117 | 0. |
| Source of drinking water | | | | |
| Improved water source ^b | 8361 | 59.2 | 5043 | 36. |
| Unimproved water source ^c | 5233 | 37.1 | 8727 | 63. |
| Other | 498 | 3.5 | 54 | 0. |
| Missing | 24 | 0.2 | 10 | 0. |
| Sanitation facilities | | | | |
| Improved sanitation facility ^d | 5639 | 40.0 | 5043 | 36. |

| Unimproved sanitation facility | 8415 | 59.6 | 8727 | 63.1 |
|--|---------------------|---------------------|---------------------|---------------------|
| Other | 53 | 0.4 | 54 | 0.4 |
| Missing | 9 | 0.1 | 10 | 0.1 |
| Fuel used for cooking Clean fuel ^f Solid fuel ^g No food cooked in house/other | 3746 10347 23 | 26.5 73.3 0.2 | 2783 11024 27 | 20.1 79.7 0.2 |

| | Unweighted | | Weighted | |
|--|--------------|--------------|------------|--------------|
| | (N=14 116) | | (N=13 834) | |
| | N | % | Ν | % |
| MATERNAL, FETAL & ANTENATAL FACTORS | | | | |
| Sex of baby | 7665 | | | |
| Male | 7665 | 54.3 | 7539 | 54.5 |
| Female | 6435 | 45.6 | 6280 | 45.4 |
| Don't know/missing | 16 | 0.1 | 15 | 0.1 |
| Pregnancy type | 12050 | 00.0 | 12004 | 00.0 |
| Single | 13956 | 98.9 | 13684 | 98.9 |
| Multiple Don't know/missing | 143 17 | 1.0 | 133 | 1.0 |
| Timing of stillbirth (stillbirth only) | 17 | 0.1 | 16 | 0.1 |
| Antepartum | 55 | 18.5 | 68 | 21.8 |
| Intrapartum | 182 | 61.1 | 189 | 60.6 |
| Don't know | 29 | 9.7 | 25 | 8.1 |
| Missing | 32 | 10.7 | 29 | 9.5 |
| Pregnancy duration (stillbirth only) | 32 | 10.7 | 29 | 5 |
| 7 months | 51 | 18.1 | 48 | 16.1 |
| 8 months | 64 | 22.7 | 63 | 21.1 |
| 9 months | 147 | 52.1 | 165 | 56.0 |
| 10 months | 147 | 6.0 | 105 | 5.9 |
| Don't know/missing | 3 | 0.0 1.1 | 3 | 0.9 |
| Maternal age (years) | 3 | 1.1 | 5 | 0.5 |
| 12-18 | 1143 | 8.1 | 1209 | 8.7 |
| 19-24 | 5111 | 36.2 | 5013 | 36.2 |
| 25-34 | 5907 | 41.9 | 5666 | 41.0 |
| 35+ | 1955 | 13.9 | 1947 | 14.1 |
| Pregnancy order | 1999 | 10.0 | 1017 | 1 |
| 1 st pregnancy | 2221 | 15.7 | 2165 | 15.7 |
| 2 nd -4 th pregnancy | 6188 | 43.8 | 6046 | 43.7 |
| ≥5th pregnancy | 5707 | 40.4 | 5623 | 40.6 |
| Pregnancy interval | | | | |
| 1st pregnancy | 2221 | 15.7 | 2165 | 15.7 |
| <18 months | 1705 | 12.1 | 1664 | 12.0 |
| 18-58 months | 9303 | 65.9 | 9174 | 66.3 |
| ≥59 months | 887 | 6.3 | 831 | 6.0 |
| Past adverse pregnancy outcomes | | | | |
| No | 11126 | 78.8 | 10928 | 79.0 |
| Yes | 786 | 5.6 | 754 | 5.4 |
| Mother's first pregnancy | 2204 | 15.6 | 2152 | 15.6 |
| Number of ANC visits | | | | |
| 0 | 4611 | 32.7 | 4969 | 35.9 |
| 1 | 1966 | 13.9 | 1912 | 13.8 |
| 2-3 | 4821 | 34.2 | 4575 | 33.1 |
| 4 or more | 2596 | 18.4 | 2272 | 16.4 |
| Missing/don't know | 122 | 0.9 | 106 | 0.8 |
| Timing of first ANC visit | | | | |
| First trimester | 2889 | 20.5 | 2569 | 18.6 |
| Second trimester | 3936 | 27.9 | 3721 | 26.9 |
| Third trimester | 2562 | 18.2 | 2459 | 17.8 |
| No ANC | 4611 | 32.7 | 4969 | 35.9 |
| Missing/don't know | 118 | 0.8 | 116 | 0.8 |
| ANC provider ^h | | | | |
| Trained provider (Doctor/nurse) | 9119 | 64.6 | 8413 | 60.8 |
| Untrained provider (TBA/CHW/Other) | 364 | 2.6 | 432 | 3.1 |
| No ANC | 4611 | 32.7 | 4969 | 35.9 |
| Don't know | 22 | 0.2 | 21 | 0.1 |
| Components of ANC received | | | | |
| | | 25.2 | | 0.5 |
| Weighed ⁱ Blood pressure measured ^j | 3576 8534 | 25.3 60.5 | 3481 | 25.2 57.3 |

| | Unweighted (N=14 116) | | Weighted (N=13 834) | |
|--|--------------------------|------|------------------------|-------------|
| | N % | | N % | |
| Urine sample taken ^k | 3323 | 23.5 | 2920 | 21.1 |
| Blood sample taken ¹ | 3195 | 22.6 | 2742 | 19.8 |
| Informed signs of pregnancy complications ^m | 3038 | 21.5 | 2888 | 20.9 |
| Informed where to go for complications ⁿ | 2564 | 18.2 | 2416 | 17.5 |
| Given or bought iron tablets ° | 5524 | 39.1 | 5290 | 38.2 |
| Took anti-helminths ^p | 545 | 3.9 | 580 | 4.2 |
| Received 2+ tetanus injections ^q | 7082 | 50.2 | 6868 | 49.6 |
| ANC quality score ^r | 7082 | 50.2 | 0808 | 49.0 |
| Low (0-5 components) | 7642 | 54.1 | 7115 | 51.4 |
| · · · · · · | 1727 | 12.2 | | |
| High (6-9 components) | | | 1636 | 11.8 |
| No ANC | 4611 | 32.7 | 4969 | 35.9 |
| Pregnancy complications | 1000 | 40.5 | 4700 | |
| Headache | 1903 | 13.5 | 1733 | 12.5 |
| Blurry vision | 1065 | 7.5 | 943 | 6.8 |
| Probable hypertension ^s | 1063 | 7.5 | 1007 | 7.3 |
| Probable infection ^t | 843 | 6.0 | 755 | 5.5 |
| Anaemia or thin/weak blood | 783 | 5.6 | 847 | 4.9 |
| Bleeding or spotting | 568 | 4.0 | 534 | 3.9 |
| Early contractions | 409 | 2.9 | 410 | 3.0 |
| Fainted/unconsciousness | 283 | 2.0 | 240 | 1.7 |
| Reduced or no fetal movement | 157 | 1.1 | 150 | 1.1 |
| DELIVERY CARE & COMPLICATIONS | | | | |
| Type of birth attendant | | | | |
| Doctor | 2711 | 19.2 | 2225 | 16.1 |
| Nurse/midwife | 3141 | 22.3 | 2740 | 19.8 |
| TBA/CHW/Relative/Friend | 7877 | 55.8 | 8488 | 61.4 |
| No one | 309 | 2.2 | 306 | 2.2 |
| Missing | 78 | 0.6 | 75 | 0.5 |
| Place of delivery | | | | |
| Home/other | 8581 | 60.8 | 9108 | 65.8 |
| Health facility | 5506 | 39.0 | 4702 | 34.0 |
| Missing | 29 | 0.2 | 25 | 0.2 |
| Mode of delivery | 25 | 0.2 | 25 | 0.2 |
| Vaginal | 12975 | 91.9 | 12867 | 93.0 |
| Instrumental (forceps/vacuum) | 628 | 4.5 | 560 | 93.0 4.(|
| , | | | | 4.0 |
| Caesarean section | 283 | 2.0 | 238 | |
| Missing/don't know | 230 | 1.6 | 169 | 1.2 |
| Complications in delivery period | | | | |
| Headache | 4830 | 34.2 | 4811 | 34.8 |
| Blurry vision | 2598 | 18.4 | 2445 | 17.7 |
| Probable hypertension ^s | 2183 | 15.5 | 2240 | 16.2 |
| Excessive bleeding | 2439 | 13.9 | 2465 | 14.2 |
| Probable infection ^t | 1805 | 12.8 | 1796 | 13.0 |
| Prolonged/obstructed | 973 | 6.9 | 990 | 7.2 |
| labour/malpresentation | 575 | 0.5 | 550 | /.2 |
| Water broke too early | 854 | 6.1 | 829 | 6.0 |
| Reduced or no fetal movement | 151 | 1.1 | 157 | 1.1 |
| Sought care for complications | | | | |
| Yes | 4439 | 31.5 | 4243 | 30.7 |
| No | 4373 | 31.0 | 4391 | 31.7 |
| No delivery complications | 5252 | 37.2 | 5148 | 37.2 |
| Missing | 52 | 0.4 | 53 | 0.4 |

Abbreviations: ANC – antenatal care; CHW – Community Health Worker; TBA – Traditional Birth Attendant

Footnotes:

^a Divorced, widowed or separated

^b Improved sources (whoweo of separated ^b Improved vater sources (Piped water into dwelling/yard/plot; Public tap/standpipe; Tube well or borehole; Protected dug well; Protected spring; Rainwater) ^c Unimproved sources (unprotected dug well; unprotected spring; tanker truck/cart with small tank; surface water; Bottled water) ^d Improved sanitation facility (Flush/our flush to piped sewer system; Flush/pour flush to septic tank; Flush/pour flush to pit latrine; Ventilated improved pit latrine; Pit latrine with slab)

latrine with slab) * Non-improved facility (Any facility shared with other households; Flush/pour flush not to sewer/septic tank/pit latrine; Pit latrine without slab/open pit; no facility/bush/field) ^h Highest trained provider if multiple providers are mentioned ⁱ Missing values (n=58).¹(n=48), ¹(n=65), ⁿ (n=69), ⁿ (n=49), ^o (n=10), ^o (n=20), ^p (n=133), ^q (n=34) ^r ANC quality score calculated by number of components received out of the 9 components (1- Weighed 2- BP taken 3- blood sample taken 4- urine sample taken 5-informed signs of pregnancy complications 6- informed where to seek care for complications 7- received 2+ tetanus injections 8- received iron/FA 9- received drugs for intestinal worms¹

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2.2 Disparities in antenatal care quality and skilled birth attendance by region of residence and ethnicity

Table A3 presents quality of ANC received and skilled birth attendance according to women's ethnicity. Figures A3 and A4 show quality of antenatal care and skilled birth attendance for women's most recent pregnancy according to region of residence.

| | Quality of ANC ^a | | | Birth attenda | nt | |
|----------------------|-----------------------------|--------------------|---------------------|---------------|---|-------------------------------|
| | No ANC % (n) | Low (0-5) % (n) | High (6-9) % (n) | None % (n) | Unskilled ³ provider % (n) | Skilled⁵ provider % (n) |
| Ethnicity | | | | | | |
| Tajik | 31.2 (1356) | 58.0 (2519) | 10.8 (468) | 1.6 (68) | 57.1 (2492) | 41.4 (1806) |
| Pashtun | 40.9 (2433) | 44.3 (2632) | 14.8 (881) | 3.1 (187) | 60.1 (3580) | 36.7 (2188) |
| Hazara | 35.8 (398) | 54.1 (601) | 10.1 (112) | 1.7 (19) | 66.7 (746) | 31.6 (354) |
| Uzbek | 27.2 (329) | 65.9 (797) | 6.9 (83.5) | 0.6 (7) | 70.6 (856) | 28.8 (349) |
| Nuristan | 89.0 (169) | 6.4 (12.0) | 4.6 (9) | 2.7 (5) | 94.8 (180) | 2.5 (5) |
| Pashai | 33.8 (107) | 58.9 (186) | 7.4 (23) | 3.8 (12) | 70.9 (225) | 25.3 (80) |
| Baloch/Turkmen/Other | 29.2 (173) | 61.3 (364) | 9.5 (57) | 1.4 (8) | 68.0 (401) | 30.7 (181) |
| Total | 36.2 (4964) | 51.9 (7110) | 11.9 (1634) | 2.2 (306) | 61.7 (8480) | 36.1 (4963) |

Table A3. Quality of antenatal care and type of birth attendant according to ethnicity for women's mostrecent birth, Afghanistan 2010

Footnotes:

Percentages presented are row percentages

^aANC quality score is a summative index score of the number of components received during antenatal care visit out of a total of 9 components (1- Weighed 2- BP taken 3- blood sample taken 4- urine sample taken 5- informed signs of pregnancy complications 6- informed where to seek care for complications 7- received 2+ tetanus injections 8- received iron/FA 9- received drugs for intestinal worms)

^bSkilled provider refers to doctor, nurse or midwife

^cUnskilled provider refers to Traditional birth attendant (TBA), Community Health Worker (CHW), relative or friend

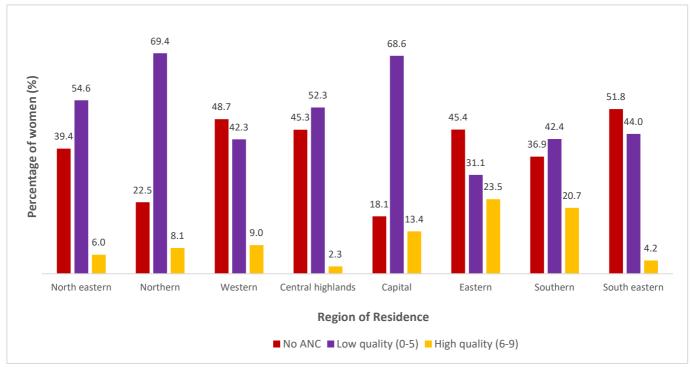


Figure A3. Quality of antenatal care for women's most recent pregnancy according to region of residence, Afghanistan 2010

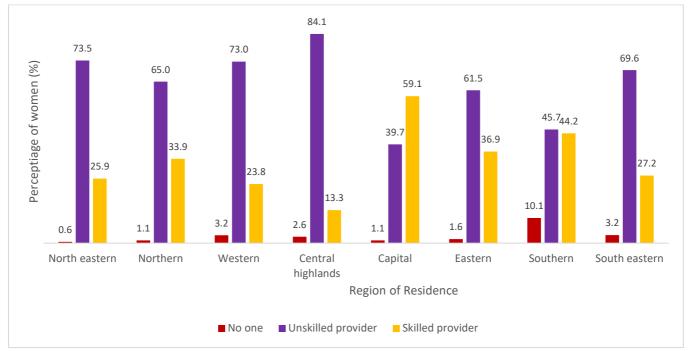


Figure A4. Skilled birth attendance at most recent birth according to region of residence, Afghanistan 2010

2.3 Calibration plots to assess model performance

To assess model performance, we generated Hosmer-Lemeshow calibration plots for each of the three final models. Figure A5 presents the calibration plots for the multivariable model on all stillbirths while figure A6 shows the plots for the final modelling on intrapartum stillbirth.

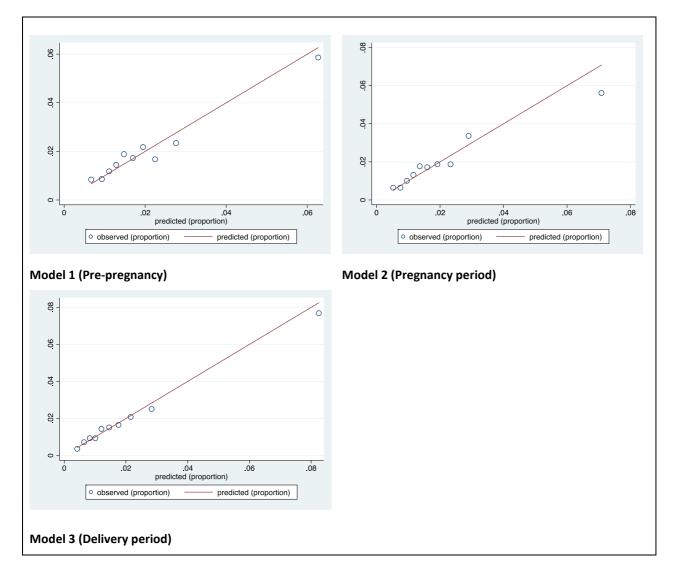


Figure A5. Hosmer-Lemeshow calibration plots to assess agreement between observed and predicted values multivariable Poisson regression of factors associated with stillbirths

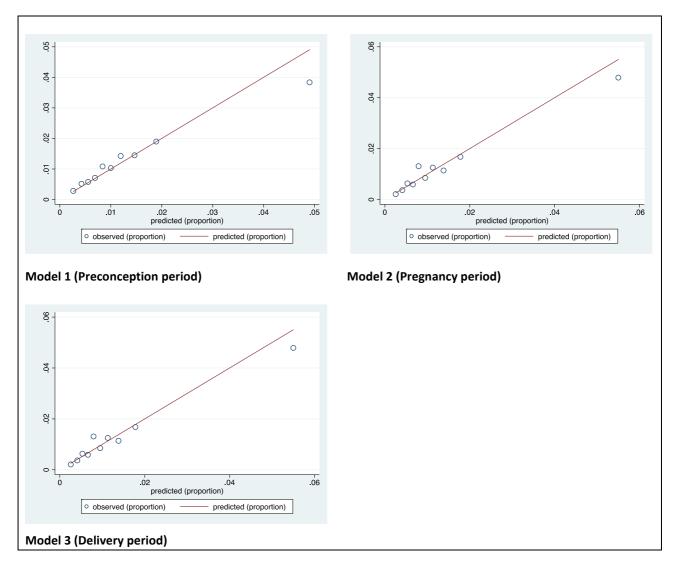


Figure A6. Hosmer-Lemeshow calibration plots to assess agreement between observed and predicted values for multivariable Poisson regression of factors associated with intrapartum stillbirths

CHAPTER THREE

CONTEXTUAL FACTORS INFLUENCING STILLBIRTH DATA QUALITY

Paper III: How community and health provider perceptions, practices, and experiences influence reporting, disclosure, and data collection on stillbirth: findings of a qualitative study in Afghanistan

How community and healthcare provider perceptions, practices and experiences influence reporting, disclosure and data collection on stillbirth: findings of a qualitative study in Afghanistan

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Abstract

Quality concerns exist with stillbirth data from low- and middle-income countries including underreporting and misclassification which affect the reliability of burden estimates. This is particularly problematic for household survey data. Disclosure and reporting of stillbirths are affected by the socio-cultural context in which they occur and societal perceptions around pregnancy loss. In this qualitative study, we aimed to understand how community and healthcare providers' perceptions and practices around stillbirth influence stillbirth data quality in Afghanistan. We collected data through 55 in-depth interviews with women and men that recently experienced a stillbirth, female elders, community health workers, healthcare providers, and government officials in Kabul province, Afghanistan between October-November 2017. The results showed that at the community level, there was variation in local terminology and interpretation of stillbirth which did not align with the biomedical categories of stillbirth and miscarriage and could lead to misclassification. Specific birth attendant practices such as avoiding showing mothers their stillborn baby, had implications for women's ability to recall skin appearance and determine stillbirth timing; however, parents who did see their baby, had a detailed recollection of these characteristics. Birth attendants also unintentionally misclassified birth outcomes. We found several practices that could potentially reduce under-reporting and misclassification of stillbirth. This included the cultural significance of ascertaining signs of life after birth, which meant families distinguished between stillbirths and early neonatal deaths; the perceived value and social recognition of a stillborn; and openness of families to disclose and discuss stillbirths. At the facility level, we identified that healthcare provider's practices driven by institutional culture and demands, family pressure, and socio-cultural influences, could contribute to under-reporting or misreporting of stillbirths. Data collection methodologies need to take into consideration the socio-cultural context and investigate thoroughly how perceptions and practices might facilitate or impede stillbirth reporting in order to make progress on data quality improvements for stillbirth.

Keywords: Stillbirth, fetal death, perinatal death, perception, data collection, Afghanistan, qualitative research

Introduction

In most low- and middle-income countries (LMIC), country-level estimates for stillbirth rely on data obtained through national household surveys due to absent or inadequate civil and vital registration systems and the high prevalence of home births (Lawn et al., 2011). Household surveys underestimate stillbirths by over 30%, and even vital registration data shows that stillbirths are under-reported by 20-30% (Cousens et al., 2011). Under-reporting and misclassification are important non-sampling errors that impact the accuracy and reliability of stillbirth data which result from omission or misreporting of deaths (Bradley et al., 2015; Lawn et al., 2010; MacQuarrie et al., 2018; Pullum & Becker, 2014). The quality of stillbirth and other mortality estimates from population-based surveys is affected by a range of factors including the methodological approach, the skill and motivation of interviewers, questionnaire design, and respondent characteristics (Deming, 2006; Pullum et al., 2018). However, disclosure and reporting of stillbirths can vary across contexts and cultures according to the perceptions and importance placed on pregnancy and reproductive loss, as these are socio-culturally constructed events (van der Sijpt, 2010). There has been little investigation into how the socio-cultural context and local perceptions, practices and experiences of stillbirth influence the accuracy of stillbirth data.

To facilitate improvements in stillbirth data quality, and methods to capture pregnancy loss more precisely, a comprehensive understanding of how contextual factors affect the accuracy of stillbirth data is required. Froen and colleagues' (2009) review of stillbirth data collection challenges, emphasised the need to examine how local perceptions either facilitate or impede stillbirth disclosure so that these cultural sensitivities are considered in data collection methodology. Pregnancy loss can be a sensitive and stigmatised issue in many settings (Frøen et al., 2011) and as with other stigmatised health concerns such as HIV/AIDS and abortion, there are underlying socio-cultural elements that affect the willingness to disclose or report these events (Iwelunmor et al., 2015; Shellenberg et al., 2011). In countries where induced abortion is unlawful, and there are consequences for women if abortion is suspected, pregnancy loss may be hidden or intentionally misreported as miscarriage or stillbirth (Erviti et al., 2004; Haws et al., 2010). Such misreporting impacts the accuracy of stillbirth estimates (Anderson et al., 1994; Lawn et al., 2009).

Existing research into the social and cultural meanings and impact of stillbirth in LMICs provides some insight into the implications for stillbirth reporting. Several qualitative studies found an absence of social recognition or value placed on perinatal losses. In South Africa and Ethiopia, there are prevailing beliefs that a stillborn or newborn that dies soon after birth are not human and

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therefore not accepted as a person (Jewkes & Wood, 1998; Sisay et al., 2014). In Eastern Uganda, Ghana, and Somaliland, stillborn babies are not recognised in society; their death is not treated the same as other human losses, mourning is discouraged, and they are often dealt with secretly (Kiguli et al., 2015; Osman et al., 2017; Sisay et al., 2014). Paudel et al. (2018) in Nepal also found that perinatal losses were perceived as insignificant events, and not counted or reported. These views and the absence of acknowledgement of a stillborn can contribute to under-reporting.

Social repercussions for women associated with pregnancy loss including stigma, shame, and violence, also contribute to non-disclosure of stillbirths and have been documented in studies from sub-Saharan Africa and Pakistan (Burden et al., 2016; Haws et al., 2010; Roberts et al., 2012). In Eastern Uganda, disclosure of stillbirth varied depending on the number of losses a woman had, and the different social consequences that existed among different communities (Kiguli et al., 2015). Similarly, in Tanzania, stillbirths and neonatal deaths were hidden and concealment was strongly determined by societal norms and consequences (Haws et al., 2010). Whereas in Nepal, there was minimal stigma associated with stillbirth, highlighting how societal responses to stillbirth can vary markedly depending on context and thus have varying impacts on the reporting of these deaths.

Local terminology, definitions, and community understanding of different pregnancy losses are also important considerations for data collection and survey question design. Stillbirth is a colloquial term for fetal death primarily used in western contexts and associated with multiple definitions (Lawn et al., 2009). Understanding how different perinatal losses are defined and interpreted at the community level can assist with improving data accuracy. Very few studies have explored terminology for stillbirth in non-English speaking settings, but those that have, noted overlapping use of words and vague definitions for different perinatal deaths (Haws et al., 2010; Kiguli et al., 2015).

Misclassification between stillbirth and early newborn deaths (END) can affect the accuracy of stillbirth estimates, and contribute to under- or over-estimates of both outcomes (Lawn et al., 2009). A validation study in Malawi comparing survey data with verbal autopsies found that one-fifth of early neonatal deaths were misclassified as stillbirths, thus underestimating neonatal deaths (Liu et al., 2016). Such misclassification has implications for program effectiveness as it can indicate misleading reductions or increases in deaths. Household surveys rely on mother's recall of pregnancy losses. The validity of this recollection is dependent on many factors including her understanding of the difference between an END or stillbirth, whether she saw her baby after birth, what was communicated by the birth attendant, the birth attendant's skills and whether they

checked for signs of life, and prevailing norms, perceptions and stigma that may surround pregnancy loss (Frøen et al., 2011; Lawn et al., 2011). Distinguishing between a stillbirth and END can be difficult especially when there is no skilled birth attendant present, and can lead to misclassification (Frøen et al., 2009). Birth attendants may also intentionally misreport pregnancy losses to avoid blame or for reasons that benefit the family, or to avoid documentation (Lawn et al., 2009).

Another important distinction when it comes to reporting of stillbirths is according to time of death. Stillbirths can be classified as either antepartum, when death occurs before labour, or intrapartum, when it occurs once labour commences, but before birth (Lawn et al., 2016). Antepartum and intrapartum stillbirths have different underlying causes and risk factors and differentiating between them has important program implications; intrapartum stillbirths are related to care received during labour and childbirth and often preventable with quality and timely intrapartum care, while antepartum stillbirths are associated with antenatal care quality and maternal conditions in pregnancy (Goldenberg et al., 2007). Timing can be estimated based on fetal skin appearance; antepartum stillbirths frequently show signs of skin maceration, while intrapartum stillbirths have a fresh, intact skin appearance. Some evidence suggests that relying on women's recollection of this may be unreliable (Gold et al., 2014).

Facility-based studies and routine health facility data are another important data source for stillbirths. Although not a representative data source for countries where home births are more common, as the proportion of institutional births increase in LMICs, these data will be increasingly used to understand stillbirth. How the socio-cultural context influences the quality of stillbirth reporting at this level is poorly understood. At an organisational level, there are known cultural and system barriers to reporting adverse medical incidents (Archer et al., 2017) and similar challenges are likely to exist for stillbirth reporting. There has been a recent focus on improving the quality and utility of routine health data in LMICs for service planning and delivery, highlighting the need to investigate the status of stillbirth data at this level (Wagenaar et al., 2017).

In Afghanistan, stillbirths have received little recognition, yet the burden remains high with an estimated stillbirth rate of 27 per 1000 births in 2015 (Blencowe et al., 2016). This rate has declined modestly since 2000 from 36 per 1000 births - an overall 25% reduction. By contrast, in the same time period, the neonatal mortality rate reduced by 45% from 61 to 42 per 1000 live births (UNICEF et al., 2018). There is some uncertainly around the accuracy of these estimates as under-reporting of both child and maternal deaths has been acknowledged as major challenge to obtaining accurate child and maternal mortality estimates in Afghanistan (Hill, 2012; Viswanathan et al., 2010). The

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2010 Afghanistan Mortality Survey found substantial under-reporting of child deaths, particularly among female children leading to an underestimate of mortality rates (ANPHI/MoPH et al, 2011). In the subsequent 2015 survey, under-five mortality rates had declined by almost half from 87 to 55 deaths per 1000 live births and were much lower than expected (CSO et al., 2017). Data quality assessments revealed that the issue was due to under-reporting of neonatal deaths (CSO et al., 2017). Concerns with under-reporting of deaths have also been observed in other population-based surveys in Afghanistan (Viswanathan et al., 2010). Given these findings, it is likely that similar measurement challenges exist for stillbirth. Therefore, we aimed to identify what factors might affect the disclosure and reporting of stillbirth at the community and health facility level in Afghanistan, and how this may impact data collection. Our approach focussed on understanding the mechanism behind how specific perceptions and practices lead to under-reporting and misclassification of stillbirth, to highlight where efforts are needed to minimise these impacts.

Methods

Study setting

The study took place in one urban and two rural districts of Kabul province, Afghanistan between October - November 2017. Kabul province, located in the east of Afghanistan, had a population of 4.3 million in 2016, ~80% of which lived in urban areas. The population is multi-ethnic; Pashtuns and Tajiks comprise the majority followed by the Hazara, Uzbeks, Baloch, Turkmen and several other minority groups. Kabul province generally performs far better in terms of healthcare coverage compared with other provinces due to the availability of specialist and referral facilities in the capital. Approximately 80% of women in Kabul province gave birth in a health facility compared to 48% nationally, and 66% received at least one antenatal (ANC) visit compared with 59% nationwide (CSO et al., 2017).

Rural districts were selected in consultation with the Afghanistan National Public Health Institute, Ministry of Public Health (MoPH) and the host organisation facilitating the research, Management Sciences for Health (MSH), based on assessment of security levels and availability of health services and active Community Health Workers (CHW) that could assist with identifying participants. The first district, located 28 km west of Kabul city, had a population of around 130 000 spread across 30 villages; while the second district, located 25 km north of the capital, was smaller with a population of 55 000 spanning 20 villages. In the capital, Kabul, we selected three referral maternity hospitals, and in the two rural districts, two lower-level health facilities through which to conduct the study. The maternity hospitals were three of the capital's largest, tertiary-level public health facilities and were chosen due to the large volume of births; they experience approximately 80-100 births per day and 20-80 stillbirths per month. The rural facilities included one comprehensive health centre (primary level facility) and a district hospital. The ethics committees of the institutional review board of the Afghanistan National Public Health Institute in Afghanistan (no. 43831), and the University of Sydney (no. 2017/566) approved the study. Written permission was obtained from participating hospitals to identify and approach women, and all participants gave verbal or written informed consent.

Study participants and recruitment

We interviewed 55 participants for this study including mothers (21) and fathers (9) who had experienced a recent stillbirth, female community elders (3), local CHWs (5), various health service providers at tertiary-level facilities (11), and government health officials (2) (<u>Table A1</u>, Appendix). This provided a comprehensive range of views, extending from the community-level, health facility-level, and the ministry level.

We used purposive and snowball sampling to recruit participants through multiple avenues (Patton, 2002). Based on advice from local investigators and senior hospital managers, we initially identified women who had a stillbirth from hospital registers and contacted them through mobile telephone using details from medical records. In two tertiary facilities, hospital staff identified and compiled the lists of women, although, many telephone numbers were missing. Women with numbers available were contacted, but due to low response (because numbers were no longer working, or the phone belonged to the husband and he would not allow us to speak with the mother, or the woman had returned to her home province) staff at health facilities also notified the study team when a stillbirth occurred. Interviewers approached women in the hospital soon after the birth or arranged interviews for a later date. Where possible, fathers were also interviewed. This latter method was also used to recruit women from the third facility as medical records were mostly missing phone numbers. We also faced some difficulties with this approach as despite wanting to share their stories, women were overcome with grief and could not fully complete interviews. Additional recruitment of participants also occurred through the networks and relatives of the interviewers, and as respondents were identified, they also referred us to others in their communities. Of all approaches, this was the most successful. In rural districts, we identified women who had a stillbirth from facility records and through CHWs who were knowledgeable about who had experienced a loss. CHWs were also familiar with and introduced us to female elders.

Key informants were selected in consultation with the local study investigators and consideration of respondents' role in the delivery or management of maternal, reproductive, neonatal, and child

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health services at maternity hospitals and within the Afghanistan MoPH. They were also chosen because of their direct experience with stillbirths and/or knowledge on the recording and reporting systems at the facility and the ministry level. To recruit key informants, study investigators approached hospital managers/directors to explain the study and introduce the study team, obtain their support, and invite them to participate. These individuals then identified and referred us to relevant health facility staff to arrange interviews.

We initially applied the stillbirth definition of stillbirth as a late pregnancy loss occurring at ≥28 weeks' gestation; however, gestational age and presence of signs of life at birth were frequently not recorded in women's medical records and were difficult to ascertain until after interviews had commenced. We, therefore, remained flexible about the inclusion of participants and accepted any participant perceived to have had a stillbirth. We made efforts to recruit women who gave birth at home as well as at the health facility as they were likely to have differing views and personal experiences.

Data collection

Semi-structured interview guides were prepared for each group of study participants covering five broad areas pertaining to their experiences, perceptions and practices around stillbirth: i) local terminology and understanding of stillbirth and other pregnancy losses, iii) disclosure and reporting, iii) perceived causes and risk factors, iv) the impact of stillbirth, vi) socio-cultural practices following stillbirth, and v) prevention practices and awareness. Community respondents were asked first to give a narrative account of their stillbirth experience and allowed to speak freely, while interviewers probed to explore the predefined topic areas. The guidelines for healthcare providers and other key informants included additional topics such as distinguishing between perinatal losses, treatment of women experiencing stillbirth, the importance of stillbirth, and strategies and challenges to reducing stillbirth. Interview guides were translated from English to Dari by a local Afghan translator and checked by an Afghan co-author. The accuracy of translations was reviewed and certified by a native English speaker of Afghan origin, fluent in Dari, and with a health background.

Interviews were conducted in Dari or Pashto (the two official Afghan languages) by three locally recruited Afghan interviewers (2 female; 1 male) trained in the social sciences and experienced with undertaking qualitative research in Afghanistan. The lead author (AC), a foreign female public health researcher, also conducted interviews with key informants in English together with local investigators when required. Conscious of the cultural context and the sensitivity needed when undertaking cross-cultural research, the lead author was guided by local investigators and

interviewers on her degree of involvement in interviews and approach to data collection (Liamputtong, 2010). She did not participate in interviews with community members as it was unknown how sensitive the issue of pregnancy loss would be, and whether the presence of a foreigner might affect participant's responses. All interviewers participated in a three-day training workshop led by three authors (AC, SMSH and MHR) which covered the study and its objectives, an overview of qualitative methods, and a review of the study instruments to ensure consistent interpretation. This was followed by two-days piloting and refining the interview guides.

Interviews were held in private locations that were preferred by participants, including offices within health facilities, and participant homes, and for cultural reasons were done by a member of the same gender. On several occasions, mothers-in-law would not allow their daughters-in-law to be interviewed alone, and so in these cases, they were also present during the interview. Interviews lasted between 30-60 minutes and were audio-recorded where permission was obtained; otherwise, interviewers took detailed notes. Approximately half of the women's interviews were not recorded based on requests by women or their mothers-in-laws'. Following each interview, interviewers completed a debrief form. Transcription of audio-recorded interviews was done verbatim in the language conducted, and Dari and Pashto transcripts were translated to English. Interviewers and local study investigators cross-checked the translated transcripts to ensure accuracy and clarify contextual meaning. The interpretation and translation of terminology on pregnancy loss were discussed in-depth among the study team and translators to ensure that meaning was translated as accurately as possible (Liamputtong, 2010). The study team discussed emerging findings and data collection processes and challenges during daily debrief meetings. Interviews with mothers, fathers, and healthcare providers continued until we had acquired a sufficient range of responses and reached a point in the data collection where no new themes were emerging (Guest et al., 2006). Identification and recruitment of female elders from rural areas was more time intensive, and due to time and resource constraints during field work, we were unable to recruit enough respondents.

Data analysis

To analyse the data, the lead author (AC) first read all transcripts multiple times and prepared an initial code list based on the interview guide topics adding new codes as additional concepts emerged. Two authors (AC, AA) discussed and refined the code list, and AC subsequently coded all transcripts line-by-line. N-vivo 11 software was used to organise and manage the data and facilitate the development of the coding scheme. Throughout the analysis, there were several discussions among the research team, including interviewers and translators, to ensure accurate interpretation of the data. To develop themes, we initially applied a deductive thematic approach (Braun & Clarke,

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2006) based on some known socio-cultural and other factors thought to influence stillbirth reporting and disclosure (Frøen et al., 2009; Haws et al., 2010; Lawn et al., 2009) identifying which specific perceptions and practices potentially impact on stillbirth reporting and disclosure in this setting. Additional themes were derived inductively and included perceptions and practices specific to the Afghan context, that could affect stillbirth data. Using these themes, we developed a conceptual framework to understand and illustrate the mechanism by which (*how*) they impact on two key elements affecting stillbirth data quality – under-reporting and misclassification. Including the perspectives of various participant types allowed us to triangulate and compare views and explore the multiple levels at which stillbirth data collection can be affected.

Results

At the community level, the key factors that had the potential to impact on stillbirth data quality were categorised under two overarching themes, i) community interpretations, perceptions and practices, and ii) birth attendant practices. At the health facility-level, factors were classified under, i) institutional values and priorities, ii) social pressure and, iii) healthcare provider practices. The potential impact that the identified perceptions and practices have on the quality of stillbirth data and the pathways through which these impacts might occur at the community and facility level are summarised in Figures 1 and 2.

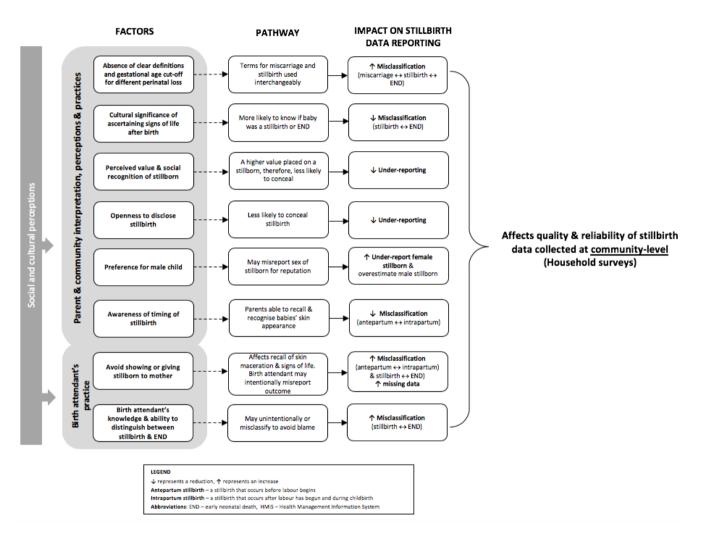


Figure 1. Conceptual framework illustrating the factors and pathways through which these factors influence stillbirth data quality and reporting at the community-level in

Afghanistan

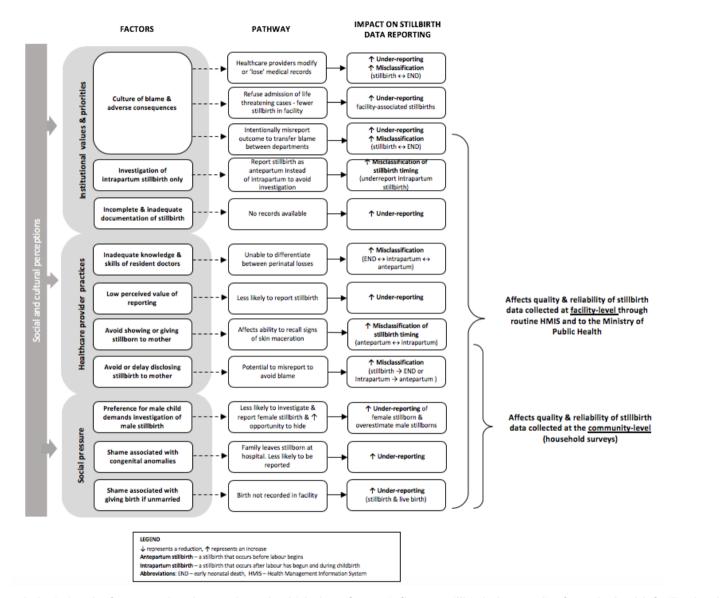


Figure 2. Conceptual framework depicting the factors and pathways through which these factors influence stillbirth data quality from the health facility-level in Afghanistan

FACTORS INFLUENCING STILLBIRTH DATA AT COMMUNITY LEVEL

Community interpretation, perceptions and practices

Terminology and understanding of stillbirth and other pregnancy losses

Terminology for different perinatal losses in the Afghan languages, Dari and Pashto, are not as clearly defined or neatly categorised as their English equivalents. There is no direct or specific term for stillbirth, and instead, the expression 'baby born dead' was used to describe a stillborn baby. Whereas for miscarriage, several terms existed which in English translated to 'aborted fetus', 'waste', or something 'lost'. There was also no explicit term for early neonatal death and the expression 'baby born alive then died', was used (Table A3, Appendix). During data collection we found there was frequent interchange in the use of the terms for stillbirth and miscarriage, especially at the community level where the terms for miscarriage were commonly used to describe a stillbirth. While we intended to recruit participants that experienced a stillbirth, it became apparent during interviews that some of the losses were not stillbirths, but early newborn deaths, indicating some confusion between these. For example, for this mother, it was not until she was asked whether her baby died after birth or died in the womb that the she said, '...it was not like other babies to cry and move its hands and feet. It was just silent...It was alive, but it was not in good condition.' [Mother#17].

Parents used the term for stillbirth to describe a baby that died during childbirth, or very near to the time of birth; whereas a baby that died before the birth - 'in the womb' - was referred to as a miscarriage. There were no clear gestational ages to differentiate between a stillbirth and miscarriage, although it was understood a miscarriage occurs earlier in pregnancy. The timing mentioned varied, and mothers most frequently defined stillbirth as a baby that completed nine months of pregnancy and was born dead, or a baby that died once it had reached 'maturity' or a certain level of development (Table A3). The exact time period at which the fetus was perceived to be fully developed was also not clear. A miscarriage was understood to be an earlier loss with the most frequently mentioned gestation ranging from 3 to 5 months, or the baby was described as 'incomplete'. However, some parents also referred to a miscarriages was reflected in some respondent's description as the fetus being 'a piece of meat'. Father's perceptions were similar to women's and they used the term for miscarriage for any loss before nine months, while a stillbirth was viewed as a baby that had reached term that dies either shortly before or during childbirth.

Compared to mothers and fathers, CHWs were generally more knowledgeable about the difference between miscarriage and stillbirth based on gestational age. They described a death before four- or five-months gestation as a miscarriage, while death after this time period was a stillbirth. Sometimes, however, instead of specifying a gestational age, the definition of a loss was dependent on when the baby started moving, as one CHW explains, *'when the baby starts moving in the womb, then it dies, it's called miscarriage.'* [CHW#02].

Differentiation between a baby born alive and born dead had specific cultural and religious implications with each receiving different rituals after birth, thus making it important to distinguish between the two at the community level. In many cases, this was also how families defined the difference between a baby that was born alive versus born dead. When asked about the difference, some parents referred to how the body was treated after death rather than describing any characteristic about the baby or pregnancy, as this father's explanation indicates, 'they performed the funeral of the neonatal death and there is no funeral for the stillbirth.' [Father#06]. Stillbirths were also distinguished between an early neonatal death based on signs of life after birth. Female elders often used this medical categorisation and distinguished between a stillbirth and neonatal death based on whether the baby moved or breathed after birth. As one respondent explains, 'When it is born it is loose and doesn't move. We wrap it up in a piece of cloth and send it to be buried. The one who moves during the delivery or opens its mouth after delivery, it is counted as alive...' [Female elder#02]. However, sometimes female elders identified a baby as stillborn even when signs of life were present, as one recounts about a recent stillbirth she delivered, '...when it was taken out after the delivery, it cried once and then died. I moved it a lot, but it was dead.' [Female elder#03].

Parents' appeared to be aware of the differences between a stillbirth that occurred before birth (antepartum) compared to one that occurred during birth (intrapartum). When a baby had died in the womb either days or weeks before, terms such as the skin being scratched or marked were used as this father describes, '*The baby had died 40 days or 30 days earlier from the delivery, while you push her head, it was soft, the skin of the baby was scratched, but the body of the baby was complete.*' [Father #09]. Similarly, this mother was aware her baby had died before arriving to the hospital stating, '...I knew it myself too. I couldn't stand, and I couldn't rotate during sleeping...The baby had turned grey and its skin was worst...' [Mother#07].

Differential customs, rituals and burial practices for stillborn

The narratives of respondents indicated that the usual practice when a stillbirth occurred at a health facility was to give the baby to a family member, most often the mother-in-law or another female that accompanied the mother, as the father and other males are often not permitted to enter maternity hospitals in Kabul. The baby would then be taken to the father or other male members waiting outside of the hospital for burial. We found that the usual prescribed rituals, customs, and practices for a stillborn differed to those for a live newborn that died, or older child and adult death, but that sometimes families deviated from the accepted practices (Table A4, Appendix). When a woman had a stillbirth, only close family members and neighbours would visit her at home and give their condolences. The news of the death would not be spread as widely in the community as the death of a live-born baby or older adult, and so not as many people would attend the burial. Usually, the father and other men would attend the burial and women would stay with the mother at home.

According to Afghan Islamic tradition, certain rituals and practices must be performed depending on whether a baby was born alive or dead. Of particular importance, was whether the baby had breathed; if the child had taken a breath, they were considered to be 'part of this world', and this would determine if they were entitled to specific rituals such as being bathed, having a ceremony (Azan), being named, and in the case of an early newborn death, receiving a funeral prayer. Only if a baby is born alive do they receive these rites. If a baby is born dead, a burial would still take place, but other rituals were generally not performed, as one father explains,

'The main reason [that rituals are not performed] is that, the baby did not cry, if she cried, or moved, then we must give it the bath and perform the funeral. When the Mullah of the mosque comes to the graveyard, then people come together and perform the funeral, but if there is miscarriage or stillbirth, they are not eligible to perform their funeral and don't want to inform people to come to their house.'

- Father#09

These customary practices influenced how families behaved after death, and so it was common to inquire about or confirm the presence of signs of life at birth as this would determine which rituals were performed. The importance and significance of these rituals are illustrated in one fathers' experience where he mourns his twins; one of which was stillborn and the other born alive then later died. As he was not present during the birth, he was not aware that one of the twins had survived the birth and hence, according to custom, deserved a funeral,

'... and we didn't perform the funeral, but I was told later that one of the babies was born alive then died...my mother told me that, you should have performed the funeral of the live one. But we have already buried (them)...'

- Father#09

Burial practices of miscarried fetus' varied and generally depended on the family wishes or the stage of development of the fetus. One CHW remarked that, '*They just bury it in the land. If it's too small, they throw it away. If it's body* (is) *complete, then they bury it.*' [CHW#04]. Parents also spoke of discarding a miscarried fetus, while for others there was some importance placed on burying a miscarried fetus despite it not being widely accepted, as this female elder describes,

'Yes, it is buried because they would be asked for burial in the other world. As much small ... it is wrapped up in a piece of cloth and buried then. I have also buried my bride's [her daughter-in-law] children who miscarried two or three months old one. I wasn't first given the child though as they thought it was an embarrassment.'

- Female elder#02

Perceived value and social recognition of stillborn

The differential customs and death rituals that exist for stillborn babies compared to newborn deaths would suggest a lower level of social recognition and religious identity is given to a stillborn. However, it was evident in our study, that even a stillbirth held significance and value and was acknowledged by their communities. Burial of stillborn babies in Afghanistan generally have fewer attendees than neonatal deaths, but one father who was a religious leader said that 'Almost 150 – 200 people came and consoled with us because it has been ten years that I am the Mullah [priest] in the mosque... As I called my villagers that such an incident has happened. They went to the graveyard and prepared the grave. I am so happy with them' [Father #02]. Funerals and condolence ceremonies for a stillborn are also not usually held, but in almost all cases, family members would visit the mother to give their condolences. As one female elder explained - this was done out of respect for the lost child, 'The people don't come to ask about someone's health, but they definitely come for the condolence ceremony... they don't come to say the mother it is better that you have recovered, but they say that they come for the dead baby and ask for the reason too...' [Female elder#01].

Many families also chose to bathe, name, or conduct a funeral for their stillborn despite these not being the socially accepted practice, as one father said about his stillborn, '*We give him a bath, performed the funeral prayer and buried him.*' [Father#04]. Funerals were less common, but we found that over half of respondents had named their stillborn, often secretly. This reinforces the perceived value a stillborn had for parents, the significance of which may not always be recognised by the wider community, and which they may not openly share in the fear of being judged.

Disclosure of stillbirth

Secrecy around stillbirths was not common among respondents in this study. Most parents openly told family members, relatives, and neighbours, and had not personally faced any issues with disclosing the death. Perspectives from others also confirmed this, as people spoke openly and generally did not try to hide a pregnancy loss. When a mother returned to her home, the death and possible reasons were discussed amongst their family and some close relatives, even neighbours,

'No, they never hide such kind of issue, they mention the issue with others and explain the reason; for example, I do a lot of work at home, or the string suffered [referring to witchcraft] or something else. Even they say, I haven't completed the period of the pregnancy and lost it before the ninth month, but they never hide it.'

- CHW#04

Parents also relayed that they did not feel there was any shame associated with discussing stillbirths or disclosing that it had happened, '…*They should not feel shame because this is not a shameful issue. Which one is better, to feel shame and lose the baby, or they should talk and protect from losing the baby?*" [Father#09]. Many felt it was better to discuss the issue openly to prevent it from happening again, as this mother remarked, '*Yes, people talk about stillbirth and miscarriage, and they say that this woman had a problem so she should find an experienced doctor to avoid it in the future…*' [Mother#11].

The community were generally very supportive of the mother after a stillbirth which may explain parents' openness to discuss these deaths. One key informant believed that the absence of shame and secrecy around stillbirths was related to the frequency of stillbirths in Afghanistan. Moreover, the commonly held belief that the death was considered God's will, reduced blame directed to the mother, thus also allowing open discussion of the loss. However, two respondents, both fathers, had different perspectives and spoke of some secrecy and reluctance around informing others about a miscarriage or early stillbirth,

'I informed people in my first baby, but I didn't inform people about the second one, because my mother told me that is not something to inform people about. Because the miscarriage is not complete; it might be around seven or six months, that is why they don't want to inform people.'

- Father#04

Other circumstances where families may actively hide a stillbirth included when it was unknown who the father was, or a woman was unmarried, or, as this female elder explains, '...because they don't want anyone to laugh and make fun of it especially if they are weak and have rivals.' [Female elder#02].

Birth attendant practices

On several occasions, mothers had not seen or held their stillborn because it was discouraged by those around them. This mother reflects on how she wanted to hold her baby, '… I wished to embrace her and have her in my arms, but my own mother did not allow me and patted me…My mother said, no don't take it into your arms, I also did not insist a lot…' [Mother#06]. A female elder experienced with attending home births explained how she avoided showing the baby to the mother believing that it would cause more harm, '…we don't show the baby to the most, but we show it to some women…Because she is so sad. We say the mother shouldn't see it, because she might go into a critical condition as many have gone in such situation…We have experienced such things, because our hairs have turned white in such things.' [Female elder#01].

FACTORS INFLUENCING STILLBIRTH DATA AT HEALTH FACILITY LEVEL

Institutional values and priorities

Culture of blame and adverse consequences

A number of healthcare provider practices arising from a culture of blame for perinatal deaths were perceived by hospital managers to be the main reason behind under-reporting of stillbirths. Hospital managers were aware of this and reported making efforts to minimise it, and in some facilities, it was acknowledged that these practices were more prevalent in the past but continued to be a challenge. Managers referred to practices such as not documenting deaths, modifying or destroying medical records to avoid any documentation, including intentionally misreporting the death to avoid blame. The problem of under-reporting of stillbirths was described by one respondent as 'endemic' in health facilities across the country, admitting that '... the reality that really the numbers, the real number, is manipulated, it's decreased. These are the issues...' [MoPH official]. Formal investigation by a quality assurance committee of the MoPH and the management and consequences for health providers were perceived to be the main reason driving these practices. Additional challenges raised by respondents surrounded health system constraints including night shifts, workloads, insufficient staff and resident doctors without adequate skills and experience, all of which led to medical errors that healthcare providers would then try to conceal.

Fear of being blamed also created a culture of silence around these deaths. One manager described how resident doctors were afraid of reporting observed incidents of altering or destroying records stating, 'There are lots of [medical] students they are keeping quiet. [They think that] If we are saying the teachers or directors of the hospital maybe they blame us. Especially in the two days of (public) holidays.' [Chief of emergency_facility#02]. Respondents also indicated that others were influencing what healthcare providers recorded in medical records, 'Most of the truths are kept hidden and sometimes they (doctors) are not allowed to mention the truth.' [Obs/Gynae doctor_facility#02]. A government official expressed concerns about how younger resident doctors were adopting these inappropriate practices and doing the same during placements at rural facilities, 'Unfortunately, they are learning such kind of malpractices in the health facility, and when they are going to the field, they are doing the same as they learned from their seniors.' [MoPH official]. Furthermore, several respondents mentioned that if an incident involved a healthcare provider that was connected to higher ranking officials in government, any staff aware of it, were more likely to stay silent due to fear of repercussions.

Fear of consequences also motivated doctors to shift the responsibility of stillbirth from one department to another. When probed about issues on misclassification and why it arises, one hospital manager described how one ward would try to transfer the blame to another, 'Because sometimes they want to hide the case of fresh stillbirth and sometimes doctor, gynae doctor, says it belongs to the neonatal doctor...' [Hospital deputy director_facility#2].

In one health facility, we were provided with very different views on the burden of stillbirth by different healthcare providers. When asked how common stillbirth was in their hospital, one senior doctor responded that, '*In a month...there will be 4-8 patients with stillbirth...most of the patients with macerated stillbirth, not fresh stillbirths...*' [Obs/Gynae Trainer_facility#01]; while a midwife from the same facility reported there were several every night, '...*during twenty-four hours that we are on duty, two or three stillbirth incidents happen which have completed their time but are born dead*' [Midwife#04_facility#03]. This discrepancy suggests there might be some concern about disclosing the true extent of these deaths.

Other practices described by respondents with implications on stillbirth reporting included doctors turning away critically-ill pregnant women presenting at facilities when it was known that the potential outcome might be serious, so that any death would take place outside of the facility. This was also used as a method to avoid blame and to evade legal issues. Women presenting in the outpatient department would be discharged and told their situation was too advanced even if

interventions were still possible, and that it is better she be at home with family. As one key informant explained, '...another example is when a mother comes with a complication to the hospital, and they say, oh this is a severe complication and we may not be able to manage this one... if we have this she might die and the baby as well, then it will increase the rate of deaths, and this will affect our reputation. So, the easiest thing for them (to do) is to discharge the woman before they are registered...' [MoPH official].

Some hospital managers spoke of making genuine efforts to change the culture of blame in their facilities to a culture of learning and positive feedback, without blame. Together with improved management practices, this resulted in some success, but managers acknowledged that the consequences faced by providers during formal investigation by the MoPH was a barrier to eliminating the problem of under-reporting. When asked why doctors might hide stillbirths one manager stated; '*They are afraid of the* (quality assurance) *committees, for that reason. But if there are some doctors who bring report and if we face with the same problem, we are very serious after that...But we don't blame them. We want to solve the problem. We never blame the doctors, but we want to bring some changes.' [Hospital deputy director_facility#01].*

Investigation of intrapartum stillbirth

The primary concern of hospitals was intrapartum stillbirths, or what was referred to as 'fresh inhospital' stillbirths, as these were perceived to be their responsibility. Whenever an intrapartum stillbirth occurred at a public health facility, this would trigger an investigation by a quality assurance committee in the MoPH, while antepartum stillbirths were not investigated. Such investigations reportedly resulted in requests for a large amount of documentation and queries to hospital staff, and harsh treatment and humiliation of the health providers involved. Hence, respondents reported that some doctors, particularly during night shifts (when fewer staff and managers were present), would intentionally misreport fresh stillbirths as macerated stillbirths, thereby leading to underreporting of intrapartum and overreporting of antepartum stillbirth. As this healthcare provider explains, '...*They* [the doctors] *are writing that when she* [the pregnant woman] *came to our hospital she didn't come with any fetal heart sound. Sometimes, sometimes it's happening...10-15%, not more than that.'* [Chief of emergency_faciliity#02].

Health providers also described how families were more likely to query the doctors if their baby died in the hospital, 'If the mother tells us that the child hasn't been moving for many days. They know that the child has died, there is no problem...But the child who has a heartbeat and dies after delivery, its difference is that both mother and her company asks why the child died.' [Midwife#04]. Doctors were also blamed by families when a stillbirth occurred in the facility as one manager explained, *'...if the stillbirth occurs in the hospital sometimes the family member has conflict with the doctors.'* [Hospital deputy director_facility#01] with reports that some families would also take legal action against the responsible healthcare provider.

Incomplete and inadequate documentation and reporting

The perspective from most healthcare providers was that all births and their respective outcomes were recorded completely,

'It is different in different hospitals...it is completely done in our hospital. It (the birth) is registered in the birthing room and children's section separately, and all these books are sent to the Ministry.'

- Midwife#02_facility#02

At this facility, however, when we reviewed register books to identify stillbirth cases, we found very little information recorded for each admission with most information missing; only Apgar scores could be used to determine the outcome of the birth. One government official also confirmed that if anyone was to search for specific information on stillbirth in health facilities it would be difficult to find,

'... stillbirth is like an added issue...most of the time it is not reported by the health facility staff. And if you go to the health facility rarely you will find the records of cases of stillbirths so this is the facts...you will not be able to easily find the information. You have to provide a...situation that the health facility staff can trust you and provide the information in a very informal way, not a formal way...'

MoPH official

Hospitals produced monthly reports on all facility deaths including stillbirths, which were reported to the MoPH's Health Management Information System (HMIS). However, the reporting forms provided to facilities by the Ministry requested only the total numbers of stillbirth, despite most facilities recording data on the timing of the stillbirth. In rural districts, there were no requests for reports from the lowest tier of health posts at the community level from CHWs, so there was no reporting mechanism to document and report stillbirths from that may have taken place in the home. CHWs were provided forms to record maternal or neonatal deaths, but not stillbirths. An official working in MIS asserted that CHWs would not be able to recognise stillbirth to report it precisely, *'…the CHWs mostly are illiterate, they don't know that* (stillbirth) *has a specific definition….'* [MoPH official].

Healthcare provider practices

Avoid or delay disclosing/showing stillborn to mother

Both parents and health providers related that stillborn babies were often given to a family member after the birth rather than the mother due to two main reasons - to protect the mother from grief and to reduce the risk of exacerbating her medical condition. Sometimes, the mother would be shown the baby or given the child to hold after being wrapped, but health providers generally tried to avoid this. As one health provider described, '...we try not to give it to the mother and never carry out the dead baby in front of its mother; we invite the family member of the baby and submit the dead baby to him and it is very difficult for the father who was waiting to receive the baby.' [Neonatal chief_facility#02].

In addition to not showing the baby to the mother, in some facilities, health providers spoke of not informing or delaying telling her that her baby has died. When questioned about when the mother was informed about her stillborn baby, one health provider responded; '*It differs, because* (there are) *those patients who visit here and know that their baby has died, but if it was delivered fresh, we don't tell them. It means we don't tell her at that time ... and even we don't tell till the last moment, but her companion is definitely told about it.'* [Resident doctor_facility#03].

Knowledge and skills & perceived value of reporting

There were both intentional and unintentional practices by healthcare providers that could lead to misclassification between stillbirth and early neonatal deaths. Hospital managers acknowledged that some doctors, particularly new graduates, were inadequately trained to properly differentiate between the different perinatal losses, and that this occurred more frequently during night shifts when supervisors were absent. It was also a common perception that inadequate understanding among some healthcare providers about the value of reporting was contributing to the problem of poor-quality data,

'...they [healthcare providers] don't consider the importance of reporting as a whole and that is why (they) easily lose the file of the patient; they are maybe throwing out, or missing that file, or putting it somewhere, or hiding it...so this is the issue - that they don't realise the importance of data use and information...They are thinking if they disclose they will be blamed or won't be good for them.'

-MoPH official

Social pressure

In Afghan society, traditional views around gender persist and the birth of male is associated with greater importance. Most parents in our study did not have a preference for male babies and often described cherishing their daughters more; however, several acknowledged that they or others in their community would be more upset about the death of a male,

'Unfortunately, it is still a problem in our village. People differentiate between a baby boy and a baby girl. They feel more upset for the boy, but less upset for the girl...There is no difference between them for the mother. They are both the blessings of Allah and there is no difference between them for us.'

- Father#01

Healthcare providers also confirmed this and explained how when a stillborn was male families became angrier demanding an investigation into why the death occurred and would even threaten staff. Such reactions were more common if a stillbirth was the first-born child or the family had no sons. Healthcare providers relayed how some families were relieved and even glad if they lost a baby that was female, and that occasionally if life-saving interventions were required, they were refused for female babies. As one healthcare provider recollected about a patient whose baby was in danger, stating that '*They* [the family] *know the baby is girl, they say ok don't worry...The mother in law! The mother, father sometimes... They are saying we don't want. It's ok if she dies, we don't have any problem.'* [Chief of emergency_facility#02].

Healthcare providers also spoke of how they observed a high frequency of stillborn babies with congenital malformations and described how on several occasions, mothers who gave birth to such a baby, would suddenly depart the hospital secretly leaving the body behind. Providers explained that this occurred because of significant shame associated with congenital anomalies. Another social issue raised by providers perceived to affect accurate recording of outcomes was for unmarried women that gave birth in the health facility. As this is socially unacceptable in Afghanistan, and to protect women's reputation, these births were frequently not documented in hospital records.

Discussion

In this study, we have described how specific local perceptions and practices around stillbirth in Afghanistan can affect the quality of stillbirth data and how an understanding of the socio-cultural context can inform more precise capture of stillbirth data. We identified community-level variation and interchange in the terminology and interpretation for stillbirth, miscarriage and early neonatal deaths that could lead to misclassification. Whereas certain perceptions and practices had the potential to reduce under-reporting and misclassification- the cultural significance of ascertaining signs of life after birth which indicated that families actively distinguished between stillbirths and early neonatal deaths, the perceived value and social recognition of a stillborn, and the openness of families to disclose and discuss stillbirths. Birth attendant practices such as avoiding showing mothers their stillborn baby has implications for women's recall of skin appearance and could lead to misclassification. Healthcare provider practices in facilities driven by institutional culture and demands, family pressure, and socio-cultural factors, could potentially exacerbate under-reporting or misclassification of stillbirths.

Our findings demonstrate the importance of investigating context-specific interpretation and terminology for stillbirth and other perinatal losses. The influence of this on data quality is particularly critical for stillbirth – a term that frequently has no equivalent expression in this setting, and one surrounded by confusion around its definition. These are important considerations for demographers and epidemiologists when developing survey questions and other data collection methods, as equivalent local terms for the biomedical classifications of miscarriage, stillbirth, and early neonatal death, do not always exist (Haws et al., 2010). The multitude of factors identified at the facility level influencing the reporting and recording of stillbirth is detrimental to the accuracy and reliability of this source of stillbirth data. Ultimately, this impacts the accuracy of reports provided to the government which can affect the prioritisation of stillbirth prevention efforts and resources to reduce these deaths.

The lack of distinct definitions, interchange in the use of terminology for stillbirth and miscarriage, and the absence of precise gestational ages to differentiate between losses that we identified have been found by others (Haws et al., 2010; Zakar et al., 2018). Haws et al. (2010) explored terminology for perinatal losses in Tanzania and found similar ambiguity in definitions and terms with no equivalent identified word for stillbirth. These findings support the importance of collecting gestational age data from mothers on the month, or preferably week they lost their baby. We found that several terms for miscarriage were in use and this is an important consideration when selecting terms for surveys that are translated from English to local languages. Gaining community insights before making these decisions would be valuable, as lay terms may not match terms used by health providers or program managers.

We also highlight the implications that socio-cultural perceptions and customary practices have on community understanding and differentiation between pregnancy losses. In Afghanistan, there appears to be a high degree of awareness around distinguishing between the different types of losses. The importance of ascertaining signs of life after birth due to religious practices means Afghan families are likely to be aware of whether their baby was born alive or not, thereby reducing the possibility of misclassification between stillbirth and early neonatal deaths. These findings suggest that the reliability of parent's responses about signs of life at birth in societies where viability has socio-cultural significance, may be better. Including survey questions on the rituals received after birth in contexts where this is relevant, could be another possible avenue for confirming whether a baby was born alive or born dead, but this requires further research.

In most LMICs, including Afghanistan, stillbirth estimates are based on data from nationallyrepresentative Demographic and Household Surveys (DHS). Currently, standard DHS surveys only include live birth histories (ICF International & Demographic and Health Surveys (DHS) Program, 2018). To capture stillbirths, the women's questionnaire in these surveys ask variations of the question, *Have you ever had a pregnancy that miscarried, was aborted, or ended in a stillbirth?*, and for each pregnancy the number of months pregnant she was when the pregnancy ended. No other information is collected and there is no opportunity for questions to probe on signs of life (i.e. *did the baby cry, move, or breathe after birth?*) to reduce misclassification. These confirmatory questions are currently limited to verbal autopsies included in very few DHSs, and selected surveys that use full pregnancy histories (Christou et al., 2017). Incorporating questions to ascertain signs of life at birth in community-based surveys can further enhance data quality and has been previously proposed (Liu et al., 2016).

Relying on only the mother's recall of fetal characteristics to determine the timing of a stillbirth may result in misclassification or a high proportion of missing responses as some mothers, and occasionally fathers, do not see their stillborn. It would, therefore, be important to determine if the mother saw her baby after birth when asking these questions, and if not, to verify these details with others present at the birth. A study in Nigeria also found that many women do not see their stillborn and a global survey of health providers from 135 countries reported only 39% of mothers 'always or often' saw their stillborn (Frøen et al., 2009; Kuti & Ilesanmi, 2011). However, parents that did see their baby in our study recollected in detail how it looked, particularly in regard to skin appearance. This finding aligns with studies from Tanzania (Haws et al., 2010), Uganda (Kiguli et al., 2015) and Ghana which found women were concerned about how their baby looked, suggesting that women's recall of fetal skin condition might be more reliable than previously thought (Gold et al., 2014). Women in our study were conscious of the timing of the death prior to childbirth, with some specifically stating that they knew their baby had died before reaching the hospital because they noticed the cessation of fetal movements. Therefore, asking women about fetal activity is another opportunity to confirm the timing of fetal death.

Men's awareness and understanding of the various perinatal losses and terminologies were similar to women's, and they were also able to recall skin condition of their stillborn. This was interesting given men's limited involvement in pregnancy and childbirth in general in Afghanistan but may be related to the religious practices that rely on knowing the timing of the death, and that men are given the baby immediately after birth. It may be beneficial to include questions for fathers about any stillbirth or death in the household, for example, during verbal autopsy interviews.

The absence of secrecy around stillbirths and openness of the community to disclose the death to their families and relatives in our study suggests a lower potential for under-reporting at the community-level, especially in household surveys. Our findings differ from a recent study in neighbouring Pakistan where a reluctance by the community to even inform local CHWs about their stillbirth was thought to contribute to under-reporting (Zakar et al., 2018). We do not report on the socio-cultural impact of stillbirth here, but our research also uncovered some social consequences for women following stillbirth, but these did not appear to affect the family's willingness to disclose the stillbirth to others (unpublished data).

Although the ability to differentiate between stillbirths and END appeared to be good at the community level, remarks by female elders attending home births pointed to the potential for misclassification. This misclassification is likely to be communicated to the family and can affect subsequent reporting during household surveys. Birth attendants may also intentionally misclassify the outcome to avoid blame from the family, as these untrained birth attendants or trained community midwives are frequently relatives of the mother.

Sex preferences for male babies is prevalent throughout South Asia and may have implications for stillbirth data. Differential reactions to a stillborn based on sex reported by respondents can potentially lead to under-reporting at the community and health facility levels for female stillborns. Social and economic pressure to have sons underscores parent's demands for an investigation into deaths of male babies and makes it more difficult for health providers to under-report male fetal or infant deaths. At the community level, it is possible that the sex of the stillborn might be misreported to family and then onto the wider community to maintain social status or to protect a woman's reputation. In their examination of child deaths in Afghanistan surveys, Viswanathan et al. (2010) found under-reporting of female deaths which they attributed to families intentionally misclassifying boys as girls, as well as omission of female deaths. The reason for under-reporting was thought to be due to social stigma attached to only having girls (Viswanathan et al., 2010). Based on our findings, the problems with under-reporting of female under-five children are also likely to affect female stillborns.

The social recognition and value placed on a stillborn baby by families and health providers in this study contrasts findings from other low-income settings where stillbirths were of lesser or no significance (Kiguli et al., 2015). Burial of a stillborn in a cemetery was a regular practice among our respondents signifying a degree of acknowledgement and respect and indicated that the family and broader community recognised the significance of this death. That parents did not follow prescribed customs for stillborns such as not having a funeral, bathing, or naming their baby, further supports this. These findings suggest that families would be less likely to avoid disclosing a stillborn in Afghanistan during data collection. This differs to findings from eastern Uganda and Ghana where stillborn babies were generally not buried (Kiguli et al., 2015), and Tanzania where they were buried secretly or only if advanced signs of maturity were present (Haws et al., 2010). On the other hand, in Qatar, another Muslim-majority country, all stillborns received funerals and were named (Kilshaw, 2017) .This only highlights the variability that exists across different settings and the importance of understanding context.

Healthcare providers' practices at the facility-level point to more concerning impacts on stillbirth reporting, particularly under-reporting. Intentional hiding, misclassification, and absence of documentation due to fear of consequences from investigation and embarrassment in front of peers was a concern at all facilities. Managers were making efforts to discourage these practices, but admitted it continued to be a challenge. Arnold et al. (2015) also found a culture of fear and blame in Afghan maternity hospitals. For their own survival, healthcare providers would transfer blame to others, including midwives, or mothers, and medical records would frequently go missing. These experiences are not limited to the Afghan context and exist in both low- and high-income country countries (Litorp et al., 2015; Waring, 2005) The ramifications of this for stillbirth in Afghanistan are that facility data on stillbirth reported to the ministry level are not an accurate reflection of the real burden, ultimately affecting resource allocation for their prevention. These findings also have

implications for the future use of routine facility data on stillbirth in LMICs to understand the stillbirth burden.

The institutional repercussions for health providers when a stillbirth occurred promoted behaviours that placed their reputation before the wellbeing of patients including turning away those in a critical condition to avoid a death in the health facility. These practices can contribute to lowering the number of pregnancy losses at health facilities, while increasing those that take place at home. Additionally, delayed disclosure or misreporting of the death to the mother may result in her believing her baby was a newborn death and gives health providers the opportunity to avoid divulging the circumstances around the death, to avoid blame. There are implications to this on the quality of data obtained from household surveys which are based on the mother's recollection of what they were informed about their baby.

Practices driven by socio-cultural and politico-legal reasons such as omission of records on pregnancies for unmarried women can lead to under-reporting of stillbirths and other pregnancy losses. In a country where women face severe consequences for pregnancies outside of marriage, this may occur frequently, and mechanisms to handle such cases and maintain documentation would be important. Some perceptions and behaviours around stillborn babies with congenital anomalies may also contribute to under-reporting at both the health facility and community level due to issues around shame. Ensuring records are maintained on such cases is important for reducing prevalence, while community education and awareness raising would assist with improving disclosure at the community level.

The focus of health facilities on intrapartum stillbirths may drive misclassification of stillbirth timing. In our study, several health providers claimed that most stillbirths in their facility occurred before women arrived at the facility, and records also document mostly antepartum stillbirths. This is unusual given that the majority of stillbirths in LMICs even at health facilities occur in the intrapartum period (Lawn et al., 2016) and verbal autopsy data from the 2010 Afghanistan Mortality Survey suggest around two-thirds of stillbirths occur were intrapartum (Christou et al., 2019). Guidotti et al. (2009) in their examination of perinatal deaths in Kabul maternity hospitals in 2006 also found that the number of antepartum stillbirths were almost double intrapartum deaths, according to maternity records reviewed. Even if delays in care-seeking and referral are considered, these are large discrepancies which need further investigation as interventions to prevent intrapartum and antepartum stillbirth differ; thus, making it challenging to identify priority areas for programmatic action. Changing facility practices would require action at multiple levels including a culture change in hospitals and re-evaluation of how formal investigations and management of responsible health providers by the MoPH are executed to remove barriers to accurate reporting. Improving healthcare provider knowledge of the importance of high-quality data would be important and has had some success in improving data completeness in other low-income settings (Mphatswe et al., 2012). Complementing this with policy-level efforts around reporting and raising the profile of stillbirth prevention would be beneficial. At the facility level, assessment of health facility constraints, health provider training needs, and improvements in documentation and monitoring of records will be required. Archer's theoretical framework of barriers and enablers to medical incident reporting outlines nine contributing factors that affect reporting (Archer et al., 2017). Fear of adverse consequences and ineffective systems of reporting were the leading barriers to reporting; while the main facilitators included organisational factors and improved reporting systems. However, to effectively address under-reporting all nine factors should be considered. This framework can be used to assess stillbirth reporting in Afghan facilities, while taking into consideration underlying socio-cultural drivers of provider's behaviour (Arnold et al., 2018). Evidently, quality improvement efforts and hospital policies such as those which require investigation of intrapartum stillbirth can have a negative impact on provider practices and these need to be considered when implementing data quality improvement strategies.

Key stakeholders stated that greater attention is paid to recording details of maternal and neonatal deaths due to demand from the MoPH. This is predominantly driven by the larger global targets for maternal and neonatal mortality. If the same importance and emphasis was placed on stillbirths at this level, this may facilitate improvements in stillbirth data. Other practices identified as problematic for stillbirth reporting at the facility level were similar to the community level such as avoiding showing the stillborn to the mother. These are driven by socio-cultural perceptions and would need to be addressed through the implementation of guidelines and training on the provision of appropriate bereavement care. Such guidelines do not exist in Afghanistan and are much needed.

Strengths and limitations

A strength of this study is the use of a qualitative approach to obtain in-depth understanding of the complexity of factors that influence stillbirth data quality providing vital evidence to guide future improvements to methods of data collection in the country and in other similar settings. Capturing health provider's perspectives and practices offer important insights which, to our knowledge, has not been explored elsewhere. A limitation of the study is that data collection was limited to Kabul

province - one of Afghanistan's 34 provinces, and the most progressive; therefore, our findings may not reflect the situation and practices in other provinces or regions. Healthcare providers were all based at large, urban tertiary hospitals; thus, results would not represent the views and experiences in rural provinces or lower-tier health facilities. Further, the number of female elders and women who had given birth at home included in our study was small, which limited our ability to adequately capture a wide range of views in these population groups. Fieldwork was also restricted to rural districts with good security, access to health facilities and active CHWs; therefore, our findings may not reflect the situation in unstable, conflict-affected regions which make up the majority of Afghanistan. Finally, we identified factors that could *potentially* affect stillbirth data reporting and, therefore, quality based on identified perceptions and practices. Our study was not designed to definitively establish if these factors do in fact result in under-reporting, and further research to assess this would be required.

Conclusion

This study demonstrates that context is critical when it comes to how perinatal losses are interpreted, perceived, and responded to, at both the community and facility levels. We have described how specific social and cultural perceptions and practices can lead to under-reporting and misclassification of stillbirth and can impact on the reliability of stillbirth data in Afghanistan. We identify key points at which interventions are needed to modify practices and change perceptions to improve the quality of stillbirth reporting. Most data improvement efforts tend to focus on improving systems and processes and enhancing skills of individuals, without considering contextual factors affecting reporting behaviours. The study findings indicate a need for policy-level strategies to address drivers of under-reporting in health facilities and greater emphasis on the importance of stillbirths nationally. Investment in efforts to address these challenges would contribute to improvements beyond only stillbirth data, but to overall data quality for all perinatal outcomes.

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Declaration of interests

The authors declare no competing interests.

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Supplementary Appendix

Table A1. Summary of study participants

| | Participant group | Definition and selection criteria | Numbe |
|-----|--|--|-------|
| CON | 1MUNITY-LEVEL | | |
| 1 | Mothers | Any woman of reproductive age that has experienced a recent ^A stillbirth | |
| 2 | Fathers | Any man/father who recently^ had a stillborn child. They may or may not be the husband of a mother included in the study. | |
| 3 | Female community elders ⁺ | Senior women in the community who have experience attending home births or have a daughter or daughter-in-law that has experienced a recent stillbirth. | |
| 4 | Community Health Workers (CHW) | CHWs are part of the health workforce in Afghanistan delivering health services in rural areas. Based at village health posts, they serve ~150 households. Only female CHWs were included. | 5 |
| HEA | LTH-FACILITY LEVEL | | |
| 5 | Midwives | Any healthcare provider trained to conduct deliveries or handle any | 4 |
| | Doctors (Obstetrician-Gynaecologists) | perinatal losses | 6 |
| 6 | Managers: - Chief of ward (Obstetric or Neonatal) - Health facility managers/directors | Any individual in a management role at health facilities. | 5 |
| GO\ | ERNMENT/MINISTRY LEVEL | | |
| 7 | Government officials/informants in | Individuals involved in reproductive, maternal and child health services | 2 |
| | maternal and child health | program management, data management or policy making | |
| | Total | | 55 |

^ We initially defined 'recent' as a stillbirth that occurred in the 12 months preceding the interview; however, this was not always possible, and interviews were often commenced without knowing when the stillbirth occurred.

* Many female community elders practice as Traditional Birth Attendants in Afghanistan assisting with home births. Traditional Birth Attendants are not recognised by the Ministry of Public Health and discouraged from practicing. Several have been trained to work as Community Health Workers or Community Midwives.

| | | Participar | Participant type | |
|---------------------------|----------------------------------|-----------------|-----------------------|--|
| Characteristic | | Mothers n=21 | Fathers n=9 | |
| Type of perinatal loss | Miscarriage (<5 months) | 1 | 1 | |
| | Early stillbirth (5-6 months)~ | 3 | - | |
| | Late stillbirth (≥7 months)~ | 12 | 6 | |
| | Early neonatal death | 5 | 2 | |
| Time since pregnancy loss | <1 month ago | 3 | - | |
| | 1-6 months ago | 7 | 3 | |
| | 7-12 months ago | 5 | 2 | |
| | >12 months ago | 5 | 2 | |
| | Missing | 1 | 2 | |
| Age (current, years) | 18-25 | 8 | 1 | |
| | 26-34 | 8 | 2 | |
| | 35+ | 4 | 6 | |
| | Missing | 1 | - | |
| | Median age | 29 | 44 | |
| Residence (current) | Urban | 11 | 3 | |
| (, | Rural | 10 | 6 | |
| Ethnicity | Tajik | 13 | 6 | |
| | Pashtun | 5 | 2 | |
| | Other | 2 | 1 | |
| | Missing | 1 | - | |
| Education | None | 17 | 3 | |
| | Primary (7-9 years) | 2 | 3 | |
| | Secondary (10-12 years) | 1 | 2 | |
| | Higher (University) | 1 | 1 | |
| Place of childbirth | Tertiary hospital (urban) | 13 | 5 | |
| | District hospital (rural) | 5 | 2 | |
| | Home | 3 | 1 | |
| | missing | 0 | 1 | |
| Sex of baby | Male | 10 | 5 | |
| | Female | 7 | 3 | |
| | Not known | 2 | 5 | |
| | One set of twins (male & female) | 1 | - | |
| Pabunamod | | | 2* | |
| Baby named | Yes | 10+ | 3* | |
| | No Don't know/missing | 9 2 | 3 3 | |

Table A2. Characteristics of study participants that recently experienced a perinatal loss

^ASome of the men were the husband of a participating woman ^CWe classified stillbirth as early if the baby was born dead and gestational age was reported to be between 5 and less than 7 months, while late stillbirths were those which occurred from 7 months onwards. The outcome was classified as an early newborn death if the respondent reported any signs of life after birth (if the baby moved, cried or breathed after birth).(Lawn et al., 2011; WHO, 2011) ^{*} Four of those that were named were early neonatal deaths ^{*} One of those that was named was an early neonatal death ^{*} (2-Question was not acked)

n/a- Question was not asked

Table A3. Terminology for perinatal losses used in Kabul, Afghanistan

| Perinatal loss | Local terminology | Equivalent English meaning | Description used | Community understanding |
|-------------------------|--|---|---|---|
| Miscarriage | Seqt (Dari/Arabic) Nuqsan (Dari & Pashto) Zayeh (Dari) | 'aborted' or 'abortion' 'lost' 'waste' | 'Immature' fetus 'Incomplete' 'Piece of meat' | 'We call it miscarriage when the pregnancy is between 45 days and 4 months. It means that it is incomplete. Later it is matured, and we call it a 'dead baby' [stillbirth]. - CHW#01 'Before completing nine months, earlier or seven- or eight-months old pregnancies are called "Zaye" and after that if it is dead born then we call it "dead baby" those who already completed the 9 months.' |
| Stillbirth | Tifle morda (Dari) Mar mashom (Pashto) | 'Baby born dead' or 'Dead baby' 'Dead-born' | Baby is 'complete' Reached 'maturity period' Baby that completes nine months | 'They say that the baby is lost ['nuqsan'] or if the baby reached the maturity period in the womb, then they say the baby is born dead.' - Mother#09 'The child who completes nine months and is born dead.' - Mother#15 |
| Early neonatal death | Tifle Zinda Tawalod Shud, baz mord (Dari) Mashom Zhwandi Pida so wrosta mar so (Pashto) | 'Baby born alive then died' | | 'The difference is that the stillbirth doesn't move because it is dead. The child who moves is alive and dies later.' - Female elder#02 'Yes, there is difference. One's baby is born alive or the other's baby is born dead. The one whose baby is born alive holds it in her arms and breastfeeds it for some days and then the baby dies. They should have a funeral prayer for it. |
| | | | | - Mother#1 |

| Prescribed Rituals | Miscarriage 3-4 months | Stillbirth (early) | Stillbirth (late) | Early neonate death |
|--------------------|---------------------------|---------------------------------|---------------------------------|------------------------|
| Bathing | No | No | No (Sometimes) | Yes |
| Burial | No (Sometimes) | Yes | Yes | Yes |
| Funeral ceremony | No | No | No (Sometimes) | Yes |
| Naming | No | No (Sometimes done secretly) | No (Sometimes done secretly) | Yes |

Table A4. Prescribed rituals and practices for pregnancy losses in Kabul, Afghanistan

*Text in brackets indicates departure from prescribed social/religious norms

UNDERSTANDING PATHWAYS LEADING TO STILLBIRTH: INSIGHTS FROM AFGHANISTAN

Paper IV: Pathways leading to stillbirth: the role of care-seeking and care received during pregnancy and childbirth in Afghanistan

Understanding pathways leading to stillbirth: the role of careseeking and care received during pregnancy and childbirth in Afghanistan

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Abstract

Introduction: While pathways to maternal and child deaths have been studied extensively, the underlying pathways leading to stillbirth in low- and middle-income countries are less well understood. Context-specific understanding of stillbirth is needed to prioritise interventions and identify barriers to their effective implementation and uptake. We explored the stillbirth experiences of bereaved parents and healthcare providers in Afghanistan to understand the contribution of contextual, individual, household-level and health system factors to stillbirth.

Methods: We employed a qualitative approach using in-depth interviews with 55 women and men that recently experienced stillbirth, female elders, community health workers, healthcare providers, and government health officials in Kabul province, Afghanistan between October-November 2017. We used thematic analysis to identify underlying contributing factors to stillbirth and develop a conceptual map describing pathways leading to stillbirth.

Results: Low-levels of healthcare utilisation was a critical factor contributing to stillbirth, underscored by women's lack of decision-making power, socio-cultural barriers to access, lack of perceived need for care in pregnancy and childbirth, and low general knowledge of self-care during pregnancy. Perceptions of quality of care and healthcare provider behaviour, and economic and physical access barriers, also affected health service utilisation. Unmanaged maternal conditions heightened women's risk to stillbirth due to resulting severe complications during both pregnancy and childbirth. Socio-cultural factors, including perceptions about caesarean sections, led to the refusal of medical intervention and stillbirth, while neglect and abuse of pregnant women at home increased their risk. Low quality of care was a recurring factor underlying stillbirth, especially the inadequate detection of medical conditions, inappropriate advice during pregnancy, and harmful provider practices. Additional health system factors led to delays in receiving care, including inappropriate referrals and inadequately equipped facilities. The impact of the conflict created barriers to accessing care and exposed pregnant women to substances with harmful effects on the fetus.

Conclusion: There are multiple and complex pathways to stillbirth in Afghanistan. Efforts are needed at the community-level to facilitate care-seeking and raise awareness of risk factors for stillbirth, and at the facility-level to strengthen the quality of antenatal and childbirth care services, ensure the availability of culturally-appropriate and respectful care, and reduce treatment delays. Our study

identifies where efforts can be directed to achieve reductions in stillbirth, but highlights where interventions may be ineffective or require adaptation to facilitate uptake.

Keywords: Stillbirth, fetal death, health services access, health system, care-seeking, Afghanistan, qualitative research

Introduction

Stillbirths were recently described as a 'neglected epidemic of grief', highlighting the inadequate reduction in the burden and lack of recognition of the impact these deaths have on families and caregivers (Horton & Samarasekera, 2016). The slowest declines in stillbirths have been in low- and middle-income countries (LMICs) which account for 98% of the 2.6 million third-trimester stillbirths every year (Lawn et al., 2016). Many stillbirths are preventable with known, low-cost interventions, but there are numerous obstacles to the adequate implementation, accessibility and uptake of these interventions, many of which are context-specific (Bhutta et al., 2011). In LMICs, limited understanding of the risk factors and causes of stillbirth has been a major impediment to prevention efforts, arising from decades of no or inadequate data, and lack of investigation into these deaths (Lawn et al., 2011; Lawn et al., 2016).

Despite the absence of country-specific information of stillbirth risk factors for LMICs (Christou et al., 2017), global analyses based on modelled data have established that over half of stillbirths occur in the intrapartum period - a sign of delayed or inadequate quality of care during childbirth (Goldenberg et al., 2007; Lawn et al., 2016). Maternal conditions in pregnancy including infections, hypertension, and diabetes also contribute to stillbirth, and are preventable through early detection and management with timely and quality antenatal care (ANC) (Bhutta et al., 2014). Stillbirths are also associated with more distal social determinants, including poverty, education, and women's autonomy (Ahmed et al., 2018; Aminu et al., 2014).

Current recommendations for policy and programmatic focus to reduce stillbirths emphasise the need to increase and improve ANC, promote skilled birth attendance, facility births and ensure quality basic and emergency obstetric care (Bhutta et al., 2014). The effectiveness of these interventions hinges on decisions that occur in the home and how families regard pregnancy, respond to complications, and subsequently take initiative to access care in a timely manner. These decisions are largely shaped by socio-cultural norms, beliefs and practices, socio-economic factors, and the perceived need and acceptability of health services (Colvin et al., 2013; Gabrysch & Campbell, 2009a; Thaddeus & Maine, 1994; Treacy & Sagbakken, 2015).

Culture, tradition, and social values also have an important role in pregnancy, childbirth and on careseeking behaviour (Cecil, 1996; Raman et al., 2016). Social and cultural norms also influence the role of women and men in society, their decision-making capacity, and access to household resources. Understanding the underlying social processes that occur at the individual, household, and community level when a stillbirth occurs, can inform the development, prioritisation and targeting of interventions and services.

In Afghanistan, stillbirth rates have remained high receiving little attention nationally. The estimated stillbirth rate in 2015 was 27 per 1000 births - only slightly lower than the neonatal mortality rate of 36 per 1000 live births (Akseer et al., 2016; Blencowe et al., 2016). Despite widespread conflict and instability over the past four decades, considerable progress has been made in reducing neonatal and under-five child mortality in Afghanistan (Akseer et al., 2016). Stillbirths, however, have been overlooked; between 2000 and 2015, the average annual rate of reduction in the stillbirth rate was only 1.9% compared with almost 3% for under-five child mortality (Blencowe et al., 2016; UNICEF, 2015).

Few studies have investigated the underlying reasons behind the high burden of stillbirth in Afghanistan. A 2006 study exploring perinatal outcomes in three tertiary hospitals in Kabul found unusually high rates of fetal death in term babies even after caesarean section, suggesting delayed or low-quality intrapartum care. In this study, women admitted with intrapartum complications had over six times higher risk of stillbirth (Guidotti et al., 2009). Our recent analysis of the 2010 Afghanistan Mortality Survey (AMS) identified key risk factors for stillbirth at the national level (Christou et al.). Women who did not receive ANC, or had pregnancy complications such as antepartum bleeding, infections, headaches, and reduced fetal movement had significantly increased risk of stillbirth. Stillbirth was also associated with region of residence, ethnicity, and giving birth at a health facility. Quality of ANC was also strongly associated with intrapartum stillbirths, suggesting many stillbirths might be prevented through early detection and management of risk factors during pregnancy. Although useful for programmatic focus, these findings do not explain the reasons why women don't access care, or why stillbirth risk is raised when women give birth in a health facility, or why maternal conditions that increase stillbirth risk remain untreated.

Qualitative studies examining stillbirth in low-resource settings are few and generally focused on understanding the experiences and impact that stillbirth have on families and are critically important (Haws et al., 2010; Hsu et al., 2004; Kiguli et al., 2015; Osman et al., 2017; Roberts et al., 2012; Sisay et al., 2014). What is not so well explored are the underlying pathways that lead to these deaths. There are no studies in Afghanistan which have explored the experiences of women, families, or healthcare providers of stillbirth to understand why and how these deaths occur. Social autopsy is a method increasingly being used in LMICs to identify the social, cultural, behavioural, and health system factors contributing to newborn, child and maternal deaths

(Kallander et al., 2011; Kalter et al., 2011; Waiswa et al., 2012). Often used together with verbal autopsy – an indirect method for ascertaining the clinical cause of death through structured interviews with caregivers or relatives about the events and illness symptoms preceding the death (WHO, 2016b) - social autopsy examines factors around care-seeking, health behaviours, cultural norms, and local practices that provide further insight into the contributing factors behind the death. Implementation of social autopsy in several LMIC settings to investigate neonatal deaths has found that although recognition of danger signs is high, there are multiple barriers to taking action to seek care, including transportation, cost, distance to facility, perceived low-quality of care, and fatalistic views (Kalter et al., 2011; Moyer et al., 2017).

Several theoretical models and frameworks exist to explain the determinants of child, perinatal and maternal deaths (McCarthy & Maine, 1992; Mosley & Chen, 1984; Stanton, 1996) and factors affecting access to care and care-seeking behaviour (Aday & Andersen, 1974; Levesque et al., 2013; Peters et al., 2008). The three delays model proposed by Thaddeus & Maine (1994) to explain why maternal deaths occur is also useful for understanding the events leading to stillbirths, as timely care-seeking is critical to stillbirth prevention. The three delays include the first delay at home to make the decision to seek care, the second delay relates to the time taken to reach care, while the third delay is the time taken to receive quality care once at the health facility. This model considers three broad groups of factors that determine utilisation and outcome; socio-economic and cultural factors, accessibility of facilities, and quality of care. Critically, it considers the decision-making process which itself is influenced by the socio-cultural context and individual and community knowledge and perceptions about quality of care. Drawing on elements of this and other models, in this study we aimed to understand from parent's and healthcare providers' experiences, the underlying contextual, individual, household, and health system factors that lead to stillbirth. By understanding these pathways, we can identify where interventions and efforts are needed to prevent stillbirths and how to adapt these for communities in Afghanistan.

Methods

Study design

We conducted a qualitative study using semi-structured, in-depth interviews with mothers and fathers who had recently experienced a stillbirth, female community elders, community health workers, various healthcare providers at maternity hospitals, and government health officials (Table A1).

Study setting

The study took place in October-November 2017 in urban and rural settings of Kabul province in Afghanistan where the capital, Kabul, is situated. This province was selected as the most feasible and secure location in the country at the time. Study sites included three of the largest referral maternity hospitals in the capital, and two lower-level health facilities in two rural districts ~25-30 kilometres west and north of Kabul city. Located in the eastern part of Afghanistan, over half of Kabul province is mountainous or semi-mountainous terrain. In 2016, the total population was 4.3 million, 80% of which were urban residents. The population is comprised of multiple ethnic groups; Pashtuns and Tajiks make up the majority, followed by the Hazara, Uzbeks, Baloch, Turkmen and several other minority groups (Barfield, 2010).

Afghanistan is one of the most conflict-affected nations worldwide and has faced protracted war for four decades (Jalali, 2017). This conflict destroyed much of the country's public health infrastructure, but after the Taliban regime was removed from power in 2002, the Afghan government with international support rebuilt and strengthened the health system and access to health care has improved considerably (Newbrander et al., 2014); the proportion of the population living within one hour walking distance to a health facility rose from 9% in 2002 to 57% in 2014 (SIGAR, 2017). However, there are many challenges that affect the delivery of services and accessibility of facilities especially in areas of high-conflict, and access does not always guarantee quality of care (Frost et al., 2016). Kabul province and the capital continue to experience increasing insecurity and are targeted regularly by insurgents (UNAMA & UNHCR, 2018). Pervasive poverty, low literacy levels, and continuing restrictions on women's mobility and autonomy are persisting challenges to ensuring access to healthcare (CSO, 2018; Samar et al., 2014). Coverage of healthcare in Kabul province is generally far better compared with other provinces due to the availability of specialist and referral facilities in the capital. In 2015, approximately 80% of women in Kabul province gave birth in a health facility compared to 48% nationally, and 66% received at least one ANC visit, compared to 59% nationwide (CSO et al., 2017).

Study participants and recruitment

A total of 55 participants were included in the study and recruited using purposive and snowball sampling, detailed elsewhere (Christou et al., 2019a). Briefly, we identified mothers who gave birth to a stillborn either from hospital medical records and contacted them by telephone if numbers were available, through notification from healthcare providers when a stillbirth occurred, or through our local interviewers' networks. Fathers were recruited through identified mothers. In rural districts, Community Health Workers (CHWs) assisted with identifying participants including female

elders. We made efforts to recruit women that gave birth at home as well as at the health facility as they were likely to have different experiences.

Healthcare providers and other key informants were selected in consultation with the local study investigators and consideration of respondents' role in the delivery or management of maternal, reproductive, neonatal, and child health services at maternity hospitals, and within the Afghanistan Ministry of Public Health (MoPH). To recruit healthcare providers, the study investigators (AC, SMSH, MHR, and AM) approached hospital directors to explain the study, obtain their support, and invite them to participate. These individuals then identified and referred us to relevant health facility staff to arrange interviews.

For recently bereaved women and men we initially used the stillbirth definition as a late pregnancy loss occurring at \geq 28 weeks' gestation (WHO, 2011); however, gestational age and presence of signs of life at birth were frequently not recorded in women's medical records making it difficult to ascertain the timing of the death until after the interviews had commenced. We therefore remained flexible about the inclusion criteria and accepted any participant perceived to have had a stillbirth. Inclusion criteria for study participants is provided in <u>Table A1</u>.

Data collection

We prepared separate semi-structured interview guides for each participant group to explore their experiences, perceptions and practices around stillbirth. Interviews were conducted by three experienced Afghan qualitative interviewers in either Dari or Pashto, the two official Afghan languages. The first author (AC) also conducted interviews in English with selected healthcare providers and key informants. Interviewers participated in three-days training on the background and objectives of the research study and interview procedure, interpretation of the interview instruments, and qualitative data collection. Interview guides were then piloted and refined over two days.

Interviews took place in private locations preferred by participants including offices within health facilities, participant homes, or in other secluded areas of public spaces (i.e. inside mosques and around markets). Prior to commencement of interviews, participants were provided with information on the study and gave verbal or written informed consent. Some women were prohibited by their mothers-in-law from being interviewed alone and so in these cases, they were also present during the interview. For socio-cultural reasons, interviews were conducted by a member of the same gender as the participant. Interviews were audio-recorded when consent was

obtained; however, over half of women's interviews were not audio-recorded due to women's concerns about privacy, or prevention by the mother-in-law. In these cases, interviewers took detailed notes which were expanded after the interview. Interviewers also completed a debrief form to document non-verbal observations during the interview about the participant or the interview environment, any new topics that arose, and challenges faced.

Transcription of audio-recorded interviews was done verbatim then translated to English. Translated transcripts were cross-checked by local interviewers and study investigators for accuracy and to clarify contextual meaning. Daily debriefing meetings were held among the study team to discuss processes and challenges during data collection and reflect on emerging findings. Interviews with mothers, fathers, and healthcare providers continued until we had obtained a range of responses and reached a point in the data collection where no additional themes were emerging (Guest et al., 2006). Recruitment of female elders from rural areas was more time intensive and due to time and resource limitations we were unable to recruit enough respondents.

Data analysis

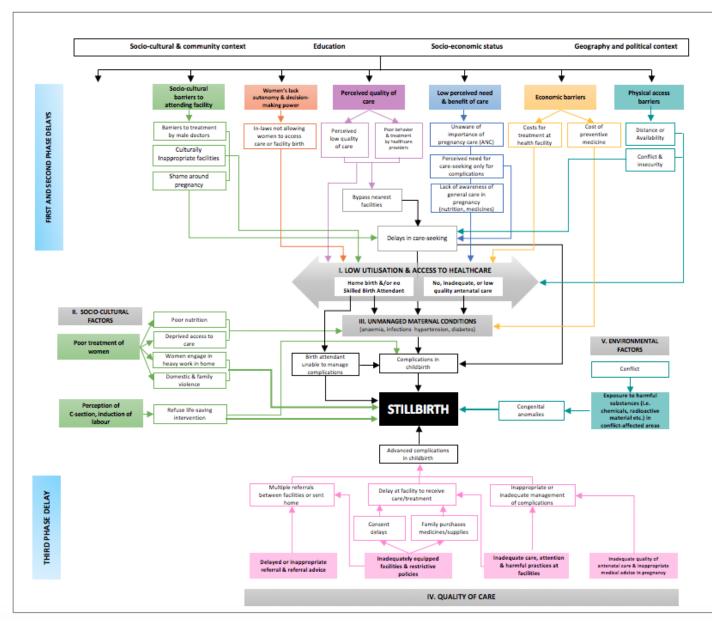
To analyse the data, the first author (AC) first read all transcripts multiple times and prepared an initial code list based on the interview guide topics adding new codes as additional concepts emerged. Two authors (AC and AA) discussed and refined the code list and AC subsequently coded all transcripts line-by-line based on this coding framework. N-vivo 11 software (QSR International, 2017) was used for data management and to facilitate development of the coding scheme. Text was analysed using thematic analysis (Braun & Clarke, 2006). Themes were key concepts identified by categorising issues perceived to have facilitated or contributed to the stillbirth/death. Theme development was guided by existing theoretical frameworks examining determinants of mortality (Mosley & Chen, 1984), access to care (Andersen, 1995), and the three delays model (Gabrysch & Campbell, 2009b; Thaddeus & Maine, 1994). Themes were revised and refined after discussion among team members. Perspectives of various participant groups assisted with triangulating findings and allowed us to obtain a more comprehensive picture of the factors contributing to stillbirth. The overall analysis was used to develop a conceptual map describing pathways leading to stillbirth in the context of Afghanistan.

Results

Participant characteristics

The demographic characteristics of women and men indicate equal representation of urban and rural residents and overall low levels of education (<u>Table A2</u>). Men were much older, with a median age of 47 years compared to 29 years for women. Most perinatal losses were late stillbirths; however, several early neonatal deaths were also included. Half of respondents had experienced a previous pregnancy or perinatal loss. Most had lost their baby at full-term, one-third attended ANC, and almost all gave birth in a health facility.

We identified several underlying themes contributing to stillbirth, either directly or indirectly, which we grouped under five categories representing the main pathways, I) Low access and utilisation of healthcare, II) Socio-cultural factors, III) Quality of care, IV) Unmanaged maternal conditions, and V) Environmental factors. Under each of these pathways, we explored the driving factors and processes that led to these, and also highlight where the phases of three delays (Thaddeus & Maine, 1994) contribute to stillbirth. We summarise these pathways into a conceptual map (Figure 1).



LEGEND/GUIDE

- Grey shaded boxes. (I-V) indicate pathways to stillbirth (direct pathways indicated in bold arrows, otherwise indirect)
- Coloured boxes are the key factors (sub-themes) that underpin the pathways
- Unshaded boxes indicate processes to explain pathways

Figure 1. Conceptual pathways map illustrating pathways leading to stillbirth in Afghanistan based on interviews in this study

Low utilisation and access to healthcare during pregnancy & childbirth

The low levels of utilisation and access to healthcare were contributing factors increasing women's risk to stillbirth. Driving factors underlying low access and utilisation were summarised under six key themes – i) women's lack of autonomy and decision-making power, ii) socio-cultural barriers to attending health facilities, iii) low perceived need & benefit of pregnancy care, iv) economic barriers to access, v) physical access barriers, and vi) perceived quality of care at facilities.

Women's lack of autonomy and decision-making power

Women's lack of autonomy and decision-making power around care-seeking during pregnancy for routine ANC, and when experiencing problems or choosing where to give birth, created major barriers for women to access care and was a contributing factor to stillbirth. This was compounded by restrictions on women, particularly in rural areas, to freely travel alone. These factors all contributed to the first delay. In Afghan households, the mother-in-law is usually the key decision-maker in the family, followed by her son, and both impeded access to health services. One mother explains,

'When I became very sick during the delivery, my mother told my mother-in-law, "As it is her first baby, we must take her to the hospital." But my mother-in-law told her, "I hadn't gone to the hospital in my time, but still I had healthy children; therefore, I won't let her visit the hospital."

-Mother#13

A CHW described how many women were prohibited by their families to give birth in a health facility, and so she and another health worker would assist these women to deliver their baby at home, '...*if there are some women whose in-laws don't allow them* (to attend a health facility), *then I and* [-name of CHW omitted-] *visit there and help them...She is also a health worker like me. Then she visits there and helps them till they deliver the baby.'* [CHW#01].

Husbands also had a central role in decision-making to seek care, and several women stated that the reason they did not access care or delayed when they faced complications was because their husbands prohibited them. A female elder who assisted her daughter-in-law during childbirth explained; '*Our males don't allow women to deliver the baby in the hospital, so I helped her in the delivery…'* [Female elder#03]. A mother of a stillborn had complained of severe headaches during her pregnancy and said she had informed her husband about her problem, but when asked why she did not seek care she stated, '*I was so worried, but if someone* (referring to her husband) *doesn't accept what I say, then what can I do?'* [Mother#17]. Another described how she had severe

bleeding but did not go to the hospital for over five days, '...I think I have done heavy work and I might have lifted a heavy sack which caused it's death. I had severe pain and bleeding...It was 5 – 6 days before I was taken to the hospital and I couldn't stand.' When asked why she did not seek care earlier, she responded, 'My husband didn't allow me. All my children are small, but I have only one young daughter and she is sick.' [Mother#07] - implying that she did not have anyone else in the home or a daughter old enough to take care of the housework. This was a recurring issue raised by several women who were not able to leave the home or delayed seeking care due to household responsibilities.

Other circumstances where women reported not having a say in decision-making was when medical interventions were required. One young mother who had a previous miscarriage followed by a term stillbirth described how in the seventh month of her third pregnancy she again experienced severe symptoms, '…I faced high blood pressure problem and my hands and feet were swollen. So, I told my father-in-law about this problem. I was serious and I couldn't be taken to the doctor. Later, it became so serious and then I told my mother-in-law about it...So, I was taken from Shamali (area north-east of Kabul) to Kabul in a Suzuki carry wagon. The doctors said I needed to have artificial pain (induction) and have the delivery, because there was no other way...They said that I might die or the baby might, but my mother-in-law told the doctor not to give me artificial pain, and we would see what happens and suggested to only prescribe me medicines...' [Mother#16]. When she returned home and went into labour in her ninth month, she started bleeding heavily, and the baby was stillborn.

Socio-cultural barriers to attending health facilities

Receiving treatment from a male doctor was a factor that deterred women from attending health facilities, particularly in rural areas where there were fewer female healthcare providers. One mother when probed about why her mother-in-law did not want her to see a health provider it became clear that it was related to the fear of having her be seen by a male doctor, *'…She is sad for my baby, but she says it is not good that a male doctor checks me up. My mother-in-law doesn't accept it.'* [Mother#13]. Additional barriers were related to the appropriateness of the facilities in rural areas, which contributed to the first, and sometimes, second delay as families would bypass lower-level facilities to attend tertiary hospitals in Kabul which had many female providers. One respondent explained,

'...some of our health facilities are culturally not acceptable because the delivery room is exposed, the venue is behind the yard, and the premises of health facilities have many

other clients, and men are coming to receive services and that's why mothers don't like to come.'

-MoPH official

Healthcare providers also stated that a key reason women were not accessing ANC was because of shame associated with getting pregnant and its association with sexual activity. This was especially problematic among younger women who were pregnant for the first time. One health provider explained, *'…they say, my husband and my family didn't let me go to the hospital because they* (the young women) *know there is shame to want go to the hospital. I don't know why this is such a big problem. The health education is so important.'* [Obs/Gynae resident doctor_Facility#01]. This added to the first delay as women would avoid disclosing the pregnancy and any problems to her family.

Low perceived need and benefit of care during pregnancy

Many of the reasons for not accessing care were underscored by perceptions that it unnecessary due to previous uneventful pregnancies or that non-attendance was the norm. Many women gave birth at home at the insistence of their husband or mother-in-law who believed it was unnecessary to attend a health facility, *'I always helped my daughters-in-law deliver the baby. You can see that all my grandchildren are healthy... It isn't necessary to take my daughter-in-law to the hospital for the delivery.'* [Female elder#03]. Fathers tended to agree with and trusted their mothers' decision, as this bereaved father asserted, *'Yes, she* (his mother) *is more expert; she said that, there is no need to go to hospital.'* [Father#04].

Over half the women interviewed had not received ANC during their pregnancy, many of whom thought there was no need because their previous births had been without problems. One mother explained, 'I was nine months pregnant when suddenly my blood pressure went high and I had bleeding. I visited a clinic nearby our house, but we were told in the clinic that they couldn't do anything, so I should visit the hospital quickly... Then I visit the hospital and the doctor did an ultrasound test. She said that my baby is lost.' [Mother#12]. When asked why she didn't have any ANC she replied, 'I always had normal blood pressure and I have delivered other children too, but I haven't had the blood pressure issue (that time)'.

Not acting on or delaying care-seeking for problems in pregnancy or childbirth was also common and led to further delays in receiving care and ultimately stillbirth. Sometimes, women themselves would delay, as one father recounts, *'…a week before he was born, my wife complained of pain…I told her let's go to the clinic…she has gone to this clinic and the doctor has given her the pills for anaemia, but on the second night she also complained of pain, I told her, let's go to the clinic, but she told me it*

will be ok, there is no need to go to the clinic. On the third night she felt pain again and I brought her to the clinic, but they referred us to Kabul city...After 20 minutes my mother came to me and told me that the son born, but he is stillbirth. Three days before the delivery he was alive in his mother's womb...' [Father#06].

Women in this study generally had little awareness of the importance of ANC, but also of general pregnancy care and expressed a desire for information. One mother who previously had a miscarriage, when asked if she was advised by anyone to seek care, she replied, *'No, no-one has told me...I have requested my mother-in-law so many times that I have lost two babies since I was married but you haven't told me what to do, because you are also like my mother to me. You haven't told me what was right and wrong...' [Mother#17]. A CHW also reiterated how women were not aware of their own care practices during pregnancy and continued to engage in heavy physical work, stating that, <i>'...they* (pregnant women) *don't know how to protect themselves. They bring pails full of water from the hand pump to their homes, they are cooking breads in the oven, and they are pulling the pails full of the grass and dung to the roof, which weigh about 21 or 28 kilograms.' She added that lack of knowledge about birth spacing was an issue contributing to anaemia and placing women at risk of adverse outcomes, but that it was also a challenge to educate women, <i>'Some of them have 8 or 9 children because there was no birth space and physically they are weak...Some of the people know the benefit of birth space, but most of the people don't know and never accept...' [CHW#03]*

Healthcare providers raised similar concerns about women's lack of knowledge of pregnancy nutrition. A ward chief in a maternity hospital who also had a private ANC clinic said, 'Our people are poor, our people don't have information about some things because they are illiterate, uneducated...They didn't have information about their feeding! [what they should eat]. That vegetable is very important, that nutrition is very important...They don't know about this.' [Neonatal ward chief_facility#01]. Inadequate intake of folic acid supplements among pregnant women was also raised as a factor, as one doctor explained, '...the main reason for stillbirth is the neural tube defect, and it can be prevented by folic acid. The gynaecologist should advise folic acid to pregnant mothers, or there should be a huge campaign for using the folic acid for mothers who want to get pregnant or are already pregnant...' [Neonatal ward chief_facility#02]. Another concern mentioned by several providers was that many women continued to take medications while pregnant that led to miscarriage and stillbirth, unaware of the harmful effects they had on the fetus, such as analgesics and medication for seizures or epilepsy which were easily accessible without a prescription.

There was an overarching belief by families that consulting a medical provider was only needed for a problem rather than as a preventive strategy, contributing to the first delay. It was common practice to give birth at home and access care only when complications arose. A father whose aunt had delivered several of his children at home stated, *'…she has good experience and all deliveries were done well, there were no problem. If there was any problem we went to the hospital.'* [Father#05]. This meant women were arriving at health facilities too late with complications. Health providers mentioned bleeding, prolonged or obstructed labour, placental abruption and placenta previa as common complications they dealt with because of this delay. One mother who was six months pregnant with her sixth baby described her birth, *'… it wasn't properly* [normally] *delivered, because I had a problem with bleeding. I had bleeding for (a) longer time and it* [the baby] *was stuck too. So, then it was taken (out) in parts…'* [Mother#14]. Doctors at tertiary referral hospitals also reported that most admitted maternity patients were high-risk,

'There are other problems also; sometimes the patient comes from other hospital – provincial hospital and private clinics in (a) bad situation. They come here and labour a stillbirth. We know that the main problem may be obstructed labour... infection, maybe PROMS...The patients come with complication! About 80% of our patients come with complications.'

- Hospital deputy director_facility#01

Economic barriers to access

Poor socio-economic status was a reason for not receiving ANC during pregnancy or giving birth at a health facility. Many parents were aware of the need and importance of seeing a doctor during pregnancy but did so only when they could afford it, '*I was taken to the doctor if I had severe pain or problem. It depended upon the money.*' [Mother#14]. Another father who lost his twins, one as a stillborn and one in the early neonatal period, acknowledged that he could not afford to take his wife to the doctor, '...the economic situation was very bad and I couldn't bring my wife to the doctor for the antenatal care.' [Father#09].

Socio-economic status also affected women's ability to pay for medication or treatments needed for conditions that would reduce the risk of stillbirth – contributing to the second delay. One respondent who suffered complications from high blood pressure and had two stillbirths expressed how she could not afford to buy medication for her condition, *'I don't have good economic condition that I can buy the medicines on my own every time'* [Mother#16]. Another woman who also lost her baby described how she could not afford preventive treatment for her condition,

'...I had a big problem. I was so weak [anaemic] and my uterus was two degrees down.... I have spent lots of money, but it hasn't been cured...I was told that I need to be surgically operated, but I don't have anyone at home to take care of children...Besides, we don't have good economic condition to have the medical treatment...'

- Mother#14

The cost of care once at the facility also discouraged families from deciding to seek care, contributing to the first delay. Families described how, despite being public facilities, they had to purchase everything from gloves to birthing kits, and staff would also demand bribes, *'…there is no good care or service for the patients in [-name of maternity hospital omitted-] Hospital. The entire world refuses to visit* [name of maternity] *hospital...There is only the package* (newborn kit) *to buy and then this package is divided for two babies... We bought gloves not only once, but 4, 5, 6 and 8 times and they ask for money...The nurses and the midwives receive such money. They take up to 100 – 300 Afghanis* [~3-4 USD]. They ask for it when a baby boy is born...' [Mother#14].

Physical access barriers

Access to facilities in terms of distance, physical availability, and security compromised women's ability to receive timely care and contributed to stillbirth through the first and second delays. The availability of health services in rural areas was also a challenge. Several women spoke of not having available services nearby. One mother who lived in rural district travelled to a public maternity hospital in Kabul to give birth as there was no public facility near where she lived, only a private hospital she couldn't afford, '*It would be very good If a public hospital was established near us.* [-name omitted-] *hospital is so far, until you reach there, the mother will deliver baby in the vehicle. There is too much traffic on the way...*' [Mother#01]. Another mother recounted how she started having pain and bleeding at night before her delivery but waited until morning because her nearest facility was too far. By the time she arrived at the facility the next day, she had lost her baby,

'...I had severe pain and a little bleeding at night. When the bleeding started, I told my mother-in-law and she called the local midwife, but the midwife didn't know what to do. She told me to visit the hospital. It was late at night and our house was far away from the hospital; therefore, I visited the next morning. I suffered the pain till the morning and then I visited the hospital. When I was checked-up I was told that the baby is lost, and I needed to do the surgical operation...'

-Mother#11

Insecurity from the ongoing conflict in Afghanistan also compromised the ability of families to access health facilities and led to the second delay. One mother described fleeing her village because of the

fighting and was not able to reach a facility in time. Her mother-in-law tried to deliver the baby, but due to difficult labour, the baby was stillborn,

'I had a nine-month pregnancy but there was battle in our village and I was in Kunduz. We left the house and escaped and came toward Kabul...We had travelled some distance then I got sick, my mother-in-law said that she needed to find a hospital. We got off the car in a village where there my father-in-law's friend was living but we couldn't reach to the clinic. I had lots of bleeding. Then my father-in-law took me to one of our relatives' house and I delivered the baby there, but it was dead... My mother-in-law and another woman helped me in the delivery. It was so difficult to deliver the baby, because the baby was not coming out, so it was forcibly pulled out and the baby died.'

-Mother#21

Perceived quality of care at health facilities

A recurring reason for not seeking care at health facilities was the perceived poor quality of care and previous negative experiences of behaviour and attitude of healthcare providers – a factor that contributed to both first and second delays,

'When you visit the clinic, they don't care about you even if you are so critical, but they only prescribe you a tablet or two and then discharge you....therefore; I don't visit the clinics... because the doctors are mostly angry and they don't have good behaviour. They even don't listen to what the patient says.'

-Mother#14.

Several women also described how they were spoken to harshly after their baby had died, and others recounted seeing women physically abused by staff. One mother, after a bad experience following her stillborn, stated, 'Yes, I won't visit this hospital (again) whenever I become pregnant.' [Mother_#00]. There was also a sense of mistrust of healthcare providers as this elder's comment illustrates, 'The hospital doesn't care about the mother. It doesn't give the baby to its mother after the delivery and steals it...' [Female elder#03]. Due to these perceptions, women would bypass their nearest facility to attend a hospital they thought provided better care, adding to the second delay, as one mother states, '...because [-hospital name omitted-] hospital is one of the best hospitals and my economic condition didn't allow me to visit a private maternity hospital. I visited this governmental hospital, because it provides proper treatment to the patients; otherwise, I could visit the hospital in Lycee-Maryam (another hospital in Kabul) which was closer to me.' [Mother#20].

Socio-cultural factors

Several underlying socio-cultural factors potentially had direct pathways leading to stillbirth, including the neglect and poor treatment of women and their health at home, and perceptions around surgery.

Poor treatment of women

Several women reported that they were mistreated and neglected by their in-laws, and occasionally husbands; they were not provided with adequate food and were denied access to healthcare during pregnancy,

'Because they (her in-laws) don't like to visit the doctor and they don't like to provide the pregnant woman with good food. My mother's house was better, because I was visiting the doctor there and I was so attentive...I have completed the vaccines for tetanus there, but I am not good with the doctor here.'

- Mother#09

Domestic and family violence against women was highlighted as contributing to stillbirth as this female elder implies,

'A dead baby was born in one of our neighbourhood. But when they asked about the reason, they said don't ask about it again. Everyone asked him about the reason. They say he might have hit his wife, but his wife said that she was milking the cow and the cow hit her.'

-Female elder#01

Perceptions and fear of surgical interventions

Prevailing social and cultural perceptions or fear about surgery and caesarean section was another impediment to preventing stillbirth. These perceptions contributed to second and third delays; they prevented women from going to the facility to begin with, but also once at the facility when the intervention was recommended, families would refuse, and stillbirth would occur. Health providers relayed that if caesarean section was recommended in one facility, families would leave and try another health facility, hoping for a different outcome. In Afghan health facilities, a family member, usually the mother-in-law, must give consent for surgery unless the mother's life is in danger. Health providers reported that many families refused to allow caesarean sections even if it was life-saving for the baby. Reasons for refusal were the longer recovery time that would delay women's return to household duties or that the surgery would cause infertility. One healthcare provider described how a recent patient's in-laws refused to give permission for a caesarean section, which consequently

resulted in a stillbirth. The mother was in labour for over 12 hours while the doctors tried to obtain permission from the family. The doctor explained how this was a common problem faced in Afghanistan, '*They* (the family) *are thinking that if we do C-section... the mother will be disabled,* (*that*) *she cannot do anything, she will not bear any (more) babies...they have mentally (an) idea...they're not giving the permission to do C-section...We are waiting because but they are not allowing us to do procedure...'* [Emergency ward chief_Facility#02].

Sometimes, mothers themselves refused to go to the hospital due to fear of surgery. One mother described what happened to her sister-in-law when she lost a three-day old newborn, 'We did not know (that) on the head of her baby, there was a large thing...Her baby was delivered in the home. We insisted she go to hospital; she did not go and replied, "I do not want go to the hospital because they will do operation!" Due to the fear of operation, she did not go to the hospital...she said, "I do not go. I (will) deliver at home; if anything happens, let (it) happen in the home." ' [Mother#01].

Unmanaged maternal conditions

Many women had underlying medical conditions that led to complications in pregnancy and childbirth that inevitably resulted in stillbirth. These conditions remained undetected due to lack of or inadequate ANC where providers had not detected or managed the illness. Others were unaware of existing medical conditions until the time of birth. Health providers stated that many women were attending facilities at delivery with advanced conditions especially anaemia, hypertension, and diabetes. For many, this was the first time they had been in contact with a health provider during their pregnancy. One mother who only saw a doctor once during her pregnancy explained that after she delivered her stillborn baby, 'I was prescribed the medicines and told that I had anaemia and the baby was weak too.' [Mother#14]. A doctor also reiterated there was high prevalence of anaemia which she believed was contributing to stillbirths, 'Our mothers don't pay attention to their food and their anaemia. When we examine them for haemoglobin, there are mothers with 3, 4 grams of haemoglobin... If this mother was under ANC of the doctor and consumed the required amount of food containing vitamin, folic acids and iron, she won't face any problems.' [Obs/Gynae trainer facility#01]. Another provider recalled a recent stillbirth to a 36-year-old woman. It was her sixth pregnancy and she had developed gestational diabetes but was unaware and developed complications childbirth, and had a stillbirth,

'We have recently a stillbirth in our hospital and this is so bad case, we can prevent it if the mother had ANC... The mother had gestational diabetes... She doesn't know about this because she lives in the village and this is the first time she has come to hospital... She was having labour pain, but in labour the water was gushing (out) from her ... mothers that

have diabetes have a polyhydramnios; it means... the amniotic fluid is increased than the normal patient...The amniotic membrane was ruptured so the cord was prolapsed around the neck of the baby. So, in this case the baby died because of this issue...' -Obs/Gynae resident doctor facility#01

Health providers also raised concerns about unmanaged infections as an underlying condition contributing to stillbirth. A neonatal ward chief stated this was particularly common among women coming from rural areas, *'…TORCH infections – toxoplasmosis, rubella, CMV, malaria, tuberculosis yeah? And in the provinces, some of the people have problems and it's not prevented, it's end of stage…'* [Neonatal ward chief_facility#01]. A father recalled his wife's description of the delivery of their stillborn which indicated a serious infection, *'…she said it was 40 days over from its exact time of delivery, the blood and pus came out from my womb smelled very bad, and its colour was black…'* [Father#09].

Quality of care

Several aspects around the quality of care provided at health facilities and by private providers were placing women at risk of adverse outcomes, primarily through the third delay. This included both provider practices and underlying health system constraints which impacted provider practices. Broadly, we grouped these factors under i) inadequate care or inappropriate medical advice during pregnancy, ii) inadequate care, attention, and harmful practices during childbirth iii) delayed or inappropriate referral, and iv) Inadequately equipped health facilities and restrictive hospital policies.

Inadequate antenatal care or inappropriate medical advice during pregnancy

We found from parent's accounts of their pregnancies and the events leading up to the birth that poor advice and care provided during pregnancy was a contributing factor to stillbirths. Several respondents explained how they visited multiple providers and received conflicting information. One father described how his wife had several check-ups during her pregnancy because of a previous miscarriage; nevertheless, their baby was stillborn,

'...my wife got pregnant, we attended ANC and visited the doctor once a month to this clinic. We had several times the ultrasound check - more than 20 times, because we are afraid from the miscarriage. The baby was normal in all the examination and checks. When she completed her ninth month, the doctors said she still had some time for the delivery; one of them said she has one week, and another said only two days left for the delivery. Finally, it reached the tenth month and she didn't deliver the baby, one day we had three ultrasound checks...With different doctors. The time of the delivery was over,

but the doctor didn't want to take her birth, and said still you have time. But the baby had died in the womb of her mother when the doctor checked, he said, "Oh! The baby is not moving, it seems that she already died."

-Father#09

Healthcare providers and parents reported that in Kabul, numerous private clinics offer ultrasoundonly examinations where parents check the health and sex of the baby instead of seeking proper ANC. Respondents stated that many of these clinics were unregulated and providers have a poor reputation and not adequately qualified or trained to use the equipment,

'I just want to mention about the carelessness of the doctors; there is no supervision to check the work of the doctor, our community is involved in corruption... Here this female doctor for the last four years has been doing ultrasound examinations; she has earned lots of money and made a very good life for herself, she received 250 or 300 Afghanis (~3-4 USD) from each...ultrasound examination. She couldn't identify the critical cases, only checking the gender of the baby.'

- Father#06

As a result of these experiences, families lose trust in healthcare providers and it was a regular practice to seek advice from multiple sources, as another father explains, *…because sometimes the machine of the ultrasound may not work well, or sometimes the doctor is not able to point out the problem. That is why it is better to do the ultrasound with other doctors as well.'* [Father#09]. Such poor quality of care and advice results in problems remaining undetected and contributes to the second and third delays as parents go from one provider to another.

The perception from government healthcare providers was that ANC provided in the public health system was also of poor quality and this was a main reason women did not seek ANC. Those who did receive ANC would visit private providers if they could afford it, as one manager explained,

'The public (system) has (a) clinic, but it's not good ANC...the quality is not good...they have clinics, but they didn't have midwives, they didn't have good doctors to consult with the patients, to give information for the patient.'

-Neonatal ward chief_facility#01

However, families also reported poor experiences at private clinics where providers also missed detecting problems,

'I have visited a private clinic. Three doctors came and examined me. They said that it was a baby girl and was healthy but when I returned home, I told my mother-in-law that it wasn't alive because I didn't feel any of its movements... I have done some chores, washed the clothes and cleaned the house, but I have got the pain, so I visited the 20-bed clinic [public facility nearby] at eight o'clock at night and had the examination. I was told that the baby is seven months and that the intestine of the baby has come out and to take me to the Lycee-Maryam hospital (specialist hospital in Kabul) because the baby's face and the entire skin was damaged, but I had the delivery in this 20-bed hospital...It means, it was left in my womb for 10 - 12 days. This private clinic told me that it was a baby girl, but it was a baby boy...Yes, I felt before the delivery, because my sister-in-law asked me to help her. So, I felt that my baby has been died, because it didn't move...'

- Mother#08

Inadequate care, attention and harmful practices at facilities during childbirth

Even when women made every effort to seek care when they had a problem or to give birth, they faced delays and poor quality of care at facilities. One mother who was expecting twins was experiencing severe pain and so visited the hospital for a check-up said, 'The doctors poorly checked me up and said it is not my delivery month and they couldn't do anything for me. They added that I don't have any pain, so we couldn't do anything, but I had pain in the womb...I told them I currently have pain in the womb. I had severe pain and I couldn't eat... but no one listened to me, so I returned home...I have visited [-name of tertiary maternity-] Hospital twice, but no one cared about me there.' [Mother#05]. She subsequently lost both her babies; one was stillborn and the second died soon after birth. Similar scenarios were reported by others where patients were ignored or refused admission to hospital. One father believed that this was the reason for his stillborn, 'When we have come the first time, the doctor hasn't paid attention to her (his wife) and refused to admit her...It was the exact time for the delivery. When Dr. R*** (personal doctor) referred her to the hospital, the doctors refused to admit her. On the second day, she felt so much pain and she told me that she was looking for the doctors in such condition too and she was telling them that she was in severe pain, but they didn't give her time. My wife is still crying for her child and she is very disappointed...' [Father#02].

A CHW also reiterated how the quality of care provided at facilities was inadequate, and contributing to poor outcomes as women with complications were not followed up or appropriately referred, 'The doctors are careless about the life of the people, no one asks the condition of the pregnant mothers, they are not following up the cases of their patients, for example, if your baby is too weak or its heart is too weak, they don't refer you to do the examination or check your baby to know the update status of your baby in your womb, and they never refer you to the Kabul city for better treatment to protect the life of your baby.' [CHW#03].

There were several instances where facility managers recounted inappropriate and harmful practices by healthcare providers due to lack of knowledge or experience, which directly resulted in stillbirths. A chief of emergency at one facility admitted that resident doctors did not have adequate skills or experience in detecting problems, *…Sometimes they are hearing the fetal heart sound but not recognizing if its good or it's bad or what is happening to this baby, so sometimes it is the fault of the student doctors.*' [Emergency ward chief_facility#02].

A concern raised at two major facilities was the inappropriate use of misoprostol by midwives where high doses resulted in a stillbirth. One doctor explained how families with connections with doctors inside the health facility request to be induced this way and this resulted in stillbirth,

'Most of the midwives do so, for example: the midwife comes to the mother, while the mother had pain, (and) she put the "Mizo" tablet without checking the dose and contractions of the mother...when a mother has given lots of contractions the baby hasn't received enough oxygen and the carbon dioxide increase and it causes the baby die in the womb of the mother. Most of the patients who have relation with doctors in the hospital faced with this problem and they lose their babies.'

-Obs/Gynae doctor_facility#02

Delayed or inappropriate referral and referral advice

Families described having to change health facilities multiple times due to referrals, or because facilities would refuse admission. On some occasions, families were referred back and forth between the same facilities. Health providers also added that the delays resulting at various stages, particularly referral between different types and levels of facilities, would place women at risk of having a stillbirth,

'For instance, you have a patient, first you refer to the [-name omitted-] Hospital, they reject them; then they go to some other private hospital, they also reject. The public hospitals are the last chance or choice of the people. However, there are some patients that come to the hospital and they were rejected by the [-name of public hospital omitted-] Hospital... so there are five to six delays that happen to the mother which cause the stillborn...'

Obs/Gynae doctor_facility#2

Another concern was with private facilities, who would only refer women to the larger government referral hospitals at the last possible stage when they were not able to deliver the baby so that they could receive payment, as one doctor explained,

'...the private hospitals try their best to give birth to the mother and solve the problems and receive money. While the patient becomes complicated, then they refer it to the public hospitals, so it was too late while they arrive to the public hospital and it is very difficult to help them.'

-Obs/Gynae doctor_facility#02

Inadequately equipped health facilities and restrictive hospital policies

The lack of availability of medicines needed to manage complications was a challenge and another pathway through which stillbirth occurred as women could not receive the care they needed at their nearest facility. This would lead to the second delay as women would to travel to higher-level facilities, and third delay to receive treatment once at the health facility. One doctor reflecting on the stillbirth cases she observed, explained that if lower-level facilities were stocked with essential life-saving medicines these could be prevented,

'...like, the mother has diabetes or the mother has eclampsia or preeclampsia; if the drug is available in the village, especially magnesium sulphate, if it is more available in the village the mother might not have stillbirth, but the mother have PPH (post-partum haemorrhage) the Ergometrin is so important ampule to save life, but she didn't have this.' -Obs/Gynae resident doctor_facility#01

Delays within the facility to initiate treatment also led to stillbirth. Several maternity hospitals in Kabul do not permit men inside, and so husbands and male relatives wait outside or leave and return later. However, hospital policy requires consent for surgery from the husband or a family member, and if they are not present this would create delays with not only commencing surgery, but also when medicines or other supplies were needed as family members had to purchase them from elsewhere - contributing to the third delay. One doctor described a recent stillbirth case where the mother had arrived in normal condition, but several delays occurred as they tried to locate her husband to obtain permission for the surgery and to purchase anaesthetics,

'We had a fresh stillbirth who (on arrival at the hospital) had a heartbeat. Then we have many delays...We had a normal patient, we admitted her. I saw that the child's heart had contraction and was getting risky. The patient was taken to the operation table. Her male company (carer) wasn't at the hospital and came here after two and a half hours delay. He agreed with the operation. Usually, the time between our decision and incision is half an hour. The patient's company came and brought anaesthetics after 45 minutes delay. Because we don't have anaesthetics inside the hospital, the people have to provide it from outside the hospital...Two and half hours delay for the anaesthetics caused stillbirth of the child...If the patients' company were here, the child would probably not die.'

-Obs/Gynae trainer_facility#01

Environmental factors

Exposure to armed conflict

Another consequence of the ongoing war in Afghanistan is that it exposed pregnant women to harmful substances from the armed conflict including chemicals, smoke, and possibly radioactive material from weapons of war. This was a direct pathway leading to stillbirth due to resulting fetal congenital anomalies. Healthcare providers believed this was frequently an underlying cause of stillbirths among women they saw who resided in areas of high-intensity conflict,

'You know the material that they make a bomb? It affects the baby in the womb of mothers, it makes stillbirth, miscarriage and others. In Afghanistan, most pregnant woman live in the village... When the mother comes here for ANC, we diagnose the baby with an anatomical defect. When we ask about where you live...'

-Obs/Gynae resident doctor_facility#01

Discussion

This analysis of parents, community, and healthcare providers stillbirth experiences in Afghanistan identified a range of complex and overlapping pathways that led to stillbirth, adding to our understanding of why and how stillbirths occur in this setting. Our study finds that the low-levels of healthcare utilisation was a critical factor contributing to stillbirth, underscored by women's lack of decision-making power, socio-cultural barriers, lack of perceived need for care and importance of care-seeking, and a general lack of knowledge on self-care during pregnancy. Perceived quality of care at facilities and economic and physical barriers, also precluded access to care. The high prevalence of unmanaged maternal conditions increased the severity of pregnancy complications and was also an important pathway to stillbirth among women in our study. Socio-cultural factors closely linked to women's status including the neglect and abuse of pregnant women and perceptions about caesarean sections which led to refusal of interventions were direct pathways to stillbirth. Quality of care at facilities was a recurring issue contributing to stillbirth, especially the inadequate detection of problems and inappropriate advice during pregnancy, and delays receiving treatment at the facility. Additional health system factors including inadequate or inappropriate referral, insufficiently equipped facilities, and harmful provider practices all led to delays in receiving care. The armed conflict was also a contributing factor to stillbirths through its impact on access to care and direct harmful effects to the fetus.

The barriers women faced to participate in decision-making around their pregnancies and health led to stillbirth both directly and indirectly. It affected their ability to access care during pregnancy and childbirth and was particularly problematic when women were experiencing complications. Women were dependent on in-laws and husbands to access food, money for medication, and healthcare. Previous studies in Afghanistan also identified barriers to care-seeking, where women's powerlessness made them extremely vulnerable during pregnancy (Newbrander et al., 2013). The mother-in-law is usually the primary decision-maker in Afghan households, and her decisions were placing women at risk of stillbirth. These decisions were based on their own previous experiences of birth, traditional values, and are also underscored by low levels of education. A task of CHWs in Afghanistan is to encourage families to allow women to seek care and give birth in a health facility (Najafizada et al., 2014). Understanding how, and to what extent, CHWs can influence the decisions made by mothers-in-law especially, and if they could be further supported or skilled-up to do so, or whether other interventions through influential individuals might be more effective, may be worth investigating.

Lack of knowledge and awareness of the importance of seeking care during pregnancy was behind the low utilisation of formal healthcare observed in our study. Rahmani et al.(2013), in their Afghan study, also found that ANC was underutilised even when available, frequently because women and their families believed it was not needed. Promoting care-seeking from health facilities has been a major challenge in Afghanistan; in 2015, 40% of Afghan women did not receive any ANC for their most recent live birth and only 48% of births took place in a health facility (CSO et al., 2017). Our study illustrates the consequences this has on stillbirth, particularly when there are complications. To facilitate care-seeking from facilities will require a major shift in communities' awareness and understanding of the benefits and role ANC can have in stillbirth prevention. At the same time, this will also require substantial improvements in the appropriateness and quality of facility care as this was a key reason that women at risk were not identified and deterred families from seeking care from health facilities.

Cultural barriers to care-seeking resulting from a lack of female healthcare providers and the inappropriate design of rural facilities was also a finding raised by Newbrander et al. (2013) in their study investigating barriers to care-seeking in Afghanistan. The Afghan government has increased female health providers in rural facilities and deployed more community midwives, but severe shortages continue to persist, especially in rural areas. Upgrades to the infrastructure of facilities is also an area that will require further investment to encourage and increase health service utilisation and reduce delays in reaching care.

Previous experience with poor behaviour of healthcare providers was a major deterrent influencing the decision about place of birth in our study. Similar concerns about the treatment of patients have been observed in previous studies in Afghanistan (Arnold et al., 2018). This poor treatment of women encouraged families to travel to facilities where their preferred provider was located, even if it was further away. This finding was also reported by Tappis et al. (2016a) in their Afghan study, and can lead to unnecessary second and third delays which are critical to avoid to prevent stillbirth. The importance of quality and respectful maternity care has gained attention globally recently with the release of the WHO guidelines in 2016 and can inform improvements to standards of care in facilities in Afghanistan (WHO, 2016a). However, this will also need to be coupled with improvements in staffing, supplies and equipment to reduce the load on already overburdened facilities.

Economic and structural barriers hindered family's ability to pay for medicines or undergo procedures to minimise their risk of pregnancy or childbirth complications as well as access to preventative and emergency obstetric care. These barriers were a major factor placing women at increased risk of stillbirth in this study. The 2010 AMS also found that the most common reason cited for not attending ANC was lack of money, followed by distance and transportation issues (ANPHI/MoPH et al, 2011). Poverty and low socio-economic status is a key stillbirth determinant, and our study also demonstrated how socio-economic status can contribute to stillbirth. The costs associated with access to care prevented families from deciding to seek care and could be addressed through initiatives such as community-based financing schemes (Jacobs et al., 2012). Services in the Afghan public health system are officially free; however, many families reported having to purchase basic supplies, kits and medicines. Additionally, bribes were demanded by healthcare providers, likely driven by low salaries and the high burden of work. These concerns have been identified in other studies in Afghanistan (Arnold et al., 2015; Tappis et al., 2016b) and will require the MoPH to put in place mechanisms to remove such user fees or address their driving factors.

Although several women in our study sought ANC, many had unmanaged or undetected medical conditions directly related to their stillbirth or leading to complications during childbirth. The poor reputation of publicly available ANC services and inconsistent quality of care from private clinics suggest improvements and closer monitoring of the quality of ANC services is critical. The 2010 AMS indicated that among women who received ANC, only 25% was from the public sector - this is likely due to quality concerns highlighted by respondents in this study. Innovative service delivery strategies such as group ANC models have been successful in high-income countries as a means to improve the experience and quality of ANC and has the potential to encourage uptake in LMICs

(Sharma et al., 2018). A feasibility study of group ANC in India found that it was positively received and acceptable to participants and providers who perceived this forum of ANC delivery as empowering; it encouraged women to be active participants in their healthcare and also addressed several health system challenges (Jolivet et al., 2018). Such alternative models could be considered for the Afghan context as addressing the quality of care received during pregnancy will be critical for stillbirth prevention in Afghanistan.

Challenges with lower-level health facilities not having adequate resources or staff resulted in multiple delays as families would be referred to specialised hospitals in Kabul which required additional travel time. Further, in many cases, referrals were either unjustified or inappropriate also placing women at risk. Establishing a functioning and efficient referral system with adequate referral guidelines that are implemented, can potentially address some of these delays.

Our findings highlight several potential areas of focus to begin to facilitate reductions in stillbirth in Afghanistan. It was clear from our study that women and families had very little knowledge on the importance of pregnancy care, particularly around how critical it was to identify underlying maternal conditions that may place the fetus or mother at risk. Simple community education and campaigns to raise awareness among all levels of the community about key danger signs that could lead to stillbirth, and encouraging mothers to act on these symptoms may be an effective strategy the MoPH to consider.

Influencing mothers-in-law's is challenging and will require some innovative approaches to encourage care-seeking and facility births. Delivering messages through religious leaders or influential community members is a strategy that has been adopted in Afghanistan to facilitate uptake of family planning and polio vaccination (Huber et al., 2010), but whether this could have any effect on mothers-in-law's views needs investigation. Community mobilisation efforts perhaps through interventions such as participatory women's groups or peer-counselling could be more effective in influencing elder women's views through the social pressure it creates (Lewycka et al., 2013). Given the misperceptions that exist around caesarean sections and the established importance of these interventions to prevent stillbirth, it would be important to identify ways in which to clearly communicate the benefits and expectations to families to make informed decisions.

Health systems strengthening efforts will be essential for future stillbirth prevention in Afghanistan. We have identified several challenges related to the availability and accessibility of facilities both economically and culturally, but also many concerns with quality of care that need to be addressed.

The skills and practices of healthcare providers at all levels on intrapartum care and monitoring needs close examination to ensure implementation of best practices. The WHO's recently published guidelines on both intrapartum care and antenatal care, as well as standards for improving quality of maternal and newborn care in health facilities can provide guidance (WHO, 2016a, 2016c, 2018). To reduce access barriers improving services and the availability of human resources and supplies at primary and secondary health facilities should be made a priority. Strengthening community-based delivery and outreach through increased engagement of CHWs and community-based midwives is another strategy that can be considered.

Our study demonstrates the utility of qualitatively eliciting individual narratives of stillbirth experiences to identify underlying factors and possible causes leading to these deaths. Given the paucity of data and studies available on stillbirth in Afghanistan, the use of social autopsy could be a potentially useful way to investigate the circumstances around stillbirth and generate populationlevel data on the social, behavioural, and health system determinants of stillbirth that can inform the strengthening of maternal and child health programs (Kalter et al., 2011). Social autopsy is also an effective means of facilitating community dialogue, raising awareness about prevention, and mobilising community response to stillbirth and other perinatal deaths (Biswas et al., 2016). This may be worth considering for the Afghan setting given the socio-cultural barriers that exist around care-seeking and could be an effective way of influencing mothers-in-law's attitudes.

There are some limitations to this study. Kabul province is only one of Afghanistan's 34 provinces and is the most progressive and has the greatest access to healthcare facilities. Fieldwork was also limited to rural districts with good security, access to health facilities and active CHWs; therefore, findings may not reflect the situation in unstable, conflict-affected regions which make up the majority of Afghanistan. Due to time and resource limitations, we could not recruit sufficient respondents to represent a diversity of ethnolinguistic backgrounds, who may have differing views and experiences. The small number of female elders included also limited our ability to capture a broad range of views and adequately triangulate responses from this group. Most women we interviewed were recruited through health facilities or CHWs and had given birth at a health facility, so we cannot generalise these experiences to women those who have had no or minimal contact with the healthcare system.

Conclusion

Through the application of a qualitative approach to explore individuals' experiences of stillbirth it is possible to obtain in-depth understanding of the underlying factors and pathways that lead to these deaths. This can generate useful information to complement quantitative studies of stillbirth determinants to not only decide what interventions are needed, but also identify factors that can affect access to, utilisation, and the effectiveness of potential interventions or services. Our findings also illustrate, that when considering interventions to prevent stillbirth, the underlying contextual factors that affect access to and uptake of key services such as ANC and skilled birth attendance also need to be addressed, as do the factors that affect quality of services. These are important to considerations for future implementation of stillbirth interventions for Afghanistan and other LMIC settings.

Our study has highlighted the multiple and complex challenges that exist to prevent stillbirths in Afghanistan. However, our findings identify where efforts and resources need to be directed to reduce stillbirths. Improvements in the quality and availability of antenatal care and care provided at rural facilities in particular, will be critical to ensure women can access adequate care during pregnancy and emergencies. Programmes focusing on raising awareness and educating women and the wider community around the importance of nutrition and care during pregnancy, and knowledge on the key factors that increase risk of stillbirth, will also be important for future reductions in stillbirth in Afghanistan.

Ethics

Ethical approval for the study was provided by the institutional review board of the Afghanistan National Public Health Institute, Afghanistan (no. 43831) and the ethical review committee of the University of Sydney (no. 2017/566). Written permission was provided from participating hospitals and all participants gave written or verbal informed consent.

Contributors

AC conceptualised the study, led the data collection and analysis, and wrote the manuscript. SMSH, MHR, AM and MKR contributed to the study design, data collection, interpretation of findings and provided critical comments on the manuscript. AA, CRG, and MJD provided overall guidance, contributed to the study design, analysis, and provided critical inputs to the manuscript. All authors have reviewed and approved the final version.

Declaration of interests

The authors declare no competing interests.

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Supplementary Appendix

| | Participant group | Definition and selection criteria | Numbe |
|-----|---|--|--------|
| CON | MMUNITY-LEVEL | | |
| 1 | Mothers | Any woman of reproductive age that has experienced a recent^ stillbirth | 21 |
| 2 | Fathers | Any man/father who recently^ had a stillborn child. They may or may not be the husband of a mother included in the study | 9 |
| 3 | Female community elders ⁺ | Senior women in the community who have experience attending home births or has a daughter or daughter-in-law that has experienced a recent stillbirth | |
| 4 | Community Health Workers (CHW) | CHWs are part of the health workforce in Afghanistan delivering health services in rural areas. Based at village health posts, they serve ~150 households. Primary tasks include treating childhood diseases, health promotion, demand creation for maternal health services at health facilities, and provision of contraceptives. Only female CHWs were included. | 5 |
| HEA | LTH-FACILITY LEVEL | | |
| 5 | Midwives Doctors (Obstetrician-Gynaecologists) | Any healthcare provider with training to conduct deliveries or handle any perinatal losses | 4 6 |
| 6 | Managers: - Chief of wards (Obstetric or Neonatal) - Health facility managers/directors | Any individual in a management position at health facilities. | 5 |
| GO۱ | VERNMENT/MINISTRY LEVEL | | |
| 7 | Government officials/informants in maternal and child health | Individuals involved in reproductive, maternal and child health services program management, data management or policy making | 2 |
| | Total | | 55 |

Table A1. Summary of study participants

^ We initially defined 'recent' as a stillbirth that occurred in the 12 months preceding the interview; however, this was not always possible, and interviews were often commenced without knowing when the stillbirth occurred.

* Many female community elders practice as Traditional Birth Attendants in Afghanistan assisting with home births. Traditional birth attendants are no longer recognised by the Ministry of Public Health and discouraged from practicing. Several have been trained to work as Community Health Workers or community midwives.

| | | Participant type | |
|---------------------------|--|------------------|------------------------|
| Characteristic | | Mothers n=21 | Fathers^ n=9 |
| Type of perinatal loss | Miscarriage (<5 months) | 1 | 1 |
| | Early stillbirth (5-6 months) [~] | 3 | - |
| | Late stillbirth (≥7 months)~ | 12 | 6 |
| | Early neonatal death | 5 | 2 |
| Time since pregnancy loss | <1 month ago | 3 | - |
| | 1-6 months ago | 7 | 3 |
| | 7-12 months ago | 5 | 2 |
| | >12 months ago | 5 | 2 |
| | Missing | 1 | 2 |
| Age (current, years) | 18-25 | 8 | 1 |
| | 26-34 | 8 | 2 |
| | 35+ | 4 | 6 |
| | Missing | 1 | - |
| | Median age | 29 | 44 |
| Residence (current) | Urban | 11 | 3 |
| | Rural | 10 | 6 |
| Ethnicity | Tajik | 13 | 6 |
| | Pashtun | 5 | 2 |
| | Other | 2 | 1 |
| | Missing | 1 | - |
| Education | None | 17 | 3 |
| | Primary (7-9 years) | 2 | 3 |
| | Secondary (10-12 years) | 1 | 2 |
| | Higher (University) | 1 | 1 |
| Previous perinatal loss | None | 11 | 2 |
| | One | 6 | 3 |
| | Two or more | 4 | 3 |
| Gestational age of loss | 4 months | 1 | 1 |
| | 5-6 months | 3 | 0 |
| | 7-8 months | 2 | 2 |
| | ≥9 months | 15 | 6 |
| Place of childbirth | Tertiary hospital (urban) | 13 | 5 |
| | District hospital (rural) | 5 | 2 |
| | Home | 3 | 1 |
| | missing | 0 | 1 |
| Birth attendant | Trained (doctor or midwife) | 18 | 7 |
| | Untrained (mother-in law, other elder) | 3 | 1 |
| | missing | - | 1 |

Table A2. Characteristics of study participants that recently experienced a perinatal loss

| | | Partici | oant type |
|-----------------|------------------------------------|------------------------|-----------------|
| Characteristic | | Mothers n=21 | Fathers^ n=9 |
| Pregnancy order | First | 4 | 1 |
| | 2nd-3rd | 7 | 2 |
| | 4th-5th | 6 | 2 |
| | 6th or higher | 4 | 4 |
| Received ANC | Yes | 7 | 9 |
| | No | 11 | - |
| | Ultrasound only | 2 | - |
| Sex of baby | Male | 10 | 5 |
| | Female | 7 | 3 |
| | Not known | 2 | 1 |
| | One set of twins (male and female) | 1 | - |

^Some of the men were the husband of a participating woman

We classified stillbirth as early if the baby was born dead and gestational age was reported to be between 5 and less than 7 months, while late stillbirths were those which occurred from 7 months onwards. The outcome was classified as an early newborn death if the respondent reported any signs of life after birth (if the baby moved, cried or breathed after birth).(Lawn et al., 2011; WHO, 2011)
*Four of those that were named were early neonatal deaths
*One of those that was named was an early neonatal death

n/a- Question was not asked

CONCLUSION

This concluding chapter consists of five sections. It begins with a summary of the main research findings of this thesis, it then discusses the contribution of the research to the literature, reviews the strengths and limitations of the research, highlights the implications of findings for policy and future research for data improvements on stillbirth risk factors in low- and middle-income countries and stillbirth prevention for Afghanistan, and ends with a concluding statement.

SUMMARY OF MAIN FINDINGS OF THE RESEARCH

The paucity and low-quality of stillbirth data from low- and middle-income countries has been repeatedly highlighted as a significant factor impeding efforts to reduce stillbirths globally (Frøen et al., 2009; Lawn et al., 2011). In particular, there is an absence of country-level information on the contributing factors to stillbirth, which is essential for prioritising programmatic interventions, for political prioritisation and policy-making, and national-level resource allocation. The work of this thesis aimed to comprehensively evaluate what stillbirth data were available at a country level to understand stillbirth risk factors to inform programmatic and policy decisions towards stillbirth reduction, and to assess the consistency of methodologies used to collect this data across countries and surveys. Using a national survey from Afghanistan, a high-stillbirth burden country, this thesis aimed to demonstrate how better data could be generated for understanding the determinants of stillbirth, and how this can be applied to other settings. This thesis also sought to understand how contextual factors can influence stillbirth data quality and data collection, and provide insights into why stillbirths occur, through an exploration of community and healthcare providers perceptions, practices, and experiences of stillbirth.

While there have been several calls in the past about the urgent need for improvements in stillbirth data from low- and middle-income countries (Cousens et al., 2011; Lawn et al., 2011), Chapter One of this thesis took this one step further by outlining in detail the current limitations and gaps in stillbirth data and proposing measures to generate immediate improvements. Chapter One was a methodical assessment of 114 DHS surveys across 70 countries to synthesise what data exists to capture the burden, potential risk factors, and causes of stillbirth at a national level. Specifically, I examined the data collection methods and measures used across DHS surveys to capture stillbirths, and any indicators of known risk factors and causes of death. This assessment showed how the variation in the measurement of stillbirths using different methods or instruments, makes it difficult to make comparisons across all countries, and stillbirth estimates must continue to rely on a contraceptive/reproductive calendar, which evidence shows, produce poorer quality stillbirth estimates and higher levels of under-reporting (Bradley et al., 2015).

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Inconsistencies and inadequacies in the phrasing of questions for capturing stillbirths were also problematic in many surveys. Several surveys had inappropriately phrased questions, and so stillbirths could not be estimated at all. The use of live birth histories instead of full pregnancy histories in most surveys meant that women's pregnancies ending in a stillbirth were not included in the subsequent modules which examined antenatal and childbirth care for pregnancies that ended in a stillbirth. This is a critical oversight given the importance of healthcare utilisation and healthcare access on stillbirth risk. Even in surveys that did implement a full pregnancy history, use of antenatal and childbirth care during pregnancy for stillbirth were not completely captured, making this data of little use. Another important finding from Chapter One was that many surveys despite capturing stillbirths according to their questionnaires did not report stillbirth numbers anywhere in the narratives of their reports and provided no explanation for their exclusion. This only serves to perpetuate the invisibility of stillbirth, as these figures remain concealed from program and policy decision-makers who use these reports to inform national-level agendas and, therefore, prevents the prioritisation or allocation of resources to stillbirth prevention.

Chapter Two of this thesis used the 2010 Afghanistan Mortality Survey - one of the surveys reviewed in the assessment of stillbirth data sources from Chapter One - to demonstrate how a modified DHS survey can produce nationally-level and comprehensive information on stillbirth risk factors. Based on the data available in this survey, we were able to identify key risk factors for stillbirth in Afghanistan, a nation where stillbirth rates continue to be some of the highest in the world and where no information on stillbirth risk factors had been previously available. The overall stillbirth rate from this data set was 23 per 1000 total births which was slightly lower than adjusted modelled estimates from 2009 of 29 per 1000 births, and confirms findings in the literature that DHS surveys tend to under-report stillbirths (Cousens et al., 2011; Lawn et al., 2011). We also found that 60% of stillbirths in Afghanistan were intrapartum stillbirths. Intrapartum stillbirths are largely preventable with sufficient, timely, and quality antenatal and intrapartum care (Bhutta et al., 2011; Goldenberg et al., 2007).

In the multivariable analysis presented in Chapter Two, after adjusting for known and measured confounders, we identified that region of residence and ethnicity were significantly associated with stillbirth; women residing in the Central Highlands region had three times increased risk of stillbirth and women of Nuristani ethnicity had nine times higher risk of stillbirth. Maternal factors associated with increased risk of stillbirth included having experienced a previous pregnancy loss (aRR: 2.4, 95% CI: 1.7, 3.6), multiple pregnancy (aRR: 3.2, 95% CI: 1.8, 5.8) and nulliparous women (aRR: 2.3, 95% CI: 1.5, 3.4). Women that did not receive any antenatal care had over three times higher risk of stillbirth

(aRR: 3.0, 95% CI: 1.7, 5.3). The risk of stillbirth was also increased by 50% in women giving birth in a health facility (aRR: 1.5, 95% CI: 1.1, 2.2), which is most likely due to bias, and case-mix. Women with complications during pregnancy including antepartum bleeding, possible infection, headaches, and reduced fetal movements, also had increased risk of stillbirth. During the intrapartum period, the main complication associated with increased stillbirth risk was reduced fetal movements. Women experiencing this had almost seven times increased risk of stillbirth compared with women that did not (aRR: 6.8; 95% CI: 4.2, 11.1).

The availability of data on the timing of stillbirth from the verbal autopsy data made it possible to conduct a separate assessment of stillbirth risk for intrapartum stillbirths. This sub-analysis showed some slight differences compared to when all stillbirths were combined. Region of residence was no longer associated with increased risk; however, women of both Nuristani and Pashai ethnicities had significantly increased risk of intrapartum stillbirth. People of Nuristani ethnicity tend to reside in the eastern region of Afghanistan, while people of Pashai ethnicity reside in the North-Eastern regions. Despite extensive internal migration and displacement resulting from conflict, specific ethnic groups tend to be concentrated in certain regions and the effect of ethnicity may have accounted for the effect of region. Antenatal care utilisation was also strongly associated with increased risk of intrapartum stillbirth; this time, women who had not sought antenatal care had a three-fold increased risk of intrapartum stillbirth. Women that received low-quality antenatal care also had over twice the risk of stillbirth compared to women that received high-quality antenatal care. This suggests that antenatal care has a vital role to play in preventing intrapartum stillbirths possibly through the detection and management of maternal conditions including gestational diabetes, hypertension, and infections that can lead to complications in childbirth and stillbirth. In terms of pregnancy complications, the only conditions that remained significantly associated with intrapartum stillbirth were antepartum headache and probable infection, while bleeding and reduced fetal movements in the antepartum period were no longer risk factors. However, reduced fetal movements in the delivery period remained an even stronger risk factor for intrapartum stillbirth, and women experiencing this had over eight times increased risk of stillbirth. Place of childbirth was no longer significantly associated with intrapartum stillbirth, indicating that it was neither protective nor did it increase risk.

Given the data quality concerns that exist around stillbirth data, particularly under-reporting and misclassification (WHO, 2007), Chapter Three of this thesis explored the contextual factors that may be influencing the accurate ascertainment of stillbirth estimates and the mechanism by which this might occur in Afghanistan. Understanding how socio-cultural perceptions and practices around

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stillbirth as well as health system factors impact on the quality and reliability of stillbirth data was a relatively under-explored area in the literature. The underlying premise behind this investigation was that stillbirths can be socially and culturally sensitive events and how societies respond to and perceive these deaths can have an impact on whether a death is disclosed, and that this would vary across different cultural settings. In many countries, particularly in sub-Saharan Africa, social repercussions exist for women around pregnancy loss including stigma, shame, blame, and abandonment that precludes women or their families from disclosing a stillbirth, possibly leading to under-reporting as well as misclassification (Frøen et al., 2011; Haws et al., 2010; Kiguli et al., 2015). Misclassification may also be driven by the difficulties with differentiating between stillbirth and early neonatal deaths.

The findings in Chapter Three demonstrated that community perceptions and practices around stillbirth could affect how well stillbirth data are captured and reported in Afghanistan. These perceptions and practices also influence parents' knowledge and ability to recollect signs of life at birth or skin appearance that allows the estimation of stillbirth timing. As a result of the lack of a direct word for stillbirth in Afghanistan, we found that people in the community frequently used the terms for miscarriage to describe stillbirth. There were also many variations in understanding of the difference between the different losses. Without clear gestational age boundaries defining stillbirth, the community tended to use other descriptive terminology to differentiate between a stillborn and a miscarriage, referring to the baby as 'mature' or 'complete', indicating a fully developed fetus. These findings support calls by other researchers to ensure that when collecting information on stillbirth from women that follow-up questions are included to confirm about any signs of life and gestational age (Haws et al., 2010; Lawn et al., 2011).

The findings from Chapter Three showed that in the Afghan context stillbirths were valued and received a degree of social recognition. Parents often named and carried out death rituals for their stillborn despite these not being the prescribed religious or social norms. Such practices and perceptions all point to a reduced likelihood that families would conceal or avoid reporting stillbirths at the community level and hence, might reduce under-reporting. However, there were several circumstances whereby under-reporting or misclassification might occur, such as when the stillborn had a congenital anomaly, or women had not had the opportunity to see their baby or know if it had breathed or cried after birth. There was also the practice of refusing interventions to save the life the baby if it was at risk and was a female. Chapter Three also revealed practices at health facilities by healthcare providers that would contribute to under-reporting of stillbirths, particularly in facility-level data. These practices were underscored by an entrenched institutional culture of blame which

forced staff to hide stillbirths, a focus on intrapartum stillbirths which drove over-reporting of antepartum stillbirth, family pressure on healthcare providers when a stillborn baby was a boy, a general disregard of the importance and value of reporting, and inadequate skills and experience among resident doctors

The findings in Chapter Four of this thesis endeavoured to place into context and complement the results from Chapter Two. Through parents and healthcare providers stories of their stillbirth experiences, we were able to gain insight into the underlying pathways leading to stillbirth and understand some of the mechanisms behind the risk factors identified in Chapter Two. Low-levels of healthcare utilisation was a critical factor contributing to stillbirth. This was underscored by women's lack of decision-making power, socio-cultural barriers to access, lack of perceived need and benefit of care during pregnancy and childbirth, and low general knowledge of self-care during pregnancy. Perceptions about quality of care including the behaviour of healthcare providers, and economic and physical access barriers also affected access to health services. Unmanaged maternal conditions among pregnant women heightened their risk to stillbirth due to severe complications during both pregnancy and childbirth. Socio-cultural factors including perceptions about caesarean sections led to the refusal of medical intervention and stillbirth, while neglect and abuse of pregnant women at home increased their risk. Quality of care was also a recurring factor underlying stillbirth especially the inadequate detection of medical conditions and inappropriate advice during pregnancy. Additional health system factors led to delays in receiving care including inappropriate referrals, inadequately equipped facilities, and harmful or inadequate provider practices. An additional context-specific issue identified for Afghanistan was the exposure of pregnant women to harmful substances from the armed conflict in rural areas that could lead to fetal death through the development of congenital anomalies.

CONTRIBUTION OF THE FINDINGS TO LITERATURE AND RELATION TO PREVIOUS RESEARCH

This thesis has made several contributions to the literature and to the field of research to improve stillbirth data and has added to the understanding of stillbirth determinants. It has outlined in detail the limitations and gaps in stillbirth data availability from national household surveys and what is needed to improve these in order to generate more comprehensive and better quality data on stillbirth risk factors. The findings of this thesis have also provided data on the key determinants of stillbirths for Afghanistan – a country where no information on stillbirths had been previously published.

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The analysis presented in Chapter One is unique as it presents the first attempt at using a modified DHS survey to comprehensively assess the contribution of a wide range of socio-demographic, maternal, fetal, and health-care utilisation determinants of stillbirth in a low- and middle-income country at a national level. Previous analyses using DHS surveys were limited to examining only socio-demographic and selected maternal factors, without taking into account women's access to care during pregnancy and childbirth and complications during pregnancy, all of which are so critical for predicting stillbirth. What made this analysis more robust, was the availability of verbal autopsy data that could be used to correct for possible misclassification in the pregnancy history and obtain information on stillbirth timing, which allowed us to identify risk factors separately for intrapartum stillbirth. The inclusion of questions on fetal movement also permitted an assessment of maternal perception of fetal wellbeing as a predictor, which has rarely been captured in studies in low- and middle-income countries. What these findings show, is that with some modification DHS surveys can potentially contribute to generating more data needed to understand stillbirth risk factors for over 80 other low- and middle-income countries that implement DHS surveys (ICF International, 2018).

The results presented in Chapter Three add to the limited literature that exists from low- and middle-income countries on community perceptions and understandings of stillbirth. Such a study has not been previously been done in Afghanistan and for this context makes an original contribution. There are very few other studies from South Asia – only one each from Nepal, India, and Pakistan which investigated different aspects of stillbirth ranging from the role of religion and the impact of stillbirth, all of which show varied perceptions and responses to perinatal loss (Paudel et al., 2018; Roberts et al., 2012; Zakar et al., 2018). Several more studies have been done in sub-Saharan Africa which explored the perceptions and values that exist around stillbirth (Attachie et al., 2016; Haws et al., 2010; Kiguli et al., 2015; Sisay et al., 2014). As with our findings in Afghanistan, most studies that have examined terminology and understandings or meanings associated with stillbirth find variations or vagueness in terms, or a lack of direct term or clear gestational age associated with stillbirth. This is important when considering how data collectors might ask or phrase questions on stillbirth or other perinatal losses. Interestingly, our finding that families tended to place significant value on a stillborn, were not found in most studies from low- and middle-income countries apart from one in Qatar (Kilshaw, 2017).

The approach of our study was novel in that it focused on understanding the extent to which stillbirth data quality might be affected by various contextual factors, and systematically outlined how each of these factors might impact on the stillbirth reporting. The only other study from a low-and middle- income country to my knowledge that has examined healthcare provider perceptions

around stillbirth was Zakar's (2018) study in Pakistan, although the focus of this study was predominantly on community-level health workers. This study also found similar challenges around the value of reporting and the competency of providers to differentiate between perinatal losses which were identified as concerns contributing to under-reporting of stillbirth (Zakar et al., 2018).

Chapter Four of this thesis explored the various pathways that lead to stillbirth in Afghanistan adding to the literature on why and how stillbirths occur in this setting. The findings have shown that through the application of a qualitative approach to explore individuals' experiences of stillbirth, it is possible to obtain in-depth understanding of the underlying factors and pathways that can lead to stillbirth. This is useful for settings where there is scarce literature or data available on stillbirth, and also to complement quantitative studies of stillbirth determinants to not only decide what interventions are needed, but also identify factors that can affect access to, utilisation, and the effectiveness of potential interventions or services. To some extent, this analysis of pathways to stillbirth is similar to the approach used during social autopsies to investigate underlying social determinants of neonatal, child, or maternal deaths (Koffi et al., 2015; Moyer et al., 2017). The feasibility of social autopsy for stillbirths has been explored and has potential, but has not yet been routinely used to the extent that it has been for maternal and child deaths (Biswas et al., 2018; Biswas et al., 2016). The benefits of social autopsy to complement verbal autopsy have been demonstrated in several studies (Kalter et al., 2016; Koffi et al., 2015), and there are currently ongoing efforts to develop standardised social autopsy tools to investigate neonatal and child deaths (Waiswa et al., 2012).

STRENGTHS AND LIMITATIONS OF THE RESEARCH

A major strength of this thesis is that it has used both quantitative and qualitative research methods to explore and outline the gaps that exist in stillbirth data, how stillbirth data quality is affected by the methods used to measure it and by the context it is collected in, and to comprehensively understand stillbirth risk factors.

The quantitative risk factor analysis presented in Chapter Two used a survey that was the first national survey undertaken in Afghanistan and the first and only one to collect comprehensive data for stillbirth in the country. The incorporation of a full pregnancy history allowed us to capture all women's births, whereas most DHS surveys only include births from women who had live births which introduces bias. The additional verbal autopsy data collected in this survey allowed us to take into account sex of the baby, multiple births, and stillbirth timing that is not usually collected for stillbirth in DHS and often not even in those surveys that include full pregnancy history. These

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indicators are important to take into consideration given they raise the risk of stillbirth. The verbal autopsy also allowed us to correct misclassification between stillbirth, early neonatal deaths and miscarriages which improved the reliability of the outcome

As the dataset used in Chapter Two was cross-sectional, recall bias is a potential limitation given that all variables are based on self-report. The period of recall, which may be up to five years, could affect the precision of reporting on maternal health services received, as well as other exposures during pregnancy. There is some evidence from studies in low- and middle- income countries which show good maternal recall of perinatal events (Mung'ala-Odera & Newton, 2001; Rao et al., 2003). This is also supported by the findings in Chapter Three of this thesis where parents had detailed recollection of events around their pregnancy loss and characteristics of their baby. Further, this dataset could not take into account all possible confounders as it did not include data on certain variables that are known to have an effect on stillbirth such as distance to a health facility, exposure to conflict (Keasley et al., 2017), consanguinity (Maghsoudlou et al., 2015; Mokhtar & Abdel-Fattah, 2001), and intrauterine growth restriction (Bukowski et al., 2014).

The use of cross-sectional survey data for undertaking risk factor analysis is not ideal. However, a study by Hammer et al. (2006) who undertook a risk factor analysis using DHS survey data and compared it to data from a prospective HDSS site in Burkina Faso, found similar results from both data sets. They concluded that DHS surveys can produce comparable results to the prospective HDSS data and that DHS data were valuable data sets for undertaking risk factor analyses (Hammer et al., 2006). Others have also investigated the differences and concluded the same (Byass et al., 2007). DHS surveys also exclude children whose mothers have died, thus introducing another source bias.

The data quality concerns surrounding the mortality data and under-reporting of deaths in the 2010 AMS survey raises the possibility of under-ascertainment of stillbirths. However, the primary purpose of the analysis was to identify risk factors for stillbirth, not to quantify the burden. This data set was also not completely nationally-representative, as only two-thirds of the southern region of Afghanistan could be sampled due to security risks (ANPHI/MoPH et al, 2011). Therefore, the risk factors identified may not be generalisable to the provinces that make up the southern region of Afghanistan. The relevance of the dataset for the current situation is also a limitation given that the data was collected almost eight years ago; however, given it is the only dataset with such comprehensive capture of information on stillbirth, it still provides important information. It is likely the findings are still applicable for the current situation given that health service utilisation during pregnancy and childbirth continues to remain low in Afghanistan. As with most qualitative studies, the findings of this thesis are not generalisable beyond the study location of Kabul province given the diversity that exists across the country with ethnicity, culture, and language, as well as the degree of conservativeness. Our sample of participants did not reflect the range of ethnicities that exist in Afghanistan, and so our findings may not represent the range of perceptions and experiences of perinatal losses that exist. However, it does provide important insights, some of which are transferable to other low- and middle-income country settings that can be considered when undertaking similar studies.

Data collection was limited to districts and areas that were relatively secure and safe to travel, although many respondents travelled through areas with high levels of insecurity to reach health facilities in the capital, which provide some understanding into the challenges faced in other parts of the country. Data was primarily collected through large, urban tertiary-level health facilities and most women we interviewed had given birth at a health facility, but in Afghanistan, almost half of women give birth at home (CSO et al., 2017). We made efforts to identify women that had given birth to a stillborn at home, but this proved challenging and time intensive so this sample of women in our study was small. We also faced difficulties with identifying female elders in the rural districts as they were usually out of home when our interviewers visited the field.

Social desirability bias may have influenced healthcare provider's responses and they may have avoided disclosing inappropriate practices. By obtaining information from a range of respondents from different levels of the community and health facilities we were able to triangulate the data to ensure that we captured an accurate reflection of the situation. As we relied on hospital directors and managers to identify suitable staff in their facilities for interviews, it is possible they may have selectively chosen more competent individuals or those more likely to provide a desired response. Given that most managers openly expressed their own concerns with existing practices in their facilities with us, there would have been a small likelihood of this occurring.

Another limitation of the qualitative research is the possibility that during the translation of transcripts to English, that interpretation and meaning of texts may have been lost or not accurately translated. To mitigate this, we used translators with an exceptionally good level of English and worked closely with them during translation to ensure that the translations were an accurate reflection of participant responses. The translated transcripts were also reviewed by the local interviewers and co-investigators.

Due to time limitations during the field work, there was no opportunity for the study team to first visit rural communities to establish rapport prior to beginning data collection. This would have been beneficial given the mistrust that exists in Afghanistan with foreign NGOs and researchers, even though only local Afghan interviewers collected data in the rural districts. Although the communities were generally very welcoming, there were concerns by some individuals about why the research team was there, particularly in one rural district. This may have affected the degree of openness and trust that respondents had with interviewers. In the second rural district, this issue was not faced as one of our local interviewers was from this district and so a relationship was already established.

IMPLICATIONS FOR RESEARCH AND POLICY, AND FUTURE DIRECTIONS

The findings of this thesis have implications for improving stillbirth data at global and national levels. Chapter One of thesis, made several recommendations to improve stillbirth data in the DHS surveys that would facilitate the generation of more and better quality data for stillbirth for low- and middleincome countries that implement these surveys. DHS surveys are the largest, nationally representative, population-based surveys carried out in the majority of low- and middle-income countries, and in many circumstances, are the only source of population data on maternal and child health indicators including stillbirth. The DHS provides an opportunity to increase and improve data on stillbirths, yet they do not routinely collect data on mother's healthcare utilisation and experience of complications during pregnancy and childbirth for stillbirths. Adaptation of these surveys to capture risk factors for stillbirths in addition to live births, as the 2010 AMS has done, by incorporating the changes proposed in Chapter One to all standard DHS questionnaires will lead to greater usefulness and applicability of the data. This data can then be used to inform programmatic strategies for targeting preventive measures for stillbirth reduction.

The wider implementation of pregnancy histories to replace birth histories would result in almost immediate improvements in the quality of stillbirth data by reducing under-reporting of stillbirths. Perinatal researchers have been advocating for DHS to use pregnancy histories as far back as 1996 when it was reported by Stanton et al. (1996). A small number of validation studies comparing birth histories to pregnancy histories have also found better stillbirth data capture using pregnancy histories and additional studies in a larger number of contexts may assist with building the evidence base to facilitate this change (Espeut & Becker, 2015; Stanton, 1996). Modification of these surveys this would require a large commitment by the DHS program to update surveys and protocols, and would lengthen the time of interviews, possibly require a larger sample size and hence increase survey costs, this would still be an investment worth making and working towards, perhaps even in a phased manner country by country initially based on individual country interest. In Afghanistan, the 2010 AMS was the only survey that collected more comprehensive data on stillbirth. The subsequent DHS survey in 2015 did not capture this information on women's pregnancies that ended in a stillbirth because of the use of a live birth history and so information about women's pregnancy care and obstetric history and other potential risk factors were not available. The Ministry of Public Health should consider including full pregnancy histories in future surveys in order to track stillbirth trends over time. This will be important for meeting the targets agreed upon in the Every Newborn Action Plan in 2014, to reduce stillbirths to 12 per 1000 births by 2035 (WHO, 2014).

The evidence provided in Chapter Three of this thesis demonstrated the significance of context and how local understandings and perceptions about stillbirth can influence stillbirth reporting. Demographers and survey designers can use such information to adapt questions more appropriately for each country context and ensure the meanings and terms are accurately translated to reflect local meanings. Engaging anthropologists and incorporating qualitative inquiry during the development of survey data collection instruments will be essential to obtain the in-depth insights required for this understanding. Ultimately, this will contribute to improved accuracy and reliability of stillbirth estimates, and a better understanding of the burden. Our findings also showed the importance of asking women confirmatory questions about any signs of life at birth to ensure that stillbirths are accurately captured to reduce misclassification. Including these questions would also contribute to improved quality of data for neonatal deaths.

Facility-based data will be increasingly used to understand stillbirth risk as facility births increase in low- and middle-income countries. The findings in Chapter Three of this thesis have raised important concerns around the quality of stillbirth data from health facilities in Afghanistan, highlighting some of the data quality issues that prevail that are largely underscored by contextual factors and pressures on healthcare providers. It is highly likely that the same challenges exist in health facilities in other low- and middle-income countries. Similar assessments should also be undertaken in other contexts to understand to what extent the same issues exist so that efforts can be made to address these. Currently, there are no published studies that examine the quality of stillbirth data from health facility records in low- and middle-income country. Such investigations are much needed to ensure the reliability and usefulness of future data from such records.

Our study examined practices only within tertiary-level health facilities. For the Afghan context, it would also be important to assess data reporting concerns at lower-level facilities. An observational

study by Broughton and colleagues (2013) investigating the accuracy of medical records in three hospitals in Afghanistan found that medical record accuracy was poor, but that errors did not follow a pattern of self-enhancement. This contrasts findings from Chapter Three of this thesis, and although our study was qualitative and did not directly involve checking medical records, healthcare providers and facility managers directly informed us based on their own experiences and observations of what was occurring in their facilities. There does not seem to be any reason or incentive for healthcare providers to admit poor practices to the study team unless they felt it was a serious and valid concern. It is also possible that in the study by Broughton, the presence of observers in the hospitals may have impacted on health provider practices, which the authors have acknowledged (Broughton et al., 2013).

Strategies are needed to address the factors that drive under-reporting and misclassification of stillbirth in health facilities in Afghanistan. Changing practices would require action at several levels including a culture change in hospitals and re-evaluation of formal investigations and management of responsible health providers by investigating committees in the Ministry of Public Health to remove barriers to accurate reporting. Improving healthcare provider knowledge of the importance of high-quality data would also be an important step and has been successful in improving data completeness in other low-income settings (Mphatswe et al., 2012). At the facility level, assessment of health facility constraints, health provider training needs, and improvements in documentation and monitoring of records will be required if any advancements are to be made.

The evidence presented in Chapter Two on stillbirth risk factors for Afghanistan have important implications for policy and programming in maternal and child health. These findings adds to the evidence-base needed to inform and prioritise stillbirth prevention measures on the national maternal and newborn health agenda, and are timely given the commitment made in 2014 by all countries, including Afghanistan, to achieve the global targets to reduce stillbirths to 12 per 1000 births by 2035 (WHO, 2014). This thesis provides important information and data to guide prioritisation of efforts towards stillbirth reduction by the Ministry of Public Health in Afghanistan.

Preliminary findings from the analysis in Chapter Two were presented by one of the co-authors on the paper (Dr Mohammad Hafiz Rasooly) during the Ministry of Public Health's Annual Results Conference in early 2018 that was attended by government health officials from the Ministry of Public Health, and other national and international partners in Afghanistan. The purpose of this annual conference is to provide a forum for researchers, clinicians, and others to present research to health system stakeholders, policy and decision-makers which is used to inform future health strategies. It was noted at this conference that this was the first time any data on stillbirth had been presented. We hope that by beginning to raise awareness of the importance of this issue to key decision makers, programme managers, and policy makers, that stillbirth prevention will gain some traction in Afghanistan. Currently, Afghanistan's national strategies and policies for reproductive, maternal, newborn and child health have no reference to stillbirth rates and do not mention any targets for stillbirth reduction (MoPH, 2015, 2017).

The disparities in stillbirth risk by region and ethnicity presented in Chapter Two are likely to be related to access to care, given that the regions and ethnic groups most at risk are those populations concentrated in high conflict areas or very remote, hard-to-reach areas in the Central Highlands. Provincial-level mortality rates are not available in the 2010 Afghanistan Mortality Survey, but the 2015 Afghanistan Demographic Health Survey reported that Nuristan province (where most of the Nuristani population reside) had the highest levels of infant and under-five child mortality, that 89% of women residing in Nuristan did not receive antenatal care, and 99% gave birth at home (CSO et al., 2017). The disparities across regions tend to be hidden by national rates, and the low-levels of healthcare utilisation may partly explain why Nuristani women experience such high rates of stillbirth. These findings point to the need for targeted interventions for these high-risk groups to reduce stillbirths. Preceding this however, further research within these ethnic groups and regions to understand the contributing factors to stillbirth and health service utilisation in greater depth would be beneficial. Ethnicity is known to be a risk factor for stillbirth, and there may be other unknown reasons for this increased risk.

Chapters Two and Four both demonstrated the impact that inadequate antenatal care and untreated maternal conditions in pregnancy has on increasing stillbirth risk in Afghanistan. It is clear, that women are not receiving adequate care during pregnancy, and that this is critically important for detecting conditions that place them at risk. Increasing utilisation and access to quality antenatal care will be critical for stillbirth prevention in Afghanistan and is an area where attention and alternative models of service delivery are needed. Given the multiple and complex challenges women face in accessing care to begin with, and illustrated in Chapter Four, and the continuing political instability and insecurity in the country, one possible strategy is to focus on identifying highrisk women by engaging and training CHWs and/or community midwives.

The success of CHWs in Afghanistan in mobilising care-seeking and increasing facility births has been demonstrated (Viswanathan et al., 2012). Currently, CHWs tasks during home visits include encouraging women to attend antenatal care and referral to a higher-level of care if any danger

signs are detected. There is no provision of doing blood pressure checks or urine tests at health posts – the lowest tier of health facilities in Afghanistan where CHWs are based. A systematic review of trials of home visits by CHWs in South Asia have showed significant effect on reducing the risk stillbirths and newborn deaths when accompanied with community mobilisation efforts in settings with low access to health facilities (Gogia & Sachdev, 2010). These trials incorporated antenatal and postnatal care during home visits and could be considered for the Afghan context. The feasibility of further engaging CHWs in more task shifting activities could be an avenue to explore. However, as CHWs do not receive any salary this would likely require a re-assessment of how CHWs are remunerated and the number of tasks they are already required to do as these are current challenges to the CHW system in Afghanistan (Edward et al., 2015; Najafizada et al., 2014). Mobile health teams were introduced in the revised BPHS in 2010 to reach rural communities and underserved populations (MoPH, 2010). It may be worth considering further expansion and more investment into mobile health teams who bring services closer to people, particularly in remote and insecure areas where access to care is challenging.

The quality of antenatal care received by women in Afghanistan was sub-optimal and inconsistent from the findings in both Chapters Two and Four. Research is needed to understand the problems with antenatal care quality in more depth and identify effective strategies to make improvements. The challenges appear to be with antenatal care provided through the public health system especially. An antenatal care handbook introduced by the Ministry of Public Health as a recording system for women to have completed during antenatal care visits is a positive step towards increasing antenatal care uptake and also ensuring that components of antenatal services are provided (MCH Handbook, 2018; MoPH, August 2016). Ensuring that facilities have adequate numbers of staff, equipment and capacity to deliver all essential components of antenatal care services will also be important. At the community level, there are several possible models that could be trialled to improve the quality of antenatal care. Recently, success was seen in a trial in Mozambique where women attending antenatal care at clinics received a medical supply kit that included supplies for evidence-based antenatal care interventions; significant improvements were observed in the proportion of women screened for anaemia, proteinuria, and receiving antihelminths (Betran et al., 2018). Group antenatal care models have also been proposed as a method to improve the content and experience of care received (Sharma et al., 2018).

Chapter Three showed that one of the key challenges to facilitating greater health service utilisation by women in Afghanistan was a general lack of awareness of both danger signs in pregnancy and the importance of acting on these danger signs. Women, as well as decision-makers in households, did not appear to be aware of how life-threatening some conditions could be. Sensitisation of women, men, and extended family about the importance of pregnancy care and acting on complications and seeking timely care as well as skilled birth attendance is needed in the Afghan setting. Some community members and healthcare providers mentioned seeing messages on television, but many had not received any information about pregnancy care. Not all women would have access to such forms of media, particularly in remote villages or mountainous areas. It would be worth testing different methods of community-based education to identify the most effective and appropriate mechanism to reach women and families with important messages. Developing clear messages for women and her health decision-maker to understand danger signs in pregnancy particularly those for stillbirth will be important. Messages about the importance of changes in fetal movement and the need to seek care without delay when such changes in activity are felt, should be emphasised. CHWs currently do home-based counselling for pregnant women and this could be added to their list of messages that they deliver (Najafizada et al., 2014).

The findings from Chapter Four also identified several deficiencies in the health system that were contributing to stillbirth. In particular, were the dysfunctional referral systems and processes that led to families spending unnecessary time travelling at critical times. These delays were leading to extensive complications in women which would then result in a stillbirth that could have been prevented with timely care. Establishing a referral network and guidelines for healthcare providers that extends from the community-level will be an important area of research for Afghanistan.

Continuing health systems strengthening efforts will be essential for future stillbirth prevention in Afghanistan. Challenges with the availability and accessibility of health facilities both economically and culturally and concerns with the quality of care that this thesis identified have also been found by others previously (Newbrander et al., 2013). Despite recent quality improvements initiatives by the government (Rahimzai et al., 2013) there are concerns about quality of care in health facilities and the capacity of health care providers to provide adequate intrapartum care and ensure detection and treatment of maternal conditions in pregnancy; all of which increase the risk of stillbirth (Ansari et al., 2019; Guidotti et al., 2009; Kim et al., 2013; Kim et al., 2012). The skills and practices of healthcare providers at all levels on intrapartum care and monitoring should be closely examined to ensure implementation of best practices in accordance with recent WHO guidelines on intrapartum care and standards for improving quality of maternal and newborn care in health facilities (WHO, 2016, 2018).

CONCLUDING STATEMENT

The findings of this thesis have made some important contributions to the literature, identifying how and where improvements can be made to stillbirth data to facilitate understanding of stillbirth risk factors for low- and middle-income country settings. It also demonstrates the impact that contextspecific perceptions and practices have on stillbirth data quality that can be considered for other similar settings to inform future improvements to stillbirth data collection methodologies. This thesis also provides the first population-based assessment of stillbirth risk factors for Afghanistan, a conflict-affected nation where stillbirth rates have shown little decline. Findings on the key risk factors associated with stillbirth in the Afghanistan adds to the evidence-base needed to inform and prioritise stillbirth prevention measures in the country. This thesis also highlights the multiple and complex pathways that lead to stillbirth and identifies where interventions and efforts could begin to focus to facilitate stillbirth reduction in Afghanistan.

Increasing efforts towards reducing stillbirths can contribute to reductions in both maternal and neonatal mortality and morbidity, and improve longer-term neurodevelopment outcomes in later life – a more than triple return on investment (ten Hoope-Bender et al., 2016). Many of the underlying risk factors for stillbirth are similar to or have implications for ensuring good outcomes for both mothers and babies, and an integrated approach towards stillbirth prevention has been recommended (de Bernis et al., 2016). Interventions to reduce stillbirths are known and related to the delivery of high-quality antenatal and intrapartum care (Bhutta et al., 2014). The indicator of stillbirth is a reflection of the quality of care received throughout pregnancy and childbirth (Fauveau, 2007). Continuing to build on efforts to improve data on, and the visibility of stillbirth in national and global health agendas, will be crucial for the future prevention of stillbirths and for facilitating progress on overall maternal and newborn survival and wellbeing.

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APPENDICES

Appendix I: Signed statements of co-author contributions

| Co-authors: | Aliki Christou, Michael J. Dibley, Camille Raynes-Greenow |
|-------------|--|
| Title: | Beyond counting stillbirths to understanding their determinants in low-and middle-income countries: a systematic assessment of stillbirth data availability in household surveys |
| Status: | Published in <i>Tropical Medicine and International Health</i> , 2017; 22: 294–311. doi:10.1111/tmi.12828 |

Co-author contributions

I acknowledge, as a co-author, that the above named publication is to be submitted to the University of Sydney, Australia, as part of Aliki Christou's PhD thesis. Aliki Christou conceived the idea and design of the study, compiled the data and undertook the data analysis, and wrote the paper. Camille Raynes-Greenow and Michael J. Dibley contributed to the conceptualisation of the study, interpretation of the findings, and provided critical comments on all drafts of the manuscript.

| Name | Signature | Date |
|------------------------|-----------|------------|
| Aliki Christou | | 08/11/2018 |
| Michael J. Dibley | | 08/11/2018 |
| Camille Raynes-Greenow | | 08/11/2018 |

| Co-authors: | Aliki Christou, Michael J Dibley, Mohammad Hafiz Rasooly, Adela Mubasher, Sayed Murtaza Sadat Hofiani, Mohammad Khakerah Rashidi, Patrick J. Kelly, Camille Raynes-Greenow |
|-------------|--|
| Title: | Understanding country-specific determinants of stillbirth using household surveys – the case of Afghanistan |
| Status: | Submitted to <i>Paediatric and Perinatal Epidemiology</i> . The paper has undergone one round of peer review and the revised manuscript has been resubmitted to the journal. |

Co-author contributions

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I acknowledge, as a co-author, that the above named publication is to be submitted to the University of Sydney, Australia, as part of Aliki Christou's PhD thesis. Aliki Christou conceived the idea and design of the study, undertook the data analysis, and wrote the paper. Michael J. Dibley and Camille Raynes-Greenow provided guidance on the data analysis, were involved in the interpretation of the findings, and made critical comments on all drafts of the manuscript. Mohammad Hafiz Rasooly, Adela Mubasher, Sayed Murtaza Sadat Hofiani, and Mohammad Khakerah Rashidi were involved in interpretation of the findings and provided critical comments on all drafts of the manuscript. Patrick J. Kelly provided guidance on the analysis and comments on the final draft.

| Name | Signature | Date |
|-----------------------------|-----------|------------|
| Aliki Christou | | 08/11/2018 |
| Michael J. Dibley | | 08/11/2018 |
| Mohammad Hafiz Rasooly | | |
| Adela Mubasher | | 29/11/2018 |
| Sayed Murtaza Sadat Hofiani | | 21/11/2018 |
| Mohammad Khakerah Rashidi | | 29/11/2018 |
| Patrick J. Kelly | | 08/11/2018 |
| Camille Raynes-Greenow | | 08/11/2018 |

 Co-authors:
 Aliki Christou, Ashraful Alam, Sayed Murtaza Sadat Hofiani, Mohammad Hafiz

 Rasooly, Adela Mubasher, Mohammad Khakerah Rashidi, Michael J. Dibley, Camille

 Raynes-Greenow

 Title:
 How community and healthcare provider perceptions, practices and experiences influence reporting, disclosure and data collection on stillbirth: findings of a qualitative study in Afghanistan

 Status:
 Submitted to Social Science and Medicine

Co-author contributions

I acknowledge, as a co-author, that the above named publication is to be submitted to the University of Sydney, Australia, as part of Aliki Christou's PhD thesis. Aliki Christou conceived the idea and design of the study, led the data collection and data analysis, and wrote the paper. Camille Raynes-Greenow, Michael J. Dibley and Ashraful Alam contributed to the study design, data analysis, interpretation of the findings, and made critical comments on all drafts of the manuscript. Sayed Murtaza Sadat Hofiani, Mohammad Hafiz Rasooly, Adela Mubasher, and Mohammad Khakerah Rashidi contributed to the study design, were involved in the data collection, interpretation of findings, and provided critical comments on the manuscript.

| Name | Signature | Date |
|-----------------------------|-----------|------------|
| Aliki Christou | | 08/11/2018 |
| Ashraful Alam | | 08/11/2018 |
| Sayed Murtaza Sadat Hofiani | | 21/11/2018 |
| Mohammad Hafiz Rasooly | | |
| Adela Mubasher | | 29/11/2018 |
| Mohammad Khakerah Rashidi | | 29/11/2018 |
| Michael J. Dibley | | 08/11/2018 |
| Camille Raynes-Greenow | | 08/11/2018 |

| | <u>Aliki Christou</u> , Ashraful Alam, Sayed Murtaza Sadat Hofiani, Mohammad Hafiz Rasooly, Adela Mubasher, Mohammad Khakerah Rashidi, Michael J. Dibley, Camille Raynes-Greenow |
|---------|--|
| Title: | Understanding pathways leading to stillbirth: the role of care-seeking and care received during pregnancy and childbirth in Afghanistan |
| Status: | Submitted |

Co-author contributions

I acknowledge, as a co-author, that the above named publication is to be submitted to the University of Sydney, Australia, as part of Aliki Christou's PhD thesis. Aliki Christou conceived the idea and design of the study, led the data collection and data analysis, and wrote the paper. Camille Raynes-Greenow, Michael J. Dibley and Ashraful Alam contributed to the study design, data analysis, interpretation of the findings, and made critical comments on all drafts of the manuscript. Sayed Murtaza Sadat Hofiani, Mohammad Hafiz Rasooly, Adela Mubasher, and Mohammad Khakerah Rashidi contributed to the study design, were involved in the data collection, interpretation of findings, and provided critical comments on the manuscript.

| Name | Signature | Date |
|-----------------------------|-----------|------------|
| Aliki Christou | | 22/11/2018 |
| Ashraful Alam | | 22/11/2018 |
| Sayed Murtaza Sadat Hofiani | | 21/11/2018 |
| Mohammad Hafiz Rasooly | | |
| Adela Mubasher | | 29/11/2018 |
| Mohammad Khakerah Rashidi | | |
| Michael J. Dibley | | 22/11/2018 |
| Camille Raynes-Greenow | | 22/11/2018 |

Appendix II: Signed ethics approval letters



د افغانستان اسلامی جمهوریت د عامی روغتیا وزارت د افغانستان دعامی روغیا ملی السیتیوت

No.



A Islamic Republic of Afghanistan Ministry of Public Health Aghenistan National Public Health Institute Institutional Review Board Date: August. 21, 2017

To: Aliki Christou, PhD Candidate Sydney School of Public Health The University of Sydney

Subject: Approval for proposal entitled, "A qualitative study of community and health providers' perceptions and understandings of stillbirths in Afghanistan".

Dear Christou,

Institutional Review Board, Ministry of Public Health has examined and reviewed your proposal entitled. "A qualitative study of community and health providers' perceptions and understandings of stillbirths in Afghanistan".

We are pleased to note satisfactory response therefore, your study is approved. However, we reserve the rights to monitor and audit your study and any violation of ethical norms during the course of study shall lead to withdrawal of given approval.

The duration of approval for a study to begin the research project is valid for six months and the implementation plan and monitoring plan should be shared to IRB secretary (irb.afg@gmail.com).

You are bound to share the result of your study with MoPH prior any dissemination plan.

Sincerely,

Bashir Noormal M Director General Afghanistan National Public Health Institute (ANPHI) & Chairman, Institutional Review Board (IRB) Ministry of Public Health

elephone No.: intail Address: Vebsite :

493 (6) 700 28 11 34 <u>desphi.ntopfr@entail.com</u> <u>www.anphi.atophr@ex.af</u> 5th & 6th Roors of the Central Blood Bank Building Behind Central Polyclinic, Citteona Panoir Area, Kabul-Afghanistan ىن: 43.11 x2 700 (0) 93 (0) ئۇرۇنيكى: <u>draphi.monh.atgmail.com</u> رىش: يېزلېزىچو ۋىشىم <u>www.anphi.monh.gevant</u> تى: مۇزلېزىچو ۋىشىم تېيىر بېگىخۇن مركزى، عكى مۇلىكىنىكەن كە د. بىلچە سىنما، امىر كەن ئانلىسكا

نمبر تینفون: ادرس الکترونین صفحه انترنتی: ادرس پستی:



Research Integrity & Ethics Administration

Human Research Ethics Committee

Friday, 8 September 2017

Assoc Prof Camille Raynes-Greenow School of Public Health: Public Health; Sydney Medical School Email: camille.raynes-greenow@sydney.edu.au

Dear Camille

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

After consideration of your response to the comments raised your project has been approved.

Approval is granted for a period of four years from 08 September 2017 to 08 September 2021

Project title: A qualitative study of community and health providers' perceptions and understandings of stillbirths in Afghanistan

| Project no.: | 2017/566 |
|--------------|----------|
| | 2011/000 |

First Annual Report due: 08 September 2018

Authorised Personnel: Raynes-Greenow Camille; Christou Aliki; Dibley Michael; Alam Ashraful; Rashidi Mohammad Khkerah; Hofiani Sayed Murtaza Sadat; Mubasher Adela; Rasooly Mohammad Hafiz;

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Documents Approved:

Special Condition/s of Approval

- It will be a condition of approval, that the offer made by the HoS A/Prof Joel Negin to fund extra insurance coverage for extraction of the student due to risks related to the DFaT 5 Advisory becoming an incident of an emergency requiring such extraction/egress are completed. Please advise the HREC Office (initially) who will arrange a discussion with the Chair if this extra insurance coverage is not implemented for any reason.
- It will be a condition of approval that certified translations of your public documents (Participant Information Statement, Participant Consent Form etc.) are uploaded to IRMA once they have been approved in English.

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Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
 - > Serious or unexpected adverse events (which should be reported within 72 hours).
 - > Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely

Professor Glen Davis Chair Human Research Ethics Committee (HREC 2)

The University of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007) and the NHMRC's Australian Code for the Responsible Conduct of Research (2007).